Slowing Down Medicine

The Plural Worlds of Hospice Care
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Abstract

This ethnography reflects on a non-profit hospice care organization in the Midwestern US where caregivers "slow down" medical care by acknowledging the plurality of forces that constitute the illness experience, philosophically departing from their biomedical, non-hospice counterparts. It demonstrates the ontological effect of "slowing down" and attending to a set of patient problems that extends beyond the biological, or any distinct, domain. The result is a medical world that privileges the embodied, lived expression of disease—rather than the statistical, clinical expression—resulting in medical care that is enmeshed in the variables of everyday life. I therefore situate hospice care in a historical moment witnessing the emergence of a sophisticated and "non-modern" (Latour 1991) form of medical care

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Introduction

Two EMTs wheeled a patient on a stretcher into the hospice inpatient unit where I worked as an intern volunteer. The 84-year-old Czech woman[1] had fallen and broken her hip, and a blood clot was forming in her lungs. As two nurses worked to stabilize the patient, the social worker and I looked at her admission file. We learned that the patient had had no major health issues until her fall, and that she was a Holocaust survivor.

The patient had been stabilized for a few minutes when her son slammed open the door. After a glance, he told the clinical director that he wanted his mother to have a hip replacement. The clinical director responded: "With a blood clot in her lung, she can't go through surgery." Dismissing her, the son demanded to speak with a surgeon. Some time later, the son, referring physician, social worker, and hospice clinical director convened a meeting in an empty room down the hall. The clinical director asked me to sit with the patient and care for her, making sure she felt comfortable.

When I saw her, the patient was miserable. Her arms had pooled with blood, turning the skin purple. Her breathing was strained and quick. She knotted her brows tightly, and her eyes were closed. Sitting down next to her, I asked if I could hold her hand. She took my hand and clasped it tightly, bringing her other hand over to meet it. "Did you ever think life would look like this?" I asked her. Squeezing my hand, she shook her head. "Would you like me to sing to you?" I asked. She nodded, and as I sang, she began to cry. When her son, physician, and inpatient team re-entered the room, I was singing to the patient, who was clasping my hands tightly and weeping. The patient died the following morning.

Measured in terms of rates of ICU admission within three days of death (Teno et al. 2013), instances of chemotherapy administered within fourteen days of death (Earle et al. 2004; Braga 2011), and high rates of patient death in ICUs (Angus et al. 2004), aggressive medical care at end-of-life is a well-studied problem that confounds oncologists, geriatricians, economists, and public officials alike. A host of factors keep the current inclination towards aggressive treatment in place. The sophistication and availability of life-extending medical technology begets aggressive treatment, creating a "technological imperative" (Fuchs 1976; Koenig 1988) to routinely employ the most advanced means available in the state of the art. Hospital reimbursement schemes pressure staff to discharge patients as quickly possible, often employing the invasive means most

immediately available for treatment. Finally, many doctors experience significant difficulty discussing end-of-life planning with their patients. Avoiding these conversations can result in patients with no advanced care plans who are treated invasively in hospitals just before dying.

In the 1970s and 1980s, Europe and North America witnessed the rise of hospice care: a volunteer-led movement dedicated to changing the medicalized, impersonal experience of death that had become the norm. A devout Christian and expert in medical pain management, Dr. Cisely Saunders founded the first contemporary hospice in London in 1967 to care for what she called "total pain": pain that encompassed physical, spiritual, social, and emotional suffering (Saunders 1996). As activists and health experts, early hospice advocates fought for holistic care for the terminally ill through an interdisciplinary model emphasizing the patient's concerns and desires. Their movement gradually gained widespread acceptance, and hospice has become one of the fastest growing areas of health care, ballooning from the first American hospice established in 1983 to over 3,000 hospice providers in 2012 (NHPCO 2014)[2].

The evolution of death into a technological, hospital-based event and subsequent rise of holistic care for the dying evidence a Weberian dialectic between disenchantment through rationalization and subsequent re-enchantment through individualized means. While the hospice movement has itself grown and fragmented over several decades, this ethnography locates in contemporary hospice care an impulse towards pluralistic, nonscientific, and therefore re-enchanted ways of thinking about and caring for patients. This article explores what I have come to call "slowed-down care": encounters that occur when practitioners engage with the irreducible complexity of their patients' problems. Slowed-down care describes the moments in which nurses and their patients sit down to tea, when they meet cousins and spouses, when appointments last over an hour, and when conversations about patients spill beyond allotted meeting times and working hours. The aim of this article is to consider how the practice of "slowing down" has allowed hospice caregivers to incorporate plural worlds into their practices. It therefore situates hospice care in a historical moment that has witnessed the emergence of a re-enchanted, technologically savvy, and perhaps "non-modern" form of medicine (Latour 1991).

Philosopher Isabelle Stengers has inaugurated a project within the philosophy of science intending to "slow down thought" (2005, 1). Stengers grounds the project in an awareness that "the political arena is peopled with shadows of that which does not have, cannot have, or does not want to have a political voice"—entities rendered nonexistent by even well-meaning systems of thinking and governing (Stengers 2005:3). But how can we acknowledge that which we cannot perceive? Stengers' project is to imbue political voices with pause, or "passing fright"—with an insistent nagging that "[we] do not master the situation [we] discuss" (Stengers 2005:3). Above all, her project insists that we slow down before claiming mastery, considering for a brief moment what might escape us before concluding "and so…" (Stengers 2005:3).

