

RE-BRANDING PALLIATIVE CARE: ASSESSING EFFECTS OF A NAME CHANGE ON  
PHYSICIAN COMMUNICATIVE PROCESSES DURING REFERRALS

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Although provision of palliative care on the United States is growing, referrals to the service are often late or non-existent. The simultaneous care model provides a blueprint for the most progressive form of palliative care, which is palliation and disease-oriented treatments delivered concurrently. Research indicates the existence of a widespread misconception that associates palliative care with imminent death, and some organizations have chosen to re-brand their palliative care services to influence this perception. The goal of this study was to assess the effects of a name change from palliative care to supportive care on the communicative process during referrals to the service.

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## CHAPTER 1

### INTRODUCTION

Dr. Ira Byock: Families cannot imagine there could be anything worse than their loved one dying. But in fact there are things worse. Most generally, it's having someone you love die badly.

Reporter: And what do you mean by dying badly?

Dr. Byock: Dying suffering. Dying connected to machines. I mean, denial of death at some point becomes a delusion, and we start acting in ways that make no sense whatsoever. And I think that's collectively what we're doing.

-From *The Cost of Dying*, 60 Minutes

Despite the proliferation of end-of-life care in the United States, many Americans experience suffering as death approaches, dying in institutional settings with aggressive medical interventions aimed at keeping them alive longer, regardless of quality of life considerations (Meier, 2010; Schneiderman, Jecker, & Jonsen, 1996). Our current health care system forces patients to choose between life-sustaining, disease-oriented treatments and symptom-focused comfort care, without the option to pursue the two simultaneously. Americans expect and health care providers order and administer costly and taxing medical tests and procedures up to the last days and moments of life. We have come to rely on physicians, equipped with cutting-edge medical technology, to eradicate illness at any stage. Sometimes health care providers are successful in these endeavors, but sometimes they are not. It is our widespread refusal to accept our own mortality that drives us toward experiencing “bad deaths” as the rule in health care rather than the exception.

### Fighting Our Own Mortality

The struggle to combat our own mortality and deny death is an unfortunate and unintentional result of advancements in medicine. Over the past several decades, the scientific

community launched us forward with giant strides in science and technology, resulting in longer life spans and greater symptom control. Meanwhile, we have grown to expect our medical providers to have the ability to cure all ailments. As a result, we have collectively ushered in a new and aggressive concept of medicine: “Almost without discussion, the primary moral principle underlying medical practice became the obligation to prolong life regardless of the toll in suffering, poor quality of life, or cost” (Meier, 2010, p. 24). This effort to prolong life at all costs contributes to the growing problem surrounding medical futility, wherein patients demand and clinicians provide medical treatments that are not beneficial to the patient (Ferrell, 2006; Schneiderman et al., 1996).

In addition to encouraging aggressive physical interventions, medical futility dramatically increases health care costs. Experts claim our system, in its current state, is financially unsustainable (U.S. General Accounting Office, 2004). Compared to all other major industrialized nations, the U.S. spends the largest share of its gross domestic product (GDP) on health care, a figure which, according to federal estimates, averages almost \$8,000 per person per year (U.S. Department of Health and Human Services, *Health care costs*, 2010). In 1980, Americans spent 9% of the nation’s GDP on health care. Today, that percentage is estimated to be 16%. Researchers also estimate that 5% of the population is responsible for almost 50% of all health care costs (U.S. Department of Health and Human Services, *Most Expensive Conditions*, 2010). Furthermore, a large portion of these costly treatments are administered just before death. Wright et al. (2010) claimed almost 25% of all Medicare disbursements were spent on aggressive, critical care interventions during patients’ final month of life, despite a lack of substantial evidence of improved outcomes. These patients are most likely not recipients of

comfort-oriented care, such as hospice, because hospice requires patients to terminate attempts to prolong their lives.

### End-of-Life Care

Due to strict eligibility requirements, hospice services contribute to medical futility by forcing patients and caregivers to choose between cure and comfort. Hospice care is delivered by an interdisciplinary team whose goal is to alleviate some of the burdens life-threatening illnesses bring as patients (often accompanied by informal caregivers such as family members) approach death. Shortly after the creation of the Medicare hospice benefit in 1982, which allowed Medicare recipients access to hospice services via federal funds, the agency also established patients' eligibility criteria (U.S. Department of Health and Human Services, 2000). One of the fundamental conditions for hospice eligibility required the patient to be certified as actively dying with six months or less to live. Another hospice prerequisite obligated the patient to abandon all attempts at life-prolonging medical interventions. These hospice eligibility requirements, which are still in place today, led to a "cure-versus-care" mentality in health care forcing providers and recipients to view cure and comfort as mutually exclusive options for care (Mazanec et al., 2009; Meier, 2010). When facing the choice either to accept death or continue efforts to extend life, most people choose any medical treatment that is available, no matter how futile the attempt.

Palliative care, a medical approach for care of patients with serious, chronic, or terminal illnesses, provides one approach for combating medical futility produced by hospice's false dichotomy between comfort and cure (Meier, 2010). However, palliative care is entirely dependent upon referrals from the primary care physician or specialist in charge of a patient's

care. Once referred, interdisciplinary palliative care teams—consisting of physicians, nurses, social workers, psychologists, and others—operate in an inpatient or outpatient manner. One benefit palliative care offers is reduction of health care costs (Enguidanos et al., 2009; Morrison et al., 2008; Snow et al., 2009). Informed patients with terminal prognoses often choose to forego costly medical treatments and opt for less expensive, comfort-oriented care (Daugherty & Hlubocky, 2008). Palliative care also lowers health care expenditures by helping patients and caregivers avoid crises that often lead to costly emergency room visits (Rehm, 2010). Meier (2010) maintained that although patient and caregiver well-being and quality of life are the focus of palliative care, cost reduction is a welcome benefit. Since cancer treatment carries the highest per-person cost in the U.S. compared to all other diseases (U.S. Department of Health and Human Services, *Most Expensive Conditions*, 2010), it deserves attention from those trying to curb costs and improve the delivery of health care in America.

### Palliative Care and Cancer

Cancer patients are among the most vulnerable to receiving aggressive and futile medical interventions during the last months, weeks, and days before death. For example, data from 1996 showed 22% of Medicare recipients with cancer started a new chemotherapy regimen within the last month of their lives (Matsuyama et al., 2006). Furthermore, research has indicated that physicians administer chemotherapy at similar rates regardless of the patient's physical responsiveness to the treatments (Earle et al., 2008; Matsuyama et al., 2006). Popular treatments such as chemotherapy and radiation often have painful physical side effects (Finlay & Casarett, 2009). Furthermore, despite major developments in cancer care, many people still associate a



cancer diagnosis with suffering and painful death. These associations contribute to increased levels of anxiety (Ahmedzai et al., 2004).

Palliative care can be particularly advantageous for cancer patients by addressing all of these issues. First, palliative care prioritizes pain management. Patients pursuing curative treatments such as chemotherapy can simultaneously address the physically painful side effects treatments often bear (Finlay & Casarett, 2009). Palliative care is also designed to maximize comfort by helping patients determine how and where they will die, rather than leaving wide open the likelihood of dying in a hospital or intensive care unit. Furthermore, in a recent study, researchers found palliative care not only had a significant positive effect on cancer patients' quality of life; they also discovered palliative care can extend life. Temel et al. (2010) claimed: "Early integration of palliative care with standard oncologic care in patients with metastatic non-small-cell lung cancer resulted in survival that was prolonged by approximately 2 months and clinically meaningful improvements in quality of life and mood" (p. 739). Overall, research suggests palliative care, integrated with traditional cancer care, can improve quality of life, reduce costs, and extend survival (Bakitas et al., 2009).

In the absence of palliative care, many cancer patients report abandonment by their oncologists when their disease is considered incurable (Back et al., 2009). Due to the nature of the disease, many cancer patients establish relationships with their oncologists over long periods of time. Researchers claimed oncologists sometimes perceive their duty strictly as eradicating cancer from the body, so when this goal can no longer be achieved, their services are no longer needed (Ahmedzai et al., 2004). The transition from curative to comfort care may also be accompanied by a transition of location and/or care team. Ahmedzai et al. (2004) described the importance of palliative care for cancer patients during this phase:

The shift away from the protective hospital environment emphasises [*sic*] the need for good dialogue and coordination between the oncology and primary care teams, and for palliative services to strengthen their involvement with the patient and family at this point, so that they do not feel abandoned. (p. 2196)

Involvement of a palliative care team alongside primary health care providers ensures continuity of care without abandonment.

Palliative care services also significantly benefit caregivers of cancer patients. For many people, a cancer diagnosis is one of the most difficult challenges they have ever had to negotiate in their lives, bringing high levels of psychosocial, spiritual, and physical distress (Loscalzo, 2008). Researchers also have claimed when caregivers witness their loved ones becoming critically ill and in need of drastic medical intervention, the caregivers often experience depression and a degree of posttraumatic stress (Gelfman, Meier, & Morrison, 2008; Wright et al., 2010). As stated previously, the integration of palliative care often decreases the occurrences of medical crises, which have traumatic effects on caregivers. Furthermore, palliative care provides caregivers the opportunity to be part of the communication process throughout the course of the illness, resulting in improved bereavement outcomes (Gelfman et al., 2005).

