On Art and Medicine: An Exploration of Values, Logics, and Care Practices

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Abstract

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Programs that foster creative activities such as drawing, creative writing, and making music are increasing in US hospitals. They are facilitated by licensed therapists, by professional artists, by musicians or poets, or by physicians. This work explores why and how these practices intersect with biomedical activities in US hospitals. This study finds that these programs are valued for their support of biomedical care practices, their positive psychosocial effects, and their economic benefit. This study also finds that certain arts activities are structured to disrupt the positivist nature of biomedical logic and embrace uncertainty. Arts activities provide a space for physicians to attend to story, build empathy, and take time for reflection. Finally, art-making activities are meaningful for patients at the end of life. They document and validate social relationships, decrease pain, and often result in the creation of a legacy object. Through creating these objects, patients often create a script for grief which patients and their family members find meaningful. This work also documents several tensions in the field of arts and healthcare, such as who can facilitate these activities (licensed art therapist or

professional artist or both), and what evidence is valued to prove the effectiveness of these programs.

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And finally, my most sincere thanks goes to those who have shared their stories with me. This work exists because of, and for, each of you.

DEDICATION

To mother Elaine and to my husband Erick –
whose examples of warm care have guided and supported this work.

And to those who combine art and healing.
Let this beautiful intersection continue.

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Prologue

My grandfather died three days before I turned eighteen, slowly. He knew the path his cancer would take, that his lungs would fill with fluid, drowning him. A natural death was his preference, and we thought that by caring for him at home we could facilitate one. This was our first death as a family, and we didn't know then that there were different kinds of dying, that consenting to advanced medical procedures would extend his life, but provide a gruesome worsening. We kept him alive by inches and days that grew increasingly painful for all, most especially for him. We followed the advice of Texas doctors who practiced heroic medicine, we halted every natural dying process and made the joys of life – eating, breathing, resting – excruciating. My mother told me later that this man who had always embodied my vision of strength, raised dirt poor but with honor during the great depression, a WWII soldier, full of jokes and stories and love of good food, asked for death. We finally enrolled in hospice care, so late on his pathway out of this world. With the ease of morphine he relaxed quickly into death. Grief mingled with relief and deep sadness, and regret.

Eight years later when my grandmother couldn't walk the stairs to our second floor apartment in Wiesbaden, my mother consulted a doctor. He agreed to pay a house call, black bag and all. It was very serious, he told us. The end was very close. My grandmother, who couldn't bring herself to share exactly why she had avoided hospitals her entire life, but made references to an experience in a Nazi death camp when she was young, did not want to leave our beloved apartment. Again, my mother chose to care for her dying parent at home. The doctor had a short conversation with my grandmother to assess her knowledge of death: “do you know the path you are on?” To her yes, he replied, “Ich werde dich begleiten – I will accompany you.” This resonated deeply with me. My mother was full of anticipatory grief, full of the sadness of loss. A generation removed, my grief was different – losing a beloved grandmother is not the same as losing a mother, your last parent. I had the perspective that comes with a bit more distance from grief. Let’s celebrate her life, I said, let’s ask her what music she loves, what she wants to eat. We hung pictures of her mother, who died when she was four, her sister killed in the war, her husband a few steps ahead of her, her daughter and granddaughter who would remain, at the foot of her bed. We washed her, massaged her limbs, brushed her hair, and brought her flowers. We played her favorite songs and sang to her. She also had to die slowly, each organ shutting down over the next few weeks, and fear and pain were present, but we accompanied her. Was it a good death? I don’t know her answer. But it was full of care, and we were all deeply present.

Afterwards I was struck by my mother’s regrets regarding my grandmother’s death, which didn’t center around treatments we should have foregone, or pain relief we should have pursued, as with my grandfather, but around unmaterialized objects. The painting she should have bought supplies for my grandmother to complete, the photographs she should have taken, the stories and recipes she should have written down. The objects we didn’t possess, which would have become her legacy. Grief, again, mingled with regret.

I became interested in the meaning of legacy making as a component of palliative care, and of legacy work as a way of caring for the social self of the patient and the family.

Funerals are for the living, and in a way, so is the dying. Yes, death is intimately personal, a doorway that each one of us will walk through alone. But our deaths enter the lives of those who remain. Ars Moriendi suggests that there are social elements of a physical death that must be attended to, and I would suggest that a consideration of legacy is such an element. There are documented benefits to the receipt of a legacy item by loved ones. In my preliminary research for this project, I found that legacy creating is a strong and important component of palliative care for the dying as well, which proves even more meaningful for the bereaved. Understanding how legacy objects are created during patient art programing, and how they are circulated in social and institutional realms, is a large component of my motivation for this dissertation project.

That death has variety, like life, did not surprise me. The fact that death could be predetermined by institutional policies, medical culture, and frightened family members, did. I was drawn to learn more about how death is shaped by the culture of US medial institutions. I was interested in what types of care are possible when curing disease is no longer an option.

I was also interested in how one heals from trauma, and considered the diagnosis of a serious illness that requires a re-evaluation of ones self and future a type of trauma. I was drawn into understanding the power of naming pain. I examined the field of "narrative therapy" which guides participants in rewriting their narrative so that the stories of survival and strength are not overshadowed by suffering and pain. In one version of your story you are a victim. In another, a survivor. Stories have power.

