

**What we talk about when we don't talk about death:
An ethnography of palliative care in the hospital**

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*For Minnie and Sara, Phoebe and Bunny, Irene, Hilary, and Laurie, Jim, David, Mary, Noah,
and the rest of the physicians*

Professor Peters-Golden, Professor de León, Dr. Berea, Dr. Graydon, my thesis classmates,
Rodger, Adam, Dani, Kar, Dillon, Aparna, Steve, Max, Kristin, Jordan, Dylan, Joe, Jake,
Tammy, Grandpa and Grandma, Grandma, Alex and Rachel, Mom and Dad

Thank you. I would not have been able to write this thesis without your guidance and support.

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How it Ends

Dr. Mary Ebner¹ and I are suiting up. Purple gloves already cover my hands and I am tying the straps of my yellow gown around my waist when the palliative medicine physician says, “You shouldn’t feel ashamed if you need to turn around or even leave the room. Plenty of people do.” While her voice is usually light and cheerful, her tone is now serious and her eternal smile is missing. We are entering the room of someone who is about to die.

The first thing I notice is the sound. An unnatural heaving or gurgling noise. We make our way through relatives. Cousins, siblings, children, and wife. All silent. People who had been sitting in chairs or leaning against the walls slowly stand and nod in appreciation as we walk to the patient’s bed. His head is tilted to the side in an unnatural position, his mouth agape, with his eyes staring off into the distance. He has labored breathing, evident by his abdomen quickly rising and lowering. Dr. Ebner sits in the chair next to the patient’s head and takes his hand in hers, ostensibly to measure his pulse. She speaks quietly and respectfully to him, but it is obvious that he cannot process what is being said. It does not matter; her real audience is the family in the room waiting for her every word. She matter-of-factly explains that the gurgling is more disconcerting to us than it is hurting the patient. Nevertheless, she decides to raise his morphine dose to ease his labored breathing. The family members are well aware that their relative will die any hour and we know that they are correct; there is not much left for us to do. After internally acknowledging this fact to myself, I turn and walk toward the exit. The family members lower their heads in thanks as I pass by. As I remove my gloves and gown, I

¹ All of the names throughout are pseudonyms to protect their identities.

look back into the room. Dr. Ebner is still making her way through, having conversations with the wife and anyone who wants to speak with her.

Outside the room, the physician and I discuss what had unfolded. As we talk, I notice the patient's son exit the room, arms crossed, shoulders slouching, looking down. His father has just died.

Death is messy, even in the best of circumstances. In this scenario, the patient was no longer in pain, and his family, as well as his medical practitioners, had accepted his fate. Shortly before my encounter with this patient, the attending physician in charge of his care had explained to the family that, due to the course of the disease, there was medically nothing more that could be done, and had called the palliative care team to manage pain symptoms. This is the care that I observed being given by the team: raising the morphine, a very powerful analgesic drug, in case the patient was still suffering.

Sometimes, however, death in a hospital is more complicated. A patient considers himself a fighter and wants to continue living at any cost, but his family and medical providers disagree on how to proceed. While his daughter insists that her father continue chemotherapy, his wife believes that the treatment is only making her husband sicker. The physician has become so attached to the patient that she cannot accept that there is nothing more to do for her patient and that the disease has taken its natural course, but at this point none of her medical interventions have slowed the disease. In the middle, the patient's condition is worsening while those around him bicker. It is precisely in these types of complicated, emotionally-charged situations that palliative care is consulted.

The practice of palliative care is not new, but its recognition as a dedicated medical subspecialty is. As such, the parameters of what constitutes palliative care are still being defined, both by medical practitioners and by social scientists, including anthropologists. The intention of this thesis is to explore one particular aspect: the dimensions of palliative care as an in-patient service at a tertiary teaching hospital.

A narrow definition holds that palliative medicine alleviates pain and suffering, providing patients with relief from symptoms and stress stemming from their advanced illnesses and their treatment at the hospital (Landro, 2014). The World Health Organization broadens that definition by recognizing that it addresses the psychological, social, spiritual, situational, moral, and religious needs of patients and their families (WHO, 1996; Kellehear, 2000). Physicians and social scientists alike have explored the spirituality of dying and palliative care's role in helping patients access it for themselves (Lawton, 2002; Cockburn, 1990; Pronk, 2005). It has been found, however, that the obligation of addressing the overall spiritual need of patients and their families at the end of life requires a different patient-physician relationship, one with which medical practitioners are unaccustomed, utilizing a different language and requiring a mutual vulnerability (Peck, 1998). Even though a consensus has been reached that honest and open communication is the best technique for communicating painful issues, providers trained in the art of healing continue to find it difficult to transmit bad news and discuss transition of care from one of fixing a broken body to one of easing the suffering at its end (Hagerty et al, 2005; Tulskey et al, 1996). Palliative care medical training can fill this void, but there is much that is not understood about how it fits into the provision of medical care as a whole.

Anthropologists have drawn on Arnold Van Gennep's theory of rites of passage as a framework to understand palliative care. In describing a ritual, Van Gennep identifies three phases – separation, transition, reincorporation – that one must pass through to complete the ritual (Van Gennep, 1960). In the study of palliative care, the process of dying is the stated ritual, with patients passing from alive to dead; in anthropological studies, focus is usually on Van Gennep's transitional phase, also called the liminal phase, often at a point where patients have already accepted their mortality and are now transitioning to their specific deaths. Julien Simard, in his research into free-standing palliative care units in Quebec, further draws on Victor Turner's exploration of liminality to view the medical staff itself as the *communitas* of "like-minded, egalitarian individuals" that helps the initiates, in this case the patients, pass through the ritual of death (Simard, 2013; Turner 1969). The English researcher Katherine Froggatt directly views palliative care's liminal phase as the space where unique (as opposed to everyday) relationships are created (Froggatt, 1997). Others, such as the Australian sociologist Glennys Howarth have used Van Gennep's and Turner's liminality to comment instead on how these patients actively continue relationships as they are in the process of dying (Howarth, 2000).

These studies, and most of this research in general, are physically situated in free-standing palliative care units, long-term care centers, or in different hospice locations, once the patient has already accepted his mortality. Palliative care, however, does not occur solely in these locations; it can also occur in the hospital (Lorenz et al, 2008). Unlike the care that is provided above, in-hospital palliative care team members often enter the discussion while the patient is still committed to a curative ideal offered by the hospital. Palliative care in the hospital is often introduced at an earlier stage, sometimes even before a patient has accepted the possibility of death, well before entering Van Gennep's separation phase. This aspect has not

been fully addressed in the research. In fact, when researchers, such as the French sociologist Michel Castra, address this stage, they focus only on how these “équipes mobiles de soins palliatifs” (mobile palliative care teams) introduce new routinized practices and a new social world into the hospital; there is no mention of rites of passage (Castra, 2007; Castra 2009). While Van Gennep’s framework is certainly helpful in studying palliative care, this thesis differs from prior studies because of its focus on palliative care in the hospital setting.

The value of this research that differs from previous work is its focus on the initial interactions that the patients and their families have with the palliative care team as they decide whether or not to enter the separation phase. In discussing this difficult phase, it is important to understand death in a hospital. The social research on this topic is comprehensive. The French social historian Philippe Ariès discusses a contemporary *invisible death* going hand in hand with the medicalization of the dying process, occurring in a hospital instead of at home (Ariès, 1977). In the absence of personal experience with the deceased, people have come to view it as shameful, discomfoting, and repulsive (Gorer, 1965). At the same time, in the hands of the medical profession, death has transformed from a social process to a biological moment (Lock, 1997). With this, doctors began to view it as an event that could be perpetually postponed; it became “conceptualized as an ailment that is amenable to intervention.” (Prior, 1989). Of course, since this is not natural, every patient eventually dies; nevertheless, loss of life came to symbolize defeat for the medical profession (Ariès, 1977). In situating themselves as the primary actors at the end of life, medical professionals assumed the role of the community, but one that is void of all emotion (Ariès, 1977). Unfortunately, even though medical professionals have redefined death and resituated themselves into the decision-making process, they proved to

be no better at discussing the reasons for and against prolonging a patient's life (Kaufman, 2003).

The goals of palliative care differ from the goals of medical care, however, in that it has no stake in determining a patient's life or death. Palliative medicine's stated objective is to alleviate pain and suffering, usually, but not always, around the time of death. Pain and suffering are inextricably linked, so much so that these terms are often combined in both social science and in palliative care research. In particular, the research focuses on how different meanings, relationships, and institutions manifest themselves as physical pain (Good and Good, 1981; Kleinman, 1988). Some anthropologists have studied pain because they view its presence as a serious deficiency in the United States' health system (Good et al, 1994), while others address the various power structures at play in defining pain and the political economic transformations in marketing different treatments for pain (Susser, 1988; Morgan, 1987).

Anthropologists study pain in this way to discover the sources of human suffering (Good et al, 1994). Medicine has focused on pain as something mostly biological, even when it results from surgical or pharmacological interventions (Good et al, 1994). Medical professionals who are insensitive and dismissive of patient's needs are viewed as harmful enough to have their relationships seen as untherapeutic (Corbett, 1986). Anthropologists have instead studied chronic pain as part of an embodied experience (Csordas, 1990).

Anthropologists have also noticed the increasing divorce between caregiving and biomedicine (Sosa, 2009). Arthur Kleinman has noted that caregiving, which he considers a primary quality of what it means to be human, is inversely correlated with status in the medical hierarchy (Kleinman, 2007). Even though there are many tasks of a professional caregiver,

caregiving is often the purview of family, friends, and the sick (Kleinman, 2007). Neither medicine nor social scientists have agreed on a single, comprehensive theory of caregiving. In spite of this, there are still a few different ideas of understanding what caregiving is. The French mid-twentieth century philosopher Emmanuel Lévinas has theorized that the responsibility to others' suffering is what brings ethical meaning to caregiving, while humanists point to Martin Heidegger's concept of life as concern and caretaking of the self (Lévinas, 1998; Heidegger, 1962). In light of this, it appears that palliative care at least somewhat reconnects caregiving with biomedicine.

