

## *FIVE*

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### THE RESCUED JOURNEY

With previous reports from staff that the adult daughter (D) of a new patient is having a hard time accepting hospice, a hospice physician (MD) enters the patient's room and begins a physical exam:

MD: She's very peaceful. We look for certain signs that she's not. I just started my exam, so I can tell you more soon. What is her story?

D: She had a UTI (urinary tract infection). [talks about Parkinson's medicine upped from one to three pills] After 2 weeks she was given some liquid and it just went into her lungs. Then they [doctors] talked me into giving her a pick line [continues to talk about treating her mother]. I thought it would be a gradual increase. I told her (the MD at the hospital) that's too much and she upped it anyway. I went to my druggist and he agreed. You know, I might lose my mother, and so I went to another hospital. [talks about giving her pints of blood and other treatments and her mother's low blood pressure] The doctor told me the kidneys were functioning normal, and he gave me such a good report and I said if you are giving me such a good report then why are you telling me to go to hospice? And he said because of the other problems. A simple UTI turned into this.

MD: It sounds like a lot of things are going on. When was she last able to communicate?

D: Yesterday. She nodded her head and said a word. But now she's sedated. I guess I'll never be able to talk to her again.

MD: [Explains the last thing to go is hearing—encourages daughter to talk to her and touch her] She looks very comfortable and that’s my main goal, and I’ll make sure that happens. I’ll do a quick exam, but typically without food or drink it’s typically 7–10 days.

D: Yes and she had TPN (artificial nutrition) at the hospital.

MD: Yes, so that will be off by a couple of days. [He explains things that will tell staff if she’s actively dying, like blood pulse, etc.]

D: Yes. [Starts crying.]

Two days later, during the patient’s routine physical exam, the daughter questions the hospice physician:

D: Do you think this is the right thing? Do we need to feed her?

MD: [Explains the likelihood of aspiration, and with no food for so long it’s likely she’s not hungry.] I think what she’s doing now is saying good-bye.

[Patient has moments when she’s opening her eyes]

D: [Cries.] It’s hard to say good-bye to someone you love so much.

MD: I think that you tell good, great stories about them. She must have been a great mother because you are here at her bedside. Tell her you love her. [He shares a personal story of saying good-bye to his grandmom.]

Three days later, the daughter began yelling and complaining about her mother’s pain medication and care. The director of the facility had to come in and mediate the situation between the daughter and the hospice physician. The hospice chaplain was there and explained that the daughter “really let herself go.” The next morning, the chaplain reported that “she’s accepting, more accepting today.” The patient died the next day.

Although the patient and her daughter were able to obtain end-of-life care that enabled a physically comfortable and pain-free death, the transition from curative to hospice care was a violent rescue for this family. The two terms, “violence” and “rescue,” might seem highly dissonant. But on closer examination, it is the violence in late-stage hospice rescue that we believe creates many of the unhappy, damaging, and broken experiences for dying patients and their families. Once hospice enrollment is posed to a family (either by referral or internal initiation) in the late stage of illness, the patient, family, and medical/nonmedical practitioners might be faced with turbulence, fury, vehement feelings, clashing, jarring, discord, and alteration of life plans that are nothing less than shocking.

In this illness journey, the rescue confronts patients and their families who have experienced prolonged suffering, unnecessary treatments in search of a cure, and numerous visits with independent health care clinicians. As hospice materializes, the abrupt modification in approach to care may seem brutal, abusive, and disempowering for patients and families who are asked to change their way of thinking about survival and care. All things curative and preventative cease to exist as they were, and all systems are forever changed by the presence of hospice. In this opening narrative, the daughter's disdain for clinicians, her account of numerous treatments and hospitals along the journey, and the desire to continue feeding her mother reflect some of the painful challenges that accompany inadequate time and communication during the change from curative care to hospice. Conflict and difficult realities emerge from the rescue, making this late-stage transition part of the reciprocal suffering for the family.

In this chapter, the rescued journey unfolds through the stories of the Von and Wall families, both of whom received hospice care and yet lived two remarkably different illness journeys. Each family story reveals real turning points that ultimately define the rescued journey: the move to palliation, the move to team management of health care, the move toward open communication about death and dying, the chance to plan for end of life, and the opportunity to gain community. The entry of hospice care repositions patients and families in an illness journey. To illustrate the complexities in this transition, the five communication characteristics of care within an illness journey (which were introduced in Chapter 1) are reviewed through each family's narratives.

## **CURATIVE-ONLY APPROACH AND THE DIAGNOSIS**

A curative-only approach to the diagnosis includes conversations about disease and illness that focus on treatment options and exclude talk about the disease trajectory and an introduction to hospice care. The physician's fear of destroying hope and being uncomfortable with the emotional reactions of patients and families contribute to the decision not to address the topic of end-of-life care (Brickner, Scannell, Marquet, & Ackerson, 2004; Weissman, 2001). Rather, a deliberate emphasis on overly aggressive care often results in and adds to the difficulty in prognosticating and predicting death (Brickner et al., 2004). Overestimates of survival and delayed conversations about end-of-life care result in hospice referral too late in the dying process (Huskamp et al., 2009; Schockett, Teno, Miller, & Stuart, 2005).

A plethora of treatment choices and options are offered to patients and families under the curative-only approach, inadvertently reinforcing continued aggressive care (Gillick, 2009). Anti-cancer therapies are abundant and provide an increased arsenal of tools available for physicians to offer patients and families (Mintzer & Zagrabbe, 2007). Ultimately, the presumption of cure informs decision making, displacing death and dying as a distant, deniable possibility. Requests for aggressive care continue as a result of insufficient information about risk/benefit balance, the prognosis, and the expected trajectory of the disease (Weissman, 2001).

The constant negotiation of treatment choices delays a hospice referral (Waldrop, 2006). For example, lung cancer patients who receive chemotherapy are less likely to have a discussion about hospice with their physician than those who do not receive treatment (Huskamp et al., 2009). Although the U.S. Medicare Hospice Benefit affords terminally ill patients 6 months of hospice care, the median length of service is less than 21 days (Centers for Medicare and Medicaid Services, 2008; Connor, 2007; National Hospice and Palliative Care Organization, 2008). A short enrollment period in hospice care increases the difficulty for families to accept death and dying as part of their loved one's illness journey, making the move to and care in hospice a frustrating experience (Schockett et al., 2005).

Short hospice enrollments also reduce the time for necessary discussions about end-of-life care issues, leaving patients and family members with a limited understanding of end-of-life care (Malloy, Paice, Virani, Ferrell, & Bednash, 2008). A lack of understanding develops from compartmentalized information and results in under- and overestimates of medical care outcomes (Fried, McGraw, Agostini, & Tinetti, 2008). For example, hospitalized patients overestimate the chance of surviving cardiac arrest and have an overall poor understanding of cardiopulmonary resuscitation (CPR) (Kaldjian et al., 2009). The opportunity to fulfill patient wishes at the end of life shrinks drastically as delays occur in end-of-life care paperwork (such as advance directives), which often is completed on the day of death (Levin et al., 2008).

Currently, we offer too many treatment choices in which they will not "work" (Gillick, 2009); this curative-only approach to diagnosis augments the willingness of patients to undergo aggressive care, delaying a hospice referral as well as the patient's understanding of end-of-life care. Despite awareness of the terminal prognosis, some health care workers continue to restrict full, open disclosure when working with terminally ill patients and their families (Field & Copp, 1999). The lack of information and time in hospice care results in a turbulent dislocation of patients and family members despite their move from the isolated to the rescued journey (Marsella, 2009). The family narratives presented here expose the uncertainty of a curative-only diagnosis and the impact it has on family communication and decision making.

## **Von's Story of Diagnosis**

The Von family's was a long illness journey spanning a decade, with acute care occurring over the last 2 years and hospice care for 2 weeks. The Von family narrative about Vance's illness is shared by son Gary.

We convinced him to get a long, long overdue physical in 1997. He had not received a physical since his recovery from a heart attack 3 years previous. Everything checked out just great, except one thing—his PSA count was sky high. Not one of us knew what a PSA count was, what it was connected to—nothing. He was sent to an urologist for medical counsel. As time went on, we learned what prostate cancer was. All of the doctors and medical personnel used the same phrase on us: "If you had to pick a cancer, this is the one you want."

Dr. J analyzed all of the data. He explained the situation to Vance like this: You have several bullets you can fire at this thing, and it is up to you how to do this. Vance chose the way that gave him the most bullets to shoot. Through the years, Vance underwent numerous treatment paths in an effort to reduce his PSA count. Eventually, his prostate was removed. This was followed by massive amounts of radiation.

Ten years later, the cancer returned. The prognosis was not good. This took us to see a doctor about using a new process called Cyberknife. The machine was fascinating, and Dad was encouraged. Well, before we could get started with treatment, more scans and x-rays were required to completely identify what and where his cancer was. This evaluation process seemed to drag on and on. A term we began to hear repeated over the next few months came up: "Due to the complexity of your case. . . ."

The role and communication of the medical professionals seen by the Von family set a precedent for the diagnosis; their illness journey was predicated on a curative prognosis. By explaining that the cancer type was "the one you want," medical staff gave the Von family the impression that Vance's cancer was curable and beatable, and that the odds of full recovery were in their favor. Although medical staff may have tempered the delivery of the diagnosis with this explanation, the family understood the seriousness of the disease. Gary explains:

We heard several doctors over the last few years say, "If you have to have cancer, this is the type to have because it moves so slowly." What they were telling us was correct but none of us wanted to know there was a "good" type of cancer. We knew enough that all cancers were bad.

Still, these statements influenced decision making during Vance's illness journey. Decisions to undergo numerous treatment protocols, remove his prostate, and endure radiation were based on the underlying possibility of cure. As Gary reflects on the journey, these statements facilitate a discursive consciousness for him; he recalls hearing them numerous times throughout the illness journey and recognizes them as meaningful:

Nothing personal but I do not want it [cancer]. Vance, my father, best friend, golfing buddy—you name it and we did it—died from prostate cancer complications. Yes, if this is the one to have, I do not want it.

Other statements soon became familiar as the “complexity” of Vance's illness progressed without improvement despite aggressive interventions. Given that the initial diagnosis was value-laden with repetitive messages regarding cure and “several bullets” to fire at his disease, Vance continued to seek remedy. Dr. J took a patient-centered approach in explaining to Vance that it was up to him “how to do this.” Plenty of treatment options, combined with an absence of the possibility of something other than cure, enabled all parties (Vance, his family, and the medical staff working with him) to stay within the performance confines of cure, negating the possibility of dying and focusing only on living.

