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# Thin Spaces: Examining Liminality and Impending Death Through the Lens of Hospice Care

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Through the lens of a particular hospice in southeastern Pennsylvania, I aim to observe how death is approached within a culture that swings between ignoring and glorifying death. Through on-site ethnographic engagement with patients of the hospice unit, informal and formal interviews with hospice staff, and scholarly analysis, I researched to discover answers to the following questions: What worlds do those who are knowingly dying inhabit? What choices do they make? What do they do and talk about? The answers to these questions offer an approach to dying that encompasses the liminal period before death, as well as the moment of death itself, as a holistic ritual. By learning from those who face death before us, I believe that we can begin to view death as a natural, sacred life transition.

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## Introduction

“Are you up for a visit?” I asked, while tapping lightly on the door. I was taken aback by Celeste’s<sup>1</sup> appearance. She looked . . . different. But in what way? Similar to most times I visited, she was sitting in her recliner in the corner of the room, under the painting of the young girl and the dog. Perhaps the difference was the large glasses she was wearing. I did not recall seeing her wear them in the past. Her hair was also a bit more disheveled than usual, though she was already dressed for the day in one of her home-sewn dresses. The most remarkable thing, I determined, was the disorder around her, and her apparent corresponding mental state of disorder. She was holding two ends of a travel toothbrush, trying—I think—to fit them together. Her hand motions were uncoordinated, making the finer nature of her chore difficult. The toothbrush task was also apparently the reason for the glasses, because once she had fitted the ends together, she took the glasses off and set them haphazardly on the table beside her. Yet her unsettled state persisted, as she seemed to be searching for something. Unsure of the role I was supposed to play, I suggested a few

places she could look for the (unknown-to-me) missing object. Was it in the drawer of her end table? Perhaps it fell below her chair?

Finally, for reasons only she understood, Celeste gave up on her search, put the toothbrush in a drawer, and turned her focus toward telling me about her morning. She had been given a shower—a regular occurrence on the day of the week that I visit, and a usual cause for an eye-roll or two from Celeste. “The water goes everywhere . . . I’m afraid the nurse is going to slip . . . You wouldn’t believe the amount of towels they need to use to clean up afterwards!” The litany of the shower event is one I’ve heard from Celeste before. Some things don’t change, for this story seems familiar, even if the messy breakfast tray in front of Celeste and the disorder of her bedside table and general demeanor seem foreign.

Just a few weeks prior, Celeste had used the occasion of my visit to tell me how she has always loved to clean, and still has a cleaning routine in this new living space. Each day, she explained, she wipes her rolling tray with baby wipes. She also uses these wipes to dust her end table and even uses them to wipe down her shoes. Today, in contrast, her breakfast tray litters

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<sup>1</sup> A pseudonym.

the rolling table, remnants of cereal floating in a bowl of milk, crushed paper napkins strewn about, and a glass of half-finished juice. The baby wipes pack is nearby, half opened, but Celeste pays no attention to it. Her recently removed glasses sit atop a glasses case on her bedside table. Beside that I observe a bowl of cookies, covered with plastic wrap. Dusting could only happen here today if the clutter disappeared.

Fortunately, a cheerful aide comes to remove the breakfast tray. Celeste asks her for water and a stack of napkins. The aide returns quickly with the desired items and then leaves to continue her duties in other rooms. Celeste fusses with the disposable lid on the plastic cup of water, finally managing to remove it. The purpose of the requested napkins remains unclear. Celeste crumples one in her lap beside a tissue she plucked—but didn't use—to wipe her nose. "The oxygen makes it run," she complains. "See, I haven't even put it back in yet, and my nose started running." Finally, she slowly maneuvers the oxygen prongs back in her nostrils, looping the plastic cord behind her ears to hold the cannula in place.

"Does the oxygen help you to feel less light-headed?" I ask, knowing that this was one of the reasons she started using it more.

"I guess." She rolls her eyes again.

I change the subject, trying to steer the conversation towards something familiar. I decide to ask Celeste about today's dress, a slightly textured maroon fabric with similarly-hued buttons running down the front. Early on in our conversations, Celeste told me that she sewed her own dresses, every one patterned in the same style: a short-sleeved shirt dress, knee-length, with a collar and buttons running the length of the front. They are simple, practical, and apparently long-lasting. Today's dress, Celeste informs me, is forty years old. I quickly do the calculations in my head: I was six years old when she sewed this dress! "It's the first one I made," she says, fingering the fabric. "I always loved textures."

"Did you sew clothes for your children?" I asked, thinking of my own mother sewing matching clothes for me, my sister and herself when I was growing up.