The studies of the ways medicine is practiced and how death is viewed in hospitals, as well as the wide-range of research on how pain and suffering are perceived and addressed, contribute to a clearer understanding of what it means to provide palliative care. A study of an in-hospital palliative care unit, as distinct from a pain or psychiatry consultation, therefore has the potential to address the anthropologists' outstanding concerns and deliver a more comprehensive evaluation and treatment strategy for suffering.

The fieldwork for this thesis was conducted from January through March 2015 at a Midwestern tertiary teaching hospital². Since this is a tertiary care hospital, the institution has, in addition to a full complement of services, the specialists and equipment to perform advanced procedures and test experimental techniques. Tertiary care centers also have sophisticated intensive care facilities with the ability to greatly prolong a patient's life and medical professionals trained to properly use them. Such institutions create a "referral bias" in the number and types of patients that they treat. (Segen, 1992). Many of the patients in these

² The name of the institution has been excluded to protect the providers working there.

hospitals are referred from smaller community hospitals, so much of the patient population has travelled great distances for specialized care. The patients and their families are often in denial of the extent of their diseases;³ they have been sent to a hospital that is much more advanced than the one where they had originally been and they expect that this new place will be able to cure them. It is difficult for them to even consider withholding any form of life support (Keenan et al, 1997). Additionally, this Midwestern health system is a teaching hospital, and it is important for the trainees to see how things work. They are exposed to unusual presentations of common diseases with strange complications, and are taught how to properly treat them. Learners at this teaching hospital include medical students, interns and residents, as well as post-graduate fellows engaged in sub-specialty training.

This palliative care consult service has two different teams seeing patients every day. Each team consists of a social worker, a nurse practitioner, and a physician, as well as any number of learners. While most medical services in the hospital operate with a principal physician, either an attending physician or an in-hospital hospitalist, with a support staff that might include nurses and physician assistants, on the palliative care team each member has an indispensable role (Kvanstrom, 2008; Cummings, 1998). In the medical professions, it is unique for every member to be equal, but on this palliative care team, everyone plays an integral part (O'Connor et al, 2006). The breadth of the services provided dictates the breath of specialists needed.

In terms of patient care, the physician becomes the nominal leader; the physicians are “guests” on the service because they change every week.⁴ The physicians at this institution only spend an average of twenty percent of their year on the in-hospital service. In the same way that

³ Mary Ebner, MD

⁴ Jim Lehman, MD

these different physicians flow in and out of the in-hospital palliative care service, they will flow in and out of this thesis.

The nurse practitioner, trained in both medical and psychosocial facets of patient care, is the dependable worker who often stays late working into the night. She is the familiar face of the team. When the rotating physician is replaced, the patient and family, as well as the physician who ordered the consult, will recognize the nurse practitioner. On this service, the two nurse practitioners, Phoebe Sovall and Bunny Vangle, are “the glue that holds the team together.”⁵ They are involved with every case and provide the moral support for the team.

The social worker often becomes the point person for the patients who require more psychosocial care. On this service, the social workers are Minnie Beyer and Sara Bowman. In addition to treating patients, they were training a social work intern, Hilary McIntyre, for the entirety of my fieldwork. The chaplain, Irene Kerney, is tangentially involved with the consult service. She attends to the spiritual needs of patients throughout the hospital, who often overlap with those being seen by the palliative care team. Additionally, the chaplain attends to the spiritual needs of the team members themselves. The social workers, nurse practitioners and chaplain will feature prominently throughout this thesis.

Most of the data were gathered through peripheric participant observation. Like Simard in his study of Quebec stand-alone palliative care centers, I held informal conversations in the “crack of activity, participating very distantly in the daily tasks” (Simard, 2013). While some semi-structured interviews were conducted with the medical professionals, most of the data are observational, with some documentation (pamphlets, PowerPoint, etc...) complementing. Due to the nature of different locations of my fieldwork, however, I had less freedom to wander around

⁵ Minnie Beyer, LMSW

the institution than he did. Therefore, like Kaufman in her exploration into dying in hospitals, I had to follow around specific medical teams (in my case the two palliative care service teams) as they traversed the hospital (Kaufman, 2005). With these teams, I entered a number of different spaces: the patient room, the provider conference room on the hospital floors, the palliative care offices, even places outside the hospital. Like others using participant observation to study palliative care, I viewed participants in relation to patients, their families, and other healthcare professionals (Hughes, 2009). Using an ethnographic methodology allowed me to observe relationships, and in the process understand the palliative care members' place in the world (Hawthorne & Yukovich, 2003). The focus was on the initial discussions regarding death and dying, and then observing the evolution of decisions being made. This is best done by looking at specific cases.

The rest of the thesis is divided into three chapters, followed by a conclusion. *Goodbye, My Ex-Husband*, presents a narrative of a representative case. It follows the palliative care team members as they treat a single patient throughout his hospitalization and through his ultimate death. Highlighted is how the team members interact with each other and with the patient, the complicated family dynamics involved with the patient, and even the architecture of the hospital and rooms inside of it.

Prove It All Night explores the integration of the palliative care team into the institution itself. The chapter explores how the actions taken when it was a fledgling service trying to find its niche still affect it to this day. This chapter ends with an exploration of the uniqueness of a palliative care consult. Sometimes, in addition to providing for the patients and their families,

the palliative care team is called upon to help alleviate the stress and suffering of other medical professionals involved in the care of these patients.

Finally, *Some Small, Good Things* discusses how the palliative care team protects and nurtures itself, allowing it to overcome the inherent difficulties in caring for the dying and their kin. This self-care is an echo of how they relieve suffering for others in the hospital. The relationships they have created with each other make them uniquely able to use the same techniques on themselves that they use for others. While preventive activities are discussed, there is still a need for humor as an outlet for stress, as long as it occurs in a safe and private environment. This chapter explores how these men and women can every day assist everyone else against the backdrop of so much pain and suffering.

Goodbye, My Ex-Husband

This first chapter is an ethnographic account of a number of days of the palliative care service at this Midwestern teaching hospital. Using a formal definition of ethnography as a written account of the cultural life of a social group or community, this chapter will view the palliative care team as it follows a single patient, from the moment that it is asked to see him for a consultation until he is discharged for the final time (Waston, 2012). What is to follow is what Geertz would consider “thick description” (Geertz, 1994). This chapter will have many details, some of which are out of the scope of this thesis or out of the interest of this researcher. However, it is still important to include them; my aim is to offer more than a “safe and closely chaperoned form of anthropological tourism” (Bate, 1997: 1150). The aim in this chapter is to demonstrate a “cultural whole” and to set the more specific analysis in the later chapters within this “cultural whole” of the palliative care team’s everyday job and within the rest of the hospital (Baszanger and Dodier, 2004:13).

Throughout this chapter, during the course of following the illness of one specific patient, the reader is exposed to different diseases common to the palliative care team. Most of these diagnoses have numerous complications and comorbidities. Additionally, the reader gains an appreciation for the distance that patients must travel to be treated at this hospital. The relationships that patients have with family and with providers are explored. Medical and psychosocial interventions are also shown, as well as the discussions related to goals of care and transitioning to palliative and comfort care. The reader sees agency being returned to the patient and his family. There are also humorous and self-care details that will be further explained in later chapters.

The semi-fictional ethnographic vignette is used here for pragmatic reasons; it allows me to share data that would be too sensitive to write otherwise without heavy disguising and redacting. I am discussing vulnerable individuals, so it is an ethical responsibility to protect them (Humphreys, 2009). In cases where anonymity is difficult to maintain due to small sample size and distinct aspects of each individual, semi-fictional accounts are appropriate (Ellen and Firth, 1984). Additionally, ethnographers do not “discover” meaning; instead these meanings are interpretations created and conveyed to the reader over a long time in the field (Emerson et al, 1995). Even though the patient, his wife and his diagnosis are composites, these interpretive constructions, and semi-fictionalized ethnographies in general, can be “characterized as ‘true’” (Humphreys, 2009: 51).

February 9th, 8:30 a.m.

My day starts when I leave my apartment and start walking towards the hospital. My short commute usually takes me through snowy sidewalks. The hospital where I did my fieldwork is a system. The main campus is composed of many different buildings connected by insulated bridges and central courtyards. This does not even include the various outpatient buildings located throughout the surrounding towns. I head towards one of the staff entrances, and use my name badge that doubles as an electronic key to enter. There is a lot of motion, even early in the morning. Orderlies pushing equipment down the hall. Mennonite volunteers walking in pairs. People in scrubs and suits alike walking with a purpose; their day has already started. I walk down the short hallway and then ride up the elevator to the seventh floor; I am heading to the Adult Palliative Medicine offices. Right, right, left out of the elevator, through a large automatic/electric door, down a short ramp, and then into what feels more like an office

building than a hospital. It is 8:30 when I walk into the office wing that the palliative care service shares with other services.

Down the hall, there is a large room. This room is shared by the social workers and the chaplain. It is also the unofficial room where nurses and physicians often congregate. The room has a continuous desk against three of the four walls, with five computers on the desk, as well as another nook that does not contain a computer. On two of the three sides, cabinets hang above the desk, while the other side is windows. The fourth wall in the room holds a white board as well as a pushpin board in the corner. In addition to the different teams for the week, and specific schedules, the boards also contain printed comic strips and amusing patient quotes. My personal favorites are: “But he’s not just a brain. What about everything else that’s wrong?” and “Amazing care in a futile kind of way”. It is here where I spend most of my time around the office.

Although every day is different, there is a certain pattern that emerges. Before 9 or 10 a.m., team members are at their computers; the social workers and chaplain in the large room, the two nurse practitioners in the small, cramped room next door, and the physicians in either the room next to that or the one next to the kitchen on the other side of the office. In addition to getting acclimated to the day and drinking coffee, everyone is reviewing the electronic medical records, learning about the patients who will be seen during the day.

We will be tracing the course of one patient, Terrence Fredrickson, a 63-year-old man, who was added to the list as a new consult earlier this morning. I join Hilary McIntyre, the social work masters student, as we learn about Mr. Fredrickson. The consult order only tells us that palliative care has been called for Goals of Care/Advanced Care Planning. Sometimes, when a consult is requested, there may be a sentence or two of clarification, but not this time.