But stories require language. As I did more research into how the brain processes trauma, how memories are sensory and separate from language, how difficult naming can be, how culture-bound talk therapy is, I learned about other tools of expression. How the effects of facilitating creative expression can mirror biblical miracles, helping the mute sing, the lame dance, the white blood cells increase lymphocyte production. *How does that work?* I wondered. This text encompasses deep interest in medical care, creative expression, and how the two intersect. I have outlined ways in which art supports medical care and how that support is valued, how it disrupts standard biomedical logic, how it promotes story, empathy and reflection, and how it supports the social self of the dying patient unto and beyond death. This last function brings me back to the reason I took up this research – to understand the total environment and logics behind the support of creative expression in hospitals, especially at the end of life.

Chapter 1.
The Drama is Part of the Cure: Intersections of Art and Medicine Historically and in the Present

The first time I met with Claudia, a member of a pediatric advanced care team in a large urban hospital, it was a typical gray, wet autumn afternoon. I waited in the lobby of the pediatric hospital holding my raincoat and scanning the diverse groupings of families for the emergence of a woman in a white medical coat or hospital scrubs. When she appeared all in black, wearing a teal scarf, I was momentarily taken aback. The child-life specialists I had worked with previously wore medical garb, their pastel scrubs blending into the clinical scene. I wondered if the activities of this child life specialist were somehow different from the others I knew. We introduced ourselves, and I explained that I was there to learn about the inclusion of art-making as a component of pediatric palliative care. I was intrigued to see that she carried a large black artist portfolio under her arm. She walked me down several floors to a lounge area near a coffee counter and chose a table for us to sit at. She laid the portfolio down. The large rigid black folder dwarfed the table. I looked on with interest and curiosity as she began to lift out broadsides, large prints of high quality, off-white textured paper, imprinted with poems and images in saturated jewel tones. She spread them in front of me and began describing how these printed poems were connected to the work of caring for hospitalized children.

Claudia was a member of a care team that offered advanced care to patients who have a very serious illness and their families. This care team was, at the time I met with Claudia, made up of a diverse group of professionals: a doctor, a nurse, two chaplains, a social worker, Claudia, who is the only child life specialist, and a poet. This team of care professionals was formed to guide families through their care journey as they made decisions for their seriously ill children. The team chose not to use the term "palliative care" to describe their work intentionally, to distance themselves from the negative associations with end of life that can be conjured by that phrase, though they provide similar supportive services throughout the illness.

Palliative care professionals agree that palliative care services should begin at the time of diagnosis, but they often begin much later. Most US hospitals do not keep a record of when palliative care services are offered, or how soon they begin after receiving a serious diagnosis. Hospice care, a form of palliative care, begins when a doctor determines that a patient is "terminally ill and [has] a life expectancy of six months or less" (Medicare 2015). The advanced care team at this hospital begins to work with families from the moment a diagnostic procedure is performed that suggests a very serious condition, such as a bone marrow aspiration, a diagnostic procedure often used to detect cancer, or the use of an ECMO machine, which helps patients breathe. Their aim is to walk with families from the beginning of their illness journey, and provide support as they make decisions about medical treatments. This care team listens to the things that matter most to patients and families, such as understanding how they define quality of life and working with their medical team to make sure treatment goals align with patient and family desires.

Comfort With Ambiguity

The members of this team, each working individually with patients and their families, build relationships early, and deepen them over time. When a serious diagnostic procedure is performed on a patient, the office computer prints out a sheet with the procedure, patient name and treatment room. A member of the team then enters the room, speaks with the child and family, and explains the services that the care team offers. Claudia spoke earnestly about this work, her Welsh accent deepening as she leans forward to describe how people are recruited for the team. One's professional title is not as important as one's sensibility toward uncertainty, and ability to speak to families about difficult choices. "You have to be comfortable with ambiguity, with asking the vague questions." Members of this team also have to work to build connection with families. The doctor has a practice of getting on one knee when speaking with families, she told me. He tells the team, "Your heart should never be higher than their heart".

As we look through the letter-pressed poems, embossed using the printing technique of inking a raised surface and pressing it into paper, she moves on to describe a unique member of the care team who works with patients: a poet. The poet was invited to be a member of the advanced care team six years ago during a pilot program; the doctor on the team thought she might be able to connect with students and generate writing that would be meaningful to families. She is given referrals to students by the advanced care team and the hospital's schoolroom.

Each day she works in the hospital she sees sometimes as few as six or as many as twelve to fifteen patients, or, as she calls them, "students". She calls herself the "Johnny Appleseed of notebooks" because she often introduces herself to new students by knocking on their doors and offering them a notebook, and the chance to participate in various types of creative writing exercises.

This poet follows the lead of the students with whom she works. She does writing exercises with children, having them describe their favorite smells, or themselves at a particular moment in time. Not all of the creative writing culminates in a poem – that is up to the student. And not all poems are crafted into letterpress prints – that is up to the poets. The poets that work in the hospital, and there are several, meet in March to review the years poetry and select the ones to be printed. The chosen poems are sent to a design school where art students study the poems and design the image for the letterpress. The art students create a run of limited edition prints; the prints are distributed to families, donors, staff, and kept for institutional display, or to show to guests, such as myself, interested in this work.

My experience with palliative care, both as a family member of patients who have received palliative care and as a graduate student interested in the field, has involved discussions with hospice nurses, home health aides, oncologists, other specialists, surgeons, social workers, pharmacists and dietitians; it has never included an encounter with a poet. I am interested in the logic of clinical care processes that include artists, in how a poet is incorporated into a medical team for seriously ill children. What benefit does a poet offer for patients and their families?

How does the creation of poetry intersect with clinical care? How is creative activity valued by the hospital, by patients, and by their families?