To illustrate the conditions of possibility for "slowed down" medicine, I first consider the operational logics pervasive within standard biomedical care that birthed hospice's departure. In hospitals, the pressure to "purify" (Latour 1991:11) dying patients into distinct bureaucratic and medical categories leads to an inability to see objects or shadows beyond the presenting diagnosis. In oncology, disciplinary demands result in the treatment of cancer as a strictly physical dilemma, rather than something with explicit social, financial, professional, or personal ramifications. We will see how many aspects of illness experience are excluded within these systems of care. Next, I turn to my own observations of hospice care to describe how certain conditions allow caregivers to slow down care and work within plural worlds.

The ethnographic observations come from my time spent at a hospice and palliative care organization in a large Midwestern city, where I worked as an intern for four months over the summer of 2013. The organization has a long history and reputation within the city, which furnishes a diverse patient base as well as a thriving volunteer community. During my time there, I functioned as a full-time hospice volunteer, making both home visits to patients (meal preparation, socializing with patients, assistance with housework, keeping vigil at time of death) and working at the affiliated hospice inpatient unit (volunteer training, mealtime assistance, socializing with patients, helping families, assisting with patient hygiene). I accompanied physicians, social workers, nurses, chaplains, music therapists, and hospice aides on patient visits, conducted semi-structured interviews, and chatted continuously with patients and their families. The following stories are accounts of patients, families, and hospice workers as they move in and out of each other's lives.

Crisis of Categorization: Biomedical Limits

In order to understand hospice as re-enchanted care for the dying, we must first situate rationalized care within standard biomedical practices. In this section, I use Bruno Latour's notions of translation and purification (1991), as well as Donna Haraway's "cyborg" (1991: 117) to describe forces that often hinder effective medical care for the critically ill. The examples below do not characterize biomedicine broadly speaking, but rather highlight key factors that have lead to the medical crisis of death in America, demonstrating the effect of rationalized disciplinary and bureaucratic structures on care for the critically ill.

Latour highlights two contradictory processes that define the "modern constitution" (1991: 19). Through purification, modern societies sort things into clean, dichotomous categories: human and nonhuman, natural and technological, science and politics. Through translation, societies give rise to bizarre and unthinkable hybrids—entities and problems that defy categorization. Modern society is organized upon the success of purification, the very foundation of which is threatened by the products of translation. Latour posits a firm link between the two processes: the desire to categorize often leads to the creation of things that cannot be categorized. As we organize societal life into categories, hybrid problems become increasingly prolific, menacing, and demanding of our attention. Multiplying hybrids encroach on the possibility of these categories on which society has become dependent.

Who are these hybrid creatures? Donna Haraway has described the "cyborg" as "a cybernetic organism, a hybrid of machine and organism, a creature of social reality as well as a creature of fiction" (1991:117). Haraway describes our modern world as one of blurred boundaries: a world with faltering distinctions between animal and human, organism and machine, women and men. Medical anthropologists have not been ignorant of these category-defying entities, which have increasingly come to define the modern medical landscape. The advent of life-sustaining technologies, an ever-expanding cornucopia of pharmaceuticals, and humans chronically dependent on medical institutions in order to live a "normal" life render purifications such as human/machine, natural/technological, and healthy/unhealthy impossible (see Dumit 2002; Lock 2002; Lupton 1999).

Contemporary hospital medicine relies on abundant purifications in order to operate. In her ethnography about death in hospitals, Sharon Kaufman (2005) illustrates how bureaucratic pressure forces doctors to diagnose dying patients with treatable illnesses and shuttle them quickly

through treatment and discharge. For the most critically ill patients, progress soon goes awry; many become dependent on the medical technology employed (such as a mechanical ventilator or a feeding tube), while others do not have specific, treatable diseases. Discharge is impeded or physically impossible. Dying patients become hybrids resisting bureaucratic purification, confounding the systems designed to handle them.

Kaufman traces the shift in hospital culture to the year 1983, when Medicare Diagnostic Related Groups (DRGs) gave diagnoses—rather than individual treatments—fixed reimbursement prices (2005:91). This immediately augmented the importance of categorizing, and therefore purifying, patients. Moving away from a fee-for-service model, in which an unlimited number of services could be performed on a patient if deemed medically appropriate, the DRGs set a reimbursement limit for each diagnosis: no matter how many procedures were needed, every person with the same diagnosis would receive the same reimbursement. The new billing scheme sent ontological ripples through the hospital system. Dying persons were suddenly not recognized as dying—they had to be categorized as treatable, lest the hospital not be reimbursed for their stay. In a treatment-based institution, lingering, waiting, and resting under watchful care are not available services. Dying patients become cyborgs: physicians cannot diagnose them, nurses cannot prepare them for discharge, families spiral between hope and fear, and the patients themselves are left to wonder where exactly they hang between life and death.

Kaufman maintains that death has now become a process completely "structured by hospital bureaucracy" (Kaufman 2005:89). When doctors and patients inhabit such a world, the field of institutional attention is constricted to a diagnosis and everything else becomes ancillary, taking on a shadowy quality.