Our next step, therefore, is to review the electronic medical records. He was admitted to the hospital four days ago with an acute gastrointestinal (GI) bleed, but he also has hepatitis C, cirrhosis, esophageal varices (enlarged veins in the lower part of the esophagus that are prone to bleeding and rupture), and alcoholism, as well as ascites (fluid buildup in the space between the lining of the abdomen and the abdominal organs). Next, we look at the social worker note to glean information about his family and social support system. Mr. Fredrickson has an estranged daughter as well as a divorced wife whom he trusts. Although Mr. Fredrickson does not currently have a Durable Power of Attorney for Healthcare (DPOA-HC) designating who can make medical decisions for him if he becomes unresponsive, he would like his divorced wife to fulfill this role. This strikes me as odd; if they are so close, then why did they divorce in the first place? But, relationships are complicated. Hilary and I next look at the hospital case manager note to establish his insurance (or lack thereof) and living conditions. Our patient lives alone. Finally, we review the consultants' notes to determine who else is involved with Mr. Fredrickson's care. We learn that he lives about three hours away. Hilary calls this part of the morning "detective work". This patient has not previously been part of the hospital system so his medical record is confined to this hospitalization. Some of the information is a bit repetitive, but that is ok. Our goal here is to round out the picture of the patient.

February 9th, 9:45 a.m.

Before the teams divide and review patients, everyone gathers in the large office for a daily ritual of thought, which has been named Word of the Day and will be described more fully below. Some are in seats, others are leaning against the walls or sitting on the wraparound desk as we read and discuss a meditative poem entitled At Least by Raymond Carver that compels us

to appreciate each and every day, to “get up early one more morning, before sunrise.” Once this is finished, the two different teams head to separate areas to review the patients. Today, I join Noah Sawyer, a doctor in his mid-thirties whose background is in pediatrics, Phoebe Sovall, a middle-aged nurse practitioner, and Minnie Beyer, a middle-aged social worker. We walk down the hall and around the corner to the naturally-lit conference room. Since this room is in the corner of the building, large windows around the exterior walls let in rays from the sun. Around a table that could belong in any kitchen, the four of us review the patients and discuss how we plan to address the day. Each of us has a patient list printed that includes general information about the patients printed out in front of us. These usually contain between four and eight names, but today they include six. Mine includes the patient’s name, age, current location in the hospital, and primary problem, but the different practitioners can personalize what the list includes. Other options include religion, primary team, attending, first contact, nurse, and code status, as well as admission day. Noah and Phoebe also have printed out the sign-off reviews of old patients by the physician on call during the weekend.

Today, in addition to the diagnosis given for Mr. Fredrickson, the other patients’ primary problems include pneumonia, acute on chronic respiratory failure, metastatic cancer to bone, acute on chronic systolic congestive heart failure, and uncontrolled pain. Mr. Fredrickson’s primary problem is listed as acute GI bleed; when his case is discussed, however, Noah remarks that this primary diagnosis is less helpful than mention of his alcoholism and hep C, which had resulted in the cirrhosis and esophageal varices that led to the bleed. For the other patients, it is similar; we parse out the underlying conditions that drive the patients’ illnesses.

This morning, Minnie called back the resident who ordered the consult on Mr. Fredrickson and learned that the ex-wife had told the resident to leave when hospice was even

mentioned. Mr. Fredrickson had also agreed with her. Therefore, in our meeting in the office, the team discusses the need to start what they call a backdoor relationship with them. Although they have never met Mr. Fredrickson, it is not uncommon for them to work with patients who have not yet accepted that they are dying. These patients are often discharged and return to the hospital shortly thereafter. It is during this repeat hospitalization that patients and their families begin to understand the gravity of their situations. However, even though Noah, Phoebe, and Minnie know that this patient will soon be discharged and return to the hospital, they can still manage Mr. Fredrickson's symptoms, in the process gaining his and his ex-wife's trust. Then, when he inevitably returns, palliative care will be a recognizable and loyal face. At that point, they can discuss goals of care. The team decides to see him after lunch, at a quieter time, and have only the physician and the nurse practitioner speak with Mr. Fredrickson and his former wife. I will also be in the room observing.

February 9th, 1:45 p.m.

After lunch, the three of us go to the sixth floor of a different building to introduce ourselves to Mr. and ex-Mrs. Fredrickson. To get there, we must ride the elevator down to the second floor, walk through the halls that weave through this building, then across a covered, insulated bridge that connects to the primary building of the hospital, around the corner from the bridge to an elevator that takes us up to the sixth floor. This commute leaves plenty of time to discuss mundane topics such as new movies and terrible snow storms as we share the elevators with all manner of people such as nurses, patients' families, orderlies and students. Even though we have to traverse different buildings, the buildings are all connected, so we do not have to brave the harsh Midwestern winter. That Noah's pregnant wife is due within the month is often

mentioned, and the irony of allowing life to enter this world at the same time as allowing life to exit this world is noted.

When we arrive at Mr. Fredrickson's room, we sanitize our hands using one of the Purell dispensers found outside every room. Mr. Fredrickson is sitting in his bed; his mechanical hospital bed is tilted up so that he can hold conversations easily without having to lean on his side to look at people. He is talking with his ex-wife sitting next to him, and she is holding his hand. This woman certainly seems to be caring for this man in his time of need. There is a pillow placed behind Mr. Fredrickson's lower back, and a cannula threads behind his ears and up his nostrils to constantly provide him oxygen. His green hospital gown is partially open near his left shoulder so that electrical leads can be placed on his chest. These are connected to a machine that shows his electrocardiogram (ECG) on a small monitor placed above and to the right of his head. His hand rests on a thin sheet and blanket, a pulse oximeter clipped to his finger, displaying his pulse rate and oxygen level on the monitor. Above the monitor, there is a clear IV bag connected to a small, flexible tube that winds down and is inserted in the vein of his arm on the inside of his right elbow.

Dr. Sawyer does most of the talking, but explains to the patient and his wife that he will be off service next week, so he brought Phoebe, the nurse practitioner, to be a recognizable face. I am introduced as a student. Dr. Sawyer begins by explaining that palliative care is about giving patients relief from their symptoms, pain, and stresses of their illnesses. Then he asks the patient what he understands about his own illness. Mr. Fredrickson seems to understand that he has had an internal bleed due to his liver disease, but it is unclear if he grasps the gravity of his overall situation. Next, Dr. Sawyer asks about pain. Mr. Fredrickson feels bloated and his abdomen hurts. He knows that there is fluid there because it had been removed at another

hospital three times in the last two months. He cannot remember exactly what it is called, so Dr. Sawyer helps him; the procedure is called a paracentesis. In the middle of this conversation, a nurse enters the room to reattach an ECG lead on Mr. Fredrickson's chest; apparently it had become disconnected when Mr. Fredrickson moved to get into a more comfortable position.

Once the commotion is over, Dr. Sawyer asks if there is any alleviation after the paracentesis. Mr. Fredrickson says that there is, adding that he can also breathe better when his abdomen is not so big. The doctor explains that his breathing is better once the liquid in his abdomen is removed because it is not interfering with the expansion of his lungs. Perhaps a catheter can be inserted into his abdomen permanently so that he or his family can drain the liquid anytime there is discomfort, even at home. Dr. Sawyer says that of course the nurses can teach him and his former wife how to properly drain the abdominal fluid and care for the catheter. The doctor suggests that trying this should remove any discomfort, but adds that should the pain persist or worsen, there are medications that can be tried. While Dr. Sawyer is speaking, Phoebe writes the term "palliative care" on the white board across from the patient's bed. When he has finished and asked if there are any questions or anything that needs to be clarified, the patient's wife thanks us, calling us the FGT, the Feel Good Team. She tells us that when the nurse mentioned that someone from palliative care would be speaking to them, she and her husband did not really know what that meant, so they were a little hesitant. The patient agrees, adding that he was very happy that the hospital has this service. Mission accomplished. A good relationship has been established. Dr. Sawyer hands out business cards for the palliative care service. Before Dr. Sawyer and Phoebe exit, they go up to their patient, one at a time, place their hands on his shoulders, and say goodbye.

Noah, Phoebe, and I walk down the hall to the team conference room, where the floor physicians stay when they aren't actively seeing patients, to discuss Mr. Fredrickson's care. This room has computers around the edges and a central table. Whiteboards with tables of who is taking care of whom and patient diagnoses are on the wall. When we enter the room, there are a number of young physicians, all wearing either scrubs or nice clothes, with white lab coats, on the phones or looking at the electronic charts or grabbing lunch when they have a moment of peace. We find the resident following Mr. Fredrickson and tell him about the paracentesis. Noah explains that he did not speak about goals of care at this time; since Mr. Fredrickson will soon be back, the importance of this meeting, in addition to managing symptoms, was to establish a relationship with the patient and his ex-wife. Noah then asks when the patient can resume even a liquid diet, and the resident responds that, since the bleed seems to have stabilized as of this morning, the liquid diet can resume the next morning. Noah nods in agreement. Before leaving the conference room, Noah says that the palliative care team will continue to see Mr. Fredrickson on a regular basis until he is discharged. The resident replies the patient will likely be discharged within a few days, barring any complications.

March 13th, 2:45 p.m.

When Mr. Fredrickson returns to the hospital about a month later, both he and his former wife are much more receptive to having a conversation about goals of care and hospice. They have brought it up themselves with the residents on the floor. Now, since Dr. Sawyer is no longer rounding with the service, Phoebe is the only one to speak with Mr. Fredrickson and his caring ex-wife. I go as well. Minnie, Hilary, and the new physician on the service for this week round on other patients, since it is a busy day, and this will be a long consult. Phoebe and I walk

to the sixth floor; Mr. Fredrickson's new room is down the hall from where it was before. When Phoebe and I walk in to Mr. Fredrickson's room, the lights are off and the ex-Mrs. Fredrickson is sitting in the seat next to her ex-husband's bed. Phoebe and I pull up chairs; we will be here for a while, and we want everyone to be as comfortable as possible. We know from reading the chart that the patient was doing the paracentesis on his own, that he had not had any more bleeding episodes, but he had become increasingly confused and weak. Phoebe starts the discussion by asking Mr. Fredrickson to explain his understanding of what is happening in his own body. We have to strain to hear his answer, so his ex-wife starts to tell us what the doctors have told them. This becomes a theme throughout the conversation; Mr. Fredrickson is tired and goes between being more and less involved in the conversation, so Phoebe sometimes directs the questions and explanations towards his ex-wife. Her ex-husband has end-stage liver disease with hepatic encephalopathy; his liver is no longer able to remove the toxins, which is affecting his brain. The usual medications are no longer working. His liver has failed.