### Challenges to Palliative Care

Supporters of palliative care maintain communication is the key to easing some of the fear, apprehension, and misunderstanding surrounding palliative care; communication that requires the involvement of health care providers, patients, and caregivers. Specifically, researchers stated, “Enhanced communication in the palliative process is vital to meeting the patient’s preferences in the end-of-life” (Wittenberg-Lyles & Sanchez-Reilly, 2008, p. 354). The need for effective communication in palliative care, however, extends beyond the conversations that take place between patients, caregivers, and members of their health care team. Some

researchers claimed palliative care faces challenges involving its widespread misunderstanding among the general public (Enguidanos et al., 2009).

One recent example involves the national health care reform debate, wherein an early version of the legislation included providing clinicians reimbursements for having advanced care planning discussions with patients and caregivers, which sometimes involve decisions regarding end-of-life care. Opponents of the legislation termed these discussions “death panels” and invoked other phrases such as “pulling the plug on grandma.” These images instilled fear in the minds of many Americans and ultimately caused legislators to remove that portion from the bill. Aside from having political implications, the “death panel” discussions affected palliative care supporters who championed that portion of the proposed legislation. Since these purportedly controversial conversations between patients, caregivers, and their health care teams are central to the general understanding of palliative care services, the proposed legislation to include them as a compensated portion of health care would likely have advanced the palliative care movement. According to some researchers, the “death panel” controversy set back the progress of the palliative care field an entire decade (Rehm, 2010).

The common misperception that palliative care is synonymous with hospice fuels the problem of medical futility. By perceiving palliative care as an option only when death is imminent, health care providers and recipients continue to propagate the cure-versus-care dichotomy. By waiting until all cure-oriented options are exhausted, referrals often come too late. Late referrals hinder the efficacy of palliative care services (Johnson, Girgis, & Paul, 2008). On the contrary, early referrals maximize the communication between the patient, caregivers, and health care providers and lead to earlier hospice referrals. These outcomes often have a positive impact on quality of life (Bakitas et al., 2009). To ensure its successful integration,

palliative care should be initiated at the time of diagnosis (NHPCO, *Palliative Care*, 2010; WHO, 2010).

### Theoretical Framework

The simultaneous care model (SCM) was designed to promote earlier and more frequent involvement of palliative care teams, which in turn, would reduce medical futility in the health care system. (Appendix A provides an overview of this model.) SCM—also referred to as concurrent care—is considered progressive palliative care. Researchers claimed by implementing curative and palliative care simultaneously, quality of life improves (Meyers et al., 2004). Incorporating traditional palliative care, or comfort care, alongside curative treatments removes the stigma that palliative care is reserved for implementation only after disease-oriented treatments are exhausted. Concurrent care requires early referrals to palliative care services, ideally at the point of diagnosis. Furthermore, the SCM provides the most consistent continuum of care as patients transition from diagnosis, through different stages of their illness, and ultimately to end-of-life care. Researchers stated, “Progressive palliative care enhances the patient/family comfort day-by-day and can promote more mindful and conscious living whether the future holds death, remission, or cure” (Meyers & Linder, p. 1413). This progressive and ideal model of palliative care aims to expand the knowledge and implementation of the benefits palliative care offers patients, caregivers, and clinicians at every stage of a serious, chronic, or terminal illness. However, the ability to widely enact concurrent care, as represented by the SCM, has proved challenging in the provision of palliative care.

## Palliative Care vs. Supportive Care

Without question, the quantity and timeliness of palliative care referrals need to improve. The current debate centers on how to achieve this goal. One approach includes re-branding the service by changing its name. As stated previously, many people, including health care providers, associate the word *palliative* with hospice or imminent death. Therefore, in an effort to remedy this problem, researchers with one of the country's largest hospitals changed the name of their palliative care center.

Since its establishment in 1999, the University of Texas MD Anderson Cancer Center's (UTMDACC) palliative care program has offered patients and caregivers assistance in managing the physical and psychological distress resulting from cancer (Fadul et al., 2009). However, although the number of patients accessing UTMDACC's palliative care service had increased over time, physicians were not referring patients early enough in their disease trajectory (Fadul et al., 2009). To address this issue and others, researchers from UTMDACC conducted a study to determine if changing the name from *palliative care* to *supportive care* would affect the frequency and timeliness of referrals to their program: "We hypothesized that the name *palliative care* compared with the name *supportive care* has a negative impact on the timeliness of palliative care referrals" (Fadul et al., 2009, p. 2014). The researchers concluded the term *palliative care* causes more distress to patients, caregivers, and clinicians when compared to the term *supportive care*. Fadul et al. (2009) admitted the palliative care movement is misunderstood: "Our findings highlight the clamant need for education of healthcare practitioners on the definition of the term *palliative care*, the role of palliative care services, and the advantages of earlier referrals to these services" (Fadul et al., 2009, p. 2019). Researchers used the study "to characterize the perceived meanings and implications of the 2 names by

medical oncologists and midlevel providers in a comprehensive cancer center” (Fadul et al., 2009, p. 2014). The results of this research encouraged hospital administrators to change UTMDACC’s *palliative care* service to the *supportive care* service, which officially occurred November 1, 2007 (Dalal et al., 2011).

Two years later, researchers conducted a quantitative follow-up study to determine if and to what extent the name change influenced referral statistics. Dalal et al. (2011) compared referral statistics during a twenty-month period prior to the name change (January 2006 to August 2007) with statistics from a twenty-month period following the name change (January 2008 to August 2009) (Dalal et al., 2011). Researchers reported a 41% increase in palliative care consultations (predominantly consisting of inpatients) and improvements for outpatients including shorter duration between diagnosis of advanced cancer and palliative care referrals as well as longer duration between palliative care consultation and death (Dalal et al., 2011). By promoting a better understanding of palliative care—or in this case, re-branding the service—clinicians were more likely to refer patients earlier in the disease trajectory. And with earlier referrals, the traditional concept and practice of palliative care transforms itself to better reflect the ideal scenario of the SCM.

Although the best approach to promoting education and utilization of palliative care services is debatable, researchers agree the need for education and increased utilization exists. Unfortunately, despite a recent surge in palliative care programs available in health care facilities across the country, Americans continue to deny death. This refusal to acknowledge end-of-life considerations in preparation for death leads to the implementation of medically futile interventions, especially for cancer patients who require advance treatment for their disease. Ineffectual treatments not only inflict physical and emotional pain on patients and caregivers but

also contribute to the financial strain on the American health care system. In the next chapter, I will further provide background information on causes and implications of medical futility, benefits and functions of palliative care, clinicians' attitudes regarding palliative care, the unique challenges cancer poses to patients and their caregivers, and how re-branding affects perceptions of and behaviors toward palliative care services.

## CHAPTER 2

### LITERATURE REVIEW

My father was diagnosed with stage four lung cancer. It took me a few minutes on the internet to find out what his life expectancy was. His doctor told him that he could "cure" his lung cancer. My father underwent terrible chemotherapy - had a terrible time and died 1 day before the life expectancy time that I found on the computer. I can only imagine how his last 9 months of his life might have been had he had the opportunity for palliative care. I learned from his experience that I would consider palliative care first if I was diagnosed with cancer and I hope that I might have the grace of some period of relative health and be able to say goodbye properly to those I love.

*EllenP63*

Most Americans want to die at home, free of pain, rather than in a hospital (Wright et al., 2010). This is what many people consider to be a "good death." However, as evidenced by Ellen's statement, people often die with unnecessary pain and distress as a result of poor or non-existent communication. Within our current health care system, patients demand and physicians provide more medical interventions over longer periods of time, often even up to the point of death, neglecting other important areas of need. Without proper communication regarding care options and prognoses, people are left with false hope and increased distress. These experiences also have profoundly negative effects on caregivers (Gelfman, Meier, & Morrison, 2008). End-of-life care, including hospice and palliative services, allows patients and their caregivers to address their psychological, social, and spiritual needs. In this chapter, I will provide a detailed review of literature demonstrating how our death-denying culture negatively impacts health care consumers and how palliative care alleviates these effects, particularly concerning cancer care.

#### Medical Futility

Medical futility is one consequence of a death-denying culture. Ferrell (2006) defined it



as “life-sustaining care that is highly unlikely to result in meaningful survival” (p. 922). As science, medicine, and technology offer health care providers greater tools for combating disease, these advancements often come at a cost—financially, physically, and otherwise—to the recipients. According to Schneiderman, Jecker, and Jonsen (1996), the following describes health care practices in America: “Means are confused with ends, effects are confused with benefits, and available technologies are confused with obligatory medical therapies” (p. 671). Clinicians, patients, and caregivers continuously consider medical options that may prolong life and/or improve quality of life, outcomes that are sometimes incompatible with one another. While medical providers are sometimes responsible for medical futility, other times health care recipients insist on excessive care.