If effective hospital care is constrained by medical purification, we can say that care within oncology is often constrained by disciplinary purification. For example, several studies have shown that oncologists often fail to recognize depression in their patients, correctly identifying less than half of their depressed patients as such, and as few as twelve percent (see Fallowfield et al. 2001, Sollner et al. 2001, Passik et al. 1998, Hardman et al. 1989). Depressed patients incorrectly identified by their oncologists were shown to experience higher amounts of pain and have poorer treatment outcomes than those who were correctly identified (Passik et al. 1998). Unless depressed patients independently arrange psychiatric or palliative services for themselves, they are handled by a health system that purifies the hybrid problem of cancer into a physical problem. In reality, however, the symptoms of cancer may be as mental, financial, social, personal, and professional as they are physical.

When an anxious patient and a busy oncologist sit down to consider a complex disease, there may be no space for the "cosmos"—in Stengers' words, the "unknown constituted by multiple, divergent worlds" (Stengers 2005, 3). Medical language, social problems, emotional distress of patient and physician, caseloads, and more reduce the size of the patient's knowable world: there is no time to slow down thought. The inability to slow down thinking results in the exclusion of all entities outside of the biological disease process, and may ironically get in the way of effective care.

Slow Medicine: the Hospice Program

Now regulated and funded largely by Medicare, hospice today is a form of medical care aimed at increasing comfort and dignity in dying persons. To enter hospice, a patient must be referred by a physician who estimates that the patient has approximately six months left to live, and is not seeking curative treatment. Each patient works with a team consisting of a physician, a Registered Nurse, a hospice aide, a chaplain, a social worker, and often a volunteer (see Figure 1). Most hospice organizations administer service through home visits to the patient's residence. Additionally, hospice organizations maintain phone lines, make emergency visits, arrange for medical equipment, provide volunteer support, offer emotional counseling, spiritual guidance, legal assistance (appointing a Power Of Attorney, writing Living Wills, and certifying Resuscitation Orders), and more. The host of potential referents that can be signified by the single word "hospice" indexes the wide domain of its operations. The word's variable deployment in common speech reveals the productive ambiguity of hospice services: families often talk about "when hospice arrived," "hospice recommended she change nursing homes," "the hospice brought her meals," etc., referring to a unified service simultaneously enacted by several different providers.

To become accredited as a hospice organization and receive reimbursement by Medicare, companies must follow stringent requirements regulating nearly every aspect of care. However, the bureaucratic substructure of hospice care reinforces, rather than undermines, the wide-ranging spectrum of care opportunities. Rather than paying for individual services, insurance providers pay a flat daily fee for the entire duration of care. This payment scheme allows for steady medical attention throughout a patient's time with hospice, rather than episodic treatment for individual medical problems. Theoretically, this structure dissolves incentives to over- or under-treat patients, as payment is equal for all patients and divorced from the particularities of care. To maintain consistency and quality across hospices, a detailed set of provisions by Medicare regulates everything from the minimum number of physician home visits required to the narrative style of evaluation that hospice caregivers must record after visits[3].

The interdisciplinary focus of hospice acknowledges a world characterized by many forces that cannot be served by a single discipline. The close proximity of so many disciplines and their even deployment within the hospice system represents the beginning of a widening of thought within hospice care. The fact that hospice home aides and physician home visits are both bureaucratic expectations denies that any problem can be handled with only one set of methods. In this model, piles of dirty dishes and laundry sit beside pulmonary embolisms and hip fractures; both sets are acknowledged as injuries to the lifeworlds of hospice patients. Conversations with God are invited into conversation alongside pain and nausea.

Thinking about William James, philosopher William Connolly (2005) describes a world that spreads beyond the reach of any single philosophy that might seek to encompass it. Rather than a "unified world knowable through fixed laws," the world James imagines is thoroughly enmeshed in everyday experience, with all of its contradictions and unknowns (Connolly 2005: 69). The world is not a rational whole—where cancer, for example, is a biological problem with chiefly biological ramifications—but a pluralistic one, constantly visited by "subterranean energies, volatilities and flows that exceed our formal characterizations of being" (Connolly 2005: 73). A philosopher of pluralism is aware of the "abundance of the world over the language through which we describe it" (Connolly 2005, 75). What is the philosophy of such a world? Connolly writes:
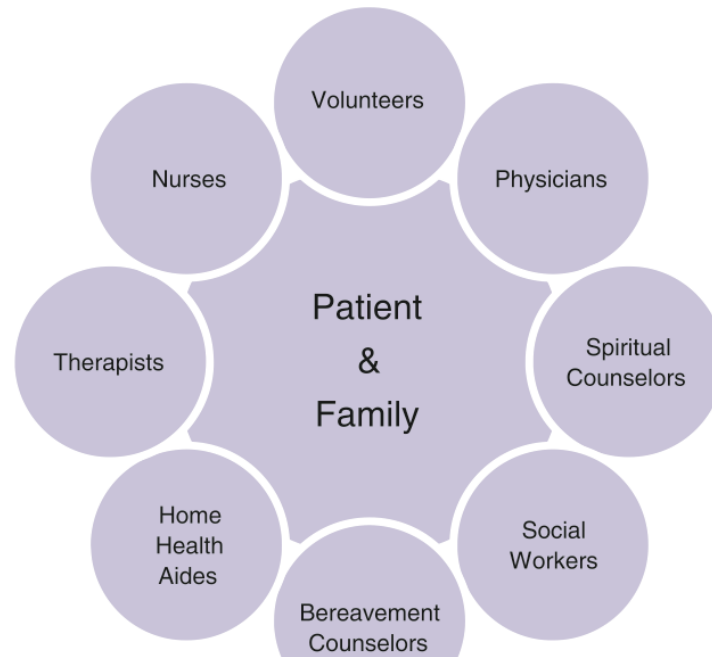
Figure 1. A commonly encountered diagram of the hospice interdisciplinary team assigned to each patient. Note that no one discipline is represented as primary or most important. (NHPCP 2014)