In a poetic way of establishing goals of care, Phoebe asks Mr. Fredrickson about his hopes followed by his fears. He wants to ultimately go back to his own new apartment, but he would not be averse to going to a step-down facility in the interim, just until he is strong enough to go to his own apartment. He defiantly says that death is his fear. Since Phoebe and I know that his physicians on the floor have mentioned that curative care is futile, and have mentioned what that implies, Phoebe uses the word "death" repeatedly, although gently, throughout the conversation. After about an hour, the patient wants to use the restroom, so we step outside for a moment to give him some time. I ask Phoebe if he would be able to leave a facility and ultimately go home, or if he would stay at whatever facility he is discharged to. Phoebe explains

that although it is possible for a person to go to a facility and eventually home, in Mr. Fredrickson's case it is unlikely.

When we reenter the room, Mr. Fredrickson asks me where I am in my training and what I want to do in my career. I explain that I am an undergraduate, and will be graduating in a few months. I am purposely vague in explaining why I am there, only saying that I plan on entering medicine. He says that I could not have asked for better people than the palliative care team members to train under. Here we are, supposedly there to help this dying man, and he is more interested in learning about a young man who had not yet said a word in his presence and complimenting his providers.

The conversation returns on topic, and continues for another half hour. This conversation has mostly been Phoebe talking, and sharing a lot of new information. Mr. Fredrickson and his wife have no questions to ask at this time; they need time to reflect and absorb what has been shared with them. Before we leave, Phoebe and I go up to Mr. Fredrickson and touch him goodbye. His former wife follows us out into the hall to thank us and hug us.

March 16th, 11:45 a.m.

When I come back a few days later, Mr. Fredrickson is supposed to be discharged to a hospice center near his home across the state the next day. In the intervening time period, Mr. Fredrickson has realized that he is probably not going to be able to return home, and has accepted this fact. He thanks us, and the team signs him out of the palliative care service. This is the last time anyone from palliative care hears from him.

About a week later, the hospice center that accepted Mr. Fredrickson emails Minnie to notify the palliative care team of Mr. Fredrickson's death. Minnie writes a handwritten note, on personalized stationery on behalf of the entire palliative care team, to the former Mrs. Fredrickson acknowledging her loss.

Prove It All Day

A number of years ago, when the palliative care team was still in its infancy at this Midwestern tertiary care hospital, a number of members were involved with a consult that is still talked about. While the specifics of the case – who was the patient and his family, what were his diagnoses, what happened to him – have long since been forgotten, a certain conversation with a nurse on the patient’s floor is still remembered clearly. The palliative care team entered the patient’s room, and before introductions could be completed, this floor nurse popped her head in the doorway, and said in an accusatory tone to the team, “I know you guys.” Without missing a beat, she turned to the patient and his family and asked “are you all right? I know who they are.”⁶ Although they never said it outright, the team members clearly got the impression that their name was being slandered before they had even properly introduced themselves to their patient, and it adversely affected their entire interactions with this patient and his family. If the palliative care team is still upset by the interaction years later, imagine how the patient and his family must have felt at the time about the palliative care team after this nurse’s inappropriate outburst.

This chapter addresses the processes that allowed the palliative care team to fit into an existing hospital system as a new care service and prove its worth in the face of considerable skepticism. While certain aspects of the palliative care team’s experience are universal to consult services, particularly a new consult service, what follows will highlight some of the unique aspects of their experience; this is likely due to inherent differences between what conventional consult services offer and what palliative care offers. First, I will discuss some of the problems that this particular palliative care service faced when it started. Then I will show

⁶ Minnie Beyer, LMSW

how overcompensation and a variation of a loss leader pricing technique was used to market the service, and some of the current issues that arise as a consequence of using this strategy. Finally, this chapter will conclude with a discussion about some of the unique aspects of the palliative care consults; how, in their alleviation of suffering, they treat other providers in the hospital as much as patients.

History

Palliative medicine was not easy to sell when the service was first establishing itself at this hospital. There was no obvious market to enter. It was offering a service that had been done by other medical professionals – who were able to incorporate all of palliative care in their scopes of practice – and it had to combat the stigma involved with mistakenly being the “harbingers of death.”⁷ In palliative medicine, the threat of death is ever present, and it appears to run counter to everything that those who devote their lives to medicine are supposed to do. New physicians often recite the Hippocratic or Maimonides oath, of which the most important lesson of “do no harm” has its own set of ethics that is ambivalent about the end of life (Jonsen, 1978). Providers sometimes viewed palliative care as actively bringing on death because palliative care is often associated with cessation of curative medicine; palliative care is the “face of death.”⁸ Death is “a massive admission of defeat” and “has allowed the old savagery to creep back under the mask of medical technology” (Aries, 1977). Aries was writing from the perspective of a social scientist; these views are naturally only amplified by medical professionals who are trained to prevent death through the use of medical technology. Physicians are sometimes in denial of death, which becomes an impediment to even mentioning

⁷ Phoebe Sovall, NP, on some of the early (and, to lesser extent, current) obstacles

⁸ Millie Beyer, LMSW, on some of the early (and, to a lesser extent, current) obstacles

the word “death” (Zimmerman, 2007). At this tertiary care hospital, with an emphasis on the newest and most advanced medical techniques and procedures, there is a “fight ‘til the end” mentality that is not always compatible with palliative medicine.⁹

It is in this toxic (for them) environment that the palliative care service entered. New physicians trying to break into an established medical community are often told by a more senior colleague about what it takes to succeed. They become familiar with the Three Pillars of Excellence: availability, affability, and ability, in that order (Victor, 1994). While local customs and practices alter the exact language used, the message is the same: to succeed, one must be available and likable (affable). It is worth noting, and often emphasized by the senior colleague, that ability is the last, not the first, criterion for success. More important is taking the burden off of the provider requesting the help. The most important aspect of being a medical professional trying to build a practice therefore becomes being available. One only exists if one is seen. Next, one needs to be affable, friendly and easy to get along with. Likable and communicative. Finally, one needs to have at least a basic level of professional competence so that there is a reason to be called. But this is almost an assumption.

As most physicians do, the palliative care consult service understood and followed these basic tenets, even if not articulated in exactly this manner; they did as any new consult service would. They accepted as many calls as possible, even if these cases could and should have been handled by the very providers ordering the consults. Much of the early work would be deemed primary palliative care, under the purview of general practitioners and hospitalists (Groot et al, 2007; Gott et al, 2012). The palliative care team became overly available, and used these

⁹ Irene Kerney, Chaplain

opportunities to build relationships with other providers in the hospital, even if the initial treatment provided by the team should not have required palliative care specialists.

That the palliative care team did provide primary palliative care service, however, is driven by a phenomenon known as overcompensation – “investing more time, greater effort in their work than is objectively required” (Aisenberg, 1988:68). They were already starting from a disadvantaged position, so they had to work harder than expected in an attempt to change the status quo and reach the level of other services in the hospital. Naturally, many groups have to overcompensate in their behaviors to fit in, such as women in academia, Jews in professional careers, or immigrants immediately following migration, to name a few (Aisenberg, 1988; Markowitz, 1994; Sluzki, 1979). There was a secondary reason for this overcompensation that went beyond establishing themselves under the Three Pillars model. They accepted more patients than they should have in an effort to combat their stigma as the “bastard stepchild of the hospital.”¹⁰

It is helpful to turn to a marketing analogy to understand how the palliative care team’s actions overcame the stigma. Over the past few decades, many qualitative techniques used by anthropologists, such as ethnography, have been adopted by marketing researchers to understand different phenomena (Goulding, 2005). Consumption, for example, represents a good topic studied through ethnography because social meaning found in material objects can be viewed as cultural communicators (Pettigrew, 2000). Despite debate, these techniques are widely accepted and even embraced among marketing researchers (Brown, 2003). Using marketing theories by anthropologists, however, is potentially more problematic. How ethical is it to equate human beings with inanimate objects, as would occur if anthropologists use theories describing

¹⁰ Rick Graydon, MD, on what the palliative care team was referred to as early on

commodities for humans? Proponents of actor-network theory have faced a similar critique: is it unethical to not differentiate between people and things. The counter-argument used, which also applies to using marketing theories, is that these are being used as analytical techniques, not ethical stances (Latour, 1997).

Loss leader pricing, also known as featuring, is a pricing strategy where a product is sold at a price below its market value to stimulate other sales (Hess & Gerstner, 1987). This is a common strategy used by firms entering a new market as a way to establish themselves, especially if the market they are trying to enter is difficult or unfriendly (Nelson & Hilke, 1991). While the palliative care service is not selling a physical product, they are still providing a service – presumably symptom management, usually associated with the end-of-life care. In the same way that a company would set the prices artificially low to entice buyers, the palliative care team offered more services to entice other providers in the hospital.

Therefore, to create this market, they went above and beyond what palliative care specialists do. Loss leading is not an applicable technique for most consult services because other specialists have such a clearly defined scope of practice. A cardiologist, for example, cannot suddenly offer to treat a gastrointestinal problem because he does not have the proper training. His specialty has to do with the heart and he needs to focus on issues involving the heart. A palliative medicine consult, on the other hand, is less defined, so it is able to be involved in patients with problems that someone else could handle.

Current

The palliative care team was successful in integrating itself into the very fabric of the hospital culture. While walking through the halls on our way to see a patient, Dr. Jim Lehman

and I were accosted by a nurse asking what we were doing. (In her defense, we were standing in the middle of the hallway finishing a conversation that we started while walking over, so it might have looked as if we were not doing anything.) When Dr. Lehman explained that he was a palliative medicine physician, the nurse's tone quickly changed into a welcoming and excited one, graciously inviting us to into the room of the patient we were about to see. At numerous times, when the team entered the hospitalist staff room, a familiar, friendly banter was continued that had been established over a number of years.¹¹ To continue the loss leader understanding, at this point, the palliative care service had fully entrenched itself within the market.