Patient autonomy is one reason medical futility is on the rise. While the health care industry is historically physician-dominated, patients have gained a great deal of decision-making power over the past several decades (Meier, 2010). In the 1960s, many patients began challenging health care providers over the rights to control decisions regarding their medical care (Schneiderman et al., 1996). Researchers described how the patient autonomy movement perpetuated medical futility:

Some patients and their families have begun to claim the right to receive whatever aggressive, high-tech medical interventions they wish, even if medical providers judge the interventions to be futile because they have no realistic chance of achieving the goals of medicine. (Schneiderman et al., 1996, p. 669)

Patients and their caregivers are involved in the conversation about their health care more often than they were prior to the patient autonomy movement. However, many patients and caregivers lack the knowledge and experience necessary to make informed decisions to improve their overall situation (Laabs, 2005).

Researchers also have pointed to media messages which perpetuate the belief that—with the use of cutting-edge medical advancements—death can be avoided (Ferrell, 2006; Segal, 2007). Ferrell (2006) explained the persuasiveness of these messages: “The era of intense media influence means that each day the public sees images of Lance Armstrong, actors, politicians, and other public figures who have overcome extreme odds to survive and thrive beyond serious illness” (p. 923). Furthermore, advertisements for health care facilities and pharmaceutical products often depict healthy, active individuals free of disease, rather than reflecting a more accurate image of illness (Segal, 2007). The media’s portrayal of health issues is often inaccurate and misleading to consumers, contributing to the public’s inability to make informed decisions when facing a health crisis (Kline, 2006).

Religious beliefs also contribute to the propensity for medical futility. In some faiths, people adhere to the belief God will intervene and heal their loved one (Ferrell, 2006). In these instances, statistically unsupported medical interventions may prolong physical life beyond a patient’s desired quality of life while the patient and/or caregivers await a “miracle” (Schneiderman et al., 1996). For example, according to stories from the Christian faith, healing is not achieved through medicine but rather through the “laying on of hands” by God (Schneiderman et al., 1996, p. 673). When caregivers’ spiritual faith supersedes clinicians’ advice for health care decisions, futile treatments often result.

The majority of America’s health care system financially rewards clinicians for providing tests and procedures for patients, but not for communicating with patients (Robinson, 2001). Critics of our current fee-for-service health care system claim we pay physicians for quantity when we should pay them for quality of care. Doherty (2010) explained how this practice may affect health care consumers: “Fee for service could even hurt patients by creating incentives for

doctors to do unnecessary and potentially harmful procedures” (para. 3). Opponents of our current system of reimbursement claimed that restructuring the system would reduce costs and benefit patients by removing the motivation to provide excessive tests and procedures (Doherty, 2010; Robinson, 2001).

Clinicians may also contribute to medical futility by ordering tests and procedures in an effort to shield themselves from costly litigation. In order to avoid lawsuits claiming negligence, clinicians sometimes adopt defensive medicine practices. Providers often choose to exhaust all curative treatment options to avoid being perceived as neglectful or failing to provide adequate care (Ferrell, 2006). As a result, clinicians—and those who insure them—sometimes prioritize providing aggressive medical care over the concerns of patient comfort in an effort to protect themselves from litigation.

When patients and caregivers refuse to acknowledge death and financial incentives dominate the health care system, medical futility occurs. Ineffectual and costly treatments near the end-of-life inflict physical and emotional pain on patients and caregivers and perpetuate the financial strain on the American health care system. Palliative care, outlined in the next section, functions to improve quality of life for patients and caregivers, reduce health care costs, and provide clinicians much-needed communication support.

### Palliative Care

Also referred to as supportive or comfort care, palliative care prioritizes pain management for the patient, followed by emotional, social, and psychological support. Of equal importance, palliative care services promote open and continuous communication between all individuals involved in a patient’s care. Palliative care also provides support for the patient’s

caregivers. Physicians, nurses, social workers, religious counselors, and volunteers, among others, work in teams to deliver palliative care to patients and their caregivers (National Hospice and Palliative Care Organization, 2010). Currently, palliative care services are primarily hospital-based programs. Patients rely on their physicians to refer them to the service in order to receive palliative care. Palliative care programs are increasing in number. In 2008, 75% of hospitals with over 250 beds reported having palliative care services (Meier, 2010, p. 37).

### Comparing Palliative Care and Hospice Care

Both palliative care and hospice care seek to provide comfort and improve quality of life for people dealing with life-threatening illness. However, one key difference between the two care services is that while hospice care requires a patient to abandon attempts at life-lengthening treatments such as surgery or chemotherapy, palliative care allows for these interventions. While some patients choose hospice care, others may not be ready to cease disease-oriented care and the goal of prolonging life. Mazanec et al. (2009) explained how palliative care bridges this gap in health care delivery:

Many individuals prefer to continue disease-oriented care until the time of death. The current Medicare Hospice Benefit is not designed to accommodate this goal. The new model of palliative care focuses on patients' and families' goals of care and enables patients to receive expert palliative care without having to forego disease-oriented treatment that is considered aggressive according to the hospice Medicare regulations and current hospice philosophy. (p. 2)

While palliative care is focused on comfort and quality of life, it does not require patients to abandon life-lengthening treatments; patients and their caregivers can seek both simultaneously. However, the success of palliative care efforts depends on the emphasis placed on communication between patients, caregivers, and health care providers.

As stated previously, in order for a patient to become eligible for hospice care services during the end-of-life stage, a physician must certify that the patient has six months or less to live. Palliative care has no such limitations. In fact, according to the World Health Organization (WHO), National Hospice and Palliative Care Organization, and other organizations, palliative care should be delivered upon diagnosis of a life-threatening or chronic illness (Mazanec et al., 2009; WHO, 2010). Although both hospice and palliative care include bereavement services for caregivers, only palliative care is designed to adapt to the needs of the patient and caregivers all along the disease trajectory. Mazanec et al. (2009) explained palliative care is highly individualized:

Palliative care needs may be extensive at the beginning of the diagnosis when patient and family physical, psychological, social, and spiritual issues can be overwhelming. Or, in some cases, patients do fairly well when first diagnosed, and the need for palliative care is greater in the midst of treatment, as patients experience the debilitating adverse effects of the therapy or begin to worry about the success of the treatment. (p. 5)

Palliative care teams are also important because they provide consistent care through the end-of-life. Facilitated by communication, palliative care does not require patients and caregivers to abruptly transition from curative treatment to hospice care.

Although hospice is a form of palliative care, end-of-life care advocates successfully urged the medical community to recognize palliative care as its own subspecialty of medicine in 2006 (Meier, 2010). Much of the enthusiasm behind the recognition of the separation between hospice and palliative care came from the 1995 landmark research funded by the Robert Wood Johnson Foundation (RWJF). Researchers involved in this study set out to determine if patients receiving end-of-life care were being treated with aggressive medical interventions. The researchers discovered that dying patients experienced high levels of pain. Furthermore, the majority of patients who were hospitalized when they died lived their last days on ventilators in

intensive care units (RWJF, 1997). This study brought attention to the needs of the dying and was instrumental in defining the current palliative care movement. The research also illuminated the importance of communication in health care, a cornerstone of palliative care.

### Communication Central to Palliative Care

Effective palliative care relies on communication among every party involved in patient care. This communication often involves providing an accurate prognosis. Prognostic disclosure failures are one impediment to timely palliative care referrals. Researchers stated, “Provider and patient reluctance to openly discuss prognostic information may result in missed opportunities for appropriate goal setting and care planning” (Finlay & Casarett, 2009, p. 255). Clinicians face several challenges in the delivery of accurate prognostic information to patients and their families. In general, poor prognoses—often referred to as “bad news” conversations—are difficult to deliver because they are upsetting to the patient and caregivers (Escalante, Martin, Eltin, & Rubenstein, 1997; Ptacek & McIntosh, 2009). Furthermore, physicians are not always able to provide an accurate prognosis (Finlay & Casarett, 2009). Moreover, some patients prefer their physicians abstain from providing prognostic information, making it difficult for health care teams to provide appropriate end-of-life care. Whether brought about by the health care provider, the patient, or the patient’s caregivers, the result of inaccurate or unknown prognostic information is the same: palliative care referrals that are either late or non-existent.

Effective patient-physician communication is challenging in situations outside of prognostic disclosure. Researchers have claimed physicians favor communication regarding medical or technical issues over quality-of-life assessments or psychosocial issues (Detmar, Muller, Wever, Schornagel, & Aaronson, 2001; Fine, Reid, Shengelia, & Adelman, 2010).

Positive patient outcomes require physicians to address issues in addition to medical concerns, particularly when physicians are trying to ascertain whether a palliative care referral is appropriate. Moreover, physicians tend to dominate conversations with patients, even when the topic is related to patient quality-of-life or advanced care planning, topics which require patients to share opinions and information with their physicians (Fine et al., 2010; Trice & Prigerson, 2009). Assessments of palliative care needs require physicians to evaluate concerns unrelated to physical pain by allowing and encouraging patients to express their desires and expectations for care. Emphasis on open communication is particularly salient when the illness is cancer.