The curative approach was also fueled by Vance's drive and desire and the collective nature of his family. There were no relational constraints within Vance's illness journey—the choices were his and his alone to make. His family supported every decision and did not question him. Gary explains, “As with most children in a good, honest family environment, you feel your family is the best. So do I.” The Von family is best typified as having a *consensual* family communication style based on high conformity and high conversation (see Chapter 3). The father–son relationship was very close yet also traditionally based on obedience to parents and parental decision making:

Most of the time, I would address him as Old Man. In no way was this meant or taken disrespectfully. My respect for him was immense. At the age of 6, I got his permission to begin calling him Dad instead of Daddy. In the last 6 months of his life, this process reversed. He went from Old Man back to Dad and finally Daddy.

Gary's description of asking permission to call him Dad characterizes the family's emphasis on family hierarchy and traditional parent–child relationships. The history of family homogeneity and collectivity deepened as Vance's illness advanced. The influence of time, suffering, and caregiving

impacted Von family roles; this is poignantly identified by Gary as he reclaimed the “daddy” name once again.

The curative approach to the Von family’s journey caused family roles to shift as the journey progressed. When the family found out that the PSA count was high, Gary explains that “not one of us knew what a PSA count was.” Von family literacy about the disease was low, yet “as time went on, we learned what prostate cancer was.” The approach to the diagnosis was collective: “We” instead of “he” learned about the disease. Medical literacy became a common goal within the family. Yet decisions regarding treatment were Vance’s, and the family supported those decisions. Thus, the diagnosis and subsequent decision making did not prompt a disruption to privacy management within the family due to its high conformity style. Yet, 10 years later when the cancer returned, Gary narrates the contextual positioning of Vance as “we,” denoting a shift in the performance of family roles. “*We* had another appointment” and “before *we* could get started with treatment” implies a more involved role for Gary in his father’s journey. This movement from Vance’s position to “we” situates Gary’s family role in the care process as manager/caretaker supreme, which grew stronger as the journey progressed.

### **Wall’s Story of Diagnosis**

The Wall family pursued a curative approach to John’s terminal diagnosis of stage IV adenocarcinoma of unknown primary, a rare and lethal cancer. John, his wife Caroline, and their son Charles endured a dramatic 7-week illness journey, including an ill-fated trip to the nation’s largest cancer center where John almost died in a hotel room. Ultimately returning home, John received hospice care for 2 weeks before dying. Here Caroline describes her recollection of their diagnostic communications.

### **Don’t Do Anything**

We called the doctor and got in to see him. “Gee I don’t think that it’s pneumonia this time. I think you’ve got gall bladder.” So we went to a different doctor, Dr. T. Dr. T. said, “Um, I don’t know what this is. I think it’s gall bladder, but I want to do some tests.” So he sent us over to the hospital for presurgical testing, which included a lot more tests than I have ever seen for anything like that [gall bladder]. So we went in for the CT scan, and I remember sitting behind the screen of the machine with the technician and looking on the screen as the test was happening. And I’m not a medical person, but I knew when I saw white spots everywhere in what I figured was his liver, and I didn’t know what that really meant but I knew that something was odd

about it. And the technician turned around and looked at me and said, "He's supposed to have gall bladder surgery tomorrow?" And I said, "Assuming that this test comes back negative." And I don't know why I said that or what was on the screen. And he said "Oh" and put his head down.

And so I kind of had an uneasy feeling that day, and that night John was preparing for the surgery, eating, drinking, and the phone rang. And it was Dr. T. He said, "I don't know your husband, and I don't know his personality, so I'm just going to tell you. There's spots on his liver." And I don't know what my face looked like, but John must have seen it and kind of got upset and stopped and he said, "What's wrong? Tell me what the hell's wrong?" And I said, "There's spots on your liver." And John kind of got upset. And I said, "Dr. T. can I call you back? This is really important, and I need to talk to my husband." And he said, "No, go into the emergency room right now, right now." I said okay. So I hung up the phone, and I told John we need to go to the emergency room right away because there is something wrong. And he said call Charles right away, our son. So I called Charles and told him I think you need to meet us in the emergency room.

So we went up to the emergency room, and Dr. T walked in and threw all of these images that I had already seen throughout the day up there. And he said these are spots on his liver. We're not doing gall bladder surgery. And I said, "Okay, what are we talking about?" And he said, "Well, we need to do tests." And he said, "I think this is cancer." And I remember my legs just getting so weak that I couldn't stand, I couldn't walk so I just sat down on the ground, just scared to death. And I looked at John, who was sitting there very, very quietly and he didn't say anything. And Charles was throwing a fit: "Well, we'll just get you to another doctor. We'll just make sure that this is okay . . . blah blah." Dr. T said, "I want to keep you overnight, and I want to do these tests in the morning. I want to do a lower scope."

By then it was day 3. They did a lower scope on him, and they came back and said he's got colon cancer. They showed me these pictures of his colon, which were just really ugly. And I thought, all right, he can get this done, but later that day they did a liver biopsy and told me that it had spread to his liver. Dr. T actually came up to me while we were in the hospital that day, while I'm panicked and worried, in front of a whole bunch of people and said, "Don't do anything." And he's pointing his finger at me and he's almost yelling at me. "Don't do anything," he said. "No surgery, no chemotherapy. Don't do anything." And I thought, don't you dare take the hope away from me. So I didn't tell John any of that. It might have been better for John in the long run, but it gave us, both of us, hope. But he never told John. He didn't get along well with John's personality, so he wouldn't even talk to him—it was always me.



So Dr. T sent us to the Cancer Center with this diagnosis. We get down there, the doctors treated us really well, and I really wished we stayed. And I remember this quote, “This is kind of like a person who has had a very bad heart attack. This is something which you are going to have to live with for the rest of your life.” He didn’t really say “You’re going to die.” He said, “This is something you are going to have to live with for the rest of your life.” Which if you think about it, it’s basically the same thing, but such a kinder way of telling me. And I thought I can live with this stuff because the word “live” was in there.

Although the Wall family managed to get a clear diagnosis—cancer—it is not clear whether they received or understood the extent of the prognosis either because it was never detailed for them or because the family had such a drive for hope and cure that they couldn’t/wouldn’t hear it. Several communication variables within the testing phase problematized their understanding of the prognosis. First, while the diagnosis was given to the family as a whole (with Caroline, John, and their son present), earlier bits of information had been provided to Caroline only. Second, Dr. T provided concrete advice about the prognosis (“Don’t do anything”), yet Caroline recalls being told this almost haphazardly in a crowded hallway. Third, medical staff at the Cancer Center said that her husband could live with this disease and compared John to a heart attack survivor. Finally, the initial diagnosis was predicated on more tests to determine a specific treatment plan. All of these factors, especially the fact that the initial prognosis with Dr. T was not formally delivered, contributed to the family’s belief that John could survive this disease (Fried et al., 2008).

Unlike the Von family, John’s cancer diagnosis sparked turbulence or a privacy dilemma for the Walls. Ironically, turbulence was not created for the patient but rather for his wife, Caroline. She was given her husband’s bad news (“There’s spots on the liver”) and was placed as a third-party interpreter for her husband. She explained that the physician “didn’t gel well with John’s personality,” and consequently her role as patient advocate emerged very early in John’s illness journey. The change in care setting, from hospital surgery room with a specific treatment plan to the hospital emergency room laced with uncertainty and continued testing, established John’s initial diagnosis as a turbulent event that triggered a call to their son and eventually a myriad of whirlwind decision making.

For the Wall family, the cancer diagnosis was a turbulent event that was approached with the hope of cure. The family struggled to find collectivity in the management of the news. Caroline, “scared to death,” was demobilized and sat on the ground. John didn’t say anything, while their son began to question the competency of medical personnel. These actions reflect great variation in meaning-making for this family, suggesting that

communication with each other would not emulate the collective decision-making style of the Von family. The absence of connectedness and interactivity, as evidenced by their lack of discussion on the topic, paved the way for challenging family decision making. John's resentful nature about his disease left Caroline as the sole advocate and negotiator of the illness journey. Caroline explains how she felt:

I felt like I wasn't doing everything that I could have. I needed, for me, not for John, I needed to know that I had done everything that I could possibly do and gone down every alley that I possibly could; it was a needle in a haystack and that's the words they used to describe his cancer.

Armed with the drive and determination to find a cure and do everything she possibly could, Caroline embarked on a shared illness journey with John to save his life no matter the cost. There was no conceptualization of the "other" (i.e., dying); she could only see living and her role in the illness journey. She was determined to make sense of his illness by talking to physicians and doing everything she could.

A disruption in boundary coordination, or the co-owning or sharing of private information that belongs to people collectively (Petronio, 2002), was caused by the medical staff who engaged Caroline instead of John. Caroline later explains that they showed her pictures of John's colon but does not recall whether John was present. When medical staff fails to adequately communicate with the patient, the contextual position of utterances (such as poor prognosis) falls to the family. Caroline was then faced with the compromising positions of 1) relaying hurtful and harmful information to her husband about the gravity of his illness, 2) dealing with the devastating information herself, and 3) organizing a plan and care for his restoration. Inevitably, based on the family communication pattern and John's reaction to the diagnosis, this creates a relational constraint for Caroline, as John now relies on her to be his voice and make decisions. He is actively dying and feeling horrible, and he is unable to manage his care even if he had the inclination to do so. The constraint here is that Caroline approaches decision making from her role, as wife and supporter, rather than from his perspective as the patient; family fear and guilt often result in continued aggressive care (Weissman, 2001).

The drive and search for cure supersedes previous relationship privacy rules or communication that regulates the flow of private information between family members. Violation of privacy rules becomes necessary to keep the hope for cure alive. Although Caroline saw white spots on the screen during John's MRI exam, she did not tell him. When Dr. T told her not to do anything (i.e., treatment), Caroline did not relay this information

to John. She felt that the only thing she could offer John at that point was hope even if that meant violating the truth about his illness journey.

Providing John with hope became a new privacy rule Caroline used to sustain their family in illness. From the beginning of the diagnosis, Caroline recalls telling Dr. T not to take hope away from her. Maintaining hope for her family helped her concentrate on the living rather than the dying aspect of John's illness journey. The diagnosis triggered change in their relationship as he became unhealthy; her approach to dealing with the dialectic in care was to ignore the present (unhealthy; dying) and restore the former (healthy; living), and she unequivocally saw her role as encourager. When she reached the Cancer Center and was told that John would "have to live with this the rest of his life," this gave substance to what she was feeling and so desired. Caroline reflects on that statement as a consciously discursive mark in John's illness journey. When asked about the best medical communication she received throughout John's illness, not surprisingly she claimed it was the staff at the Cancer Center:

They took all of the grouchiness upon themselves and turned around and were the sweetest. And even nice to me, they didn't forget the fact that I was there too. They weren't focusing constantly just on John. "Mr. and Mrs. Wall let me get you something to drink, some fruit." I would give them an A+ on how they treated us. They couldn't help us, they couldn't save his life, they couldn't offer him anymore but they were apparently determined to help us deal with this—they were the ones that said it was like a bad heart attack and you can live with it.