An unintended consequence of this success is that it magnified problems such as inefficiency and it allowed some providers not to take proper responsibility for their patients; these are problems that are emblematic of many medical consult services, both in the United States and abroad (Pozen & Cutler, 2010; Van der Geest, 1982). In some ways, however, the palliative care service became a victim of its own willingness to see any and all calls.

At this point, had they been selling a physical product, they would have increased the price to the true market value, and consumers would have either accepted the change or stopped buying the product. The equivalent of this would have been the palliative care team deciding to stop accepting primary palliative care patients. Palliative care, however, does not have the ability to completely alter what it had been providing. Not only would they face ethical dilemmas, but there would be repercussions from the medical community that has become accustomed to a certain level of service. Currently, they try to limit their accessibility to only appropriate calls, attempting to provide more sophisticated palliative care. In spite of this,

¹¹ It is important to realize that personal relationships can be highly variable based on the individuals around. That said, I have received confirmation from a number of different palliative care team members that these positive relationships are more standard now than earlier.

providers expecting the same level of service they were receiving before continue to consult for what amounts to primary palliative care.

The patient's problem list is long: dumping syndrome¹², anemia, malnutrition, lung cancer, radiation-induced esophagitis, altered mental status, and constipation. He reported to the hospital because of unspecified "pain". Additionally, the patient is engaging in "splitting"; he changes his story depending on which provider he is speaking with. Even though he is only now beginning to tell his true story, it is still difficult to determine his current problem. The service is consulted to discuss pain management.

The physician, Dr. Katee McDonnell, nurse practitioner, Bunny Vangle, and I set off to speak with the hospitalist to gather more information and create a plan. Sara Bowman, the social worker, is not involved with this patient because it appears to be a medically-focused consult instead of a psychosocial one. We try to find the hospitalist, a physician dedicated to care solely for the hospitalized patients, but she is neither in the hospitalist staff room nor at one of the satellite desks.

Reasoning that there are many more patients to see during the morning and trying to minimize the time lost searching for the missing hospitalist, Dr. McDonnell leaves to round on her other patients, leaving the nurse practitioner to wait for the hospitalist. Not five minutes after she leaves, the hospitalist finds Bunny and me sitting at one of the satellite desks and, without waiting for the doctor, begins the presentation of the patient to the nurse practitioner.

It is a complicated case. The patient is exhibiting classic signs of drug-seeking behavior. The hospitalist believes that something atypical is needed, but she has not been able to speak

¹² Dumping Syndrome is a group of symptoms (abdominal cramps, nausea, diarrhea) that occurs when undigested food moves too rapidly through the small bowel. Although it is usually caused after surgery to remove all or part of the stomach, this patient has not had any gastric surgery.

with the patient. It is difficult to talk to the wife because she is, according to the hospitalist, simple and unsophisticated. Additionally, the family and patient are inconsistent in their thoughts; even though they had requested that he enter hospice the week before, now they believe that the palliative care team wants to “put [their loved one] down like a dog.” They were refusing specific medications and procedures while asking for others. The hospitalist finishes her update by telling Bunny that she is going off service tomorrow, and she wants to resolve this problem in an effort to pass on a smaller service to the next person. Then she moves on.

Less than five minutes later, the palliative care physician returns. Bunny is able to reconstruct the presentation made by the hospitalist, but as a physician, Dr. McDonnell has her own questions she needs answered before a plan can be made. With questions left unanswered, the consult is abandoned for now. A morning wasted.

I returned to my fieldwork four days later and asked Bunny for an update on this patient. The attending who took over from the hospitalist was able to handle it without palliative care. The patient was discharged to his own house, a bad situation due to poor family dynamics, but nothing better could be done. The patient will probably be in and out of the hospital until he is eventually transferred to a dementia facility.

Undoubtedly, this is an extreme case. But it was hardly the only time a consult that might not have been necessary was ordered. This occurs with palliative care consults in the same way that it might occur in cardiology or nephrology. A hospitalist seeks multiple consultations to help in patient care. A cardiologist might be called for chest pain, which while atypical and unlikely to be from heart disease generates the consultation to reduce medicolegal risk. A nephrologist might be called for a mild decline in kidney function. The difference with palliative care, however, lies in the breadth of possible consultations. Frustration that multiple

subspecialists have not been able to help a patient might generate a consult. An uncomfortable hospitalization might generate another. If the primary team cannot make progress with treating the patient, palliative care may be called in for a wide range of reasons. Consequently, the social worker accepting the calls spends time-consuming hours triaging patient requests, leaving less time in the day for actual consults with the patients.

Difficulties arise because what entails palliative medicine is somewhat vague. It is defined as “providing patients with relief from the symptoms and stress of a serious illness”, but this service’s mandate has become the alleviation of suffering (“What is Palliative Care?”, 2012). A cardiologist will know if a consult is reasonable; his or her expertise is highly specialized yet limited in scope. On the other hand, it is far more difficult for the palliative care team to determine if a consult is reasonable. The mandate is not only vague, but also broad, especially if suffering occurs when the “intactness of the person as a complex social and psychological entity” is threatened (Cassell, 1982: 639).

In the hospital setting, potentially everyone is suffering, even the employees (Kufe et al, 2003). For example, a survey of general practitioners found that 86% associated encounters with death with their own suffering in their work (Schaerer, 1993). That study also found feelings of uselessness, failure, and ending the patient-physician relationship as major causes of this suffering (Schaerer, 1993). Essentially, everyone in the hospital could eventually benefit from a palliative care consult. In this sense, providers do not necessarily “dump” patients on the palliative care team because they do not want to be responsible for a problem patient (although that can still happen); instead, the palliative care team can be seen as a last resort.

The challenges in reducing unnecessary consultations are significant. Sometimes despite questions asked over the telephone and a review of the chart, a determination about whether the

consult is appropriate cannot be made. There is simply not enough information to perfectly triage the requests. Additionally, if it is deemed that palliative care service is not needed, due to the hierarchy inherent in this (and most) institution, the palliative care physician may need to call the attending physician ordering the consultation. Furthermore, the palliative care consult has to spend time determining what the real problem is, and sometimes, like the example described above, it is a psychosocial consult instead of a medical one, or vice-versa.

A Different Type of Consult

Sometimes the palliative care team is treating the consulting team as much as the patient. Twenty percent of their work is directly for other providers as opposed to patients.¹³ In these instances, it can be difficult to differentiate between when a provider is calling out for help because he really needs it or because she is stuck and wants to pass a patient off to someone else.

Dr. David Eagle, Phoebe Sovall, Minnie Beyer, Hilary McIntyre, and I enter the Bone Marrow Transplant (BMT) unit. We are here to discuss a patient complaining about migraine headaches who had a double cord blood transplant a month and a half ago. When Minnie spoke with the provider over the phone, it became obvious that the consult was asking more for a social visit because the patient responds well to people dotting on her and showing her sympathy. We are there to speak with the BMT providers.

The palliative care team knows from reading the electronic charts that the patient received the blood transplant to treat her plasma cell leukemia. She had been discharged, but returned to the hospital within a day with fever. Additionally, her comorbidities include chronic

¹³ Jim Lehman, MD

nausea, anorexia, anxiety, constipation, depression, GERD (acid reflux), irritable bowel syndrome, obesity, and a urinary tract infection.

The BMT team wants medical help for the patient's headaches. They also want someone to speak with her in a social visit. Even though the patient is not dying, the BMT providers still want help with her symptoms. Essentially, they do not know what help they want; they do not have a specific problem for the palliative care to address, which is necessary for a palliative care consult. Neurology had been previously consulted and was not successful, and the team was hesitant to consult psychiatry because they thought that they were too quick to "throw drugs" at a problem patient. Different chaplains had seen this patient but were not helpful.

Further questioning from Minnie and the rest of the palliative care team reveals that the patient was a former nurse who critiqued her own care; the BMT team had realized that she was looking for something to be wrong. They notice that she is holding her husband hostage by guiltting him into staying with her all the time, even though they live over two hours away. She also acts immaturely with her own mother, adopting a childlike manner when "her mommy" was around. It later emerges that the patient's emotional problems had led to her difficulties in holding a position at different hospitals.

The palliative care team does not want to directly become involved in this patient's care because it is afraid that going into the room and seeing her will directly play into her manipulative hands. The headaches could be a side effect of the medications, but the patient has also had terrible headaches since her twenties. Everyone in the room believes that they are likely her way of coping with difficult situations. Minnie whispers that she doesn't "think anything will work for her headaches". Near the end of this discussion the BMT team is asked what they expect to happen if this patient gets better. They come to the realization that the

patient likes being doted on, and will likely not get this amount of attention once she is discharged.

Unlike other consult services, which further compartmentalize and focus only on the specific problem that they have been consulted for, the palliative care team sees itself as unique because it offers a more holistic approach. The team asks the larger questions which get different types of answers, and is trained to communicate these back to the providers (as well as patients and families) in a way that leads to profound realizations on the part of those they are helping. For example, the palliative care team helped the BMT team realize that their patient wants sympathy more than she wants to get better. This allowed them to treat this patient with a different approach. The above example was about meeting face-to-face with a team that had tried numerous approaches that had all failed and providing guidance in seeing the big picture.

Some palliative care consults have more of a teaching component. That is, teaching the young resident physician or social worker how to deal with difficult interactions that they were not formally trained to handle. The palliative care team members are trained in how to properly deliver bad news. They know how to give a patient permission to die. They know when it is appropriate to tell a family member that she can leave her loved one's room for some personal time. They know how to help a patient and family accept they are dying. These skills were not taught in schools of medicine, nursing or social work.