"A little," Celeste answers, without elaborating. Instead, she shows me how the fabric of her dress is thin from age and washings, holding the fabric away from her withered legs so I can see the light shining through.

Most Tuesday mornings during the past year, in my capacity as a hospice volunteer, I've visited individuals like Celeste receiving care at an inpatient hospice unit.

Patients who decide to receive this care are considered terminally ill, with a six-month or less life-expectancy. Rather than continue to pursue therapies, medical tests, or hospitalizations, these patients and their loved ones decide instead to focus on care and comfort in the time they have remaining in this life. While many hospice patients prefer to stay in their homes to die, some patients spend their final days in an inpatient unit out of necessity (lack of available caregivers at home or extensive care needs) or personal choice.

The particular unit I volunteered in encompassed a mix of very short-term (days) and longer-term (months) hospice patients, all over the age of seventy years old. While each person had their own private bedroom and bathroom, with space for family to gather, some larger rooms also included an attached sitting area that provided extra space. Additionally, the unit's floor plan included common meeting spaces—a large living room, dining area, and outdoor balcony, and separate rooms for a nurses' office, lounges, a library, a chapel, and a kids' playroom. While it was not the same as staying in a private home, it most definitely was not like staying in a hospital either. All floors, with the exception of the bathrooms, were carpeted. The furnishings were similar to those seen in a home or a nice hotel. Patients could decorate their rooms with wall-hangings and personal bedding, and stock shelves with favorite collections, family photos, and books. Most significantly, while the hospice physician and nurses were nearby and available to care for the residents of the hospice unit, they were not there to offer therapies, tests, or treatments. Instead, they were there to offer care and comfort as the individuals on the floor faced final illnesses and diagnoses that would end in death.

Death, in both general American culture and the subculture of American Christianity, is rarely a comfortable or popular topic. While certain facets of death seem glorified in holidays like Halloween or Day of the Dead, as well as through the increased popularity of skeletons in yard decor or skulls on trendy clothes, many people shy away from talking about, thinking of, or planning for the reality of death. I sought to explore this dichotomy of glorification and ignorance by examining death through a particular lens. Specifically, I came to know a community of people living and working in an inpatient hospice unit and immersed myself in their experiences in order to better understand what a healthy approach to the end of life can look like. In particular, I examined the worlds that those who were approaching the end of

their life inhabited. I paid attention to the choices they made—what they chose to do or not do, and what they chose to dwell on and talk about.

As I read and researched over a period of approximately four months, I began to identify some key anthropological themes that dovetailed with what I was learning about and witnessing in the hospice setting. Chief among these, and the main focus of this article, is the concept of liminality. Originally articulated by Van Gennep (1909), and later fleshed out by Turner (1991), the idea of rites of passage describes three stages one goes through as they transition from one ‘world’ or stage of life to another. First, they *separate* from their current world; for example, a child steps away from the world of childhood in preparation for entering a more adult world. Second, the person spends a period of time in a *margin*, or on the threshold of a new world. Turner (94) adopts the Latin word, “limin,” which literally means threshold, to describe this time. Finally, during *aggregation* the person in transition reintegrates; this may mean they resume life in a new stage, or that they enter a new ‘world,’ such as the world after death.

Through examining themes, such as liminality, as well as retelling the stories of those I met in hospice, my hope is to begin conversations about death. C. S. Lewis (1996) wrote after the death of his wife, “It is hard to have patience with people who say, ‘There is no death’ or ‘Death doesn’t matter.’ . . . You might as well say birth doesn’t matter . . . She died. She is dead. Is the word so difficult to learn?” (15). If individuals, families, and church communities can begin to view death as an event that is as much a part of life as birth, and thus, as worthy of contemplation and discussion, we can also begin to move beyond our culture’s dysfunctional poles of glorification and ignorance of death. By learning from the examples of those who go before us, I desire to demonstrate how we can learn to approach the liminal ritual of death in a healthier way, and thus claim and retain a measure of agency over an event that we all expect to face one day.

### **Anthropological Resources**

Victor Turner (1991) is best remembered for building on and illuminating Van Gennep’s (1909) ‘rites de passage.’ As I spent time with patients who seemed to dwell in a time and space between active life and death, Turner’s work on liminality proved remarkably relevant. In major life transitions—or passages—such as birth, puberty, marriage, and death,

there is often a ritual marking three stages of the passage: a separation from the previous life, a period of transition, and then reentry into a new type of life. In this middle space—Van Gennep called it “margin”—it is as if the person is perched on the threshold between one life and another. Thus Turner adopted the Latin word for threshold, ‘limin’, and began referring to the period of margin as “liminality”. In the forward to his book, *The Ritual Process: Structure and Anti-structure*, Turner explains that, “. . . in order to live, to breathe, and to generate novelty, human beings have had to create—by structural means—spaces and times in the groups which cannot be captured in the classificatory nets of their quotidian, routinized spheres of action” (1991: vii).