> The disturbing, or beguiling, thing is that such a philosophy is not, in James's presentation, susceptible to neat, clean delineation. The overlapping forces propelling the world are themselves messy. Pluralism is the philosophy of a messy universe. (2005: 69)

Hospice slows down care for the critically ill by acknowledging the volatile, hidden forces that govern the experience of illness. The bureaucratic recognition of such forces, as evidenced by the imperative to make several care disciplines available to each patient, is central to such a perspective. But while the bureaucratic structure of hospice demands wide-ranging awareness of patient experience and encourages interdisciplinary collaboration, slowed-down care is not the immediate result. True acknowledgement of the uncategorizable, complex forces that constitute the experience of illness requires individual caregivers' abilities to consider patient experience from a perspective that goes beyond a single discipline. While hospice institutional regulations allow for the central inclusion of many often-ancillary disciplines within medicine—social work, chaplaincy, creative therapy—strictly following a single disciplinary checklist rules out the possibility of slowing down care. Rather each individual perspective must expand beyond the boundaries of a single disciplinary vocabulary.

New Objects of Care

Despite its kinetic nature, my work at the hospice had a grounding routine: every day I visited patients, every week I attended interdisciplinary team meetings, and every month the entire staff gathered for general announcements. A hospice identification card let me enter hospital wards, nursing homes, and apartments, and a friendly self-introduction lead me to many bedsides

and deathbeds in my capacity as a volunteer. My bicycle let me crisscross the city several times per day, visiting patients and meeting staff members strewn across town. Over time, I became familiar with the objects and vocabulary that fill the daily lives of hospice patients. I adjusted my vision as the once-strange world of end-of-life medicine became my own daily practice.

Over and over I noticed that when patients switched into hospice, medical attention previously devoted to a specific diagnosis became dispersed across the patient's body and life. Instead of medical care being fixed on one diagnosis or problem—a hip fracture or pancreatic cancer—myriad objects of care emerged: fear, anxiety, joy, nightmares, the longing to reconnect with a relative, hallucinations, invisible tingling sensations, nausea, loneliness, bedsores, pneumonia, fractured limbs, sepsis, simple tasks out of reach for the bedbound patient, the desire for physical contact, for help calling a friend, or to pass the idle hours. Sometimes a newly blind patient needed someone to read to them. These were handled and treated alongside more visible objects, such as pain and the patient's primary diagnosis. I watched hospice caregivers discover and treat these varied issues with unexpected methods: rearranging furniture, cleaning out the refrigerator to relieve a bad smell, talking to family members, telling stories, administering antibiotics, wrapping wounds, or simply sitting in silence. As a young intern with lots of time on my hands, few formalized responsibilities, and an inoffensive demeanor, I was often dispatched on unbelievable tasks: take this wheelchair-bound patient to the aquarium, celebrate a birthday with this patient who wants to drink cream soda, help this patient eat ice cream. It took time to understand that these activities were often central to the effective care of terminally ill people, and not as ancillary as they initially seemed.

The weekly ritual of the Interdisciplinary Team Meeting ("IDT meeting") was the axis around which the hospice turned. In a feat of logistics, IDT meetings gathered otherwise mobile caregivers together for an entire morning of thinking about patients. Over the course of several hours, each member of the hospice care team shared updates, stories, observations, news, or any significant information about each patient on the census listing. Of the 15-25 people in attendance, a few ate breakfast, some rushed out of the room periodically to accept phone calls from patients, and most found a way to make jokes during the meeting. I attended these meetings for months both as an observer and occasional contributor.

At IDT meetings, the social workers, nurses, chaplains, physicians did not present disciplinary reports—they had conversations. A patient's name, demographic information, and primary diagnosis were first read aloud. Then someone would give an update, state a problem the patient was having, or report on general decline or improvement. If the patient had a new or significant problem over the past week, then a mix of perspectives, stories, and questions poured in. The problems usually exceeded the bounds of a single discipline. For example, a nurse once observed that a patient seemed to be experiencing the side effects of a certain drug, which the social worker noticed was the major factor in that patient's recent dispute with a relative. Alternately, the medical director inquired about the usefulness of a bulky hospital bed recently delivered to a patient's home. The chaplain, who had paid a visit just after its installment, noticed the considerable stress all of the equipment was inflicting on the patient's husband.

A philosophy recognizing the overlapping forces that constitute illness was employed in an IDT meeting when confusion about a patient's diagnosis arose. "Is Mrs. Solomon's dementia gaining behavioral disturbances?" the clinical director once asked. "We got a call from the nursing home that she was really agitated last night, hollering out all night. They want to increase her doses." Dr. M, the team physician and an oncologist, responded: "Well, she's agitated certainly,

but behavioral disturbances? I don't know. I mean, she's not happy there, and her family is on the other side of town. They don't like that very much. Well, I'm scheduled to see her on Wednesday. I think we have to find a way to transfer her [to a nursing home] closer to her family."