### Palliative Care Addresses Challenges of Cancer

Living with cancer—a disease that is often successfully eradicated from the body only to recur again—requires many patients to seek medical care for months, years, and sometimes decades. The American Cancer Society (ACS) estimated over 1.5 million new cancer diagnoses will occur in the year 2010, and over 11 million people are living with cancer or a history of the disease (ACS, 2010, p. 1). Although the ACS estimated almost 570,000 Americans died of cancer in 2010—approximately 1,500 every day—cancer is not the terminal disease it was once considered to be (ACS, 2010, p. 3; Rehm, 2010). Successful advances in the treatment of cancer are due, in large part, to oncologists and other physicians who are responsible for overseeing the curative treatment of the illness. As stated previously, because of the nature of the disease, oncologists often establish important relationships with patients and caregivers over long periods of time. However, when cure is no longer a feasible goal, the primary role of the oncologist essentially ends, and patients face transition to end-of-life.

## Patient Abandonment and Cancer

When palliative care is not present, cancer patients and their caregivers sometimes feel abandoned by their oncology team when transitioning to hospice care. By involving a palliative care team at the earliest point in the disease trajectory, ideally at diagnosis, patient abandonment can be minimized (Mazanec et al., 2009). In these cases, as the oncologist's role diminishes in order to integrate palliative care, patients have already established relationships with specially trained members of the palliative care team who help the patient and caregivers transition through challenging end-of-life decisions (Ngo-Metzger, August, Srinivasan, Liao, & Meyskens, 2007). Schofield et al. (2006) described this complementary relationship: "This permits patients and their families to establish relationships with the palliative care professionals, while maintaining a parallel care relationship with their oncologists. Gradually, primary responsibility for care can shift to palliative care health professionals as the disease progresses" (p. 403). When palliative care team members are involved early in the disease trajectory, patients experience a continuity of care and decreased feelings of abandonment (Mazanec et al., 2009). Consequences of patient abandonment are not reserved for the patient. Patient abandonment is difficult for caregivers as well.

## Caregivers' Vulnerability and Cancer

Caregiver burden is a significant issue in cancer care. Cancer patients experience high levels of physical pain and emotional distress, which often have profoundly negative effects on caregivers (Gelfman et al., 2008; Wright et al., 2010). As outlined in the previous chapter, cancer patients are often the recipients of aggressive and sometimes painful medical interventions near the point of death. Researchers have indicated caregivers suffered increased levels of distress



after witnessing their loved one undergo aggressive treatments (Gelfman et al., 2008; Wright et al., 2010). Caregivers reported feelings of powerlessness, sadness, and fear during times of intensive care for the patient (Loscalzo, 2008). Wright et al. (2010) described how treatments for critically ill patients affected caregivers: “[R]esearch suggests that family members of critically ill patients experience greater psychological distress relative to the general population, including anxiety, depression, posttraumatic stress, and prolonged grief” (p. 1). Caregivers sometimes experience physical distress including functional impairment (Gelfman et al., 2008).

A large portion of palliative care is directed toward caregivers. As mentioned previously, palliative care reduces crisis situations wherein patients are likely to be rushed to the emergency room where they receive aggressive medical care (Meier et al., 2010). By reducing these crises, caregivers are less likely to experience traumatic effects of witnessing their loved ones in distress. Moreover, in contrast to traditional medical care, palliative care is designed to provide support for caregivers as well as patients. Specifically, palliative care provides opportunities for communication so that caregivers can have their voices heard by the medical team, thereby relieving some of the anxiety and distress associated with end-of-life issues (Brinker & McCauley, 2002).

### Disease Variability in Cancer

The drastic variability among different types of cancers inhibits early referrals to palliative or hospice services. To date, the ACS has identified over 200 types of cancer, each of which is considered an individual disease (ACS, 2010). The variation makes prognostication difficult, particularly as the disease progresses into the later stages. For example, physicians approach hematological cancers, such as leukemia or lymphoma, differently than solid tumor

carcinomas, such as breast or prostate cancers (ACS, 2010; Auret, Bulsara, & Joske, 2003). Focusing on challenges to palliative care referrals for hematological cancers, Auret et al. (2003) stated, “Different patterns of deterioration compared with solid cancer patients and prolonged focus on potentially curative treatments may also hamper easy involvement of palliative care, resulting in more patients dying during an acute hospitalization without adequate preparation or warning” (p. 567). Cancer poses various prognostic challenges to clinicians. However, involvement of palliative care as early as possible minimizes issues involved with disease variability.

### Cancer and the Elderly

Older people with advanced cancers are a particularly vulnerable population. Approximately 78% of all cancer diagnoses occur in people 55 years of age and older (ACS, 2010, p. 1). However, researchers stated that although aging is a risk factor for acquiring cancer, “terminal cancer care for the elderly is underrepresented, most likely the result of age bias in referral by clinicians” (Wittenberg-Lyles & Sanchez-Reilly, 2008, p. 352). Older cancer patients are also likely dealing with health concerns related to aging in addition to their cancer illness. While the medical community’s ability to manage cancer effectively prolongs life in many cases, it often hampers transitions to end-of-life care. Wittenberg-Lyles and Sanchez-Reilly (2008) claimed, “Consequently, many elderly patients with advanced cancer have PC [palliative care] needs but never reach a point in their illness trajectory when they clearly meet guidelines for hospice enrollment” (p. 353). Again, when palliative care is integrated early, holistic needs of the patient and caregivers are addressed, even when hospice is not involved.

## Clinicians' Attitudes toward Palliative Care

Inclusion of palliative care is dependent upon referrals from primary care physicians and specialists, therefore their understanding and recognition of the service are paramount to its success. Unfortunately, Meier (2010) indicated referrals to palliative care services were often non-existent or too late in the disease trajectory to be effective. Researchers have claimed that clinicians often associated palliative care with imminent death, and therefore only referred patients for palliative care services when the illness was considered incurable (Fadul et al., 2009; Finlay & Casarett, 2009). Similarly, research indicated some clinicians viewed palliative care and hospice synonymously (Enguidanos et al., 2009; Fadul et al., 2009; Finlay & Casarett, 2009). Clinicians' association of palliative care with imminent death can have far-reaching consequences for their patients. Misunderstanding and misuse of palliative care may lead to reluctance to accept the palliative care interdisciplinary team and a deterioration of the patient's and caregivers' feelings of hope regarding the patient's prognosis (Marsella, 2009). On the contrary, Marsella (2009) stated, "Early integration of the palliation professional as part of the multidisciplinary treatment team can facilitate a smoother transition and enhance the continuum of care" (p. 188). When physicians view palliative care and hospice synonymously, palliative care referrals only occur when all disease-oriented treatments are exhausted.

Duong and Zulian (2006) claimed the challenges of palliative care referrals stem from a lack of medical training provided to medical students. They argued, "Most medical students do not receive appropriate pre-graduate education with the objective of preparing them to deal with end-of-life issues" (p. 551). The emphasis on curative medicine in American culture leaves many clinicians uneducated and therefore uncomfortable dealing with end-of-life issues, including referrals to palliative care services. Proponents of palliative care have suggested increasing the

awareness of and education for health care providers so they may, in turn, inform patients and their caregivers about their options for complementary care (Enguidanos et al., 2009; Meier, 2010).

### Palliative Care Re-Branded

A service or entity's name can be the most influential aspect of its perception and identity. The name—or brand—of a service within a health care setting provides a great deal of information about what patients should expect from that service. According to Karreman and Rylander (2008), branding can be understood in terms of managing an entity's meaning. The researchers also explained that a brand has both an internal and external function for the organization. In other words, the name of a service or center, such as *palliative care*, serves to inform not only patients (external function) but other clinicians (internal function) regarding the nature of the branded entity. Moreover, according to Miller and Muir (2004), brands exist only in people's minds and consist entirely of perceptions. In addition, the decision to re-brand a service or entity sometimes allows for that service or entity to remain the same, relying solely on the new name to improve perceptions.

The palliative care movement faces challenges related to misunderstandings of the service's purpose and role in health care as well as a lack of knowledge of its existence among care providers and recipients alike. Furthermore, when some form of palliative care is implemented, it is often too late in the disease trajectory to maximize its efficacy. As stated previously, the simultaneous care model (SCM) (see Appendix A) addresses many of the perceptual challenges facing palliative care, and will, therefore, serve as the theoretical framework for this study. This version of palliative care goes beyond simply allowing for

disease-oriented treatment concurrently with comfort care. The new palliative care model incorporates both approaches: disease-oriented treatments and comfort care. Furthermore, as stated in the previous chapter, one approach to this issue is to rename palliative care altogether in hopes of facilitating a more accurate understanding of the service. Proponents of the palliative care movement are constantly seeking to improve it and expand its educational reach. My goal in this study was to participate in that larger objective by examining physicians' perceptions of palliative care through the lens of the SCM and to determine how this perception affects the communication between physicians and patients in the referral process. Specifically, I questioned:

Research Question 1: What are the University of Texas MD Anderson Cancer Center physicians' perceptions and understanding of the services provided by the supportive care service?

Research Question 2: How does this understanding influence the communication between physicians and patients in the referral process?

Research Question 3: To what extent does the re-branding of *palliative care* to *supportive care* reflect the communication expectations set forth in the simultaneous care model?

In the next chapter, I outline my methods for attaining the information to answer these questions.