I discovered these spaces and times in the hospice unit. The patients were no longer moving about physically—nor even often emotionally engaged—in the routine everyday existence that I was coming from. Instead when I met with them, it was always in the same spaces: their rooms, or in the common areas on the unit’s floor. When we talked, it was almost never about the current-day politics, news, or technology. Instead, I heard stories about World War II, or memories of talking on a party-line telephone. The people I met were not confused; most, despite some being of advanced age, were remarkably clear-minded. Rather, they were letting go, or separating, from the outside world and preparing for aggregation (Van Gennep’s term) into a world to come after death.

While Turner’s work on liminality focused on African tribal rituals, the concept transfers well to the ethnographic setting in which I was immersed. Death, looked at from the perspective of the liminal time period and space of hospice, bore resemblance to ritual. Indeed, Turner was one of the first anthropologists to really take a deep dive into the rituals of the societies he studied. He, however, credits Monica Wilson (1954) and her husband Godfrey, as the chief inspiration for his work. “Rituals reveal values at their deepest level . . . I see in rituals the key to an understanding of the essential constitution of human societies” (Wilson quoted in Turner 1991, 6).

Turner’s work showed me the importance of transitory experiences in life that move us from one world into another. Yet I knew from my conversations with others, as well as my own observations about American society, that death was often treated with either ignorance or glorification. In other words, Americans—even Christian Americans—seemed uncomfortable with death. If, as Wilson postulated,

rituals hold a key to understanding society, what was I learning? At this point in the conversation, works by Michel Foucault and Nancy Scheper-Hughes helped me to more clearly understand what I was seeing. Scheper-Hughes's (1982) first book, *Saints, Scholars, and Schizophrenics*, took a look at a society through a predominantly medical angle (specifically mental illness in rural Ireland). "I thought I would learn as much or even more about Irish society from the patients of the district mental hospital than I might from the village curate or schoolmaster . . . society reveals itself perhaps most clearly in the phenomena it rejects, excludes, and confines" (13).

Foucault (1965), in his book, *Madness and Civilization*, looks at the historic treatment of madness in Western society. Some level of dementia is often present once individuals reach an advanced age, causing moments of confusion and opacity. While Foucault's ideas could be applied broadly to these dementia-based moments of confusion and opacity, I found his insight on delusion<sup>2</sup> more helpful. I leverage his insights to help me make sense of "The Twilight Zone" of a patient's personal experience with delusions. Additionally, Foucault's work, like that of Scheper-Hughes, and Mary Douglas (2002), showed a side of society that is seen only through the weak, excluded, or marginalized. "As for a common language, there is no such thing; . . . the constitution of madness as a mental illness . . . thrusts into oblivion all those stammered, imperfect words" (Foucault 1965, x). His book, he continues, is not about the history of the articulated sane majority, but of the 'silent' mad.

In seeking to move beyond either the glorification or the ignorance that death is accorded in society—in a sense, to listen for the silent language describing the reality of death—I utilized a variety of written sources. In a more practical vein, the mandatory and supplementary hospice training I received as a volunteer, as well as the wide variety of printed resources we were given, helped me to understand much more of the vocabulary and the process of natural death. From an anthropological perspective, *Death and the Regeneration of Life*, by Bloch and Parry (1982), was a helpful collection of papers on death and funerary rituals from around the world. In particular, the discussion on good and bad death in the introduction provided key insights for my work.

## Methods

### *Informal Interviews*

The bulk of the research for this project was carried out simply by spending time with patients in an inpatient hospice care unit. I had already been volunteering to visit patients in this unit for about six months before obtaining permission to begin formally collecting experiences. I agreed to use pseudonyms for the patients, as well as blur certain identifying details, including the name of the particular hospice I was observing. I also agreed to abstain from taking photographs of the residents and of the facility itself to maintain greater anonymity. Nevertheless, the substance of the patients' experiences in hospice was retained.

I determined that face-to-face interactions with people receiving hospice care was a superior method to simply asking for written answers using a vehicle such as a survey or questionnaire. One reason for this approach was that I wanted to discover what the patients themselves deemed important to talk about as their death approached. Asking a preconceived series of questions would have inhibited this process. A second advantage for personal visits was the direct window that this provided into the patients' realities. For instance, I could observe the spaces within which they spent most of their time. I could observe their obvious physical symptoms—for example, difficulty breathing or walking, drowsiness, agitation, mottled skin, or confused speech. I could even observe changes from visit to visit in the patients I learned to know well.