She focuses on how the staff included her. Although she recognizes that they could not cure him, she was thankful for the provision of hope, something she needed to perform her role in the journey.

## THE STRUCTURE AND COMMUNICATION OF MEDICAL CARE

The compartmentalization of medicine formulates a dichotomy in the type of care services offered, situating one care type as *not the other*. Movement from curative to hospice care requires patients and families to switch to a narrative genre that includes death and dying as central to care expectations. Narrative genres form a recognizable type of story influencing expectations, understandings, and responses. In the United States, the predominant illness genre focuses on cure and the general belief that death

arises from the misfortune of dying before a cure is found (Callahan, 2009). Given a curative-only approach following diagnosis, the introduction of hospice care in an illness journey can result in “a contest over genre choices,” creating a dialectical tension prompted by a sudden awareness of death and dying (Frank, 2009, p. 170). The dialectic between living and dying becomes identifiable as patients and families work to assimilate the already known hospital narrative with an unfamiliar hospice narrative. These are not narratives of the patient/family’s conscious choosing, but an awareness of these two narratives, and the ways in which patients/families perform and live them enables us to understand the family experience in the illness journey.

In the *Hospital Narrative*, there is a closed awareness of the transition into care for the dying (Glaser & Strauss, 1965). We extend the notion of mutual pretense, when a terminal diagnosis is ignored or denied, by applying the term “closed awareness” to contrast it with Glaser and Strauss’s binary partner—open awareness. Closed awareness is made possible when medical staff, family and friends, and the patient agree to behave as if the patient is not dying. To accomplish this, a complex, mutually achieved but often unspoken coordination is necessary (Glaser & Strauss, 1965). This narrative genre influences expectations—for example, questions such as, “Shouldn’t we take an x-ray?”, “What about her blood pressure?”, and “How can we get her to eat?” reveal an assumption that medical personnel should be/are working toward patient restoration.

Families struggle with the hospital narrative when there is a discrepancy between their loved one’s physical performance (what the body is doing) and the description of this performance (performativity) given by medical staff. When a patient’s length of stay is longer than normal for diagnosis, there is conflict among multiple providers in terms of plan of care, or if the patient does not respond to treatment as expected, family members become frustrated with the medical system as these events are not conducive to the hospital narrative (Baker, Miers, Sulla, & Vines, 2007). A lack of understanding and communication leads family members to continue making cure-oriented decisions that actively illustrate “doing” family, a behavior recognized and regarded by others as the appropriate performative behavior for a hospital setting. Gillick (2009) describes how this can be reinforced when an alternative care type is suggested by clinicians: “Families are expected to switch from asking about the most recent hemoglobin level to authorizing withdrawal from the ventilator. Not surprisingly, families often balk and, to the chagrin of the physicians and nurses, insist on continuing vigorous treatment” (p. 122).

In contrast, the *Hospice Narrative* is characterized by an open awareness of death and dying. This narrative showcases an understanding and awareness of the relocation in care. In response to the narrative genre, talking about caregiving and care become the caregiver identity performance

within the context of hospice care. For example, the daughter of a hospice patient reported to staff: “One of her biggest fears was that she [the parent] didn’t want to suffocate because of her breathing problems. So I push the button [for her pain medication] for her when she gurgles.” This daughter found an active way to contribute to her mother’s care during hospice and demonstrates her realization that her mother is dying.

The hospice narrative involves a comprehension of terminality that surfaces from the interrelationship of information, the patient’s physical and cognitive decline, and subsequent changes to personality and role (Waldrop, Kramer, Skretny, Milch, & Finn, 2005). Comprehension materializes in hospice care through education and understanding about the illness as well as observation of the physical progression of the disease (Waldrop et al., 2005). Although the inherent focus on preventive/curative-only medicine assumes an active role in care among the living (hospital narrative), patients and families must learn to identify a performative role of caring in dying (hospice narrative).

The following excerpt from an initial hospice consultation between a hospice physician (MD) and the daughter (D) of a patient illustrates the hospital narrative genre within hospice care:

- MD: We should talk about a couple of things. We are going to stop [tube] feedings.
- D: Well no. We were told that he would be examined this morning and then we’d decide.
- MD: [Explains benefits and risks of tube feeding] For someone not actively dying but is unconscious like he is it could provide nutrition. But it can also cause the risk of infection.
- D: Our main concern is comfort. To us, taking the feeding away would cause discomfort. And we want him comfortable.
- MD: [Explains that patient is “winding down”]
- D: Will he stay on the anti-seizure medicine?
- MD: I think that’s a good idea.
- D: I don’t want him to hurt himself.

Despite their rescue to hospice, this exemplar shows the mismatch between narrative genres as conflict occurs when the medical team and patient and family view the same story (i.e., the illness journey) from different genres (hospital vs. hospice) (Frank, 2009). In this exemplar, the daughter is making decisions that align with the hospital narrative. She is against stopping the tube feeding and emphasizes the continuance of anti-seizure medicine. Ironically, both the physician and the daughter want comfort, but each defines it differently. The daughter defines comfort in

terms of living (her father needs food and protection from prior medical problems, i.e., seizures), whereas the physician defines comfort in terms of dying (no more food intake because it complicates the dying process). The physician agrees to continue anti-seizure medicine to demonstrate to the daughter that she also wants the patient comfortable.

The continued use of anti-seizure medicine for this patient is a symbolic intervention employed during hospice care to assist the family in their movement away from the hospital narrative. Symbolic interventions provide “ineffective but harmless treatment that is of symbolic value to families” (Gillick, 2009). Most commonly, families experience the dislocation of care when they can no longer fulfill the provision of nutrition during the dying phase (Gillick, 2009). However, artificial nutrition represents an active contribution to care congruent with the hospital narrative. The rapid shift from aggressive treatment to hospice care can create family conflict with staff about treatment withdrawal (Norton, Tilden, Tolle, Nelson, & Eggman, 2003).

Communicating the transition between curative care (hospital narrative) and hospice care (hospice narrative) is considered a major clinical challenge (Marsella, 2009) as it creates opportunities for miscommunication about patient preferences and goals of care (Hauser, 2009). Miscommunication can create major safety problems for patients and result in re-hospitalizations, back-and-forth placement among the nursing home/home/hospital, and increased visits to the emergency room, all of which are prompted by changes in the patient’s body caused by disease or treatment (Meier & Beresford, 2008). Inadequate communication during this time creates fear, hesitation, and uncertainty for families involved in care decisions (Marsella, 2009). The rescued journey focuses on labored movement from one specialist to another, aggressive interventions, experimental options, and for both our families referrals to M.D. Anderson Comprehensive Cancer Center.

As the Von family sought restoration by potential Cyberknife treatment for Vance, son Gary details the numerous specialists encountered along his father’s illness journey.

## **Everything Revolved Around Health Care**

As a treatment plan was developed, Dad began experiencing complications from the cancer. October soon turned into November. The consistent thing was more doctor visits without a specific plan of treatment. This became very frustrating. Still, Dad’s health was not improving, and there were no specific plans for improvement. December came. The Cyberknife treatment was ruled out because Dad’s cancer was too complex.

Cancer was found where Vance's prostate had been, in his urethra, and later at numerous other tumors sites. Gary reflects: "The doctor wrote a referral to MDA so we could get their opinion. It seemed there was a possibility of radical surgery that might cure him. The surgery would basically mean removing all of Dad's urinary tract. We were cautioned to be open-minded and not get our hopes too high."

During the time spent with MDA, a total of three visits, Gary recalls: At this point in my Dad's life, everything revolved around health care. Doctors and more doctors. There were the chemotherapy treatments, scans, x-rays, and more doctor visits. The amazing part was his enduring desire to become well. He believed in his heart of hearts what was being done would heal him . . . it was agonizing to watch and hear. I went to great lengths not to quench that spirit. I knew what the outcome was probably going to be, but I wanted those times to go and do things again."

We were told that the referral process would take 2 or 3 weeks to get Dad to MDA. It actually took almost 4 weeks. Numerous phone calls were made to get the arrangements made. More doctor visits and a trip to the emergency room. According to Vance, the people at MDA were going to heal him.

On the second trip to MDA, the Von family found out the tumors responded to chemotherapy treatment. However, a subsequent visit at the end of May revealed Vance's condition had actually worsened, and there were new metastases. He was hospitalized for a week on two different occasions between visits.

It was determined to insert a tube directly into the kidney to remove the urine that way. The problem was that it could not be done until later. We were sent home and told to wait for a phone call.

Consistent with the hospital narrative, the Von family pushed forward and explored every treatment option. However, Vance's life in illness seemed to be driven by the hospital narrative despite that no specific treatment being apparent and no direction in care provided. Although family frustration and angst were increasing, they continued to engage in thinking around the hospital narrative, and the search for the possibility of cure continued. The continual waxing and waning of health care services during this time left the family frustrated and empty-handed (Wright & Katz, 2007). Still, they remained committed to the promise of cure.

New family experiences emerge as the responsibility of care during a loved one's illness journey falls outside the hospital narrative. As cure

becomes distant, exhaustive patient care becomes a new family focus as all day and night activity centers on the pursuit and administration of health care. As the hospital narrative begins to fade in utility and meaning, families must deal with and negotiate care *within* or *outside* of the family; care that emerges from *within* the family creates relational constraints among family members who are tasked with caregiving responsibilities (Ragan, Wittenberg-Lyles, Goldsmith, & Sanchez-Reilly, 2008). The Von family's commitment to maintain caregiving *within* the family suggests that caregiving obligations were a component of their consensual family communication style. Gary explains:

I sat down with my management and explained Dad's health issues. I made it perfectly clear that when "the Old Man" called, I was leaving to take care of him. As far as I was concerned, I did not have a choice because it was what I was going to do.

Vance's need and desire for family-supplied care prompted increased family interactivity during his illness journey. Caregiving became a "family affair":

My heart still ached for my Dad's slipping health, but I never deterred from my task. When he called, I dropped everything and went. It became a family affair to take care of my parents. My wife and I took over the medications. We prepared meals on a daily basis . . . . The roles had completely reversed—Dad was no longer the provider, but my wife and I provided for them.

A change in setting, such as going to MDA, can serve to fortify the already held hospital narrative or mark a transition in the illness journey. For Vance, the change in setting brought hope as he believed that "the people at MDA were going to heal him." Consistent with the hospital narrative, it brought hope for something new—the possibility that cure was just over the horizon and available at a different location.