## CHAPTER 3

### METHODS

Palliative care offers cancer patients and their caregivers support during what is often one of the most challenging periods in their lives. This support includes management of physical pain, which is common to cancer patients receiving medical treatments such as chemotherapy and radiation. The palliative care team also addresses the psychological, social, and spiritual distresses that often accompany a cancer illness. Furthermore, at the point in the disease trajectory when curative treatments are no longer beneficial, palliative care provides patients and their caregivers a continuum of care often interrupted by patient abandonment. In the event of the patient's death, palliative services provide bereavement support for those mourning the loss of their loved ones in an effort to improve or restore the survivors' quality of life. Palliative care is most effective when initiated at the point of diagnosis. The University of Texas MD Anderson Cancer Center (UTMDACC) has both an outpatient and inpatient clinic, in addition to a consult service at the request of primary oncologists. The palliative care clinicians provide care for approximately 100 outpatients per week. The hospital also includes a 12-bed inpatient palliative care unit wherein the palliative care physicians act as primary physicians.

Palliative care services depend solely on referrals from the primary care physicians or specialists in charge of patient care. Therefore, clinicians' awareness and understanding of the services are crucial to their implementation. Moreover, acceptance of palliative care depends upon patients' understanding that palliative care is not synonymous with hospice or a terminal prognosis. Communication is central to each of these elements of referral. Specifically, the palliative care team is responsible for communicating the benefits and availability of their services to oncologists, and oncologists are responsible for communicating effectively with

patients and informal caregivers regarding their services. Oncologists need to maintain open dialogue with patients and caregivers concerning all parties' needs and goals for care. This communication requires the engagement of health care recipients and providers alike. Patient acceptance of palliative care often depends upon the clinicians' perceptions and presentation of the services as well as the timeliness of the referral. By asking them to share their views in this study, I sought to examine how physicians perceive palliative care, how these perceptions affect the referral process, and whether or not re-branding the service assists in providing the most progressive model of palliative care (curative and comfort care provided simultaneously). This chapter describes the study's participants, setting, procedure, measures, data analysis, and interview protocol used to attain this information.

### Participants

Participants included medical oncologists charged with patient care who are responsible for referring patients to UTMDACC's palliative care service. In accordance with UTMDACC research policy, I obtained agreement from a faculty member (Shalini Dalal, MD, Assistant Professor, Department of Palliative Care & Rehabilitation Medicine) to act as a co-investigator for this study. Dr. Dalal assisted in the recruitment of participants. A total of 80 physicians were initially contacted via email to inquire about their willingness to participate. Seventeen physicians agreed to participate and were interviewed for this study.

### Setting

All participants were recruited through their UTMDACC email address. Eleven interviews were conducted in-person inside the physicians' offices on the UTMDACC campus.

The remaining six interviews were conducted over the phone. Each interview was audio-recorded with permission from the participants.

### Procedure

After an oncologist agreed to participate in the study, I scheduled a date, time, and place to conduct an interview with each participant. At the beginning of the in-person interviews, informed consent was presented and signed. For those conducted over the phone, informed consent was procured via email. All interviews were audio-recorded and transcribed. The interview questions were primarily geared toward eliciting open-ended responses, but also included demographic information. Identifiable information was coded for confidentiality, and all audio files were kept in a secure location.

### Measures

The interview questions for this study were designed to acquire specific information about oncologists' perceptions of palliative care and to determine to what extent re-branding the service impacts the communication process during referrals (See Appendix B for Interview Protocol). For Research Question 1 (What are the University of Texas MD Anderson Cancer Center physicians' perceptions and understanding of the services provided by the supportive care service?), I asked the following questions: (a) Are you familiar with the supportive care service?, (b) What are the functions of the supportive care service?, (c) How do your patients benefit from their services?, (d) How do family members/informal caregivers of your patients benefit from their services?, and (e) How do you as a physician benefit from their services? For Research Question 2 (How does this understanding influence the communication between



physicians and patients in the referral process?), I asked the following questions: (a) How often do you refer patients to supportive care?, (b) What factors are you looking for when determining whether or not to provide a referral?, (c) When do you think is the best time in the disease process to refer a patient to supportive care?, and (d) Have you had a patient or family member ask you for a referral? If so, how common is this?, and (e) Please describe the ideal patient scenario that would trigger you to refer a patient to supportive care. For Research Question 3 (To what extent does the re-branding of *palliative care* to *supportive care* reflect the communication expectations set forth in the simultaneous care model?), I asked the following questions: (a) How has the term *supportive care* rather than *palliative care* impacted your practice of making referrals?, and (b) Do you think the name change has made it or will make it easier to refer patients?

### Data Analysis

I applied a thematic analysis to the data to extrapolate results. After transcribing each interview, I applied a grounded theory approach to the data. Grounded theory, also known as the constant comparative method, is a popular qualitative research technique that allows theory to emerge inductively from data (Chesebro & Borisoff, 2007). The first step to this study's grounded theory approach was open coding, wherein "[t]he analyst usually goes through the texts...line by line and marks those chunks of text that suggest a category" (Lindlof & Taylor, 2002, p. 219). I then developed a codebook for the data, which listed all categories, provided code names and examples for each category, and recorded the number and location of each coded incident (Lindlof & Taylor, 2002). I then applied a process of integration called axial coding in order to connect categories that shared relational content (Lindlof & Taylor, 2002).

Dimensionalization was the next step in the data analysis process wherein I tried “to tease out key variations” from the incidents in each category (Lindlof & Taylor, 2002, p. 222). After thoroughly and repeatedly combing through the data, I reached a point of saturation where no new data could be extrapolated, thus completing the data analysis process. The next chapter summarizes the study’s findings.

## CHAPTER 4

### RESULTS

As the palliative care movement gains recognition in the U.S., proponents express the need for earlier and more frequent referrals from primary physicians. These referrals depend on the physicians' perceptions and understanding of the functions of palliative care services, as well as their ability to communicate the benefits of palliative care with patients and their caregivers. However, physician perceptions of the services vary, and health care professionals have different ideas about how to increase the frequency and timeliness of referrals. In order to address these concerns, oncologists from one of the nation's largest cancer hospitals were interviewed concerning their perceptions of palliative care. Following the hospital's implementation of a name change for their palliative care center, the oncologists were asked how this change influences their referral practices. The data was analyzed using the constant comparative method to extrapolate themes. This chapter details the findings of the study.

#### Overview of Findings

Seventeen medical oncologists were interviewed for this study. The participants ranged in age from 35 to 58, and the average age was 43 years. The oncologists interviewed included 8 women and 9 men. Eight care centers/departments within the University of Texas MD Anderson Cancer Center (UTMDACC) were represented consisting of: *thoracic* (n=2), *gastrointestinal* (n=2), *genitourinary*(n=2), *gynecological* (n=1),*breast* (n=3), *sarcoma* (n=2), *melanoma* (n=1), *investigational cancer therapeutics* (n=4). The majority of oncologists (71%) identified themselves as White, Asian (24%), and one declared "Other." The majority of the participants (59%) had been delivering cancer care for at least 11 years. Interviews ranged in length from

3:31 to 20:16 in duration, with an average of 8 minutes 12 seconds. (The interviews were short in relation to most qualitative research practices. Since these interviews were all conducted while the oncologists were working, this brevity is a result of the participants' busy workload.)

In order to assess the likelihood that patients were appropriate for palliative care, oncologists were asked what proportion of their patients had advanced cancer. The majority of participants (94%) declared that a "substantial proportion" of their patients had advanced cancer. Additionally, a majority of participants (71%) reported that a "substantial proportion" of their patients died within the past year. Fourteen participants (82%) reported that they referred a "substantial proportion" or "most" of their patients to the palliative/supportive care service, while three (18%) claimed they refer a "small proportion" of their patients.

The following section describes findings specific to the study's research questions. The first research question assessed oncologist perceptions and understanding of the supportive care center services, and descriptions revealed a focus on pain and symptom control, end-of-life, informal caregiver support, and easing physician workload. The second research question evaluated how this perception influences oncologist communication with patients and informal caregivers during the referral process. Responses demonstrated an awareness of the timeliness of referrals, recognition of boundary issues regarding referrals, and management of the conversation when patients or informal caregivers are the ones who initiate the referral process. The third research question assessed how the re-branding of *palliative care* to *supportive care* impacted their referral practices with respect to the SCM, and responses revealed that although the name change does not impact their communicative approach, oncologists perceived improved patient receptivity to the referrals. These themes are discussed in more detail below.

## Perceptions and Understanding of the Center

### Delivering Patient Care

Oncologists' primary understanding of the supportive care center at UTMDACC focused on two specific elements of palliative care; patient symptom control and end-of-life care. While all of the oncologists were familiar with the center and its services, the majority of them cited "symptom control" or "symptomatic relief" as a primary service provided by the supportive care team. Specifically, oncologists described the service as assisting patients with common symptoms such as nausea, vomiting, and weight loss, while also including an emphasis on the center's attention to psychosocial issues such as depression.

Several of the oncologists explained that while they—as medical oncologists—manage symptoms, the supportive care team members provide greater expertise in the provision of symptom control. One oncologist explained, "Although we do have some skill and expertise in managing some of those symptoms, we recognize that the symptom control team...may be able to offer support that we maybe would not be able to provide patients." Another oncologist perceived the center as useful when a patient presents signs of degeneration:

If...they are having difficulty coping, concentrating, motivation, more pain, disease progression, tiredness, everything, and coming and going is difficult, then we see that change where things aren't like the way they were before. By that time, I think it's [involvement of supportive care] especially important and beneficial.