To Dr. M, the problem exceeded what could be contained in medical language—it spilled over into the patient's environment and the new and frightening distance from her family. The experience of illness expands beyond neurochemical "behavioral disturbances" into the patient's neighborhood ("so far away from the patient's family") and her environment ("she's not happy there"). The IDT meeting furnished space for this multidisciplinary problem; sitting around a table with social workers, nurses, physicians, and chaplains, problems were rarely contained by the vocabulary of a single discipline.

In this way, hospice caregivers often encounter the messy reality of patient experience. In an interview, a nurse described a recent visit to a patient with Congestive Heart Failure:

> For a few minutes I checked her vital signs, organ function, blood pressure—the basic stuff. There was some fluid in her lungs, and her breathing was fast, but she said those things weren't bothering her too much. Everything else was stable. I know she enjoys my visits, so I offered to just sit with her for a few minutes and keep her company. I asked if anything was on her mind. And she just came out with it, like: "Am I going to suffocate? How is it going to happen?"

The nurse did not arrive simply to check on the progress of a diagnosis and depart. Rather, the nurse allowed the patient to express a deep fear. Suddenly, the most salient aspect of the patient's suffering was foregrounded. The nurse, who was initially visiting to check on the patient's organ function, now confronted the patient's fear as an object of care. The nurse considered the patient's fear, taking the question seriously without dismissing it with medical facts:

> I basically just sat with her for a long while and listened to what her fears were. I told her: I've watched hundreds of people die, and cared for thousands of dying people. Not a single person can say what happens at that moment. We're going to keep your lungs clear and open, and you'll breathe just fine. But we don't know what that moment is gonna feel like.

At that moment, the object of care in the patient with Congestive Heart Failure was not her heart, lungs or blood pressure: it was her fear of dying. Responding to the patient required that the nurse step outside of disciplinary bounds and confront the patient's fear honestly.

No single discipline could contain the overlapping forces constituting the illness experience of Mr. Donald, a thin man with a red bandana and two long, grey braids down his back. Clearly the envy of his nursing home with a full pack of Marlboro Reds in the pocket of his denim shirt, Mr. Donald took the hospice social worker and myself on a tour of the smoking deck, where he lit a cigarette. Homeless most of his adult life, Mr. Donald enjoyed the nursing home. But the stakes for the social worker's visit were high: the nursing home wanted to kick him out for not quitting smoking and drinking despite having advanced lung cancer. Leaning forward, he explained to us: "I'll tell you one thing, life ain't life if I can't live it! I'm sick of them telling me this and that. I'm not stickin' around for that kind of shit life. Throw me out if they want to. Look, I'll do it myself—be a good day for me! [coughs, wheezes]."

We shared more thoughts, including the patient's advice to the social worker about how to get out of a parking ticket she received last time she visited ("swap your plates!"). When we left, the social worker made a phone call to another nursing home—a place with fewer staff and less scrutiny—to see if they would take him. Although not a nursing home that many patients would ordinarily seek out, the nursing home was suited to Mr. Donald's character and final wishes. She arranged for his transfer, and when she described the new home to him, Mr. Donald was thrilled.

If his caregivers had seen the world as unified and knowable through fixed laws, then treating Mr. Donald would have gone differently. Medically, smoking with lung cancer can worsen cancer; therefore the team would have required the patient to quit smoking. Legally, a patient who does not comply with the rules of an institution should be discharged from hospice. But neither tried to purify him with disciplinary dichotomies such as healthy/unhealthy or compliant/disruptive. Slowing down thought at an IDT meeting, Mr. Donald's nurse explained, "he knows what [smoking and drinking] is doing to him, but life wouldn't be worth it without it." As Mr. Donald's painful cough worsened and energy waned, he spent several calm weeks in his new nursing home, continuing to smoke. On my last visit with him, he was in bed trying to work out a riddle someone had told him years ago. "It's called Ezekiel's triangle," he offered, closing his eyes. "Tell me if you ever hear anything about it."

Consider Mrs. Reyes, who was admitted to hospice with metastasized stage IV stomach cancer. The hospice physician's first visit was quiet. The patient slept most of the time, said very little, and frowned when she was awake. In an IDT meeting, the physician shared that the patient was Catholic, and her tiny apartment was full of crosses and images of the Virgin Mary. The patient lived alone and cancer had made her bed-bound, so she hired a part-time aide to prepare meals and help her use a portable toilet. The aide was Ukrainian and didn't speak English very well, so they couldn't communicate.

Weeks later, the patient's discomfort and illness had increased. A nurse had been making bi-weekly visits to massage the patient's legs to prevent bedsores and blood clots. One day at an IDT meeting, the nurse reported:

> [Mrs. Reyes] has been opening up to me a little… Basically, she has a lot of anger about never getting to retire. She worked her whole life at an insurance company and had been saving all of her money to start a new life after retirement. She had plans to travel, to go to Mexico to visit her family, to go to Hawaii on a cruise ship. And she just never got to do any of it. She's very angry at God for making her sick instead. She feels like she's just waiting to die.