However, a change in the care setting represented a deviation from the narrative for Gary. The trips to MDA brought about contradiction in the illness journey. During these trips, Gary began to question the reality of fulfilling the hospital narrative as he became aware of the futility of further treatment and reflected on the history of attempted interventions. This contradiction is enhanced by Gary's recollection that the family was "cautioned to be open minded" for the first time since the initial diagnosis. This marks a distinct change in the narrative genre for Gary, influencing his own meaning-making as he explains that Vance's "enduring desire to become well . . . was agonizing to watch and hear." As time passed, Gary became



cognizant of the degrading changes in Vance's health. He vividly recalls their last golf outing:

As we played the 10th hole, a relatively short par 5, I noticed for the first time how much my father had declined physically. In his younger days, this would have been duck soup time. He would have taken this hole by the throat and made it his own. He was struggling just to advance the golf ball short distances. Each swing he took cut me to the marrow of my soul to watch. Here was one of the strongest men I knew pound for pound, and he could not hit the ball more than 100 yards at a time. He was frustrated. I was crushed. On that 10th hole, it was all I could do to not cry in front of him. I held my composure . . . I made a decision to cut the trip short. Dad wanted to know why I wanted to go home. I did something I am not good at—I lied to him . . . it was the first time I had lied to him since I was a teenager, and it was killing me inside. . . . Afterward, I went home to my wife. I walked in and grabbed her. I wept. My whole being hurt from head to toe.

This golf outing was pivotal in Gary's understanding of his father's illness journey. It was during this time that we can observe Gary's narrative genre switching from hospital to hospice. Gary knew that this was his last golf outing with his father, and he realized the tension between what had been (healthy father) and what would be (decline to death). His reaction to the cure/comfort contradiction was to mask his feelings and the tension he felt when his dad asked why he wanted to go home. Thus, to sustain the relationship that he had with his father, Gary changed a long-held practice of truth-telling and "went to great lengths" to practice a hospital narrative in his Dad's presence.

After several tests at their local hospital and closest cancer center, the primary site of the cancer could not be found (common for unknown primary cancer diagnosis), and John Wall and his family were also referred to MDA in Houston for further testing. Caroline, his wife, explains that she did some research and discovered that MDA was the "best cancer treatment center in the world."

### **It Had Taken Over**

I asked the doctors [at CC] and they said yes, we will work with any doctor at M.D. Anderson, whoever you want. They [doctors at CC] were very kind and very sweet to us, we didn't have conflict. They gave us a little hope by saying that John would live with this for the rest of his life. They didn't provide any treatment plan. They said that this was the fastest-growing cancer they had ever seen; they had

never seen anything growing faster, and it was imperative that we find out what it was as soon as possible so that they could do some chemotherapy.

So I called and got an appointment with M.D. Anderson, but we had to wait 3 weeks. He had 3 weeks to do nothing except worry until this appointment happened. So we went on a little vacation and tried real hard to have a good time, but with what was going on with his body it wasn't easy. He would call me over and say, "Come here and look at this." And I would look and it would be dark red or orange [urine]. And I said honey I think you need to drink more water.

So we finally got our appointment at M.D. Anderson. The morning that we were supposed to go, John got sick for the first time. So I called the CC and they said stop on in and we'll give you some medication to help you get there (to M.D. Anderson), and so we did. So we showed up at M.D. Anderson on a Sunday. Well on our way down there, I checked my messages and there was one from M.D. Anderson that said, "Well we just can't get a hold of you so we are just going to cancel your appointment." Oh my gosh. . . . So I called them and said no you are not cancelling.

So we went down there and the doctors basically they said this is not good, but let's run some more tests. So they hooked them up to show the pictures, and they compared the two, and I could see the difference. In the original picture, I could see white spots everywhere, and in this picture I saw half of his liver was white and the rest of it looked like someone had taken white paint and done this with it [paint strokes with her hand]. It had taken over in a matter of 3 weeks, it had just taken over.

In 3 weeks, the Wall family had seen their local physician (Dr. T), medical staff at a local Cancer Center (CC), and made a trip to M.D. Anderson Cancer Center (MDA). With no treatment plan, as Caroline was told that chemotherapy was possible once they found out what type of cancer John had. Although she recalls hearing that it was the "fastest growing cancer they had ever seen; they had never seen anything growing faster," Caroline continued to follow the hospital narrative and expected curative treatments from the trip to MDA.

Caroline's description of the 3-week wait for the MDA appointment demonstrates the deliberate focus on the hospital narrative. Despite the news that John had cancer, they continued to focus on living by taking a vacation. Caroline explains that the vacation was not ordinary, and they both were preoccupied with changes in John's body. The interactivity between John and Caroline is evident as John shared the many changes to his body with his wife, looking to her for interpretation of these "changes."

The hospital narrative was maintained when John needed to receive treatment from the CC prior to departing for his trip to MDA. When patients have uncontrollable symptoms and pain, their illness narrative is

challenged as outstanding physical needs reveal the inadequacy of the hospital narrative. Patient transfers and referrals underscore failures in the medical community's ability to provide cure and care (Wright & Katz, 2007). However, the open revelation of ineffective curative-only care for the Walls was stymied by the temporary treatment John received prior to his departure to MDA. This restorative response by the CC medical community gave encouragement to John and Caroline Wall that new answers would be found at MDA.

John's quickly advancing disease, coupled with a disturbing phone message from MDA threatening cancelation, forced the Wall family to negotiate John's care *outside* their family. In contrast to the Von family, Caroline and John did not have enough time to consider caregiving tasks *within* the family. Caroline became John's sole caregiver responsible for managing doctors' visits, medication, and paperwork. Her commitment to her husband's illness was evident from the moment he was diagnosed.

In addition to working with three different entities (local hospital, regional CC, and MDA), Caroline faced yet another unique struggle in the management of her husband's care. Days prior to John's diagnosis, the Wall family had changed health insurance plans and had yet to receive insurance verification cards. Consequently, they were treated as "no pay/non insurance" customers at MDA. This added to the complexity of the experience:

When I checked in the first morning they gave [me] my medical records after I gave them \$7,000. . . . We had an insurance problem where we had new insurance but it hadn't kicked in yet—so they treated us like we were no pay. And that was terrible because every time I turned around, I had to write a check, and I felt like we were treated like that. Every test and medication we had I had to pay for ahead of time.

Caroline was unaccustomed to this process, and her reflection reveals the disparity of care within the health care system. In one particular instance, she was asked to pay the cashier by 5 p.m. and it was a quarter to five. The payment had to be received before John could receive chemotherapy.

### **I Was Ready to Shoot Somebody**

So I get there and it's just like right on the dot 5 o'clock, and I said I've got to pay you, I've got to pay you. And she said okay. So she took my money and wrote me out a receipt and passed it back. And I said, "So now you are supposed to call this number before you close and tell that it is okay to give my husband the chemotherapy." And she said, "I'm sorry but we're closed." And I said, "No, no, no.

You don't understand, this is life or death, you've got to do it." She said, "Ma'am, I said I'm closed!" Bitch! I know I was angry, and I know I probably wasn't the nicest person in the world, but I was really insistent "Call this number—you've got to do this." And to me, I'm desperate, it was like hanging onto a rope. And to her, she was like, "ha ha." So she dials this number and then hangs up. And I thought, oh dear, what's this? Well, here comes security. I turned around and looked at the security guard who said, "What's the problem?" And I said, "I just paid her \$7,000 and I need her to call this number and tell them that it's okay to give my husband chemotherapy tonight, his first chemotherapy treatment. I need her to call this information in." And the security guard looked at her and said, "Why didn't you do it?" And she said, "Because I'm closed." And he said, "You had enough time to call me, CALL"—and he just looked at her—and he was obviously on my side. She picked up the phone and called, and the security guard said, "Ma'am I'm sorry." I was ready to shoot somebody.

Here, Caroline's acute desperation to extend the hospital narrative at all odds is portrayed through her intent to obtain chemotherapy for her husband (although the MDA oncologist had recommended against this), the \$7,000 upfront expense of the treatment, and her negotiation with the bureaucratic structure of the hospital. It is during these occasions that we can observe her making the most sacrificial efforts imaginable to cling to the hope for cure embodied by the hospital narrative.

### **MUTUAL PRETENSE VERSUS PRODUCTIVE EXPERIENCES**

Repositioning from the hospital to hospice narrative requires the patient and family to gain a functional literacy about the disease process and terminal prognosis. The curative-only approach to diagnosis establishes the groundwork for families to operate using the hospital narrative; thus, many families are illiterate in the ability to understand and access hospice care, especially when overloaded with curative-only treatment options. There is recent evidence that individuals with low or marginal health literacy are more likely to prefer aggressive care at the end of life than those with adequate health literacy (Volandes et al., 2008).

Curative-only pursuits are consonant with statistical illiteracy, creating mutual pretense (closed awareness) about the disease. This has enormous consequences for health care, and its consumption as talk about the disease is limited to numbers and risks (contributing to the practice of mutu-

al pretense) rather than talk about specific changes to the body as a disease progresses (productive experiences). Health illiteracy leaves family members believing that the most aggressive treatment equates to the best care possible (Wong & King, 2008).

When patients and families are embedded in the hospital narrative, they jointly enact a closed awareness of dying in which all parties behave as if the patient is not terminally ill. This mutual pretense transpires from expectations affiliated with this narrative genre. However, as treatments fail and disease progression ensues, changes in the patient's body run contrary to the expected outcome of the hospital narrative, creating disillusion for the patient and family. Patient and family begin to feel angry at medical professionals who appear to be chasing the disease ineffectively or not as vigilantly as they should (Holst, Lundgren, Olsen, & Ishoy, 2009).

The drive for curative treatment is so fierce, and the concepts of death and dying so foreign, that patients and families find it hard to believe that effective curative treatment is no longer available (Callahan, 2009; Casarett & Quill, 2007). The beliefs inherent in Western medicine exclude ideas about dying and death, and the suggestion of such can seem illogical to some (Weissman, 2001). Disillusion stems from closed awareness of death and dying and impedes patient self-determination; for example, caregiver denial of the patient's terminality is more likely to result in patient placement in an inpatient facility rather than at home (Reese, 2000).

A lack of understanding can leave family members reluctant to accept hospice because it is perceived as giving up hope (Apatira et al., 2008; Ford, Nietert, Zapka, Zoller, & Silvestri, 2008), and family caregivers report difficulty in hearing the news about hospice care (Cherlin et al., 2005). Hope is consonant with the concept that modern medicine and technology will cure. Spiritual and religious beliefs contribute to the patient's and family's decision to continue curative treatment, including the hope for a miracle, refusal to give up on God's grace, a belief that life is a gift from God and should be preserved, and a belief that suffering has redemptive value (Brett & Jersild, 2003). Religious-based coping is also associated with the drive for intensive life-prolonging medical care (Phelps et al., 2009). Family commitment to remain hopeful can result in late enrollment in hospice (Ford et al., 2008).