Several of the oncologists explained that while they were comfortable administering chemotherapy and treating the cancer, the center was useful in managing complex symptoms that accompany disease.

Furthermore, some of the oncologists expressed appreciation for the supportive care team's assistance with the communication process involved in transitioning patients to end-of-

life care. One participant described the communicative benefit of supportive care from the physician's perspective:

The fact that we can actually explain to patients that it's not that we're going to stop taking care of them, but that we're shifting the focus of our care to intensive management of symptoms and quality of life, I find is a very positive thing to be able to offer our patients. And for someone who's been taking care of a patient, it feels much better than simply getting to the point where you don't really have much else to offer in terms of your own treatments.

Oncologists explained how the center helps with continuity of care even after standard anti-cancer treatments are no longer appropriate.

In contrast, a small number of oncologists stated supportive care sometimes prolongs patients' lives. One referred to a recent study cited earlier in this research (Temel et al., 2010) in which the authors found longer survival rates in lung cancer patients with early palliative care intervention. He stated, "I thought the lung cancer study was great. Overall survival, I mean if that was a drug, people would be going crazy. Some pharmaceutical company would be going crazy." Oncologists cited their ability to increase or extend chemotherapy treatments as another practical application for the involvement of supportive care. One oncologist explained, "I have patients whose symptoms are better controlled and then I can sometimes give them more chemotherapy. They tolerate their chemotherapy better." Other oncologists claimed that patient enrollment in clinical trials, which are often initiated by the supportive care team, sometimes lengthen survival. One oncologist stated, "...if they are working on a clinical trial, that definitely gives that patient a chance to improve their performance status, and also they can tolerate a new treatment." Clinical trials are sometimes successful themselves with lengthening lives, and other times they improve a patients' symptoms enough to extend their anti-cancer treatments.

Similarly, oncologists emphasized that the center is useful for patients even if they are not dealing with advanced cancer. One oncologist explained the center provides services that

“help patients live better with a better quality of life with their disease or even after they have no evidence of disease.” Another claimed:

They [supportive care team members] are the best thing in the institution...The service is very important because we’ve broadcast to the whole world that we can cure cancer by crossing that cancer out [referring to the UTMDACC official logo], so when a patient comes here, they have very high expectations. We can not cure cancer. That’s a fact. When patients are told there’s nothing more we can do, it’s devastating, and they either get very angry, they get very depressed, or they can’t accept it. So the palliative care service—or supportive care service—is necessary in anything. As long as we tell them we can cure cancer, they are necessary here.

This oncologist’s perception of the center is specific to UTMDACC and its promise to eliminate cancer. She explained that the hospital owes their patients effective supportive care from the point of diagnosis as well as through all stages of disease since they are not able to eradicate cancer cells from every patient as their logo suggests.

### Providing Informal Caregiver Support

All of the oncologists agreed that the center provides much needed emotional, social, and spiritual support to the patients’ caregivers. Oncologists perceived that caregivers benefited from the services in two specific ways: (1) reducing caregiver anxiety, and (2) assisting with communication about disease and end-of-life. The reduction of caregiver anxiety was directly associated with the benefits of patient symptom relief. One oncologist explained:

...for the family members, they often are very relieved to see that the symptoms, which are in many ways the most distressing thing for the family members to see the patients go through, the emphasis on controlling those symptoms and improving those symptoms can bring a lot of relief to the family as opposed to simply aggressive treatments for the cancer which may not address symptoms patients are experiencing.

Oncologists claimed that by doing a better job controlling the patients’ symptoms, supportive care decreases the caregivers’ level of anxiety. One oncologist stated, “Caregivers, as well as the patient, are under a great amount of stress. Their relationship can suffer, their communication

can break down, and [supportive care] can help with that.” Other oncologists identified the center as helpful for families dealing with long-standing issues often unrelated to cancer that are brought to the surface when facing a health crisis.

In addition to reducing caregiver anxiety, oncologists also perceived that the center is vital to the communication process between patients, caregivers, and physicians. Effective communication is paramount when caregivers are having difficulty accepting the patient’s mortality. While one oncologist stated that supportive care “helps [caregivers] to accept the inevitable,” another elaborated on that point:

When patients are ready to die, they’re ready to die, but sometimes the families urge them to take on therapy that they don’t necessarily need. So to be able to talk about this with someone non-biased or in a neutral environment where it’s not the treating physician that they have to tell it to, it’s much more conducive to honesty and true confession of the things they need to discuss.

Furthermore, some oncologists specifically cited the role the center plays when patients have young children. These oncologists described how members of the supportive care team assist with the psychosocial concerns of patients who are struggling with how to communicate with their young children about their disease. One oncologist stated, “I have a lot of patients, unfortunately, who have young children. And how do you talk to your kids about death and dying and cancer? And [supportive care] helps with that.”

### Easing Physician Workload Burden

Most oncologists understood the involvement of the supportive care center as providing a sense of relief by easing their workload, particularly during outpatient clinics. Some oncologists admitted they simply do not have time to manage the complex issues their patients often experience. Therefore, in a practical sense, the center is vital to meeting patients’ needs. One



oncologist stated, “Because I’m allotted 15 minutes while I’m trying to treat them for their metastatic cancer, it really does not give me appropriate time to deal with a lot of the issues.”

Another claimed:

I think they do a very good job of kind of getting everyone involved and working through some of those emotional issues that patients and families have. I don’t really have another good solution for that. I could do family meetings I guess, but it’s just tough in a busy day. I haven’t currently carved out time to do that.

Several oncologists perceived involvement of supportive care as an important time-saving application, whether they are assisting with symptom control or communication issues surrounding end-of-life.

Oncologists have a broad understanding of supportive care, which encompasses patient symptom control and transition to end-of-life care. Some even view the center as a means of prolonging patients’ lives. Most oncologists understand that the center reduces anxiety for informal caregivers and assists in the communication process during all stages of illness. And finally, oncologists perceive supportive care as a practical and useful means of easing their workload. The next section explores how oncologists’ perceptions and understandings of the center influence communication in the referral process, the focus of Research Question 2.

### Communicating Referrals to the Center

“The Earlier the Better”

Almost all of the oncologists expressed the understanding that early referrals to supportive care maximize benefits for patients, caregivers, and themselves. Specifically, most of them used the word “early” when describing the optimum time in the disease process to refer a patient to the center. According to one oncologist, “I try to involve the symptom control service

as early as possible so that relationships can be established and can then be monitored over the long run and not just when symptoms get out of control.” Another stated:

I refer the patient actually even earlier than when they need supportive help, not at the end of their course when they cannot get any more therapy because, at that point, they have no time to form a relationship with the supportive care physician, and it may be too late for them to do anything for the patient at that time except send them to hospice, which I can do.

A couple oncologists took a more hard-line approach regarding timing of referrals. They stated that if supportive care could not be involved early in the disease process and the patient’s prognosis is less than six months, supportive care should be avoided and the patient should be referred directly to hospice. One oncologist stated simply, “I do not refer patients there who are on their way to hospice.”

### Recognizing Boundary Issues

While many stated that early referrals to supportive care are preferable, several oncologists revealed that the communication involved with the referral process is often challenging. One oncologist discussed how transitioning a patient to the center disrupts the balance of power between physicians:

There are some physician ownership issues, which in some ways is a good thing. If you want to take good care of somebody, it’s your duty, you want to take the responsibility to do that in its totality. You don’t want someone kind of potentially changing what you’re doing.

As stated in the previous section, supportive care is commonly initiated after the patient has failed standard cancer treatments. One oncologist who self-reported a high level of referrals described his hesitation providing referrals even towards the end of the disease trajectory:

...one area that is tough for me and I think is tough for other people is, you know symptoms increase at the end, but often you’re not quite at the hospice stage, and

sometimes they increase and I feel like I'm able to control them, but then it kind of gets tougher and there's just too many things going on.

Given the predominant perception and understanding of the center as providing symptom management, many oncologists reported that referrals were made by focusing on symptom control rather than curative measures.

Furthermore, several oncologists acknowledged the moment at which to cease chemotherapy and initiate a more palliative approach to care is not a clear-cut point in time. One oncologist described these boundary issues and the need for communication among health care professionals:

The area where I could conceive of more utilization would be in this kind of symptom management with ongoing transition to, or maybe going to hospice down the road. I think we need to be more consistent in working out what the boundaries are a little bit. If I'm talking about doing two more cycles and then we'll kind of make the decision, and they're [supportive care] talking to the family about hospice, that's when it becomes a little bit messy.

Oncologists who perceive the functions of supportive care primarily as controlling symptoms after curative treatments have ceased and/or as a transition to end-of-life care reported difficulties deciding when to involve their services and how to manage responsibilities upon incorporation of supportive care team members.

#### Managing Patient/Caregiver-Initiated Referrals

Although physicians are responsible for referring patients to supportive care, several oncologists claimed it is not uncommon for patients or caregivers to broach the topic first. One oncologist described what may be a trend:

I feel like people are much more savvy now about palliative care and it may be from reading on the web or just from networking with other patients, but people know a lot more about palliative care and supportive care now than I feel like they used to, even two years ago.