If the nurse had visited the patient solely to devote attention to the patient's legs, she may never have discovered the more "total" pain the patient was experiencing. Similarly, if there had been no opportunity for the nurse to share this patient's total pain with other professional caregivers, it may not have been attended to as carefully. When Mrs. Reyes' situation came up at IDT meetings, the staff took equally seriously the patient's negotiations with God, the delivery of the proper circulatory socks, and the removal of acid from her stomach. After nine weeks on hospice care, the patient died of stomach cancer.

Here we can see how slowed-down caregiving invites in the cosmos—the subterranean energies Connolly describes, or the divergent chaos that Stengers alludes to. Slowly, the team and patient together cared for these unsightly, frightening aspects of the patient's experience of illness.

Silent, pervasive, and world-destroying, Mrs. Reyes' anger eventually began to fade. By the end of the process, the nurse had witnessed a change in the patient: the patient smiled when she arrived and began telling stories of her past. When she became too weak to read, she requested that the hospice chaplain read the Bible out loud to her. According to the nurse originally administering massages for the bedsores, the patient died at peace.

Care and the Ontological Politics of Embodiment

Anthropological and medical literature have witnessed a prominent (re)surfacing of the notion of care. Annemarie Mol (2008) criticized the way in which the reification of values such as rationality, autonomy, and choice have created a health care system that understands patients as independent agents who make authoritative decisions about their health based on value-free information. Her intervention is to demonstrate that, in practice, there are no such things as "bare facts," but rather messy complexity, and framing health care as a series of rational choices between neutral options, generates an illusion of control over one's health that is simply not possible in practice (Mol 2008: 43). According to Mol, the "logic of choice" ignores the imprecise, unpredictable reality of illness.

To return to an earlier question, is cancer simply a physical object, or is cancer an entity that can cause bankruptcy and depression? Or does the real cancer hang invisibly between these two, omnisciently manifesting through different channels? Moving away from theories of perspectivalism and constructionsim, Mol looks at how diseases are "enacted" or "performed" in practice (Mol 1999:77). Observation is not a passive act that discovers different aspects of an invisible essence: each observation is itself a performance. In fact, Mol finds that there are multiple ways of "performing" reality—multiple forms of reality (Mol 1999). Understanding that illness is performed in many ways, and therefore understood and acted on in many ways, can decentralize preeminence of the clinical performance amidst other performances of reality.

Hospice care uniquely exemplifies the fruitfulness of this shifting ground: it is a medical practice that takes the embodied performance of illness as the primary way of understanding and treating it. The hospice caregivers I observed privileged the embodied over the clinical, spending their time in patient's homes instead of clinics and laboratories. They learned about how patients performed and experienced illness in the middle of everyday life, instead of how their biological characteristics deviated from statistical norms. They noticed that a patient was unable to reach the bathroom, and so held his bowels and experienced constipation; that a patient was depressed because her family did not visit; or that a patient believed he would go to hell. The solutions they generated were therefore grounded in everyday practice, rather than yielded from laboratories. This kind of care is no less medical or effective; it simply works on a version of reality that is typically absent from the central concerns of biomedical care.

To illustrate the attention paid to the embodied performance of illness and the practical nature of the treatment that results, we can consider the care of Mrs. Roosevelt, an 89-year-old African American patient with Parkinson's disease. On a hot afternoon, I rode my bike across town to visit with Mrs. Roosevelt, finding my way to the peacock feather-patterned chair next to her bed. The hospice chaplain had requested that I make social visits to Mrs. Roosevelt, since bed-bound isolation had left her depressed. Over several visits, we had befriended one another easily; she

liked to tell stories, and I liked to listen. Her stories meandered slowly as she remembered thirty years of working as an elementary school nurse ("oh, I did love those children…but sometimes you wanted to smack 'em! Oh, you know…").

To my surprise, when I arrived that afternoon, the team social worker was also paying a visit. The social worker sat in the kitchen catching up with the patient's daughter, who was in town on a weekend-long visit. I exchanged greetings with them, and the three of us chatted for a while. The patient was having a bad day, they said, and needed cheering up. When I approached her bedside, Mrs. Roosevelt looked concerned. "Are you an angel?" she asked me. "Are you here to take me home?" Not knowing how to respond, I sat down next to her and pulled my chair up to her hospital bed. "I'm your friend from the hospice, and I'm just here to spend time with you." But it didn't register. She went on asking questions. "But how am I going to get there? How are we going to go there together?" We chatted about possibilities. At one point, she closed her eyes and squinted them, in what I thought was an attempt to imagine what death would feel like.

Later on during the visit, the social worker asked the patient about her Parkinson's symptoms. The patient had a mild case of the disease, which paralyzed only her left hand. Small and dovelike, Mrs. Roosevelt's hand perched above the covers in a blanketed nest. She said it was driving her crazy; because she was bed-bound, all she could do was concentrate on the bizarre pulsations and spasms that took place in her left hand, which heightened her delusions and hallucinations. At this point, we thought about treatment. The social worker, the patient's daughter, the patient, and I thought about the hand-spasms, the delusions, the curiosity about death, the angel-sighting. We slowed down to understand Mrs. Roosevelt's fear and boredom. The social worker asked Mrs. Roosevelt if she wanted to try Parkinson's medication again, but they both agreed it would be better not to (last time she took the Parkinson's medication, she had frightening hallucinations and nightmares). That wouldn't suit. The social worker paused for a minute, thinking. "Why don't we try massage therapy?" she asked. "Even if the mobility in your hand never comes back, maybe Juan [the hospice team physical therapist] can teach you how to deal with some of the muscle tension." Mrs. Roosevelt liked the idea, which addressed the discomfort she was experiencing in her hand, and left out the Parkinson's medication. "He's very cute, too," the social worker winked, "You'll like him."