In contrast, productive experiences can transpire from open awareness about dying and death and communication that acknowledges the limits of medicine. In communicating a diagnosis, two kinds of hope align with the narrative genres of hospital and hospice; namely, the specific hope for outcomes (hospital genre) and generalized hope for a nonspecific sense of hopefulness (hospice genre) (Whitney, McCullough, Fruge, McGuire, & Volk, 2008). For many families, a terminal prognosis eliminates specific hope, yet a sense of nonspecific hopefulness can be found within the introduction and transition to hospice and the hospice narrative that reassigns what patients

and families hope for. The relational history among physician, patient, and family contributes to the believability of a terminal prognosis, as trust is a necessary component when discussing end-of-life care (Weissman, 2001). Productive experiences can emerge when communication with patients emphasizes what can be done for symptom control and emotional support, realistic goals are set, and day-to-day living is the focus (Clayton, Butow, Arnold, & Tattersall, 2005; Ragan et al., 2008). These discussions extend beyond medical facts and include the difficult task of addressing emotions, values, and cultural beliefs tied to family (Weissman, 2001).

The variance between mutual pretense and productive experiences represents the dialectical tension that delays and complicates hospice enrollment. In the rescued journey, turning points are shared among patients, families, and health care staff that can lead to productive experiences and ultimately to hospice. A turning point is conceptualized as a relational event or occurrence that results in either positive or negative relational change (Baxter & Bullis, 1986). Turning points in the hospital narrative emerge either as a result of effective, clear communication with health care professionals or because the body's decline is so stark and vivid that the patient and family come to the conclusion that there will be no cure and, in fact, dying is central to his or her illness journey. However, as our family narratives illustrate, turning points can enable transition toward hospice, and missed turning points can lead to further delays in hospice enrollment and prolong/intensify patient and family suffering.

## **I Looked at the Paper**

In January, Vance Von and his family took their first trip to MDA in Houston. Several days were spent having tests and waiting. The urologist put a tube directly into Vance's bladder, which was connected to a urine bag. Vance looked at his son and said, "Maybe this will get me on the golf course sooner!"

The magical curing surgery that he [Vance] had hoped for was not going to happen. Seems everything was too complicated. We had heard this before. Dr. A explained we should try a regimen of chemotherapy for a period of time and return to MDA in 6 weeks. If there was significant improvement, maybe they could do the surgery. He [Vance] continued to hold hope that the treatments would heal him. I asked how he was handling the treatments, and I got the same response: "I do not have a choice but to continue. It is the only chance I have."

During one of the visits [to MDA], I had to take Dad to the laboratory for blood work. He got his blood draws done, and I took him

back to the doctor's office. The laboratory technician handed me a piece of paper and instructed me to give it to the nurse. I agreed, took the paper, and got Dad settled in. Then I looked at the paper. My heart sunk. I never have read anything as devastating as that day. The paper explained that Dad was a 73-year-old male with stage IV prostate cancer. I read the paper again. And again. And again. I finally walked to the nurse and gave her the paper. I excused myself and went outside. Crying is not a strong enough word. I wept. This was the first time for me to cry about either of my parents that I can remember . . . I called my wife, a friend, and my sister. We all agreed we did not know for sure what stage IV meant, but we were pretty sure. The next few days led to research on the American Cancer Society webpage, as well as other research. None of it was good or encouraging. The rest of the day at the doctor's office, I tried to be nonchalant and funny.

Medication became a constant struggle. Dad was diabetic on top of everything else. Every medication has an impact on medications taken to control diabetes. . . . There was more. The tube put in at MDA was also a full-time job. We were not prepared for that. When the original was installed, no instructions were given [about how to unclog the tube]. We soon learned.

The side effects of chemotherapy set in, and Vance often complained that his feet were on fire.

For 6 months, if someone came in and was willing to take the time, he would have you rub a certain lotion on his feet. The other part of that was his feet became very dry and scaled. The lotion (on his foot) gave him some relief to the dryness, but he wanted you to rub hard enough to "help with the pain." It was only temporary. Within a very short amount of time, the pain and discomfort would return. Then there was the walking. Just walking became more and more complicated. By May he was in a wheelchair. The biggest problem now was the chemo wasn't helping but hurting. Dad's blood levels were awful. Instead of every week, it was every 2 or 3 weeks between treatments.

A pivotal turning point for the Von family occurred during their last visit to MDA. Gary described it as a "major change in how we approached life with my dad."

She (nurse) asked, "Do you have any allergies?" He responded, "Yes, two." My mother, sister, and I all perked up. We knew the answer, and it was one. Only one. He had been allergic to Penicillin since

given the stuff as a child. WE KNEW THIS. We could not wait to hear the new allergy. "Mr. Von, what are you allergic to?" she said. He cut her a look of agitation. He said, "Penicillin and Houston!" We cracked up. When the nurse did not understand the response, Gary interpreted, "He is allergic to Penicillin only. He just does not want to be here in Houston." Dad's demeanor changed instantly. He smiled and laughed with us. It was a magic moment. . . . I understood a little more than Mom and my sister. He was done. He did not want any more of this long-distance treatment. . . . Later during the drive home, I asked Dad, "You don't want to come back to Houston do you?" "Do not take me back. There is nothing there for me." I promised no one would take him back. He thanked me. I thanked him. I admired his courage, but I was growing tired of seeing him suffering. Sadly, it was getting more difficult for me to spend time with him. I did not slow down, but it was difficult.

I called the doctor in Houston the next day. I asked whether there was any real need to bring him back to Houston. She beat around the bush a little bit. I asked again whether there was anything MDA could do to heal my father. She said no. Dad never returned to MDA. My sister wanted to take him back. The answer was no, and she did not argue the point.

Consistent with a hospital narrative and a curative-only approach, the Von family's illness journey focuses on cure as long as the patient's body can sustain it. Mutual pretense, a closed awareness about death and dying, is performed by the Vons as they journey to MDA. First, the binaries of care (cure only and palliation) are not introduced, resulting in a fixation on potentially successful treatment plans and options leading to cure. Subsequently, Vance and his family remain committed to undergoing a cascade of interventions (chemotherapy, radiation, possible Cyberknife therapy and surgery) offered by health care practitioners. If-then statements from health care staff ("If there was significant improvement, maybe they could do the surgery") perpetuate a closed awareness for patient and family as staff don't acknowledge or introduce the potential of comfort-only care.

Second, there are no distinct, specific discussions about terminal prognosis. In this absence, the patient and family still believe in a curative diagnosis and set their energy toward achieving this outcome. We note that the family only moves to research prostate cancer after Von has lived with the illness for more than 10 years and once Gary learns his Dad is stage IV.

During an MDA visit, Gary's worst fears were confirmed when he read the paper that stated his father had stage IV prostate cancer ("I have never read anything as devastating as that day"). Up until this point, not one health care practitioner had told him or explained to him, his family, or his father that the disease was at stage IV and what stage IV cancer meant.



When Gary called MDA to inquire about bringing his father back for another visit, he recalls that the doctor “beat around the bush a little bit.” When he asked again, the doctor explained that there really wasn’t a reason to bring him back. Mutual pretense describes the doctor’s desire to offer curative care rather than facing the dialectical turn in Vance’s prognosis—that is, acknowledging poor prognosis. Consequently, the opportunities to communicate with Vance and his family that the prognosis was stage IV and that he was hospice appropriate were missed. It is due to these missed experiences that violent rescues are necessitated.

Third, prior family collectivity can breed mutual pretense (a closed awareness of dying and death) if this precedent is set forth by health care staff. That is, the mutual pretense of terminal illness by health care staff transferred to the Von family. When staff rendered curative treatment choices as the only options for care, the dialectical tension between living and dying was not engaged. The absence of full disclosure results from staff compartmentalization as only certain sectors of medical information are shared with the patient and family (Werner & Baxter, 1994). Consequently, there was no dialectical tension for Vance, just a dominating focus on living (“It is the only chance I have”). Despite experiencing numerous costly side effects from treatment and managing multiple physical problems at once, Vance essentially denies the possibility of not living.

Closed awareness about dying and death triggered a change in the relationships within the Von family, especially between Vance and Gary. Recall that Gary had seen noticeable changes in his father, foreshadowing the end of Vance’s illness journey. Gary’s awareness of Vance’s stage IV diagnosis confirmed what he had privately suspected. The dichotomy of awareness between Gary (who now has open awareness) and Vance (who is still practicing closed awareness) was a family *turning point*, as Gary’s own communication moved away from a consensual family communication pattern to a protective family environment. Gary begins pretending (“I tried to be nonchalant and funny”) in order to protect Vance by conforming to Vance’s desire for cure and a belief in the hospital narrative (Werner & Baxter, 1994). As a result, mutual pretense continued within the family, and discussions about serious issues, such as Gary’s new awareness of the prognostic findings, remained suppressed. The absence of open conversation caused Gary to conceal his own feelings about his father’s illness. Despite the turn in Gary’s own understanding, he worked feverishly to feign alignment with his dad’s curative goals. Gary explains:

Here is a man in declining health. His body is shutting down piece by piece. Not so slowly anymore. His days revolve around problems, not solutions. Complication after complication. What do you do in this circumstance? What did he do? He kept fighting the best he

could. Every chemo treatment was the one that would fix him up. The next doctor had the answer. I finally asked why he was so insistent. He turned those pale blue eyes right at me and calmly said “It is all I got.” He confirmed what was known already—whatever he wanted or needed, I was going to do the best I could to give it to him.

In the performance of mutual pretense, Gary’s own feelings (“Sadly, it was getting more difficult for me to spend time with him”) were concealed and kept private to protect Vance.

The Von family maintained a closed awareness about death, dying, and the practice of end-of-life care, following Vance’s lead to focus solely on decisions about cure. Family collectivity and communication, along with the relational history of family members, influenced the Von family’s approach to illness. Still, Vance’s body continued to change and decline; planned treatments gave way to irreparable side effects, more decline, and new problems. Vance began to suffer deeply. He and his family experienced limited resources (“No instructions were given about how to unclog the tube”), resulting in numerous trips to the emergency room to obtain assistance and instruction. The contradictory nature of the care and the lack of a specific care plan because “everything was too complicated,” a statement Gary recalls hearing numerous times, initiated a turn away from the hospital narrative.

Productive experiences, characterized by an open awareness of dying and death, began to slowly emerge for Vance in his illness journey. A second family turning point came when Vance told the MDA nurse that he was allergic to Houston. Gary frames this event as a “magic moment” as he understood this to be a turn in Vance’s own illness goals. For Gary, this was the moment he saw his father acknowledge a possible outcome other than cure, which allowed Gary to test Vance’s transforming goals. The two share a productive experience as Gary now feels comfortable to ask him whether he would like to go back to Houston. Vance’s response and the promise not to take him back mark a turning point that opens the door for more productive experiences and the possible introduction of hospice. They came to this place on their own; the topic was not broached by health care staff.