Creativity And Palliation

The palliative care doctor Dr. Ira Byock has written movingly on the topic of end of life care in the United States (1998), and on what constitutes *The Best Care Possible* (2013). He writes of sharing with his patients the concept that serious illness can be viewed as an opportunity for human development, for personal growth and for relationship building. In an interview titled "Contemplating Mortality" (2013) with journalist Krista Tippet, the host of the podcast OnBeing, Byock stated treating a life limiting illness is not only about the administration of pain medication, it is also about fostering the opportunity for individual growth.

> I don't want to romanticize it. Nobody looks forward to it. But we shouldn't assume that it's only about suffering and its avoidance or its suppression. That in addition to, concurrent with the unwanted difficult physical and emotional social strains that illness and dying impose, there is also experiences, interactions, opportunities that are of profound value for individuals and all who love them. (Byock and Tippet 2013)

I wrote to Dr. Byock describing the intersection of creative arts professionals and medical professionals on a palliative care team, and asked for his thoughts about creative activities being a part of palliative care. He replied, "poets and writers in general can contribute to palliative care teams in very positive ways." In addition, he said, "I believe that art can expand people's experiential context, contributing to a reframing of their own experience of living in a manner that helps them connect with a larger enduring construct" (Byock, personal correspondence).

Though I was initially surprised to learn that a poet was a member of a palliative care team, the more I learned about the broad mandate of palliative care, the less surprising it became. My past experience with palliative care had led me to believe that it involved the administration of pain medication and other comfort measures after treatment had stopped. I came to learn, through my conversations with the advanced team and other palliative care professionals, that palliative care can be administered at the same time people are actively receiving other medical treatments. The term "palliative care" today can be used to describe biomedical procedures that are focused on the diseased body, such as the use of radiation, chemotherapy, or the administration of morphine to provide symptom management and pain relief. Yet palliative treatment is not only about managing pain; palliative care is committed to a holistic view of treating the person, and includes psycho-social support as well as medical support (Byock 2012; Gawande 2014; Twycross 2002).

Robert Twycross, a physician who was an advocate of hospice care in the 1970s and helped shape the field of palliative care, has written that the focus of palliative care is on quality of life: "[t]he main goal of palliative care is to help patients live as actively and creatively as possible until they die" (Twycross 2002). What I found so interesting about my conversation with Claudia was the recognition that art making has a place in medical care for seriously ill pediatric patients. In what other types of care do medicine and art making intersect? And what are the institutional logics that support an increase in activities that foster creative expression as part of the medical space? I was meeting with Claudia to learn about pediatric palliative care, my which was my focus when my research began. Intrigued by the wider intersections of creative activities and medicine, I decided to broaden my research to pay attention to not just the moments when art making is included in palliative care, but to understand why, when, and how art is valued as an important activity in the medical milieu.

The Evolutionary Origins of Art-making

The origin stories of art and medicine are many. They invoke the biological evolution of the human race, the formation of cultural practices, and the professionalization of healing practiioners. The practice of art making, independent scholar Ellen Dissanayake argues, is a universal, biological human behavior that has been selected through the process of evolution. Dissanayake, taking an ethological approach, asks *What is art for* (1990)? It is a most interesting question. "'Why did a behavior of art arise at all?' What does art - like language, tool making, symbolization - contribute to the human species that would account for its appearance in the human repertoire?" (1990, 6). Dissanayake exams the selective value of art, and finds that the proof of art making's value to the human race is indicated by the fact that arts activities are ubiquitous, integral to many activities of life, and are a source of pleasure. She describes the practice of the aesthetic as a behavior, something that people experience and do (1995).

I learned of her work through an art therapist who had heard her give a public presentation. The therapist said that what she most remembered from Dissanayake's talk was the idea that the human behavior of art-making was about ceremony. Indeed, Dissanayake does discuss the ritual nature of art, and also how it is similar to the human behavior of play. Both ritual and play are highly social, make use of tension and release, surprise, elaboration; and both, along with art, are concerned with metaphor and are communicative, "'saying something' to viewers or participants. In fact, both provide a language in which otherwise incommunicable things can be said (Feld 1982, 92)" (1990, 89). "Making special" is an aptly descriptive term, although one, Dissanayake told me when we met, which unfortunately did not gain academic traction. Making special refers to "shaping" or "embellishing" an object with "intent or deliberateness" to "place the activity or artifact in a 'realm' different from the everyday" (Dissanayake 1990, 92).

Given the blurred edges of this what art is, what it means to make it in a clinical space, who may participate and who may facilitate, defining the practice of art making was important, and difficult. I chose to build upon Dissanayake's definition of art as a behavior, as an action, as something we *do.* I define art as engaging in a creative activity, to include visual arts, creative writing, poetry, and music by anyone in the medical setting, such as patients, family members of patients, hospital staff, and medical personnel. Because a majority of hospitals have art on the walls, and because these art displays require passive engagement, my study did not examine art in the environment; I chose to look at art programs that required active engagement. Such programs represented a bigger commitment from the institution in terms of budget and staff, and required engagement from patients and other participants. Creative activities or exhibitions that required observation or listening, to include art on the hospital walls or listening to musical or theatrical performances, were not at the center of this study. Although, you will see, they did creep in; if a hospital arts director highlighted such a program, I would follow the conversation to understand how it was integrated, how patients engaged, the value the institution saw in such activities, and the motives of the professionals who performed.

To describe active engagement in creative processes I use the terms arts engagement, art-making, creative activity, and creative expression. I interchange the terms to signal that participation in a creative program requires engagement, active participation in the construction of an object or sound, and self-expression. These various terms also echo the different ways in which those that facilitate these activities describe the work that they do. Gary Christenson, chief medical officer at the University of Minnesota's student health center, and ringmaster of Cirque de-Stress, has recently published a detailed view of creative practices in medical settings, which include, in addition to the ones I have listed above, drama, clowning, and magic (2014). I have also spoken with people who facilitate laughter clinics, theatre performances, and quilting and knitting groups. These practices are interesting, and deserve attention, but are not included in the scope of this study.