The beauty of ethnographic research is the access to unique insights and personal stories that come as a result of deep observation and careful listening to individual people. A topic as broad as death, or even end-of-life care, seems nebulous and impersonal until we link it with the way it impacts a single story. Anthropology encourages looking through seemingly small windows to observe and make sense of the galactic vastness of the human experience.

### *Formal Interviews*

In addition to my personal visits with residents of the hospice unit, I scheduled several interviews with

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<sup>2</sup> Foucault's definition of dementia is intended in a more general sense, and should not be confused with the technical medical definition, elucidated in the *Diagnostic and Statistical Manual of Mental Illnesses*, fifth edition, as involving acute brain failure.

hospice staff. I chose this method primarily due to the busy schedules of the persons I wanted to interview. I conducted two separate interviews with a hospice social worker. I also interviewed one of the hospice chaplains. For each of these interviews I developed some specific questions ahead of time. However, I was also open to learning about what the person being interviewed wanted to communicate with me. I was pleasantly surprised with the degree of openness and transparency from my respondents. The questions I asked generated the kinds of information I was seeking; in fact, I scheduled a second interview with the social worker to finish covering some of the topics we didn't have time for in the first interview! Their openness seemed to mesh with my own desire: to increase healthy dialogue about the end of life, not to 'sell' the concept of hospice in particular.

### *Cultivating Relationships with Staff*

While I chose not to conduct scheduled interviews with the head nurse on the unit, as well as other hospice nurses and nurses' assistants, I cultivated relationships with the staff who covered the unit during the daytime hours, the timeframe during which I typically visited the hospice. I would check in with these nurses when I arrived or left—often telling one or more of them whom I hoped to visit, or whom I had visited that day—and I sought them out when I had a specific question about what a resident was experiencing or how a resident was doing physically or emotionally. These informal conversations had the benefit of focusing on what was happening in real time.

### *Participant Observation*

Within the field of anthropology, 'participant observation' in the ethnographic process involves a balance between subjectivity and objectivity. "The ethnographer's personal experiences, especially those of participation and empathy, are recognized as central to the research process, but they are firmly restrained by the impersonal standards of observation" (Clifford and Marcus 1986, 13). In other words, I was actively involved in conversations and in building relationships with patients and staff in the hospice unit. I was physically present. Yet I was also not a patient or a staff member. I could come and go at will. I was observing my surroundings without controlling them, trying to let the 'experts'—the dying themselves, their family

members, and the hospice staff—guide my focus and teach me.

In the following section I will record many of the interactions I had with patients, whether conversing with them, or sitting by their bedside as they lay actively dying. I will also describe what I observed when I visited the hospice unit: the appearance of patients' rooms, the general layout of the unit floor, and the sounds of oxygen pumps, television shows, and music.

While no ethnography can fully capture a culture, my aim in conducting fieldwork was to utilize a variety of methods: formal and informal, subjective and objective, verbal and written. My hope was to produce a compelling picture with which a variety of readers, both academic and lay, can engage. Hearing from different voices, experiencing the hospice unit in various ways, and learning from other experts in hospice, and in the fields of anthropology and theology, can provide a starting point for teaching a different way of conceptualizing death.

## **Ethnography With Anthropological Analysis**

### *The Space Between*

"Good luck," two of the nurses' aides remarked as I told them who I intended to visit one morning. Bruce was new to the hospice unit, and he came from another part of the campus with a reputation. Although Bruce had declined most visitors, my supervisor felt I could handle his strong opinions and criticisms and recommended that I stop in to see him. With the less-than-helpful wishes from the staff, I set off to find the correct room. Though I had never been in this part of the hall before, Bruce's room's layout was identical to other rooms I was familiar with: a reclining chair in the corner by the window, a single bed by a wall of windows overlooking a small sitting room, and a series of built-in cabinets to hold clothes and possessions. I knocked on the door and introduced myself, peering around the wall dividing the sitting room from the sleeping area. Bruce was sitting in a chair in the corner of the room, hooked up to a portable oxygen tank. Unlike Celeste, who always sat upright during our visits with both feet on the floor, Bruce was reclining a bit with his legs elevated on a footrest. He was wearing a short-sleeved t-shirt that exposed arms blue with mottled blood. Talking seemed to exacerbate his wheeze and cough, but he was open to my visit and very willing to tell me about himself. First, though, he

commented on my use of a manual wheelchair to get around.