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The Wall family trip to MDA confirmed John’s cancer diagnosis and revealed that the cancer had spread voraciously in a matter of weeks. Caroline shares her recollection of the events that ensued and her memories of conversations with medical professionals. These narrative reflections remain as Caroline’s experience despite the likelihood that other components and subjects were included in her conversations with clinicians at MDA. The significance here is that these are the details she retains.

## I Don't Want It

John had said, "I don't want to be here. I'm sick. I'm going back to the hotel room." At this point, he could pretty much do what he wanted to do. I took him back to the hotel, and I went back to speak to the doctor's assistant [possibly a fellow]. And she told me, "John's going to die. I don't know if he's going to die today and I don't know if he's going to die in the hotel or if you are going to be able to make it home." And I said, "You are giving me no hope." And she said, "There is no hope." I mean just that, shut up, you have nothing. And oh I was devastated, and I remember being angry and I remember thinking how dare you treat me like this. Somebody can do something. So I threw a fit and said, "Don't tell me there's no hope. You've got to do something." And she said, "Well, wait 'till the doctor comes." And finally the doctor came back. And I said, "This is terrible. Don't be telling me that he is going to die like this without you guys even trying to do anything." And he explained to me that it was ACUPS [type of cancer] and what it was . . . and that there wasn't a whole lot to do, "but if you want to we will try [chemo], it probably will not help, it will just make him sick. But it's all we can do."

So I went back to the hotel and I got John, and I said they are going to give us chemotherapy, we need to go to the chemotherapy room. So we did. I never told him how bad he was. I remember him being absolutely terrified, and he was sitting in a wheel chair, and I remember John was kind of teary, and he was not that kind of guy, and I said, "What's a matter honey?" He said, "Chemotherapy, I don't want it." And I said, "It's the only thing we've got. It's our only hope right now. It's all we've got." And he said, "Well I guess I'll have to take it, but I don't want it." And I said, "Alright, what do you want to do?"

And you know, it was his life, and I wanted to support him. And I'm sure I made a lot of mistakes, but at the time I wanted to do the very best that I could do. So they went ahead and gave him the chemotherapy, and the next day he was very sick and he stayed very sick and had mouth sores and I couldn't get him up anymore.

Caroline's steadfast commitment to a hospital narrative for her husband overrides all recommendations as well as John's own wishes in this illness journey. When the fellow tells Caroline that John will not survive this illness, she denies this possibility, arguing instead for *anything*. She becomes angry when nothing is offered for her husband, seeing this as a contradictory response from a doctor based on her husband's clear and desperate physical needs. As a result, she feels isolated by the absence of a cure (see Chapter 4) and also subjects her husband to futile chemotherapy that severely reduces the quality of his last days of life. For John and Caroline Wall, this moment represents a *missed turning point* in the illness

journey. A closed awareness of dying and death results when the fellow and the doctor ineffectively convey John's prognosis. Their communication only spurs Caroline on to more heightened levels of desperation, subjecting John to a finally disabling medical cocktail of chemotherapy. Caroline explains that she was assigned a social worker for further assistance:

I did get a social worker at M.D. Anderson, but by then it was too late. She called me and she said she would help me through all of this. I had one meeting with her. She was not a nice person. She did not have a good personality, all she could say to me was you don't have enough time, you haven't been here long enough, you are in such turmoil because he's dying there's not a whole lot I can offer you. It was more or less unhelpful—and then I could never get hold of her.

The rapid progression of John's disease, the poor prognosis, and the limited treatment options left Caroline feeling disillusioned. All of these insults were further met with injury as a result of the poorly implemented communication of medical staff/clinicians.

Mutual pretense is further sustained when the doctor defers to Caroline's pleas and orders chemotherapy, knowing that chemotherapy is not only futile but further devastating to John's quickly decaying condition. The doctor's orders preclude the opportunity for a productive, open experience and rather create a symbolic intervention for Caroline (Gillick, 2009). Holding out hope against the known odds becomes Caroline's active performance of "family" during John's illness journey:

I'm looking for hope, I'm grasping at straws, give me something to do, don't tell me there's nothing. But Dr. T was probably right in the end. So I wish I had been given better information. But how would I have changed it? I don't know. My thing at this point, after John died, I didn't want to feel guilty for anything. I wanted to feel like I had done everything I possibly could and I did. But in the end the very first piece of advice I got was not to do anything and that might have given me more time with him.

She continued to seek treatment, thereby demonstrating to others as well as confirming to herself that she performed her expected family role of caregiving wife.

However, Caroline's drive for hope negates the possibility of any productive experiences for the patient at the end of life. Chaos emerges because Caroline and the medical staff exhibit commitments to dissimilar stories (Frank, 2009). Chaos narratives involve anxiety and vulnerability,

with a belief that life will not get better. Family history also contributes to Caroline's drive. Given that this was both John and Caroline's second marriage, there were other family members to consider when decisions were made. Each family member may have a different narrative preference when it comes to a "good death" narrative (Frank, 2009). When Caroline was asked who she talked to most in her family about what to do, she explained:

Charles (son). We were not eye to eye. He is still [implying out of her life]. . . the doctors at M.D. Anderson are pretty much showing me all of these pictures and that he [John] is going to die and Charles just pretty much burst into the room and they wouldn't talk to him because John hadn't given them permission and I'm going it's okay, this is my son. They said I'm sorry we can't. . . . So I said "Charles I will be with you in just a minute." And I think that that really angered Charles . . . . Charles and I are not even speaking right now [7 years later].

### **MISSED OR EMBRACED OPPORTUNITIES TO PLAN FOR END OF LIFE**

Productive experiences can pave the way for integration of the hospital and hospice narratives (Werner & Baxter, 1994). Active engagement in talk about living and dying materializes as hospice care ensures awareness, allowing patients and families to embrace the opportunity to plan for end of life. Physicians, patients, families, and other health care providers agree that preparation for end of life includes ensuring that the family is prepared for their loved one's death (Steinhauser et al., 2001). Family members are most satisfied with hospice services when they are informed regularly and receive social support from staff (Rhodes, Mitchell, Miller, Connor, & Teno, 2008).

The emphasis on communication during this uncertain time is evident for patients as well as caregivers (Hebert, Schulz, Copeland, & Arnold, 2009). Mortality communication, or talk between terminally ill patients and families about impending death, is encouraged in the hospice narrative (Bachner, O'Rourke, Davidov, & Carmel, 2009). Most terminally ill patients wish to use this time to discuss spiritual and psychosocial matters with family members that have not been broached before (Baker, 2005). Hospice provides an environment conducive to talking about death and dying as a natural process, ensuring that patients and families jointly plan funerals, preparing for life after the death of their loved one, and making the patient's death "a good death."

The opportunity to plan for end of life is greatly impacted by the progression of the patient's dying process; when the process is slow and drawn out, it can afford family members time in hospice care. As families struggle to find meaning in the patient's dying, they engage in explaining/showing/doing, a reflective effort that sustains the hospice narrative as family members begin to understand the end-of-life performance around them. Family history, patient's personality, and illness history all influence family interpretations of the individualized dying process. The transition between narrative genres requires constant self-reflection and interrogation and can enable patients to enjoin a successful transition to a hospice narrative, ensuring rescue prior to the death event (Frank, 2009).

However, given the strong propensity for a hospital narrative journey and predominant curative approach to diagnosis, many family members miss the opportunity to plan for end of life. Missed opportunities result from continued denial of the contradictions occurring in a terminal illness that is being approached curatively. Family members still operating in a hospital narrative perspective consider speaking about end-of-life care issues in the presence of the patient offensive (Abbott, Sago, Breen, Abernethy, & Tulsy, 2001). More commonly, families request that patients not be told about their diagnosis and hospice enrollment (Gentry, 2008). Some families have a relational history of avoiding difficult topics or speaking indirectly about serious topics; still, limited disclosure about hospice care can facilitate protection of family emotions and sustain denial (Gentry, 2008).

Avoiding impending death forces family members to serve as health care proxies (i.e., make quick decisions about the patient's end-of-life care, including DNR orders, a process that involves quality communication and support from health care staff (Handy, Sulmasy, Merkel, & Ury, 2008). Proxies and surrogates commonly express guilt, ambivalence, and conflict over the decision-making process, especially when prior family discussions have not occurred (Handy et al., 2008). Family guilt, such as fear of abandoning the patient, can manifest when a loved one is dying, contributing to the unwillingness to make decisions (Goold, Williams, & Arnold, 2000). Limited time in hospice only exacerbates surrogate decision making. The following family narratives poignantly depict the violent nature of the hospice rescue as it is forced from the hospital narrative, showcasing relief for one family who embraces the opportunity to plan for end of life while another struggles in the face of missed opportunity.

### **A Decision Was Coming Soon**

The shared conversation between Gary and Vance about not returning to MDA afforded the Von family a productive experience about Vance's illness

journey. Gary reflects on the meaning of these conversations, following the final return from MDA.

This was a significant change. I was actually very happy about this. Just talking about this let me know he was mustering courage. . . . I was thrilled to know he wanted to go home [be buried in his hometown]. It was a good decision, but it took courage for him to admit he was dying. It was the first time that he had admitted his personal mortality. Not even when he had his heart attack had he gone down this road.

As courageous as Dad was, he slipped a little more each day. June became July. Paul, the home health nurse, called several times, suggesting talking to Dad about hospice. I could not do it. Dad was still fighting and as long as he wanted to fight, good for him! Mom and I talked about it [hospice]. I proceeded to attempt to learn all I could. I learned the difference between curative and palliative medicine. Finally, I decided to talk to Dad. My strength was gone, but we knew we had to take the next steps.

Dad sat in a recliner as we began to talk to him. I said, "Dad, I do not know how much longer Mom and I can take care of you. Maybe we need some help." My goodness it was hard to say. He agreed it was getting difficult. I suggested we could get help from hospice care. He thought and agreed. I went outside and called Paul (home health nurse). Tammy from hospice came right over. We talked about what hospice was. We talked about how they could help. Somewhere in the middle of this, I lost it. For the first time since I was a child, I was crying uncontrollably in front of my Dad. I wanted to die for him! I would have taken the bullet for him. Let it be me and spare him.

Dad was agreeing with this. Finally, he asked whether this meant the end of chemo and treatment from the oncologist. Tammy said he could go back to the other treatment if he so desired. Arrangements started for hospice care. My sister contacted Dad's oncologist. His office said they would not take him back as a patient if he started hospice. Dad immediately decided against hospice. We were devastated.

A few phone calls the next day clarified the oncologist situation. We decided to give this some time and see where we went from there. Dad's spirits seemed to improve, but his health did not. A decision was coming soon.