Also, many art programs take place in psych wards in hospitals; in fact, a many of the artists and art therapists who work in hospitals do their work in psychiatric treatment units. Given the close historical tie between art making and psychoanalysis, which I will discuss briefly, this is logical. But I was interested in the relatively new practice of how and why creative activities are facilitated in hospitals. For a similar reason, although I did speak with several Child Life specialists, and volunteered making art with patients under the supervision of a Child Life specialist myself for a brief time, I did not focus on the profession of Child Life. For child life specialists, making art with children in hospitals is part of their professional job description. For this study, I am interested in the constructed practice of facilitating creative activities in US hospitals; I am interested in why and how artists and art therapists, whose professional domains do not traditionally lie in biomedical institutions, chose hospitals as places to work.

Origins of Art and Culture

Another origin story of the behavior of art making connects it with the illness experience, and with the formation of culture. Making meaning of illness and producing art are some of the earliest human practices. Medical anthropologist Elisa Sobo examines the practices of art, religion and medicine as ways of engaging with the difficult questions inherent in the embodied human experience. Connecting the origins of art and religion to the development of humanity, she writes “culture emerged 70,000 years ago, when tangible evidence of social conventions, such as tools, adornment, statuettes, and cave paintings emerged…It is widely agreed that human beings by then had developed the capacity for spirituality and religious beliefs" (2009, 51). This quote suggests that art objects represent important values that reflect how people made sense of the phenomena they experienced, and how they accounted for the experiences in their world and in their bodies they could not understand. Sobo continues, "Some say that without cultural belief systems to justify or at least make sense of the tragedies and trials that inevitably accompany human life cycles, the anxiety that must have accompanied humanity's increasing intelligence and self-awareness would have been too much to bear" (Ibid). Art not only reflects cultural belief systems, art making is a meaning-making process, by which belief systems may be reproduced, challenged, and altered as people make sense of the 'tragedies and trials' of illness. Art production has, since its inception, incorporated themes of illness, suffering, death, care and community. Art has also been produced by those who are well, those who suffer, and those who heal. By paying attention to how art, illness, healing, suffering and meaning making intersect in modern US medical institutions we can understand how art making can be a practice of care.

A biomedical ethos, by stark contrast, touts patient choice as an integral part of medical care. Treatment options are presented by the expert medical provider, and the patient, however inexpert, must choose his or her treatment pathway. Atul Gawande refers to this social role as "Dr. Informative". The doctor presents options, citing risks and benefits (though this information is often notoriously incomplete), and then asks patients, which pill do you want, the red one or the blue one? (2014). Offering patients choice was seen as a positive change to medical paternalism. Annemarie Mol, a Dutch philosopher and ethnographer, offers a different way to think about patient choice. In the logic of choice, the actions, and the consequences of those actions, fall on the shoulders of the patient (Mol, 2008). "The ideal of choice carries a whole world with it: a specific mode of organizing action and interaction; of understanding bodies, people and daily lives; of dealing with knowledge and technologies; of distinguishing between good and bad; and so on…It does not offer a superior way of living. More specifically: it does not offer a way of living superior to the life that may be led in a world infused by the *logic of care*" (Mol, 8, 2008). The logic of care provides an alternate model of interaction: a doctor connects with a patient where they are, and does the hard, unglamorous and often time consuming work of entering into a patient's social world and seeing the patient as an actor with important goals. The doctor connects with the patient to together make a choice that supports the patient's values. The doctor or nurse checks in, revisits, tinkers with, and evaluates the choices with the patient, and then together make new choices with the new information (Mol 2008). This is a positive alternative to the isolation that offering a patient a choice and then stepping back can create. Such shared decision making, when it happens in conversation over time, is a care practice Mol describes as "tinkering" (2008), in which choices are continuously revisited, and small adjustments are made and fine-tuned, and empathetic care provided throughout a patient's treatment.

Doctors who participate in creative expression have shared with me that they are able to know their patients more completely, better understand their goals, and are more comfortable caring for patients who's disease pathway and prognosis is uncertain or limited. Patients have shared that they are able to relax, express themselves, and focus on their goals and priorities. These statements highlight how art-making can lead to, or can itself be, a practice of care. In reviewing these benefits of creative engagement, I find that Mol's explanation of "care logic" is useful to think about how art is practiced, how it functions, and how it is valued. As Dick Willems wrote, building upon Von Wright's description of "varieties of goodness" (1963), "there is not just one version of good care, neither for human caregivers nor for care technology. There are varieties of good care…" (2010, 258). I will use Mol's framework to examine how art making in hospitals offers a model of how care logic is enacted, and how the facilitation of art practices offers us a model of not just good care, but better care.

The Origins of Scientific Medicine are Intertwined with Dramatic Poetry

In addition to art making's connection to understading the illness experience, artistic activity and healing spaces have been interwoven since the beginning of the practice of scientific medicine. The staff of Asclepius is a well-known symbol, the serpent encircling a rough staff appearing on the crests of the top medical schools such as Yale and Stanford, in popular literature and media, and is featured in many tattoo catalogs. Asclepius, son of Apollo, was the Greek god of healing, who learned how to reverse death and was the patron god of healing (Perloff 2012). He was also associated with poetry and song. The cult of Asclepius arose in the 5th century BCE, a dynamic period of change when the treatment for illness no longer consisted of a ritual supplication to the gods, but involved a new practice of scientific medicine as outlined in the Hippocratic texts (Mitchell-Boyask 2008 11). During this time, healing was also administered through purifying rituals, both in the healing temple and in Greek drama. Healing was incomplete without the benefit of both scientific medicine and dramatic poetry.