“I couldn’t use one of those. But I can use a power wheelchair. I’d like to use one to ride over and surprise my wife, the way she surprises me when she comes over here.”

Bruce and Cara’s love story starts at a local roller skating rink, when she was 13 and he was just a “shy country boy”. She asked him to skate, and then asked if he could take her home, beginning a four-year period of dating that led to a marriage that’s still strong 73 years later. His wife is his favorite topic of conversation: “I’m just so proud of her,” Bruce says, reaching a shaking hand toward a folder in his nightstand. He digs through a disorganized pile of hospice admittance paperwork until he finds a photocopied news article from the 1970s about his wife’s promotion to police detective. Then he digs through another drawer until he finds an envelope of pictures: one showing his wife with her fellow police officers and another of his brother. “He died at age 19 in the Battle of the Bulge,” he tells me.

“Oh, Bruce, that’s so hard!” I exclaim.

“We were very close. But he died for something he believed in,” he tells me. His acceptance of his brother’s unfair death at such a young age seems almost unsentimental. Yet one of the few earthly possessions he still keeps close at hand at the end of his own very long life is a picture of the brother who didn’t even make it to his twentieth birthday.

Many times, when I drive away after a hospice visit, I find myself fighting a sense of disorientation. I actually need to mentally prompt myself to pay attention to the roads and my driving because I feel like my mind is somewhere else. As I bid Bruce farewell and got in my van, I realized for the first time that I, too, am occupying a liminal space—in between the reality of inhabiting the world of memories with my patients and the reality of the present moment. I remind myself to stop and look both ways before turning left out of the health campus, my mind still ruminating over the loss of Bruce’s brother. It’s a bit like waking from a particularly vivid dream. Even after getting out of bed, you find yourself questioning if what you were just ‘living’ in your dream actually happened, or you feel your mind slipping back into the ‘reality’ you felt present to just a moment before waking. I continue my drive, and by the time I reach home, the presence of the past is fading.

Turner’s (1991) focus of research centered on African tribes, specifically participants in tribal rituals.

As these rituals varied, so too did the age and sex of the participants. In all cases, however, Turner refers to these participants as ‘threshold people,’ a term he intends to mean “ambiguous,” “neither here nor there,” and “betwixt and between,” (95). During my visit with Bruce, he seemed to aptly fit Turner’s definition of a threshold person. Yes, he still exists in the present world. He is still alive, and dealing with lack of oxygen, an annoying cough, shortness of breath, and the inability to independently ambulate around campus to see his wife. Yet our visit did not concentrate on the present. It was almost completely concerned with the past: Bruce and Cara’s first date, the loss of Bruce’s brother in World War II, Cara’s career, and children they fostered.

Similarly, almost every hospice patient I have interacted with seems to dwell primarily in the past and define themselves to me through their personal history. I’ve heard many stories of how someone met their spouse. I’ve learned about individuals’ careers, childhoods, and hobbies. While this situation is not completely surprising, upon later reflection, I found the trend puzzling. Why did most of the patients I met seem almost oblivious to their physical and emotional present? Did their choice to dwell primarily on their past suggest some sort of coping strategy in the face of a world without a future? Or was it simply a symptom of the way the human mind works as we age?

### *Liminality as a Battle Ground*

Turner’s seminal work, *The Ritual Process* (1991), speaks of the liminal stage of ritual being a space of preparation. As he studies various fertility, puberty, and initiation rituals among the Ndembu tribe of Central Africa, he portrays the actors as separated from their everyday life. In this period of liminality, the subjects undergo rituals that prepare them for the next phase of their life. For instance, a woman unable to successfully bear children enters, along with her husband, “a ‘moment in and out of time,’ and in and out of secular social structure” (96). The significant acts, words, and participants of these rituals are meant to repair the fertility problem and thus, prepare the woman and her husband to reenter society—normal life—with the ability to successfully bear children in the future. Likewise, a girl or boy in a puberty ceremony undergoes specific activities, or rituals, that prepare them to reenter society as a woman or man, rather than continue life as a child. Turner notes that those undergoing a period of liminality often exhibit “passive

or humble” behaviors (95). Ironically, this type of behavior seems to stand in stark contrast to the initiative of agency I observed in all stages of the dying process. Could this period of liminality—this ‘thin space’ between life and death—also be a battleground between agency and surrender?

Of all the patients I came to know, Celeste seemed to embody this struggle the most. Accustomed to being fiercely independent after her husband died, she came to the hospice unit angry and unhappy. Although she understood her need for more care, she was actively grieving the loss of her beloved apartment and her familiar routines. My introduction to her came about at the suggestion of one of the nurses, who mentioned Celeste had endured a rough night due to pain. Since I regularly experience the same kind of pain, she thought I could commiserate with Celeste and, perhaps, lift her spirits.