The date was August 3, a Sunday morning. Dad was near rock bottom. Paul came to see Dad. I was there when he got there. I asked Paul to talk to Dad about hospice. Paul explained what was possible. Dad listened intently to every word. Paul stopped talking, and Dad sat quietly. Dad looked at Paul and asked, "If this were you, what would you do?" Paul was a little taken aback. Finally, he said, if it were him, he would choose hospice so they could get help with

the pain and other arrangements. Dad immediately agreed. Calls were made for hospice to begin as soon as possible. Gary remembers, "As I left that evening, I was as low and exhausted as I have ever been in my life. Subconsciously, I had given my father a death sentence. That was not true, but that is what I felt."

Productive experiences, such as the conversation between Gary and Vance about not returning to Houston, are conversations that inherently acknowledge the dialectic of life and death. Vance began to share his wishes for where he wanted to be buried and what funeral home should make the arrangements (see Chapter 3). Gary recognizes this time as a "significant change" characterized by Vance's courage to engage both living and dying. It is within this significant change that narratives between father and son start to parallel, returning family communication back to a consensual pattern as they are rescued from the interpersonal work of pretending and ignoring.

The active integration of both living and dying occurs between Gary and Vance through these conversations and restores their dyadic relationship. This healing facilitates more conversation and allows Gary to introduce the topic of hospice to his father. Given their close relational history, Gary broaches the topic by focusing on his role as caretaker ("I do not know how much longer Mom and I can take care of you"). By using this contextual position, Gary is able to focus on hospice care as a solution to his own personal needs rather than his father's need for care. Still, there is an inherent understanding between the two men that allows them to discursively balance the true meaning of hospice. Gary's emotional state during the hospice conversation symbolizes the return to consensual family communication; the open discussion of hospice among all parties frees Gary from privatizing his feelings from his father.

Still, for the Von family, the rescue to hospice care is violent. A considerable amount of time and adequate care for Vance was lost during the search for cure, eventually leaving Vance and the Vons with only 2 weeks of hospice services. The transition to hospice did not occur because a physician met with Vance and his family to openly discuss Vance's prognosis. Rather, the family became desperate for help as Vance's body continued to decline. When notified about hospice, the oncologist's office threatened to deny care to Vance, pitting cure versus care. [*Note: Under current hospice Medicare guidelines, hospice patients cannot receive curative treatment.*] This runs contrary to Vance's own work to balance living and dying and forces him once again to choose a side. Now unable to be handled within the family, a home health nurse is asked to intervene on their behalf and influence Vance to agree to hospice care, leaving Gary feeling left out and distant from his dad.



With the emergence of hospice care, families are encouraged to embrace opportunities to plan for end-of-life care. Because Vance and his family had already started to address some of these topics (burial, funeral home), these conversations were very open. During Vance's stay in hospice, Gary recalls:

"I need to talk to you. That woman has been in here and says I need to talk to you," Dad said. The question was asked what he needed to talk about. He was quite clear, "my funeral." I was taken aback. At the same time, I was amused at his direct approach at a subject never broached before. Not only had this never come up, it was never even close to coming up. We agreed we needed to talk about this. Typical of my Dad, he looked at mom and said, "Gary knows where I am going to be buried. He knows where I want my funeral, too." I assumed Mom did not know, which she did not. We discussed who was to preach the funeral. . . . The eerie part of this is Dad's eyes never left me the whole time we had this conversation. I knew he was not finished because I had seen this before. Finally, he squinted a little looking me directly in the eyes and says, "You can say a few things, too, if you want to." He did not have to say this because I knew from the look in his eyes it was coming. I stood up and walked over to him. "Dad, I do not know if I can do this one or not!" I told him I would take it under advisement. He and I both knew dog gone well I could not stand up and speak at his funeral. He just wanted me to know he wanted me to. The way this worked out was pretty remarkable. The whole incident lasted less than 10 minutes.

For Vance, this was the last detail to be discussed. Under hospice care, staff encouraged him to take the opportunity to discuss and plan his wishes with family. Vance performed this task literally, as Gary acknowledges that the topic "was never even close to coming up." Through this conversation, Vance is able to share with Gary some final parting thoughts.

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Staying in a hotel during their visit to MDA, John Wall became very sick as a result of chemotherapy and disease progression. Caroline reflects.

### **The Last Ride Home**

And I got him to the emergency room and they ignored him. And I sat in there in the emergency room for a long time, I'm gonna say maybe 2 hours, it might not have been but felt like it was. I got frus-

trated at one point, John was so sick, and I went up to the lady at the desk. I told her, “My husband is cold. I need a blanket and I need a pillow and I need some help,” and I just started throwing an absolute temper tantrum. And this big burly guy comes over and says, “Ma’am we’ve got a lot of people in this hospital and a lot of people in the emergency room and they’re a lot sicker than he is.” Oh I just, I don’t remember what my reaction was at the time, but I was throwing an absolute fit. Finally, they did come in and take care of him and sent him back to the hotel room . . .

And I kept calling for help because he was vomiting and he was so sick. . . . And I’m on a weekend at this point. I needed to get home. So I kept trying to call the emergency room and the doctor’s office and I couldn’t get them to answer me. And the one assistant just kept telling me, “Well, if you won’t take him to the emergency room, then there’s not much else I can do.” And at this point I was just wanting home health care to come in and help with—to come and give medication or whatever because he’s not going anywhere.

So I ended up calling the private nursing plane to have them fly us back here [home] that night because John was so sick. So finally Monday morning the plane was going to get John, but I only had like a 2-hour window because of weather. John was extremely sick; I got him into a wheelchair. The doctor did finally send over a patient advocate, finally, to help me that morning. He took me to a place where John got some fluids, and I said now the minute that plane lands they are going to call me and the minute that happens then get that needle out of his arm because we are going home. I had already packed up everything, and I was ready to go.

Once John walked in the house from the plane trip, he never left again. He didn’t even go outside. He went to bed, and he basically never even got up, maybe a couple of times. After that, he maybe went to the bathroom, but after that home health brought a bedside commode and different things like that. Signed up for home health care that day, she talked to me about it [hospice].

The next day she came to check on him, and she said I would really like to have you put him on hospice. But to sign a hospice paper meant that I was willing to relinquish all curative care and I really wasn’t. So the home health care nurse, since this is a small community, home health care and hospice service was the same. And she talked me into it. She said, “I could do so much more for him if he were on hospice. If you put him on hospice, I can get him the drugs he needs to keep warm at night, get all of the medical equipment that you need,” and she explained to me about how hospice was just about relinquishing everything to allow him to die, and I finally did sign those papers.

But it was like signing a death warrant. It was awful to have to sign those papers. But I had to use my head and go ahead and sign those papers because I knew that they couldn’t do a thing without

them, and he was in terrible pain. He hurt everywhere. He said his spine hurt. His mouth was full of sores from chemo, and he was pretty miserable. He had built up edema, where the fluids don't go through the liver anymore, the fluids go out through the abdominal wall, and it causes huge sores. And he had built all of that up, and it was just awful. And we had to give him fluids. From the time I signed him up for hospice until the time he died, it was only about a week. He was still talking a little bit until about 3 days before he died. And he wasn't eating. And I was still trying to give him liquids, but he couldn't swallow anymore.

For families like the Walls, opportunities to plan for end of life are missed in the absence of hospice. Isolation set in for Caroline and John Wall as his body continued to decline and they struggled to find resources. Patient abandonment was evident as Caroline recounts numerous calls to the doctor's office and limited assistance—at least this was her experience now articulated in narrative. During this turmoil, John's care was sporadic at best, receiving fluids to borrow extra time, yet still not addressing the overall need for true care. Caroline summarizes what she needed during this time:

What I really needed was for somebody to guide me. To be able to sit with my husband and to talk to him and to explain to him. I didn't get that. What I got, was deal with this and deal with that and if you have time to speak to your husband . . . but it was so quick. But after he died, I would wake up in the middle of the night with nightmares left over from M.D. Anderson about running around trying to pay people and dealing with staff.

Without careful attention to needs and direct communication about the next step of care, the Wall family was left feeling abused and abandoned, struggling to find and manage their own resources to deal with the crisis. This poorly managed illness and death experience leaves Caroline with dark memories detailed by difficult stories and hostile communication exchanges.

Similar to the Von family, the transition to hospice was a violent rescue for the Walls but for very different reasons. The lack of direction in care left Caroline in denial about John's disease:

At the time that we came back, I did not sign him up for hospice. I signed him up for home health care because I still had hope. I don't know why, nobody had . . . to me it felt like he was just going. . . . I could handle it.

Upon returning home, she was without resources and still in need of health care assistance. To fill this need, she called home health care because it was the only thing she knew to do. The home health care nurse suggested hospice, as was the case for the Von family. However, this nurse approached Caroline from a different contextual position—hospice was needed for John to manage his pain and make him comfortable. This was the first person to prioritize John's comfort. The decision to choose hospice was difficult ("like signing a death warrant") for Caroline because this symbolized a movement to passive care and giving up the hope for life she had been preserving. As a result, hospice care came much too late to truly benefit the Wall family, as John had suffered so much during the time leading up to hospice. His pain had not been managed, and his rapid decline left him unable to communicate his wishes to his wife and family. Caroline explains:

It was over very quickly, before I was even ready to accept the fact that he was even sick and died. And I think that all of the treatments, all of the things that I did for him, were probably the wrong thing to do for him. And I remember being told by Dr. T, "Don't do anything, no surgery, no chemotherapy," and he was probably right—don't do anything. If I had done nothing, he might have lived a little longer, but he might not have been so sick.

However, during hospice care, Caroline continued to focus on care of the living, attempting to give him liquids despite John's inability to swallow. Her commitment to the hospital narrative was unwavering despite the transition to hospice care, constraining her from negotiating the dialectic between John's life and impending death.

## **ISOLATION VERSUS COMMUNITY**

In the rescued journey, families who transition in their comprehension of terminality are able to obtain a sense of community from members of the hospice team. Hospice rescues them from prior feelings of helplessness and isolation and provides a support group willing to listen and encourage active, open discussions about dying and grief. The acute administration of care is lifted as family responsibilities begin to focus on comfort only. Family members feel satisfied with hospice services when they are informed about their loved one's condition on a regular basis, feel the team provides them social support, and are able to identify one nurse as being in charge of the patient's care (Rhodes et al., 2008). The dialectical tension

is resolved as the body's performance aligns with dying and death—both are talked about and recognized.

Still, some families never make this transition, experiencing hospice as a brutal stage in comprehending their loved one's illness journey (Weissman, 2001). These families remain isolated within the resources of hospice care as they continue to set expectations that are conducive to the hospital narrative. A hospice nurse summarizes, "We can solve or fix any type of physical pain so the deaths that are not good are due to emotional needs of the family." Because patients and families have been offered a myriad of interventional treatment choices, a transition to hospice care negates this interventional behavior and introduces what many patients and families consider a passive role in the care process. Families struggle with the guilt of hospice placement as a result of misunderstanding the prognosis and disease trajectory, and a short hospice enrollment impedes them from relocating their loved one's illness journey to a hospice narrative. As both of our families experience the dying and death of their loved one under hospice care, the variance in their journeys affords one family community and the other continued isolation.