Oncologists explained patients who initiate supportive care referral conversations are usually seeking greater symptom control or assistance with end-of-life transitions. When patients or caregivers initiate referrals for those reasons, they reinforce oncologists' perceptions and understanding of supportive care.

However, more than half of the oncologists claimed that patients and caregivers rarely ask them for a referral. One oncologist, who stated she is usually the one who initiates the communication with her patients, said the reason they are not discussing it may not be because they are not aware of the service. She stated:

...most patients come here wanting to fight and they don't want to tell you that they want supportive care or that they are weak. They all try to be peppy and happy, and that they can do everything and be strong. So they need the doctor to be realistic and say, 'Listen, I need you to get some help so I can push you and I can help you and focus on your cancer.' So I usually am the one that refers patients.

Another oncologist offered a different explanation for why his patients are not initiating the referral:

They expect that if they have nausea, that I control the nausea with medication. If the patient has pain, that I prescribe things to control the pain, because I'm the one they know the best, and they are not eager to be seen by a new doctor.

Regardless of who initiates the referral to the center, several oncologists acknowledged this communication is often challenging. Furthermore, although many oncologists acknowledged that referrals early in the disease process provide better care, most did not describe supportive care as useful when symptoms or disease are under control. As discussed previously, the decision to change the name from *palliative care* to *supportive care* was made to ease these communicative problems and promote referrals earlier in the patients' disease process. The next section addresses how re-branding the service has impacted the communication process.

## Communicative Impact of Name Change

While none of the oncologists claimed that the name change from *palliative care* to *supportive care* has impacted their referral practices, many stated the new name enhances patients' responses to their referrals. One physician stated:

A name is a name for me. It doesn't make a difference. It helps the patient, though, to tell them I am referring them to *supportive care*. Some patients take it easier than if I tell them I am referring them to *palliative care*. They think it is hospice...So the patient may have a different intake, but that doesn't change my practice pattern.

Another oncologist echoed that sentiment:

I don't know if it would change my use of them, but I think it's better for patients. I think patients like that better. I think *palliative* clearly does have some other connotations. I think it was a good move that makes it easier for us to refer. I don't think it's changed my referral numbers per se, but patients react better to it.

Several oncologists supported the re-branding effort because they believe when patients are more receptive to referrals, implementation of supportive care increases.

However, some oncologists stated that the name change would have no affect on their referral practices because they will not alter the language used during referral consultations.

These oncologists provided different reasons for this response. One stated that he still identifies supportive care as a service synonymous with hospice or end-of-life, regardless of the name change: "I really have not made that transition to referring people much earlier on to the supportive care side of things...I would say I primarily utilize the palliative care element."

However, other oncologists stated their referral practices will not change because they are already using supportive/palliative care services frequently and early in the disease process.

According to one oncologist:

...I've never viewed them as a service who only takes care of the patients who are terminal. I've always viewed them as a service to take care of symptom distress. So I've always used them with patients who we're treating with curative intent if symptom distress dictates that they need to see them. So I didn't really change my practice.

Although most oncologists claimed it would not impact their referral practices, they still supported the name change.

A couple of oncologists were not in favor of the name change to *supportive care*; one prefers *symptom control* and the other favors keeping the name *palliative care*. He stated:

*Supportive care* seems like we are not going to palliate, that we are just going to support them. So to be able to palliate them psychologically, physically, symptom wise, it seems that we are achieving something...So I feel that *supportive* is a little bit too passive, whereas *palliative* it seems that we are doing a little bit more than *supportive*. To me, *palliative* does include *supportive*.

Furthermore, one oncologist claimed the name change is merely a “marketing” strategy that will not impact the center’s referrals. Regardless of whether or not they are in favor of the name change, all the oncologists’ responses provide insight into how care is provided by clinicians at UTMDACC, including medical oncologists and all members of the supportive care team. When and why oncologists involve the center influences to what degree their care reflects that of which is outlined in the SCM, which is the focus of the next chapter.

## CHAPTER 5

### DISCUSSION

One of the primary goals of simultaneous care is to eliminate the need for patients and informal caregivers to choose between disease-oriented treatment and palliation of symptoms during a serious illness such as cancer. Serving as the most progressive form of palliative care, the simultaneous care model (SCM) provides a blueprint for holistic health care from diagnosis to death wherein patients and caregivers are considered one unit for which to provide care (Meyers & Linder, 2003). Just as hospice care is one type of palliative care, palliative care is only one portion of simultaneous care (Loscalzo, 2008). Health care that adheres to the SCM necessitates the concurrent provision of curative treatments, such as chemotherapy or radiation, and palliative care, including attention to physical pain as well as psychological, social, and spiritual distress. The aim of this study was to determine if re-branding palliative care to supportive care influences the communicative referral process and ultimately results in care that more closely resembles that of the SCM. The study's findings provided insight into oncologists' perceptions of the service itself and their opinions regarding effects of the name change. Ultimately, there are areas wherein care provided correlates with the foundation of the SCM, and other aspects to be addressed and improved upon. Although some studies have asked physicians about their perceptions of palliative care and referral practices, I am not aware of any that use the SCM, the most progressive model of palliative care, as a theoretical lens. Hopefully, this new perspective will contribute to existing knowledge regarding palliative care.

This study revealed University of Texas MD Anderson Cancer Center (UTMDACC) oncologists' perceptions and understanding of the main functions of palliative/supportive care primarily correspond with the principles of the service. Specifically, almost all of the oncologists

in this study stated symptom control and assistance with end-of-life care are two main objectives of supportive care, an understanding which is on target with the philosophy of palliative care (Meier, 2010; National Hospice and Palliative Care Organization, 2010). However, although a couple oncologists insisted that no advanced cancer needed to be present to involve the palliative/supportive care team, most oncologists described the shift in focus from curative measures to symptom management as a point of initiation for referrals. This perception contradicts goals of implementation and care set forth in both palliative care philosophy and the SCM, allowing for both disease-oriented treatments and palliation concurrently (Mazanec et al., 2009; Meyers et al., 2004). This misperception may exist because, despite efforts to distinguish palliative care from hospice, some oncologists continue to perceive them as synonymous. Researchers have suggested the service remains stigmatized by an inaccurate association of palliative care with end-of-life (Fadul et al., 2009; Mazanec et al., 2009).

The majority of oncologists in this study also included addressing caregivers' needs as part of palliative/supportive care. Again, this assessment of the service is consistent with the holistic approach embedded in palliative/supportive care principles (Loscalzo, 2008). Oncologists accurately acknowledged how the service is useful in addressing psychosocial needs, which are included in the principles of palliative care. However, referrals stemming from issues other than physical pain were primarily embedded in caregivers' needs as opposed to patients' needs. More specifically, oncologists were more likely to provide referrals to palliative/supportive care based on patient physical symptoms and/or caregiver psychosocial distress rather than patient psychosocial distress. Palliative care philosophy features patient psychological, social, and spiritual distress as important foci for treatment rather than physical pain alone (Gelfman et al., 2008; Meier, 2010; World Health Organization, 2010). Perhaps



oncologists, whose specialized training is concentrated on targeting cancer with curative treatments, often do not have the training, resources, or expectations to consider non-pain-related symptoms primary reasons for referrals to palliative/supportive care. Medical schools have only recently begun to require inclusion of aspects of palliative care as a condition of accreditation, and physicians have demonstrated increased understanding and implementation of palliative care over the last ten years (Meier, 2010). Findings from this study suggest that great strides have been made in improving oncologists' knowledge base and understanding of palliative care; however it also illustrates that more work is needed to help oncologists understand that palliative care services need to be introduced to serve patients' total pain needs (physical, psychological, social, and spiritual).

Furthermore, oncologists claimed one of the advantages of involving the supportive care team is to assist with the communication process between all parties, including symptom management, psychosocial distress, and issues regarding family dynamics. They also expressed appreciation for the team's assistance with the often challenging conversations surrounding transitions to end-of-life care. Although this description of palliative/supportive care resonates with the philosophy of the service (Gelfman et al., 2008; Meyers & Linder, 2003), oncologists simultaneously acknowledged several challenges they face regarding the communication processes. Specifically, some oncologists described difficulty deciding when to initiate the referral conversation and how to proceed with communication following the inclusion of the palliative care team. Although almost all of the oncologists claimed palliative/supportive care referrals should occur early in the disease trajectory, many of the same oncologists described reasons why they hesitate to initiate referrals. Furthermore, although oncologists claimed early referrals are best, they also described diverse indicators to prompt the referrals. This ambiguity

often results in late referrals. Perhaps oncologists' hesitation to introduce palliative/supportive care is due, in part, to their drive to eradicate disease. Furthermore, researchers have indicated oncologists (and other physicians) sometimes hesitate to discuss death and dying with their patients because the physicians perceive it as a failure on their part to "cure" the patient's illness (Ahmedzai et al., 2004; Fine et al., 2010). Despite their knowledge that palliative care benefits are maximized when implemented early, perhaps oncologists' ambiguous perceptions of the service and unspecified timing of referrals contribute to delayed referrals.