Archaeological excavations of the ruins of the Theater of Dionysus in Athens and the theater of Epidaurus show that the shrine of Asclepius is located very near to each theater. In Epidaurus, the shrine of Asclepius was built first, and was the major center of healing in the Classical Greek world. The site grew rich from the alms of sick pilgrims and their families, and a great theater was constructed. Archaeologist Olga Psychogiou described it as "the finest and most renowned of its kind" (Psychogiou 2012). Mitchell-Boyask writes that the proximity of healing shrines to theaters was intentional; the drama and song, the "tragic pharmacology" of Euripides, were essential to curing the sick. "Thus, theaters do not stand next to Asclepius shrines so that sick people can catch a play during their cures; *the drama is part of the cure*…" (117, emphasis added).

In scientific medicine's origins artistic practices were deeply incorporated in healing rituals; as illness and death became increasingly medicalized, creative activities were excluded from medical spaces. We are currently witness to a moment in which the interconnection of art and medicine is beginning to be, however faintly in this beginning, formalized and institutionalized. This work seeks to understand: how, and why, to what ends, and with what effects are artistic activities and medical practices coming together in US hospitals?

Incorporating the opportunity for art making in a medical institution allows for certain types of practices to happen, practices that some argue should happen as a part of a good death (Foster et al 2009; Foster 2010; Byock 2013), or a good illness experience. One of the benefits of patient art-making discussed in the literature is that it promotes the discussion of care preferences, and end of life care plans. Another benefit that has been highlighted as deserving more attention is how creating art in the context of serious illness can lead to the construction of a legacy project, which increases measures of well-being, pain relief, and peace (Foster et al 2009). The benefits I have described are individual, but there are also biomedical, social, institutional, and relational effects of art-making. These effects surprised me. This dissertation is the story of my surprise, how I held up two things, art and medicine, and began to unravel the threads that meaning and practice have woven between them. It is the story of how I encountered complementary and contrasting ideas: the concepts of patient compliance and medical subversion, the juxtaposition of economic concerns and the importance of maintaining provider empathy, and the desire for clinical evidence versus understanding art making as a moral good. It is a story of holistic personhood and medical practices, of individual expression and social palliation. And it is a story of meanings. This dissertation examines what it means to care for someone when a cure is possible, uncertain, or unavailable; what it means to suffer and to attend to suffering; what it means to be uncertain, as a care provider, of what to do and how to cope; and what it means to care through and beyond death.

The Practice of Art Therapy in the United Kingdom

Tracing the history of art therapy leads to two paths of professionalization, one in the United Kingdom, and one in the United States. Adrian Hill, a patient and a painter undergoing treatment in a British tuberculosis sanatorium in the 1940s, first coined the term "art therapy". During his slow recuperation from tuberculosis he painted from his bed. Noticing the interest of his fellow patients, Hill began to offer informal instruction in painting. Patients who were listless, showing little interest in, or actively resisting, therapeutic activities became more spirited and proactively involved in their care when they painted during the day. Veterans who were wounded, or tubercular patients who were permanently weakened, gained skill in a craft that could provide employment once they returned to their homes and communities. The interest of the patients in art workshops was so strong, and the results of the art instruction so positive, that Hill returned when well and created a formal painting program and rotating art exhibit in the hospital. Noticing the purchase that the new practice of physical therapy was gaining in the medical community, he named this practice "art therapy" to stress the therapeutic benefits of art-making for patients. The medical profession encouraged early art therapy programs within hospital walls and employed artists as auxiliary medical staff (Hogan 2001). In 1945 he published *Art versus Illness, a Story of Art Therapy*, the first published book to use the term. Despite his success and promotion of the use of art therapy, and his close integration with medical teams in hospital, Adrian Hill was ousted from the profession of art therapy when it became professionalized in the 1960s. As Beaer has described, the practice of professionalization and licensure in biomedicine functioned to limit narrowly who could practice medicine, and how, and served to exclude those who weren't licensed by the dominant professional organization. A similar movement happened in the field of psychology in both the United Kingdom and the United States that served to limit the practice of art therapy to licensed mental health practitioners.

The Practice of Art Therapy in the United States

What is art therapy?

"To be honest with you, I always thought, "Well, you go into the room and draw the picture of the man that hurt you and what he did." That's what a lot people are taught about art therapy. It's just *very* much about trauma. And it is now that I realize, "Oh, my goodness, was I ever wrong about what it is." – *Physician*

Today, the term art therapy refers to what has become a specialized field of practice and expertise. The idea that art therapy addresses psychological trauma is not invalid. Art therapy professionals are licensed mental health workers, and their business cards display a long line of acronyms that illustrate their professional credentials. Art therapy for mental health purposes does exist in medical spaces, and art therapists deal with mental issues on the psychiatric wards of hospitals. The use of art making as a therapy for psychological trauma has its roots in the practices of Margaret Naumberg and Edith Kramer, the two matriarchs of the field of art therapy in the United States. Kramer, who grew up in Austria during the Third Reich, studied art with her beloved teacher Friedl Dicker. Persecuted by the Nazi government, Dicker fled to Prague, where Kramer followed her, helping her teach art to the children of political refugees (Junge & Wadeson 2006, 70). "It was during this work with uprooted children that I first experienced how art could help them regain their emotional equilibrium" (Kramer in Junge & Wadeson, 2006, 12). Dicker was deported to Theresienstadt, and then was transferred to Birkenau, where she perished in the gas chambers. Leaving Czechoslovakia shortly before the Nazi invasion, Kramer travelled with her family to the US and began working as an art therapist. She published a description of her work and theory in *Art Therapy in a Children's Community* in 1958.