Unlike most of the other patients, Celeste did not introduce herself to me through her past. This difference in first impressions was not necessarily attributable to Celeste’s degree of health or distance from death. She presented like many of the other patients that I visited: elderly, in pain, low on oxygen, and lacking much ability to ambulate independently. The difference, I believe, had much to do with Celeste’s force of will. Opinionated, blunt, and feisty in temperament, she was still actively mourning the loss of living on her own in her apartment, with its familiar surroundings and life rhythms. She told me she was used to staying busy and doing things herself. When she was younger, she sang in the church choir, sewed all her own clothes, worked in her yard, meticulously cleaned her house, and canned and froze food. Now she complained that she has problems even picking things up without dropping them. This war between a zest for life and an impending death, between independence and forced dependence, brought an added dimension to Celeste’s experience of the liminality of hospice.

“People say they want to live a long time, but it’s not fun to be old,” she said. In fact, Celeste seemed to want to skip over the whole ritual of dying and get right to the end, saying more than once, almost casually, that she would “rather be dead” than experience more pain and disability.

This war between surrender and agency manifested itself in the conversation topics Celeste chose during my weekly visits. Some days, I would hear all about the recent TV shows she had watched or the magazine articles she read. During my third visit, Celeste detailed

her current morning cleaning routine: wiping down all the surfaces she could reach from her chair with baby wipes. The topic of cleaning, however, launched Celeste into the past, as she remembered the dogs her family had kept over the years and how difficult they were to clean up after. As the weeks went on, and Celeste became more accustomed to her new home, I heard less about the immediate past and witnessed her traveling deeper into her history in a way similar to that of the other patients I visited. Then one fall morning our conversation began with a jolt and subsequently introduced me to a new form of liminality.

### *The Twilight Zone*

As I knocked lightly on her door and called her name, I realized that all the lights were off in Celeste’s room and the curtains were drawn. When I came around the corner and saw her empty chair, I briefly thought that she must have left her room or traveled off-campus for the morning. Then I saw her lying in bed. This was unusual. As soon as she saw me, Celeste leaned forward and announced, “When you said you’d be back in two weeks to see me, I thought, ‘no you won’t, because I’ll be gone.’ I’m dying. I know I’m dying.”

Somewhat stunned by both this stark announcement and Celeste’s appearance—she was still in her nightgown and her hair was mussed and unwashed, a far cry from her usual tidiness—I stammered out a response, asking if she felt much worse.

“I don’t mind that I’m dying,” she continued, ignoring my question. “When you live as long as I have, you know to expect it.”

Perhaps it was the surprise of Celeste’s sudden announcement or her declined appearance that distracted me. It certainly took me some time to realize that her style of speaking this morning was different than that of previous occasions—more rapid, with less pauses taken to remember. As she soliloquized, it gradually dawned on me that what she was sharing couldn’t be true. While some aspects of her story were familiar, like her favorite TV shows, other points seemed wildly improbable. Her former neighbor actually worked on her favorite TV show! He pretended he was blind and changed his name on the show, but she knew it was him because of his smile. Much of the story she had to tell me that day revolved around this man, ‘Mike,’ who kept morphing: from working on the television show, to impersonating Celeste’s late husband, to being both a sex offender

and her neighbor, to becoming her building supervisor and a con man, to even being an employee of the very hospice unit Celeste lived in.

As I attempted to listen attentively and tried to act as though what Celeste was saying made sense, I also wrestled inwardly with what was going on. This didn't seem like the woman that I had come to know. She had often been forgetful before, but not paranoid and delusional. This elaborate, continuously transmuting story about Mike that she was relaying *couldn't* be true, but did that mean that nothing Celeste was saying to me today was true? And did the fact that the story wasn't true—but she believed that it was—mean that the delusional person telling it to me wasn't truly Celeste either?

In his exploration of insanity, Foucault (1965) writes of the need for those experiencing delirium to wake up. "Since delirium is the dream of waking persons, those who are delirious must be torn from quasi-sleep, recalled from their waking dream and its images to an authentic awakening" (184). Perhaps this is a helpful way of viewing delirium: existing in another version of reality, similar to the 'reality' we occupy when dreaming during sleep. Thus, it was as if I were given a window into Celeste's dream (nightmare?) world; a world usually hidden from view but made visible through a form of madness.