Slowly, the process of care unfolded, back and forth across multiple hands and people. Before leaving, the social worker and I talked to the daughter some more. The daughter worried that her mother's confusion—benign in company—would turn depressive and scary at night. The social worker pulled Mrs. Roosevelt's medication list out of a folder to see if she was taking medication for anxiety and distress—she was. "I'll talk to Dr. M about increasing the doses, so that she is more relaxed at night—these are very low doses." The daughter was relieved.

Through conversation, the four of us responded to the embodied performance of illness. It took place in the disorganized world of Mrs. Roosevelt's lived experience—her house, loneliness, and the nagging spasms that agitated her—not in a neurologist's office or a CT scanner. The messy, embodied way of performing disease leads to a set of solutions: the massage therapist will come, doses of medications will be reconsidered, volunteer visits will continue. The solutions are generated from a performance of disease that takes place within the physical world, but also within the cosmological world, with all of its spinning, orbital, and chaotic energies.

Navigating Cosmology

The theoretical hardship confronting the notion of care is its unboundedness: caring for unquantifiable concerns exists in opposition to the neat, orderly world knowable through science and augmented through purification. As such, it is inefficient and unattractive to instrumentalize care as a precise tool: where does care start and end, what does it require of the caregiver, what problems can truly be cared for (see Russ 2003)? Is care inextricably linked to femininity and altruism, or can it be mobilized more freely (see Mol 2008)? Perhaps because it is not a precise science, care has not enjoyed the same ease of deployment as more immediately rational biomedical logics have in modern medical practice. These ethnographic examples have helped demonstrate that the domains of other performances of reality can, too, be successfully navigated. Rather than a straightforward obstacle to care, the domain we can label "cosmological" can be cared for when attention is directed towards it.

As an example, consider the case of Mrs. Lillie. On a hot afternoon, the hospice chaplain and I visited a patient with severe Alzheimer's at a state nursing home. The patient experienced frequent and disturbing hallucinations over the course of her care.

> Reverend Joe, the hospice chaplain, knocks softly at a door on the second floor of a crowded nursing home. "Hello, Mrs. Lillie! Today seemed like a nice day to come visit with you." We sit on either side of the patient, a 72-year-old African American woman with dementia. Mrs. Lillie is lying in bed wearing a light blue hospital gown. A nursing home staff member has just removed the tray of mashed potatoes, green beans, and chicken that Mrs. Lillie picked at. A long silence ensues. "There's someone trying to kill me here," she says to us, "one of the new nurses here. He's waiting 'til all the other nurses get off their shift for the night, then he's gonna come in here and kill me. Then take my body to the bins out back." Reverend Joe looks concerned. "Now why do you think that?" he asked. "He killed another patient, right down the hall. Now I'm next on his list." Reverend Joe shakes his head. "Do you know anything else about him?" The patient's eyes are closed. "He told me he was gonna kill me," she said. "When did he tell you that?" "Two weeks ago." We sit in a long silence.

The patient was performing the lived, frightening reality of her Alzheimer's. In its clinical performance, treating Alzheimer's looks very different: diagnose and treat the pathological mechanism and its checklist of symptoms, in this case paranoid hallucination and agitated behavior. Locating the problem in degenerative brain cells, a clinician sympathizes and acts kindly toward the patient, but ultimately fits the variables into a diagnostic category and works primarily within biological and psychological domains.

But the lived performance of dementia was the one experienced by Mrs. Lillie in front of us, and its treatment was far less straightforward. The chaplain listened. The object of care made itself abundantly clear. He was absorbed into her fear for a moment, and then responded to it.

> Reverend Joe asks, "May I pray for us, Mrs. Lillie?" She nods and clasps his hand and mine. After a moment of silence, his prayer begins: "Heavenly Father, this is your son Joe. I'm sitting here with your daughter Lillie and your other daughter Lilly on this hot summer day. Lord, we are your faithful servants. This afternoon we have one great request. Please come into this room with Mrs. Lillie. Protect her every breath, when she goes to sleep and

when she wakes up. Watch her all day and all night. Allow her to know peace in your loving embrace. Thank you for listening to us." Mrs. Lillie says "Amen," and our hands unclasp. Another long silence passes. "You know what that means, Mrs. Lillie. You'll be safe and sound in here now." Mrs. Lillie rests her hands on her stomach and closes her eyes. She doesn't say anything for the rest of our visit.

The clinical and lived versions of paranoid hallucination are two very different problems. The first can be contained within a neat listing of symptoms, while the second spreads out and encompasses the room in terror. Reverend Joe treated the embodied performance of dementia: he sat with her, listened to the terrible fear, and responded to it. The chaplain employed certain assumptions about prayer and healing, but he acted on the exact terms—the exact performance of reality—furnished by the patient. He took her fear seriously, he took the threat of death seriously, and he manually eased both by acknowledging them and praying for their dispersal. He worked directly with the rich multiplicity of affective states experienced by Ms. Lillie.