There was no medical or psychosocial reason for the palliative care team to be involved with this consult at all. In fact, had it been a particularly busy day, Dr. Lehman and I would not be sitting in this family meeting at all. We were there, though, for the new resident, who was so nervous that she had called for help. Earlier in the day, Dr. Lehman had spoken with her over the phone and walked her through how one of these meetings goes. He suggested using basic

language, such as talking about the patient's "kidney function" instead of his "creatinine levels," and presenting a clear recommendation. But, this resident, who had never led a meeting of this kind before, still wanted help, and asked Dr. Lehman, as well as her own attending physician, to be there as safety nets for her.

Fifteen minutes before the family meeting, we met with the resident, as well as her fellow and attending to walk through the entire meeting. It was to be an informational meeting for the patient's family alerting them that the patient was close to dying. Additionally, getting approval from the family for a Do Not Attempt Resuscitation (DNAR) order would be prudent. It was obvious that this resident knew everything about her patient, but she was still asking a lot of questions to Dr. Lehman about how to phrase certain ideas and what kind of questions to expect from the family. Dr. Lehman was happy to answer all of the questions.

The resident ended up doing a good job leading the family meeting. She repeated the term "death" numerous times, like she had been trained to do, but did not use it so much that the family became defensive. Not surprisingly, her anxiety made her talk too much and not allow enough space for the patient's family to speak and respond at times. However, the meeting was still a success. The family realized that more care was futile, and agreed to the DNAR order, even though the patient had told his brother a month ago that he wanted everything possible done to him to keep him alive. Dr. Lehman only spoke when the family asked what the palliative care doctor suggested, and he said that he agreed with the plan of action laid out by the resident.

Dr. Jim Lehman and I were involved with that consult for the sole reason of helping that resident. Dr. Lehman viewed it as a teaching opportunity. While conducting these meetings is his normal, it is not this resident's normal; if the resident views Dr. Lehman's presence as

therapeutic, then he is more than happy to help.¹⁴ Dr. Lehman provided emotional support to this resident in the same way that he provides emotional support to a patient and her family. This palliative care team views its job as treating providers in the same vein that it treats patients and families.

Conclusion

The palliative care service still has to prove itself even though it is already established within the hospital. Problems sometimes arise from prior strategies and techniques used by the service to integrate in the hospital. In these cases, it has been able to differentiate situations where a physician is simply passing off a patient from those in which a physician truly needs help.

Oftentimes, the palliative care consult is as much about providing for the providers as it is about providing for the patients and their families. Not only is this to alleviate provider suffering; this time is also used to teach about appropriate ways of discussing death and dying. The palliative care team is always striving to maintain that balance between treating everyone and treating those most in need, and of caring for and of training the next generation of providers.

¹⁴ Jim Lehman, MD

Some Small, Good Things

On a number of occasions during my fieldwork, before entering a dying patient's room, the palliative service physician took me aside to say that it would be acceptable, even normal, to excuse myself; they have witnessed plenty of learners at more advanced stages of their training run out of the room. These learners, by definition of their transient relationship with the service, do not have the same communal coping methods, so they are more prone to let the stresses of the day – impossible situations, difficult and complex patients, all under the shadow of death – affect them.

This chapter will delve into the importance of certain techniques of self-care employed against stress. This chapter will explore three preventive activities to respond to stress. It will also investigate the use of gallows humor and sarcasm as controlled manifestations of this stress. These are confined to the privacy of a safe environment and used in such a way as to not negatively impact their work. While these will be considered as separate entities presented in a vacuum, it is important to note that, in practice, there is much overlap among them.

Stress is real

A study of general practitioners and hospital managers in England found that over half of the staff and managers suffered high levels of stress (Caplan, 1994). Factors that lead to stress among physicians include: feeling overloaded and taking the stress home, feeling poorly managed and resourced, and dealing with patients' suffering (Ramirez et al, 1996). Among nurses, three similar sources are found: work load, feeling inadequately prepared to meet the emotional demands of patients and their families, and death (Gray-Toft and Anderson, 1981).

Many of these factors that lead to stress are also shared with the palliative care team members. Due to the nature of a referral hospital, the patients have complicated histories, with numerous comorbidities, that can often only be treated (or attempted) at a tertiary care center. While the nature of such a hospital is to do anything and everything to keep the patient alive, as discussed in *Prove it All Day*, the palliative care team is frequently consulted to help the patient and family understand the provider and help the provider understand the patient and family.

The shadow of death is ever-present in these interactions. Some patients will die in the hospital or enter hospice. Others may be discharged without hospice, as noted in *Goodbye, My Ex-Husband*, but those patients usually return to the hospital, well aware that death is near. For the professionals on the team, the stress is throughout the day, not just in the rooms with patients, and rarely lets up.

It shows up in the morning meeting to discuss the upcoming day, for example, before any patient has been seen:

The first patient was a thirty-seven year old with chronic myelogenous leukemia. The leukemia seemed to be stable according to the charts, but the rest of the patient's body was failing. She had a number of young children, and both she and her husband kept on pointing to the fact that her leukemia was stable to show that she would be fine. It was going to be a difficult and emotionally draining family meeting. Throughout our discussion in the conference room, long moments of silence and gazing in separate directions, people stuck in their own minds, were broken by someone sighing and returning us to the conversation. Then, back to the silence. People wore long faces and stared at the charts, as if the answer somehow lay in med list or physiological measurements.

It re-occurs after rounding on the patients, in the safety of the office:

Dr. Mary Ebner walked into the communal office room and plopped down into a swiveling desk chair, her arms flailing over the armrests. She sighed deeply. She had just returned from another difficult morning of rounding. Minnie Beyer, a social worker who rounded that morning with the other palliative care team, swirled around in her chair to look at Mary. “Do you know Mrs. Connors? That patient with stage IV COPD? Her son was back.” Mary groaned, and her head dropped. She knew all about Mrs. Connor’s son. “He was at it again with the death camp analogy and how our health system is a form of extortion.”

It even presents at five o’clock on a Friday afternoon:

We had already discussed this patient with the resident and intern taking care of him earlier that day. He was on dialysis due to his kidney failure, and had a history of open-heart surgery, as well as pleural effusion. He had Parkinson’s disease and was now delirious. He was flinging his sheets off and swinging at anyone in his vicinity. He was pulling out his IV lines, and the nurses were afraid to go near him. The residents thought that his family was unreasonable and warned us that this would be a contentious family meeting with the patient’s wife and two sons.

They were wrong. The family was extremely supportive of each other, and the sons repeatedly mentioned that, even though they have their own preferences, they would support their mother’s decision. The patient’s wife stressed that she did not want to tear her family apart if she chose something that one of the sons did not want. One of the sons repeated that he wanted everything to be done for his father, and that if the providers did the best they could, he would be ok if his father died from not surviving the attempted resuscitation. This particular son wanted CPR to be attempted, but he did not want his father to end up in the ICU. He did not originally understand that these were connected. Slouched in his chair in the corner of the

room, he started to grasp this idea. The other son was more open-minded and requested guidance. He asked the providers in the room if they had ever dealt with this in their own families, and if so, what had they decided to do. The wife was crying and kept on dabbing her eyes with the tissue set in front of her, and the sons' faces were red and their voices cracking, fighting back tears, and being strong for their mother and each other. Watching them realize the inevitability of their husband's/father's death and struggling with it was difficult, especially after a long, hard day. I realized, and confirmed it afterwards, that it is hardest when the family is good instead of belligerent and difficult.

Preventive Stress Busters

As expected, professional burnout is a very real possibility. Burnout, which includes emotional and physical exhaustion, cynicism and depersonalization, and low sense of personal accomplishment, affects nearly half of all physicians across every field (Maslach et al, 2001). The threat is real for these professionals, especially for palliative care providers (Shanafelt et al, 2012). Accordingly, it is important to address burnout and create strategies to prevent it. Some effective measures documented in the literature include mindful meditation and reflective writing, adequate mentoring and sustainable workload, supportive work community and justice in the workplace, and self-care activities and stress-reduction for the team (Swetz et al, 2009). A comparison of hospice and palliative medicine techniques for stress reduction and methods favored by oncologists shows that palliative care focus more on burnout prevention (Swetz et al, 2009; Lyckholm, 2007). While the oncologists more frequently report strong boundaries and limits, indicating a protective and private approach, palliative care physicians indicate the importance of professional relationships and talking with others, which suggests a more social

approach (Swetz et al, 2009; Lyckholm, 2007). The palliative care physicians also tend to discuss their own mortality and role in the world (Swetz et al, 2009).

The palliative care team that I observed is exemplary in adopting the techniques supported by the research on hospice and palliative medicine physician burnout. The team has created scheduled, preventive measures with varied levels of structure: informal breakfasts at Americana Diner¹⁵, team-wide Palliative Care for Palliative Care lunches, and daily “Word of the Day” discussions.

Breakfast at Americana Diner

The first preventive measure is the informally scheduled breakfast at a local diner near the hospital. About once a month, the providers assigned to the service that week and some of the learners meet for breakfast before work and sit in a backroom that, due to the early hour, becomes a semi-private area. The waiters are recognized by the team, and each team member’s preferred dish is known. In other words, they are diner regulars.

The importance of this location cannot be overlooked; as Minnie expressed, “there is something cathartic about being outside the hospital.” These breakfasts were first conceived when the palliative care team was much less integrated in the hospital, so these breakfasts were originally used more as an opportunity to vent and complain about the culture inside the hospital. Now, as the team’s acceptance in the hospital has improved, the purpose of the breakfast has changed.

Stories are traded and laughs are shared. Some of the conversations are self-deprecating, such as this tale about crazy calls:

¹⁵ The real name of the diner has been changed.

This probably happened around two years ago. I was checking on a patient when he died right then and there while I was in the room. The patient's daughter told me to resuscitate him. I explained that he had a DNAR (do not attempt resuscitation) order, so she started giving her own father chest compressions. I tried to stop her and then the social worker on the hall comes in and erroneously says that it is the wife's decision as to whether resuscitation should be attempted. The poor wife fainted and hit her head against the plastic bedframe of the bed. It was a nightmare. It's a good thing that I left the room and then did not return. In the daughter's view, it looked like I just killed both of her parents!¹⁶

Most importantly, though, breakfast is simply breakfast with friends, without any structure or explicit work-related purpose, and the conversations mirror what you might find in any diner across the country. Complaints about bosses (here mostly aimed at hospital policies), TV shows and movies, news, and vacations and travels. It is in these mundane conversations that, for example, Sara becomes Sara, instead of just The Social Worker.¹⁷ This is the new importance of having it outside the hospital. It is only outside the work setting that the professional relationships the literature deems so important can become more than simply professional relationships. Friendships are created.