Margaret Naumberg, born in the US in 1890, also began to practice and write about art therapy in the late 1940s. She published her first book on the practice of art therapy in 1947, entitled *Studies of the "Free" Art Expression of Behavior Problem Children and Adolescents as a Means of Diagnosis and Therapy*; she followed this work with *Dynamically Oriented Art Therapy* published in 1966. As the titles of these works suggest, art therapy was "utilized both as a diagnostic tool and a mode of treatment" (Malchioldi 1993). Medical art therapy, or the use of art therapy with medical patients, began appearing in the literature in the early 1980s, two notable examples listed in Malchioldi being Jeppson's "Creative approaches to coping with cancer: Art therapy and the cancer patient" and Spiegel's 1989 study on the "Effect of psychosocial treatment on survival of patients with metastatic breast cancer" in the Lancet. The specialization of medical art therapy continues to grow in the United States (Malchioldi 1993).

Art therapists are not the only ones creating art with patients, families, and medical staff in hospitals; they are one of several professional groups working to facilitate art making experiences   Artists also have a robust presence in US hospitals, as do Child Life Specialists, who work with pediatric patients to normalize the hospital experience provide support in coping to children and their families, often using art and play. In fact, "[h]ospitals in the U.S. support nearly equal numbers of artists, arts therapists, and child life specialists" (AFTA 2014, 11). In many hospitals, volunteers also create art with patients, or work in other ways to support art programming. Doctors themselves use art in patient care. This confluence of various people facilitating different types of art experiences in hospitals can, and does, lead to disputes over the values, practices and ownership of art making with medical patients, as will be discussed below.

How Art Came Into US Hospitals

The benefit of visual art in hospitals has been established since a 1984 study by Dr. Roger Ulrich, professor of architecture and healthcare design, found that patients who were able to look out a window facing nature recovered approximately one day sooner and required half the pain medication of those whose window faced a brick wall (Ulrich 1984). Being able to interact with natural scenes, either via walking through a healing garden or a looking out a window, has been shown the most effective in promoting healing; in sealed internal spaces in hospitals such as treatment rooms, recovery rooms, or patient rooms without access to such a view, visual art depicting natural scenes has also been demonstrated to be correlated with reduced patient recovery time and reliance on pain medication (Hogan 2001; Domke 2009; Komiske 2005; AFTA 2014). Attending to this finding, a majority of major U.S. hospitals have built and displayed extensive visual arts collections over the past several decades. The development of such hospital art programs has been fueled by the One Percent for Art Ordinance, adopted by many U.S. cities in the 1960s, 70s and 80s,which requires that one percent of public funds received by a public facility be allocated to art installations or programs.

In the past ten years, hospitals have significantly expanded their use of art programs in supporting patient and staff well-being by supplementing visual and 3-D art installations with interactive patient programming that fosters creative expression. Such programs include art-making activities at patient bedsides, group art sessions, poetry workshops, musical recitals, literary readings, and other similar projects. Why is this growing? What value does the institution see in artistic activity?

Even before Ulrich's study demonstrated how interacting with nature reduced reliance on pain medication, shortened healing times, and improve patient outlook (1984), artists, art therapists, and volunteers were making art with patients and staff in hospitals. Adrian Hill, described above as the painter who first used the term “art therapy”, wrote about his struggle to bring in artwork for patient observation, and how he had to convince the disapproving nuns and nurses that worked in many hospitals that the framed canvases on the walls would not promote infection or unsanitary conditions, and that it would not detract from their work or increase their labor. A doctor, hearing positive reports of Hill’s art appreciation lectures and art instruction, became a believer in the program and promoted within his own local institution and several others. And this is the way many programs begin: with a champion who has seen or experienced the benefits, who believes in the arts professional, and who believes in promoting or broadening the experience for as many participants as possible who wish to receive the benefit.

Art and Biomedicine Today

People come to the hospital for a cure. They want to be cured. They’re not coming here for art therapy. But if it’s all equal in their mind, perhaps if they see a robust program that has other choices to assist them or their family member through the process, then they elect to come here. -Hospital administrator

In the United States the biomedical model of care, which privileges science and technology in the treatment of disease, is dominant, and in some senses infallible. “Feidson (1970) has likened the position of biomedicine in modern society to that of a state religion” (in Baer 2001). In locations where resources do not permit the widespread use of technological treatments, and in historical contexts before such treatments were available, separating scientific medicine from the healing properties of art, religion and non-biomedical curative therapies and religion is a more difficult task. In the 19th century United States a plurality of medical systems existed. European American, Native American and African American folk medicine were practiced alongside regular medicine, which consisted of "'heroic' procedures such as bleeding, leeching, and strong drugs," and homeopathic medicine (Baer 2001). Because technological discoveries have led to spectacular advances in the treatment and prevention of disease (vaccines, penicillin, the recirculating heart), and through corporate and political support, biomedicine has risen to dominate other healing modalities. Hans Baer, a professor of social and political science at the University of Melbourne, provides a critical interpretation of the rise of biomedicine. He writes that biomedicine is "a medical system based on systematic scientific research and controlled experimentation. With it's emphasis upon pathogens as the cause of disease, biomedicine provided corporate leaders with a paradigm that allowed them to neglect the social origins of disease while at the same time, in at least some instances, restoring workers back to a level of functional health essential to capital accumulation" (Baer, 4, 2001). Carving out the ailing body from the body social, and narrowing the gaze to focus on unseen inner and microscopic regions of the body has become modus operandi in clinical trials and modern hospitals. If the practice of using technology and science to treat what ails the body has become the prevailing model of care in the United States, why, then, are US hospitals making space in their buildings and their budgets to include programs that foster something as far removed from the biomedical model as creative expression?