A final example is the care of Mrs. Rose, a 78-year-old woman who in spite of significant physical decline managed to neatly apply lipstick and comb her grey hair daily. A recent stroke took away her ability to form sentences, leaving her confused and frightened with a diagnosis of aphasia. The inability to make her needs known devastated her family, who maintained a constant presence in her apartment. At an IDT meeting, the nurse described a scene:

> I got there right after, and it was a mess. The patient couldn't make a sentence, everyone was crowded around her, and she was just panicking. It just broke my heart, the family huddled around her, not knowing what to do, asking her questions right up in her face. Some of them were crying and crying. It was a big scene.

In this case, the ramification of illness was dispersed through both worried family members and the bewildered patient. The performance of the illness was a room full of chaos. How could this nurse respond to this embodied performance, in the midst of familial panic? In this situation, aphasia is not a malfunctioning of a certain region of the brain, but rather emotional upheaval and panic. The nurse made her way to the bedside, took out her kit, and sat down next to her. In her words:

> To calm her down, I sat down with her and held her hand first, telling her it was going to be okay. Then I felt her pulse, took her blood pressure, tested the strength in both of her arms to make sure she was okay otherwise. I asked the patient if she wanted some medicine for anxiety and she nodded yes. I looked into the patient's eyes and promised her we would help her feel better. Then I talked to the family. I told them it was going to stress her out if they try to ask her questions. Yes or no questions—they'll learn how it works. Just sit with her and hold her hand. Look at her eyes and you can tell how she feels. You do the talking. Hold her hands and watch her eyes.

Conclusion

Bruno Latour hypothesized that to resolve the discord wreaked by purification and translation, society must "slow down, reorient and regulate the proliferation of monsters by representing their existence officially," and further, that "conceiving of hybrids" actually "excludes their proliferation" (Latour, 1991:12). I have maintained that hospice does exactly this by bureaucratically and medically acknowledging that illness exceeds disciplinary classification, as well as by working on its embodied performance. If we believe, with Latour, that present crises reveal that society has never actually been modern, then the world has never really been disenchanted. By avoiding purification and acknowledging the hybrid and messy nature of illness, hospice care thus emerges as both non-modern and (re-)enchanted.

Hospice is admittedly a lucky site to take on such an orientation. Perhaps hospice workers, not tasked with the job of curing illness and restoring patients to a baseline, have more room to experiment, or pragmatically just "do whatever works." But this reading would take society's present form for granted. In fact, in 2010 a controlled study at Massachusetts General Hospital revealed that lung cancer patients who were simultaneously enrolled in palliative care and oncology significantly outlived their prognostically-similar peers enrolled just in oncology—even though the palliative care group received fewer rounds of aggressive treatment (Temel et al. 2010). The study and its aftermath have begun to provoke discussion within the medical community about the hybrid character of disease. Acknowledging such aspects of illness seems to have a demonstrably positive effect on tangible markers of disease, not even considering the intangible ones.

As long as the medical community continues to privilege clinical realities over embodied ones—"knowledge over actions" (Mol and Law, 2004:45)—hospice care will remain a practice outside of medicine, considered not fully medical, but something different. Biomedicine and hospice will be to one another like architect and housekeeper: one measuring, creating and building, while the other works on the mundane, quotidian aftermath. But it is the everyday details that make up life—what James calls the "litter" that philosophers so relentlessly try to erase from pristine accounts of the world (Connolly 2005:72). As widespread discontent with end-of-life care practices continues, many caregivers have directed their attention towards the everyday experience of illness. When "incompleteness, looseness and volatility" surface in illness, perhaps patients and practitioners will both seek out philosophies that treat these entities with respect and regard them as part of the whole (Connolly 2005:72).

Acknowledgements

Notes

(1) All names, locations and identifying characteristics of patients have been changed to protect anonymity.

(2) Recently, the hospice industry has witnessed the growth of for-profit companies taking advantage of this payment scheme in order to capitalize on "down days," or days when patients do not receive any service but the hospice receives payment. The advent of for-profit hospice can be compared to the for-profit hospital industry in terms of advantages and disadvantages. The compromised care resulting from profit-orient incentives may undermine the basic tenants of the hospice philosophy, but I do take up problem here.

(3) Hospice has come a long way from its volunteer-led, activist roots. Many have expressed concern that the growth of hospice from a countercultural movement to an institutionalized, bureaucratized, largely for-profit industry is compromising the founding ideals of the movement (McNamara 1994; James and Field 1992). Because my participation took place within a single, non-profit, reputable hospice, I cannot comment on the decline in quality of hospice services as for-profit companies capitalize on the unique funding structure of hospice care. I maintain here, however, that such changes have not dismantled the underlying mission of hospice care, which is supported by a novel bureaucratic structure, the often-personal motivations of caregivers, and the still-aggressive status quo of the majority of deaths in America. On the other hand, regulatory encroachment upon the previous freedoms of careworkers during less-regulated years was often invoked as a source of stress and demoralization among some workers. While these dynamics deserve more extended comment, they do not figure in the main argument of this paper.

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