Palliative Care for Palliative Care

Palliative Care for Palliative Care, a semi-monthly lunch in one of their office conference rooms is an officially scheduled function, unlike the informal breakfasts at the diner. In one sense, Palliative Care for Palliative Care was conceived as a way to “debrief tough and emotional

¹⁶ Mia Darbi, MD (paraphrased)

¹⁷ Dr. Jim Lehman mentioned this in regards to communal dinners at a conference that many of them attended, but the same principle applies here.

situations.”¹⁸ It is a chance for older team members to guide and offer support to less experienced members. It is also a good experience for learners who are with the team for a short time. Fundamentally, this activity is an opportunity to vent in a controlled environment. In a deeper sense, however, debriefing is a chance to learn from what one is venting about; “to experience post-traumatic growth instead of post-traumatic stress disorder.”¹⁹

Even though Palliative Care for Palliative Care is scheduled into the monthly calendars, it is purposely without structure. The sessions are free flowing because people need not be restricted in order to have it as beneficial as possible.²⁰ Sometimes it serves the same purpose as the breakfast – a means to strengthen personal relationships. At one meeting, the conversation ranged from old movies to Mel Brooks to quoting funny movie lines. Finally, some of the married folks talked about songs that they first danced to at their weddings. Everyone laughed throughout the entire lunch. Not once throughout the hour-long lunch did anyone mention work.

Other times, humorous topics first addressed during breakfast continue at lunch. For example, a running discussion is how the entire service is going to start a new business; they are going to create a hospice and palliative medicine clinic on a cruise ship and name it The Last Resort. This conversation follows a standard script, starting out talking about the pros and cons, as well as the logistics, and moving on to such morbid topics as dropping bodies off the side for an all-inclusive burial at sea.

Palliative Care for Palliative Care is often leaderless: if any team member wants to do a specific project, then he or she may lead it. For example, Sara decided that she wanted to spend

¹⁸ Irene Kerney, chaplain

¹⁹ Jim Lehman, MD

²⁰ Jim Lehman, MD

one of these lunches with everyone creating a collage identifying things that are important in their lives, such as hobbies and pets.²¹

Word of the Day

Providing for the providers on this service is, however, a mission taken on by Irene Kerney, a hospital chaplain specially trained in palliative care. She is, of course, available to talk with people seeking personal help. More globally, she offers steady reminders to the team to not “let the perfect get in the way of doing good” and to realize that “taking care of yourself is not being selfish.” In her capacity as staff support, she implemented Word of the Day, a morning gathering which she believes is unique. Each morning, the physicians, nurses, social workers, chaplain, and any learners gather to discuss a poem, short story, song, or thought. Word of the Day is a bit of a misnomer; a more accurate name would be *Words* of the Day. Irene usually chooses the selections, and there is a variable distribution.²² God, life, mourning, and celebrating dead loved ones are common topics, though none of them are religious per se. While there is an aspect of pure distraction – “to just put people’s heads in a different place for a few minutes”²³ – the selections are thoughtful and help reinforce the idea that there is a bigger world outside the hospital.

²¹ Although I was not there for this activity, some of the social workers and nurse practitioners taped their collages above their desks.

²² Sometimes Minnie chooses purely humorous selections, such as Chuck Norris quotes: Chuck Norris died 20 years ago, Death just hasn’t built up the courage to tell him yet.

²³ Irene Kerney, chaplain

We are all in the nerve center.²⁴ The lights are off, so that only the natural light of the outside through the wall-length half windows illuminates the room. Irene has chosen Primary Wonder by Denise Levertov as the poem to share.

Days pass when I forget the mystery.
Problems insoluble and problems offering/their own ignored solutions
jostle for my attention, they crowd its antechamber
along with a host of diversions, my courtiers, wearing
their colored clothes; caps and bells.
And then
once more the quiet mystery
is present to me, the throng's clamor
recedes: the mystery
that there is anything, anything at all,
let alone cosmos, joy, memory, everything,
rather than void: and that, O Lord,
Creator, Hallowed one, You still,
hour by hour sustain it.

-- Denise Levertov

We decide that the poem demonstrates the struggles between the problems and distractions in life as opposed to the mystery of the cosmos. After briefly discussing the meaning of the title, Dr. Anna Berea brings it back to the work that they do. "I now schedule time in my work to appreciate the big picture. You know, it's interesting, but I now go to church every Sunday, even though this was not something that I did growing up." (She also has a puppy, and, now when she walks him, she has a chance to literally smell the flowers.) The conversation transitions to setting aside time to read. Sara mentions how she awoke early the day before so that she could read before her day officially began. I mention that I set aside time every night to

²⁴ When I asked how to refer to the large office room shared by the social workers and chaplain, Tina, a nurse practitioner student, suggested this term. Sara agreed, noting that sometimes physicians and nurses type their notes on an extra computer or just sit and chat.

read for my own pleasure, and Hilary, the social work intern, agrees.²⁵ The conversation further transitions to libraries and how we can no longer physically peruse bookshelves online, which further morphs into praising beautiful libraries around the world. Finally, Irene concludes the conversation by stressing the importance of needing to have something bigger, whether it is faith or taking a walk, and not being on the go-go-go all the time.

This is a good example of Word of the Day. There is a brief discussion of the piece being shared in the general sense, and then someone connects it to the palliative care work, the conversation wanders on a slight tangent, and then someone, usually Irene, wraps it up. Practically everyone speaks. Even though the discussions can go in many directions, there is often a work/life balance aspect. Throughout the discussions, various people share personal experiences, and through it all, people get to know their team members in different ways.

When Irene first started at the hospital, there was minimal staff support for the palliative care team. “There was not much focus on the necessity of having actual chances to support the team emotionally. The ethos of the hospital has always been to suck it up, and to me it was a crying need to do something.” So she did.

Through this Word of the Day, team members share their own techniques to avoid burnout, at this point without prodding by Irene. Themes of faith, nature, boundaries, spirituality, remembering that there is a larger world outside the hospital, family, and sometimes remembering specific patients arise throughout the Word of the Day gathering.

²⁵ My reasons for sharing were twofold. I was also seeing these impossible situations and could benefit from this self-care. Additionally, I did not feel comfortable as an emotionless researcher as people were sharing such personal and revealing information.

One reason these communal preventive measures work for this palliative care team is that team members are already accustomed to working in conjunction with other providers. Palliative medicine by its nature utilizes an interdisciplinary approach. Providers from diverse disciplines share the different coping techniques brought from their own training. Additionally, Irene is very committed to supporting the emotional aspects of the team. Dr. Graydon, the medical director, has been supportive in this.

The Americana Diner breakfast, the Palliative Care for Palliative Care lunch, and the Word of the Day gathering each has a unique degree of organization and purpose. Yet, as programs to deal with stress, they are all interconnected. They create a close community, and a safe place to directly discuss the difficulties of the work. This is especially successful because of the shared experience and knowledge of what each member is going through. It can be difficult to discuss the work with people who do not experience it every day; a number of individuals told me the difficulties of sharing with their spouses. With this model, however, coworkers become an adopted family willing to listen and help.

Visceral Stress Bombs

Sometimes the best preventative measures are not enough to hold back the tidal wave of stress and something more is needed. Providers need a stronger outlet, and humor is just what the doctor ordered. Gallows humor, named after Freud's story of the condemned man who joked as he was led to his execution, is a feeling of levity used to relieve anxiety in tragic and dangerous situations (Robinson, 1991). While not light-hearted, it is also not derogatory (Watson, 2011). It has been described by a physician as "the difference between whistling as you go through the graveyard and kicking over the gravestones" (Wear et al, 2009). Antonin

Obrdlik was the first to directly address this type of humor in a social science framework in 1942 when he analyzed its use by the Czechs under Nazi occupation (Obrdlik, 1942). He concluded that, for the oppressed, the humor acts to bolster morale and diminishes the fear of the moment.

While it can seem inappropriate to others, this humor can be used as a defense against overwhelming stress, resulting in a “bitter emphasis on the absurd that makes us laugh so that we will not cry” (Friedman, 1965: 355). Aberrant humor in different medical units is used to face a series of unresolvable problems (Sayre, 2001). It is a coping behavior used for numerous staff anxieties rising from the healthcare system (Beck, 1997). Humor in medical interactions has been found to arise for building rapport, reducing stress, distancing self from threat, normalizing feelings, and creating camaraderie in a group (Frances et al, 1999).