In essence, delirium is a kind of liminality all its own. The world Celeste was occupying on this particular morning was not fully the reality of the present moment or the reality of her past. Instead it was somewhere in-between, interweaving elements from both the past and the present alongside appearances of the bizarre. She knew who I was as she was relaying her monologue to me; we had established near the beginning of our visit that she remembered my name, the time I usually visited her, and where I lived. She also announced right away that she knew she was dying—another true facet of her current reality. Likewise, portions of her delirium included true elements from her past: her late husband made an appearance, and she referenced the two different apartment complexes she lived in after she and her husband sold their home. Yet this in-between, 'twilight zone' of delirium packed in a creepy man that kept popping up all over the place, and, later, statements to the nurse that her bed was wet and needed changing. (The nurse whispered to me that this, too, was untrue; however, she told Celeste they would change her sheets.)

After leaving Celeste's room that day, I checked in with the nurses to process what I had just experienced. They affirmed that Celeste had been mostly delusional for several days, ever since she had argued with her children over the weekend. The nurses thought the root of the argument was her children not believing what she was saying. At least, Celeste perceived that they disbelieved something she was saying—perhaps her strong belief that she was near death? As a result, the hospice staff had been trying to affirm her statements, however bizarre, as much as possible. For example, as mentioned above, the staff was changing the sheets on Celeste's bed because she believed that they were wet, even though they were actually still dry. The nurses hoped that as Celeste felt validated, her delusions would diminish.

Though delusions can be a sign that death is imminent, Celeste's type of delusions were not serving her well. They were scary, unsettling, and misleading. In essence, the nurses hoped that by validating Celeste, they could 'wake her up,' to use Foucault's terminology. While reducing distressing delusions may not ultimately prolong a patient's life, it will aid in making their preparation for the next leg of their journey more peaceful. In Celeste's case, when her delusions ceased, so did her preoccupation with death. A week later, she would declare that she had "rebounded," and she seemed to no longer believe that she was actively dying.

## **Ethnography With Theological Analysis**

### ***The Sacrament of Suffering***

Eleanor looked small and birdlike lying in her bed. She was skeletal, had difficulty moving, and could no longer project her voice. But her face still bore evidence of a lifetime of smiles. Between brief periods of dozing, Eleanor told me that when she moved here, she had reconnected with a childhood friend who was also receiving care. She hadn't seen her recently, she whispered, "but when you get to be my age, people just disappear." In his summation of Van Gennep's (1909) 'rites de passage,' Turner (1991) delineates three stages: separation, margin, and aggregation (94). The majority of my time in this paper has been—like Turner's work—devoted to the middle stage, "limin, signifying 'threshold' in Latin" (ibid). We cannot, however, spend our lives poised on the threshold. In the ritual of death this means completing the journey

to whatever lies beyond, or in Eleanor's words, "just disappearing."

Schemmann (1973) notes that from a Christian mindset, disease—not health—is the 'normal' state of humans on earth. While the secular world attempts to defy disease and restore health at all costs, the Christian realizes that, in the words of Jesus, "In this world you will have trouble" (Jn. 16:33). Equating sacrament with the concept of passage or transformation, Schemmann writes, "in Christ suffering is not 'removed'; it is transformed into victory. The defeat itself [death] becomes victory, a way, an entrance into the Kingdom, and this is the only true healing" (Schemmann 1973, 102). Thus, for a Christian, death becomes not a battle, the enemy, an end, or even a final "disappearance," but rather a sacrament, or transition, from life to Life.

As patients move through the liminal period of life, transitioning into death, I've found that their desire for the spiritual grows more acute the closer they come to their final days. If they are a few months, or even a few weeks removed from death, they are often still focused on reminiscing, culling their lives for bits of wisdom, or remembering earlier activities and seasons of life. They may even show interest in the continuing activities of the world outside the doors of the hospice unit: political elections, the stock market's rise and fall, upcoming activities of their children and grandchildren, or major weather events. As they approach their time of active dying, or transitioning, however, these other foci fall by the wayside, replaced with a stronger desire for, and appreciation of, familiar scriptures and hymns, beloved poems, or blessings.

While I can only guess what patients are thinking in this final stage, I wonder if they reach toward the spiritual—whatever that looks like to them—due to a desire for comfort and a desire for preparation. In reflecting on her work as a hospice nurse, Hadley Vlahos (2023) writes, "In my experience, the people who are happiest at the end of their life are those who have achieved a sense of peace in regard to how they've lived, and who are comfortable in their belief about what comes next" (249). Additionally, the words of the scriptures and hymns suggested to us in our volunteer resources often focus particularly on what is to come, helping the dying to shift their focus from the scariness of the unknown to the hope of an anticipated future.