In addition to ambiguity regarding timing, this study reveals that physicians' ambivalence about their role after the inclusion of the palliative care team may also contribute to fewer and/or later referrals to the service. Physicians would benefit from continued research and curriculum development on communication skills. Furthermore, physicians need to learn how to communicate with colleagues to facilitate concurrent care. Currently, only two portions of required medical education include interpersonal communication training. First, medical students are required to pass a Clinical Skills Assessment as part of the United States Medical Licensing Examination (USMLE, 2011). Training includes role-playing, and the examination "test[s] medical students and graduates on their ability to gather information from patients, perform physical examinations, and communicate their findings to patients and colleagues" (USMLE, *Clinical Skills*, 2011). Secondly, the Accreditation Council for Graduate Medical Education requires medical students to demonstrate competency of interpersonal and communication skills (ACGME, 2011). This accreditation requires students to demonstrate the ability to "create and sustain a therapeutic and ethically sound relationship with patients, to use effective listening skills and elicit and provide information using effective nonverbal, explanatory, questioning, and writing skills, and to work effectively with others as a member or leader of a health care team or

other professional group” (ACGME, *Outcome Project*, 2011). Researchers have claimed that communication skills training should be increased and improved (Back et al., 2007; Wittenberg-Lyles, Goldsmith, Ragan, & Sanchez-Reilly, 2010). Future curriculum work should address how to manage professional boundaries and communication with palliative care team members.

Early referrals, ideally at the point of diagnosis, are a principle of both palliative care and the SCM (Johnson et al., 2008; Marsella, 2009; Manzanec et al., 2009; Meyers et al., 2004; WHO, 2010). Oncologists in this study expressed a clear knowledge of this principle. However, as stated above, they also expressed difficulties initiating referrals. While oncologists saw the need for early referrals to palliative/supportive care, they were not necessarily enacting the referrals as early as patients and informal caregivers indicated a need for them. While the SCM provides a blueprint for concurrent and progressive care, it falls short of providing the infrastructure needed to instruct physicians how to navigate through this model of care. Perhaps more attention should be paid to developing a detailed instructional process to guide physicians through simultaneous care provision.

Since medical oncologists focus on traditional cancer therapies that target disease, incorporation of another team of specialists through patients’ disease process requires a great deal of communication and a shift away from their usual approach to treatment. For example, oncologists expressed concern for disruption of the balance of power when other physicians and health care professionals are involved in patient care. A lack of infrastructure to guide them through the communication processes may explain why some oncologists tend to withdraw their services when cancer is considered incurable (Ahmedzai et al., 2004). Furthermore, some oncologists described difficulties delineating where their duties end and those of the palliative care physicians or team members begin. Research indicates oncologists perceive themselves as

experts in provision of cancer-directed therapies but not in symptom management (Snow et al., 2009). The SCM does not require physicians to become experts in symptom control, however, it does call upon them to proficiently communicate with the palliative/supportive care team members throughout the disease process.

Although quantitative data (Dalal et al., 2011) revealed referrals have increased since *palliative care* became *supportive care*, most oncologists in this study insisted the name change has/will not affect their referral processes. Therefore, no connection between communication and the increase in referrals post name change can be established as a result of this study. However, although oncologists who favored the name change claimed they will not alter their communication, they expect patients will be more receptive to *supportive care* as opposed to *palliative care*.

#### Limitations

The main limitation of this study lies within the recruitment process. Although oncologists were broadly and randomly selected during initial recruitment, those with greater propensity for referrals to and utilization of palliative/supportive care services at UTMDACC were more likely to agree to participate. Therefore, a more favorable interpretation of the center's services may be reflected in this study's findings compared to that of the general population of UTMDACC oncologists. Furthermore, even with a participant population favorable to palliative/supportive care, there is still disagreement on perceptions and implementation of the service. Secondly, data consisted of oncologists' self-reports of their perceptions and practices. Although eliciting oncologists' responses from their points of view

was essential to this study, the reliability of self-report data is always questionable because it is dependent upon the participants' subjective perspectives.

### Directions for Future Research

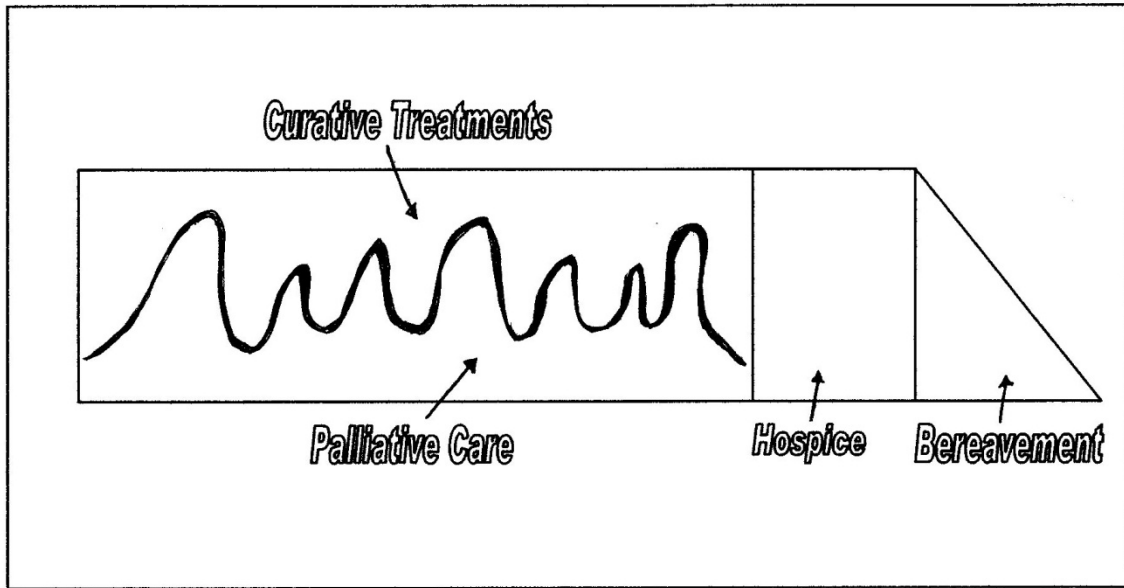
Future research should expand upon the SCM by contributing to the construction of an infrastructure that guides physicians through each phase of simultaneous care. Medical training should include role-playing of palliative care referrals with patients and caregivers and management of care with palliative care team members. Although research, including this study, reveals increased acceptance and inclusion of palliative/supportive services in oncologic care, oncologists need more assistance in the areas of communication for referrals and provision of simultaneous care. Furthermore, research indicates patients' and informal caregivers' awareness and understanding of palliative care is on the rise (Meier, 2010). Oncologists in this study expressed the same assessment. Therefore, examination of the patient/caregiver perspectives of *palliative care* and *supportive care* would add to the breadth of knowledge palliative care researchers presently possess.

### Conclusion

This study concludes that although simultaneous care should be the goal of comprehensive cancer care, more work needs to be done to develop instructions for negotiating palliative care through the SCM. Oncologists understand early referrals to the service and communication between health care providers will improve continuity of care for patients, but they need specialized training tailored to implementing referrals and managing care alongside palliative care team members. Furthermore, although re-branding *palliative care* may be an

effective approach to improving perceptions of the service—particularly for patients, as this research suggests—more research is needed to determine whether re-branding is the best way to approach the issue. Overall, as oncologists provide earlier and more frequent palliative/supportive care referrals, patients and those caring for them will have a better quality of life and unnecessary pressures on our health care system will be alleviated.

APPENDIX A  
THE SIMULTANEOUS CARE MODEL



The simultaneous care model (SCM). [Adapted from “The New Model of Palliative Care” (Mazanec et al., 2009).]



APPENDIX B  
INTERVIEW PROTOCOL

Demographic Information

Age: \_\_\_\_\_ Gender: M F

Race: Asian Black/African American Hispanic Other White

Years in Cancer Care:

<5 5-10 11-15 >15

Patients with Advanced Illness:

None Small proportion Substantial proportion

Patients Dying in Past Year:

None Small proportion Substantial proportion

Patients Referred to Palliative Care:

None Small proportion Substantial proportion Most of my patients

Specialty/Subspecialty: \_\_\_\_\_

## Interview Questions

RQ1: What are UTMDACC's physicians' perceptions and understanding of the services provided by the supportive care service?

- 1) Are you familiar with the supportive care service?
- 2) What are the functions of the supportive care service?
- 3) How do your patients benefit from their services?
- 4) How do family members/informal caregivers of your patients benefit from their services?
- 5) How do you as a physician benefit from their services?

RQ2: How does this understanding influence the communication between physicians and patients in the referral process?

- 6) How often do you refer patients to supportive care?
- 7) What factors are you looking for when determining whether or not to provide a referral?
- 8) When do you think is the best time in the disease process to refer a patient to supportive care?
- 9) Have you had a patient or family member ask you for a referral? If so, how common is this?
- 10) Please describe the ideal patient scenario that would trigger you to refer a patient to supportive care. [Probe: At what point in the patient's illness would a referral be appropriate?]

RQ3: To what extent does the re-branding of *palliative care* to *supportive care* reflect the communication expectations set forth in the SCM?

- 11) How has the term *supportive care* rather than *palliative care* impacted your practice of making referrals?
- 12) Do you find feel the name change has made it or will make it easier to refer patients?

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