## **The Piano**

Soon after Vance agreed to hospice, he was transferred to the inpatient hospice facility. Gary remembers:

Dad loved the hospice facility from the beginning. It resembled a high-dollar hotel more than a hospital or medical facility. Beautiful carpet, wonderful appointments in each room—just wonderful. . . . Mom was able to stay overnight and take meals with Dad. The staff there fell in love with my mom and her devotion to Dad. A pain medication regimen was set up for Dad, and he began to respond quickly. In fact, the first week he was there was a marked improvement in his general demeanor. He "looked" better and sounded better. I went over every evening to visit. It was a wonderful and blessed time. . . .

Sometime after noon, the most glorious thing I ever had the pleasure to witness happened. Dad began to cough and stir. His eyes opened. The staff came in and used suction to clear his throat and airway. Dad began to look around the room. His eyes moved quickly. It was obvious he was watching intently for something. Very suddenly, Dad sat bolt upright. His eyes were fixed on one location in the general direction of the corner of the room. He extended his right arm in that direction and started talking the best he could. We got very close. He was attempting to leave the bed, but his body would not allow him to get further. Dad stayed fixed on that point and

very clearly said, "It's the Lord!" He repeated it again. I asked him why he saw the Lord. He turned those blue eyes to me and said it clear as day, "He's come to get me. Take me home."

I was thrilled, shocked, scared—all of those things at once. I thought for a moment and stood up as tall as I could. I said, "Daddy, go ahead on! Just go with him and leave us behind!" He smiled and fell back into the bed. He was alert for another hour or so. Then he trailed off into his coma. I never heard him speak again.

One evening, my children Craig and Susan were there visiting. As we walked in, Craig saw the piano. Craig is an accomplished pianist, so he was interested in the instrument. At the end of the evening, I heard the piano playing from Dad's room. I knew who was playing. I went in with Craig and Susan. He played and we sang. . . . I looked up and saw about 10 people standing outside the library, listening. I told the kids it was time to really sing. I knew the only reason the people were here was the same reason we were—they were waiting for someone to die. It was our opportunity to lift someone's spirits. We sang for quite some time, louder with each song.

Hospice care enabled immediate rescue for the Von family. Caregiving responsibilities and stressors associated with Vance's care were alleviated by a complete staff of hospice nurses, nursing assistants, and an on-site hospice physician and pharmacist. With no more concern for Vance's overall well-being, the family was left to focus on each other and Vance. Gary describes this time as "wonderful," "blessed," and "glorious" as it allowed the family to regain a sense of normalcy in terms of family communication. The Vons were able to regain support from within their family structure, as well as afford support for others.

In hospice care, staff encourages families to embrace death as a last opportunity to say good-bye, share memories, and profess love to create shared meaning and positive dying experiences for families and patients. Ultimately, community arises from the joint enactment of recalibration or the reframing of the situation so that living and dying are no longer in opposition of each other (Werner & Baxter, 1994). Community is also created from hospice staff. Gary explains how hospice staff impacted his role in his father's illness journey:

These are such sweet people and did so much for us! How does anyone get through something this traumatic without friends and spiritual guidance? It was a wonderful thing to have folks on our side during this impossible time. In fact, this went from impossible to something we could and would do. I have witnessed families that are completely crushed and devastated in a time of need like this. With the help of others, much like hospice, we survived.

A team of health care professionals, including social workers, chaplains, nurses, and the hospice physician, were available to counsel, listen, and assist the Von family with all of their needs. With adequate time, communication, and assistance, hospice care enables families to transition in their understanding of death and dying, provides physical assistance and pain management, and sets the stage for a supported dying experience.

### **I Know You Love Me Too**

With John Wall now signed up for home hospice, his wife Caroline recalls his care.

And once we got him home, I never left him because I had a baby monitor by his bed. And the baby monitor, the night that he died, I remember that a friend of mine had come over, hospice had told me that I needed somebody to stay with me to help me with John. I didn't understand what that was about but found out later that was more for me. They didn't want me to be alone. I didn't understand that. They told me that I needed help in case he fell. This friend of mine came over and she brought pizza. I wouldn't allow any hot food in my house because the smell bothered him. So, the pizza sat outside until it got cold and when it got cold she brought it in. And I had just sat down to eat a piece of pizza and I heard him yelp . . . I don't remember what it was, like moan or something, and I went in there, and that was also the day that we put him in a hospital bed; I heard this noise over the baby monitor and I went in to find out what was wrong with him. And he wasn't speaking because of course he wasn't speaking for days, and I looked at my friend and she was standing in the doorway, and I said I don't know what's going on but I am going to stay with him.

So I stayed in there with him, and then I realized he was dying. He was looking at a family picture on the wall. And he was looking at one person and then the next. And I remember thinking, "Oh my gosh, he's dying, right now, he's dying." And I remember that the hospice people had said that it would be a lot easier for John if I told him that it was okay. But it wasn't. I wasn't accustomed to lying to him about anything. So I couldn't do that. But I also know that they were right in what they said. So all I could say to him was I love you. And I remember, I said to him, and I was holding his hand, I looked at him and he was looking at me and I said I love you. About that time we were saying good-byes, and I said and I know you love me too. And that is when he stopped breathing.

What was weird is that later I found out that my friend who was there never heard anything on the baby monitor. The baby monitor, she said, there was no noise. She said that I just jumped up and ran.

I think it was God saying get up there—she said I was in there for an hour, and it felt like it was 5 minutes. I was just sitting there, holding his hand, and I said I know you love me too.

Because Caroline and her husband found hospice late, it was only able to rescue the Wall family in terms of the death event—that is, John died at home, peacefully, pain free, with his loving wife beside him. Yet late-entry hospice was not able to afford them the opportunities to plan and process the end of life, and thus their journey included many aspects of the isolated journey, including numerous doctor visits and patient abandonment. Caroline sums it up this way:

That 7 weeks was both the worst time of my life and the best. And when I say the best time of my life, I mean the most precious. It was all I had, and those 7 weeks were separate from the rest of my life and had nothing to do with the John I know today or before. Those 7 weeks were a whole different lifetime.

The Walls experienced isolation despite a rescued journey of hospice care. Many of Caroline's stories reveal her isolated feelings similar to the isolated journey, but she and John are narrowly afforded some limited comforts during 2 weeks of his life. Were it not for Caroline's ambition and caregiving resilience, John would not have spent those final days in his own home accompanied by his spouse and children.

## OVERVIEW OF THE RESCUED JOURNEY

Families experiencing the rescued journey are common in our medical structure today. In 2005, it was estimated that one in every three deaths caused by disease in the United States was under hospice care (Connor, 2007; National Hospice and Palliative Care Organization, 2008). These patients and families aggressively seek curative therapies for the early, middle, and late stages of their disease processes. Similar to isolated patients and families, the energy of this group is also channeled into finding, receiving, and recovering from curative treatments despite the cost of time and futility (Huskamp et al., 2009; Zhang et al., 2009). This population is not exposed to palliative concepts of care in the course of illness or offered effective pain management. Their physicians are specialists in the area of illness and also secondary and tertiary areas of specialty (e.g., oncologist, pulmonologist, and dermatologist—all dealing with effects of disease and



its therapies). Patients and families focus on cure and survival and spend little energy thinking about an active dying phase or making preparations for death and bereavement. The group in this class of care is careening toward isolation and disillusionment as well as a most complicated set of ethical medical decisions.

But this group, in the 11th hour, does receive late-entry hospice care. What moves them into hospice care is as variable as the families/patients who weather the isolated journey. For some, their primary physician discharges them and recommends the patient as hospice-appropriate. There is significant literature that discusses the abandonment some patients/families experience when this occurs, as the phenomenon of physician referral without patient/family conference is still widely administered (Ragan & Goldsmith, 2008; Ragan et al., 2008). Other primary physicians conference with patients/family and make a recommendation for hospice with the knowledge of the patient/family. Still another segment of this group pursues the acquisition of hospice on their own through conversations with nurses, home health workers, and friends or by their own volition. In any case, those who are part of the rescued journey step into a new paradigm of noncurative hospice care in the final days of their lives.

At this point, all things change for the patient and the family. No longer is their schedule driven by therapies and recovery. Total comfort becomes the primary goal. A medical team now provides care for patient *and* family, and there is significant attention given to dying and bereavement planning, whereas before these ideas were absent from conversation and thought. The concept of dying is now an awareness that all parties are encouraged to attend to openly and directly so that important matters such as advance directives and medical power of attorney can be addressed, relationships can be mended, and caregivers can begin finding relief and support after months of draining reciprocal suffering and caregiver burden. This journey, although we frame it as a rescue, is wrought with conflict and difficult realities for a family. After months of curative care, transition to comfort care in a matter of moments can be most difficult and even impossible to accept. Some patients and families harbor intense resentment for their primary physician(s) or the hospice medical team—as they can be seen as the bearers of deathly news.

Robin Romm's (2009) memoirs of the final 3 weeks of her mother's breast cancer illness found a place on the *New York Times* Best Sellers list in January 2009 likely because so many could resonate so well with her untempered haze of fury about cancer, death, suffering, and loss. Her focused stream of anger ultimately savages the hospice nurse who nearly moved into the family home to care for her mother during the final and most acute throes of pain and dying. In Romm's writing, we can identify the iconic marks of the rescued journey:

Barb, our hospice nurse, has bluish teeth and frizzy black hair styled to look like a hunting cap. . . . In one of the many fantasies I've concocted over the last few weeks here, I own a mess of owls and they wait, talons clutching the branch in their ornate cage. When Barb comes—when she looks past me to my mother to that voice she listens to when she's not listening to any of us—I will set them free in her face. . . . I'd like to ask Barb if she likes her line of work, if there's a particular thrill in being so close to it: someone else's tragedy—how much she gets paid and if she thinks work like this will get her into heaven faster. . . . I can't help thinking that when Barb dies, she'll have to have a hospice nurse. Or maybe she'll get hit by a car and not need one. But if she has a hospice nurse, I wonder what she'll think. I wonder if she'll comply.

"It needs to be where you can always find it," Barb says. In the kitchen, I find my father rummaging in a drawer for some tape. He paws through a tray of pens and, finding the last dregs of a roll, secures the paper crookedly to the fridge. DO NOT RESUSCITATE, it commands. My mother sits rigidly at the table. Just a couple of days ago, with a weak chin and shaking hands, she signed her name. (Romm, 2009, pp. 3–5)

This immediate, unforgiving, and misplaced attack on Barb (their hospice nurse) directs us back to the violence and anger that accompanies an illness journey that has been previously treated as survivable. It is one that resonates with the American audience and one that needs adjustment.

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