As persons reach the end of limin and anticipate an imminent cross over the threshold, their thoughts are rightly consumed by the new reality they are stepping into rather than the old reality they are leaving behind.

In essence, according to Turner, that is the purpose of the liminal period; it is a time to slough off the old and prepare for the new. "It is as though [those in limin] are being reduced or ground down to a uniform condition to be fashioned anew and endowed with additional powers to enable them to cope with their new station in life" (1996, 95). From a theological standpoint, the dying person is exchanging mortality for immortality. As such, their focus at the very end of life shifts from the "things of this world" to "the things above."

### *I'll See You On the Other Side*

After the visit where Celeste announced that she was dying, I learned from the head nurse that her delusions had mostly abated, and she had even started getting out of bed again, claiming that she had "rebounded." Nevertheless, Celeste's food intake remained poor and she was very drowsy when I visited the next time—both common signs of diminishing life. Two weeks before her death, Celeste was back to spending most of her time in bed. Though she was still alert and would answer my questions, her voice was so faint I needed to lean close to her bed in order to hear what she was saying. One particular morning was bitterly cold with a layer of frost on the ground, so I asked Celeste about her opinion of snow. "Did you—do you—like snow?" I asked, inadvertently using the past tense with a woman who was still alive.

Ignoring or missing my gaffe, Celeste answered with her typical bluntness, "No!" She elaborated that she hated shoveling snow, especially when her family moved to a bigger lot with more space to clear. She also brought up the dogs—that she claimed to hate—again, remembering how they didn't want to go out when it snowed. Though I struggled to catch everything she said, I was pleased to see her smile as she reminisced, a success I recounted to the head nurse on my way out that morning.

I knew after that visit that I didn't have much time left to visit Celeste. Sure enough, the snow conversation was the last time I heard Celeste's voice. Two weeks later the hospice staff decided that Celeste was now actively dying. When I entered her room on my typical morning to visit the hospice, I knew that this would most likely be my last time to see her. The room was dim when I entered and Celeste was lying on her left side, wearing a pink, plush, button-down robe. Though the robe looked store-bought, the buttons down the front reminded me of the style of dresses she

sewed for herself and wore when I began visiting months before.

Celeste's eyes were closed, and her breathing was calm and even. She gave no indication that she knew I was there as I reached to hold her hand and started a one-way monologue. I reminded her of how much she had loved cleaning and cooking. I reminded her of the past places she had lived, including the beloved apartment where she had last lived independently. I mentioned her family members by name, and told her that she would soon see her husband again (whom she had lost suddenly a few years before). I commented on the weather; it was still cold enough to snow I told her, but her snow-shoveling days were finally done! She was allowed to rest.

After my life review, I pulled out a book of prayers and my Bible. When I finished praying, I read several passages from the Bible: 2 Corinthians 4:16-18 and Psalm 23. Finally, singing over top of the hymns that were playing softly on CD, I sang "It is Well With My Soul." As I finished the last chorus, a nurse came in to change Celeste's sheets for the day.

"I don't need to interrupt," she said when she saw me. "I can come back."

"Just give me five minutes," I said.

Holding Celeste's hand one last time, I told her how much she had enriched my life in just the few short months I had visited with her. I thanked her for being willing to visit with me, for her unique spirit and sense of humor, and for her eye rolls. "I probably won't be back to see you before you go," I said, tears filling my eyes. "But I know where to find you. I'll see you on the other side."

## Conclusion

Four months after Celeste died, I was sitting with another hospice patient in her sun-drenched room talking about dogs. Unlike Celeste, who talked a lot about dogs for not claiming to like them, this woman told me, "I never met a dog I didn't like." After a few minutes of chatting, Mary stopped talking and just gazed at the television playing in front of her. A year ago, I might have rushed to ask another question, to fill the silence, to make an excuse and flee. This time, though, I followed her gaze, and silently sat beside her, my hand on her bed, to watch *Perry Mason* on TV.

Talking about death is difficult. We don't like to think of our own mortality, and we don't want to think about life without those we love. Yet I hope recounting my interactions with hospice patients has demon-

strated a few things that we can learn if we stop either ignoring or caricaturing death, and instead join the conversation without fear. Death, like birth, is a part of every human experience. We have long recognized the sacredness of birth, celebrating not only the moment itself, but the time leading up to it and immediately after it. For those choosing hospice care in the unit I observed, the time leading up to the actual moment of death became a liminal time of reflection, life analysis, rest, and preparation for the next reality. This liminal posture was teaching them the beauty of *being* in a world of doing. By allowing ourselves to journey along with our loved ones during this liminal time, we too can learn the beauty of being, and can witness the sacredness of this time on the threshold of a new reality.

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