According to a 2007 survey of 1,807 institutions, the most recent of its kind, arts programs exist in nearly forty-five percent of US hospitals, and the numbers of such programs are increasing: there has been nearly twenty percent growth in the percentage of arts programs funded by major U.S. hospitals' general fund since 2004 (AFTA 2014). The majority of these programs consist of a permanent art display (thirty-eight percent); however, bedside activities (twenty-two percent) combined with arts activities for staff or in waiting rooms (eleven percent each) are rising in frequency. Hospitals usually begin to integrate art into the medical space by curating a collection of art to be displayed in the hospital environment.

A large majority of the artists and therapists I spoke with said that the hospitals in which they worked did not require them to track patient progress over time, or demonstrate a benefit or evidence of patient improvement, though many keep their own detailed notes out of desire for professional improvement. If hospitals are not noting therapeutic value of such programs, what is their motivation in increasing their support? On the other hand, art therapists and artists do cite a definite therapeutic benefit to their work creating art with patients, and, increasingly, hospital staff, and are seeking opportunities to share this information with nurses and physicians by noting their observations in patient charts or during grand rounds. How do they understand the work that they do, and how it fits into the medical scene? And how is the art making activity understood by patients and their families, who participate in them sometimes for years during while receiving medical treatment? After analyzing my data from interviews, field notes and observations, and considering the discussion about art and medicine in professional and academic literature, I found that there are three primary values, or logics, that underlie the practice of making art in a clinical space: 1: understanding how art making supports biomedical care; 2: art making provides a necessary subversion to biomedical logic; and 3: art making provides a conception of care that extends beyond the biomedical. In this text I will consider how creative practices in hospitals are valued, meaning what type of evidence is summoned to demonstrate their effectiveness. I will examine gaps in biomedical logic and how engaging with creativity helps patients and physicians to face uncertainty. Finally, I will look at how art making can promote relational practices of care unto and beyond death.

Tension Between The Art Therapy And Therapeutic Art

Often art-making activities are facilitated by a resident or visiting art therapist, but just as often they may be facilitated by nurses, volunteers, or artists from the community. I have purposefully chosen to refer to the art-making that happens within a medical institution as patient art-programming, or the facilitation of creative arts activities, and not art therapy for an important reason regarding the use and ownership of the term “art therapy”. As described above, in the 1960s the field of art therapy was appropriated by psychology and psychotherapy as a means of diagnosing mental illness; as art therapy professionalized it moved out of the hospitals and into the realm of psychoanalysts (Waller and Gilroy 1992). Since it has become professionalized, only licensed art therapists who have a degree in community or relational counseling can claim to practice “art therapy” or “medical art therapy” (Malchioldi 1999a). Other individuals and organizations that create art with patients use a variety of terms to capture the work they do, and see various benefits to their work that may or may not include mentally therapeutic benefits. Such benefits of therapeutic art making in hospitals include distraction from or disruption of the hospital routine, a tool for pain management, a form of empowerment, or vehicle of expression. Medical art therapists recognize and promote these benefits in their work too, but they see their work as different from therapeutic art.

Let us consider the differences between art therapy as facilitated by psychotherapists, and therapeutic art produced in medical contexts. Art therapy is a practice that uses art-making as a method of exploration and expression, and often some form of clinical assessment, and is not concerned with the aesthetics of the end product (Malchiodi 1999). In fact, much of what is produced in art therapy may not be aesthetic, and is usually not intended for an audience beyond the therapist and client. Given that art therapy is more about the process and benefits of art-making, and less about the finished product, art therapy could simply mean exploring art materials such as clay, watercolor or pastels with no outcome specified. Perhaps shapes on a piece of paper emerge, or a small sculpted object if formed from clay, and then the client and the therapist discuss it for insights it reveals about the client’s cognitive state. An art therapy session could also involve directed art activities that are then interpreted by the therapist, or in conjunction with the client. The goal is not to create something beautiful, but to create an object that elicits dialogue. Sometimes the art object created may be dark, painful, and troubling to behold. If we do not equate the aesthetic with only beauty and pleasure, but also with "feelings of discomfort, the idea of ugliness and the potential for pain" (Perkins and Morphy 2005, 14), then the work produced in art therapy could be understood as belonging in the realm of the aesthetic; but according to those who facilitate art therapy, whether or not the product is a work of art meant to be displayed to a larger audience as an aesthetic object is a determination lies with the producer of the object.

Therapeutic art produced in a medical context has many elements in common with art therapy: it may involve undirected exploration of art materials, and the result doesn't necessarily have to be aesthetically pleasing. But often, art-making programs do result in a specific end product that is meant for use or display by the creator, and the objects are not used to evaluate a mental status. They are not intended for the private audience of client and therapist – they enter systems of familial or social exchange within the hospital, and circulate in interesting ways. The entrance into a social system is part of the care work that results from such programs, and will be further discussed in Chapter 4: Art making as an extension of biomedical care.