Humor

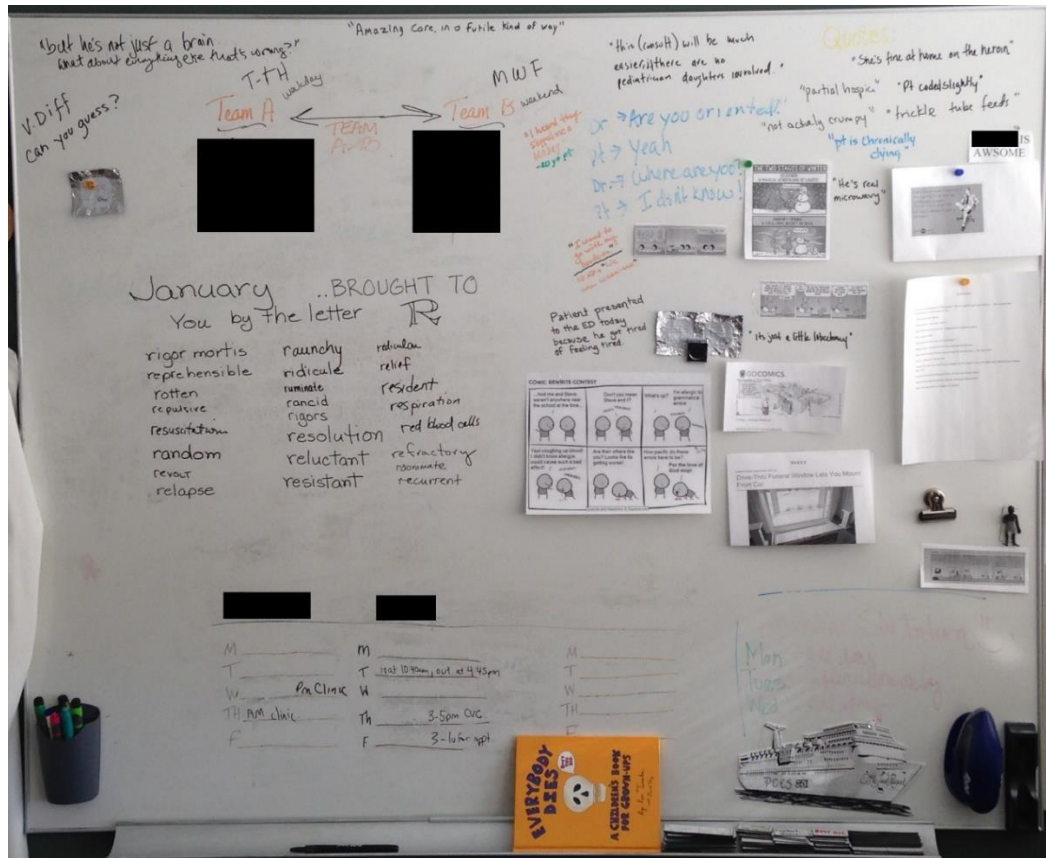
In medicine, gallows humor is a way for providers to embrace the absurdity and impossibility of situations without having these situations consume them. While medical professionals are hardly abused by patients, situations and circumstances that almost always inevitably end in death can certainly feel oppressing – “like having my head in a vice sometimes.”²⁶ It is not surprising that the palliative care team uses humor throughout the day.

Jim, Minnie, Hilary, and I were sitting around the conference room desk discussing an Ann Arbor ethics competition that Jim participated in the night before. They talked about creating a team for next year, and the conversation inevitably transitioned to team names. “I was thinking about Go Out There and Kill It.” “I think that’s a bit too long, and not everyone would appreciate it. How about The Talking Dead?” We all laughed.

²⁶ Phoebe Sovall, NP

Verbal humor is not the only humor used; in the palliative care office, an environment has been created that mocks death throughout. The largest office room contains a voodoo doll, miniature coffins and skull, little plastic sun catchers in the shapes of skeletons and ghosts, as well as a whiteboard containing that week's schedule and team makeup that doubles as a quote board from particularly strange interactions with patients, families, other providers, and palliative care team members. There is a zombie valentine card displayed and the *Everybody Dies* children's book on the board. Additionally, there is a second quote sheet posted in the kitchen alcove. In various drawers throughout the social worker room, there are water guns, a blow-up hammer, and a Wham-It! anti-stress device because they are "always stuck between a rock and a hard place."²⁷ During particularly stressful days, the team will take out the hammer and whack it on the desks. Everyone gets a turn. This happens a few times a year.

²⁷ Minnie Beyer, LMSW



In a model of the social functions of humor, humor that is judged as disparaging an outgroup serves the purpose to both “increase the morale and solidify the ingroup in addition to foster a hostile disposition toward that outgroup” (Martineau, 1972: 119). The verbal humor discussed above accomplishes the first purpose. The quotes and macabre objects accomplish the second purpose. However, the outgroup is the impossible situations and the deaths that are implicit, not the specific patients or providers. One quote is “the patient coded slightly.” This means that the patient has colloquially died, as his heart stopped pumping or she stopped breathing; it is impossible to code slightly as it is a binary situation. This quote does not ridicule the provider who said this, but rather makes fun of death. Even the quotes that do not directly address death, such as “patient presented to the ED today because he got tired of feeling tired,”

while admittedly funny, mostly due to the phrasing, still implicitly acknowledge the difficulties that the patient is experiencing throughout his end of life process, while presenting it in a funny way. These quotes serve to normalize these difficult situations (Holdaway, 1984). By this stage, it should be self-evident that even though the humor and sarcasm seem to be patient-directed, in reality the real villain is not the patient or family or other providers: the villain is the impossibility of the situations surrounding end of life and death.

Safe Environment

Humor, as well as the sarcasm that goes hand in hand, can be violent and reprehensible. And definitely funny. It can easily be misconstrued as unemotional and insensitive if one does not understand the reason for its use. Therefore, humor needs to be in a safe environment. The palliative care team has its permanent offices in a building connected to the hospital, but restricted to patients. (The backroom of the Americana Diner is also a safe environment.) Accordingly, this “backstage” behavior by the team only occurs in a space separate from public view (Goffman, 1959; Punch, 1979). Thus, this private space becomes an outlet for the stress, preventing the stress from coming out in front of the patient to the detriment of treatment. This place is where providers know they can go when everything goes wrong. The private space allows the providers to use humor strong enough to counteract the outrageousness of the experiences that blindside the provider and bulldoze the calmness allegedly created by the preventive measures, without fear of being misunderstood.

As an outsider whose sole purpose for being there was to study and observe the palliative care team, I was contaminating that safe space. At the beginning, humor was slightly repressed around me. For example, after particularly humorous exchanges in the office, as everyone was

cracking up, someone would remind people that I was there and would write this up in my pocket notebook. This quickly halted the laughter. Fortunately, this only lasted a short while; I was quickly able to join the ingroup.

I was not the only breach of this safe environment. The various learners can also contaminate it. Before my fieldwork was conducted, the team went overboard (pun intended) in The Last Resort extended joke mentioned earlier in this chapter. They had a small table separate from the desks that housed a miniature cruise ship, *The Last Resort*. Over time, this scene gained waves, a beach with sand and palm trees, even people. It was taken down, however, because they were afraid that the myriad of students spending time shadowing the unit would misconstrue the humor behind it.

Conclusion

There are many aspects to the work done by the palliative care team that is out of its control. The work is high stress, and the team gets bombarded from the patient and family as well as from their medical providers. Even when these relationships are smooth, the nature of the work is emotionally draining. There is nothing curative that can be done for the patient.

Preventive measures are taken in an attempt to control the stress inherent in the palliative care team's work. When these preventive measures are not enough, then humor and sarcasm become emotional responses, potentially misconstrued by outsiders looking in, but when exhibited in a safe place, essential to the team's emotional wellbeing. My observations of the palliative care team included witnessing much regenerative laughter in private and deep, engaged, and empathetic care to the patients, their families, and providers in public. The yin and yang, always entwined and ultimately forming a circular whole.

What We Talk About When We Finally Talk About Death

Like many young researchers, I began my project with illusions of grandeur, setting out to find some ultimate truth. In my case, this was to discover whether the specialty of palliative care represents a paradigm shift in the treatment of patients, or whether it reflects the maturation of a new subspecialty in the integrated care of a patient with an advanced illness. I wanted to know how this seemingly contradictory specialty fit into the rest of medicine. And I hoped to find a better way to incorporate palliative care into a hospital and export my knowledge to the rest of the country.

I quickly learned that I needed to narrow the focus of my research. I was only studying a single palliative care service at a single hospital, with its own idiosyncrasies. I would not have enough breadth of data to make any sweeping conclusions. In response, I dove further into the study of this palliative care team. I wanted to know what did and did not work *for them*. I learned how *they* interact with patients and their friends and family, how *they* treat other medical providers in the hospital, how *they* care for each other. I pushed my original inquiries to the back of my mind, and focused on presenting *this* palliative care service in the most honest and nuanced way that I could.

In doing this, a funny thing happened. In concentrating solely on this one palliative care service, I found that I could return to my large question and answer it. Palliative care is not at all inconsistent with the rest of medicine; it is providing healing at the end of life. Instead of viewing death as a finite defeat, it is viewed as a process.

One of my personal favorite cases occurred the Friday before Valentine's Day. I accompanied Dr. Lehman as he rounded on an elderly man he had been following for the week.

This man, sitting in a chair next to his bed, joked with the “doc” about procuring a rose to give to a nurse who he had had his eye on. A few minutes later, a lady walked into the room, and the patient introduced us to “that nurse”: his wife. Simply thinking about giving his wife a flower was not enough for him, the importance lay in the act of actually giving her the flower. Even though all roses eventually die, they represent the love that lasts beyond the death of the flowers. Although he was explaining this to Dr. Lehman and me, he was looking at his wife, who by this time was sitting at the edge of his unoccupied bed, and he held her hands in his. When he finished, she brought the interconnected hands up to her face, leaned in, and kissed the intertwined fingers.

Palliative care allows healing and peace at the end of life, and helps everyone else frame it in this same way. Death is no longer seen as a defeat; end of life instead becomes another time to provide care. The body may no longer be healing, but the palliative care teams heal the soul, allowing patients and families to have a sense of control again. It is working with the patient and his family to achieve their goals, and respecting all of their wishes, whatever they may be. One patient’s wish was to attend one more hockey game, so Minnie spent hours coordinating with the hospital and the local NHL team to make this a reality. I also learned of a Pentecostal patient whose wife would not agree to change his code status to DNAR even though his care was futile. The hospitalists could not understand why the wife was allowing her husband to needlessly suffer, and the patient’s wife could not understand why they were pressuring her to change her husband’s code status. The wife would not even speak with the hospitalists due to this perceived bullying. The palliative care team spoke with the wife and learned that she believed that everything has to be done for her husband and to continue to believe in God’s ability to save him because if she stopped believing in God, then her husband will die. The palliative care team

explained this understanding to the hospitalists, who then spoke to the wife every morning and explained what they would do for the patient that day. The palliative care team is hardly simply a pre-hospice service, nor are they the dreaded death panel. They help patients achieve their version of a “good death,” whatever and whenever it may be.

Sometimes, all that is needed for the patient is someone to hold his or her hand and listen. In the same way that hands pull the baby out of the womb, now the medical providers are holding hands and allowing the patients to exit the world on their own terms. The truth is that palliative care providers are not so different from other medical professionals; they are just part of what is valued in medical care. Even though their work occurs at the end of life, they still have the same ideals as any provider. Formulate a plan that makes sense for the patient and family. Listen. Communicate. Empathize. Heal.

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