Ongoing Conversations

Although some physicians I spoke with for this study could eloquently describe the work of art therapists and artists in hospitals, most could not. Almost every art therapist I spoke with attested to how pervasive the misunderstanding of healing art modalities is at the hospitals in which they work, and how it frustrates them. “I can’t tell you how many times I hear – oh, it’s the craft lady!”, or “She gets to color all day long. You’re so lucky just to color all day.” An art therapist working at a cancer institute relates the following story: A person [who saw me with my art cart] said, “Are there children upstairs?” And I said, “No, I’m visiting adult oncology patients.” And she goes, “Ohhhh . . . .” It was okay if kids were going to go play, but once she realized it was art therapy, or it was a serious thing, it became very uncomfortable. They don’t want to hear that this is for adults.” This art therapist went on to describe how there is a stigma attached to making art, and limitations in the popular imagination about who can do it, to what ends, and by what means. Art making is simultaneously seen as something childish, that children do, and something so highbrow and elite it is inaccessible to all but a highly educated few, that it is Art with a capital “A”. The artists and art therapists I spoke with were grounded in the belief that engaging in creative activity is for all patients, and for families, hospital staff, and physicians as well. Who could do the work of guiding the art making was not so clear; as discussed previously, who can facilitate art in the medical space is also fraught with tension. In the hospitals I toured, in the conversations I had, in the observations I engaged in, none of these questions had been neatly resolved. The conversations are active and ongoing. Definitions of this work are also being shaped by the institutions in which they take place. Descriptions of art making projects are being forged as creative programs come into the clinical space. Such programs might be titled “Healing Arts”, “Arts in Medicine”, “Creative Expressive Therapies” or “Arts Integration”, and fall under departments as varied as patient services, volunteer services and ChildLife, and palliative care. Funding for such programs is sometimes a part of the hospitals general fund, but most often it is secured via philanthropic donations.

My Method

I am an anthropologist studying the intermingling of medical and artistic practices. The early practice of medicine medicine, the field of art history and anthropology share a tradition of deep attention to local context. The local lifeworlds of patients, subjects and participants in each context matter greatly. In anthropology, this deep attention serves to construct an ethnography. An ethnography can be understood as creating a picture of a cultural milieu, following the roots “ethno”, or human culture, and “graph” or image. Ethnography is both a process of conducting interviews, listening, observing, participating, being present, writing fieldnotes, and a product, the written description of a group of people living in a particular place and time

(Sanjek 1998). In this study, I am presenting a description of the people involved in making art in hospitals in the United States in the beginning of the 21st century. In addition to a description of the spaces in which this happens and the people involved in making it happen, I am tracing the particular types of logics that are involved in facilitating, sustaining, and justifying the intersection of art making and medical care.

To Bronislaw Malinowski, one of the founders of anthropology and a robust proponent of the ethnographic method, understanding the types of logics that people use to explain their behavior is a central purpose of ethnography, "of which an Ethnographer should never lose sight" (1922).

> This goal is, briefly, to grasp the native's point of view, his relation to life, to realise *his* vision of *his* world. We have to study man, and we must study what concerns him most intimately, that is, the hold life has on him. In each culture, the values are slightly different; people aspire after different aims, follow different impulses, yearn after a different form of happiness. In each culture, we find different institutions in which man pursues his life-interest, different customs by which he satisfies his aspirations, different codes of law and morality which reward his virtues or punish his defections. To study the institutions, customs, and codes or to study the behaviour and mentality without the subjective desire of feeling by what these people live, of realising the substance of their happiness—is, in my opinion, to miss the greatest reward which we can hope to obtain from the study of man. (Malinowski 1922, 24)

The "natives" in my study are those who create art in hospitals (patients, families and medical staff), those who facilitate the creation of art making in hospitals (artists, art therapists, music therapists and poets) and those who are professionally involved in supporting the creation of art in hospitals (hospital administrators, child life specialists, chaplains, etc.). To understand the local meanings of creating art in hospitals, I take up the practice of deep listening, participant observation and negotiated interactive observation (Wind 2008)[1], and sustained contemplation to reflect on the practice of art making in US medical institutions to produce a "thick description" (Geertz, 1973) of what people are doing. In tracing the intersections between art making and healing, I used ethnographic methods to pay deep attention to these topics. To understand the nature of art making activities in the medical space, including how they are planned, facilitated, and evaluated, I spoke with those who facilitate art-making sessions in hospitals: art therapists, music therapists, artists and poets. To learn more about how medical personnel conceptualized the benefits of art making I spoke with physicians, including internists, palliative care doctors, surgeons and neurologists and medical students. To understand what patients thought about making art I spoke with them, and read personal accounts. As I began to get deeper into this space, I spoke with other people who are involved in supporting or participating in art making activities in some way, such as child life specialists, social workers, chaplains, and medical students, hospital administrators, and members of non-profits working on this topic. I conducted a total of sixty-seven interviews. I had permission to record forty-five of these. I transcribed half of the recordings, and the other half were transcribed by a professional transcriptionist. I analyzed the

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[1] Gitte Wind, a medical anthropologist conducting research in hospitals in Denmark and the

transcripts and other secondary data using the qualitative data analysis software Atlas.ti. Analysis involved coding the data, discussing the codes with colleagues and mentors, and revising the codes based on feedback and further immersion in the data. I organized the codes into themes, again receiving feedback and suggestions on thematic organization from peers and professional qualitative researchers. When I was satisfied that the themes captured the patterns that emerged in the data, I began to draft memos that explained the links between themes and codes, and the relationships of themes to each other, that informed this text.

In addition to formal interviews, I had over fifty informal conversations with other physicians, patients, and artists about the topic of art making in a medical space. I had targeted questions for each participant group, but found that the themes of these interviews showed a synergy among categories and topics.

I also analyzed secondary data, including professional websites and conference literature, training videos, workshop videos, training manuals, hospital policies, descriptions of hospital art work, artists' statements regarding work they have displayed in a hospital, patient recruitment materials, and other professional and academic sources.

True to my anthropological training I practiced "participant observation", which means that I observed people doing things while I did them too. I attended hospital grand rounds in which the topic of art making was discussed or practiced, art making sessions, patient art performances, rehabilitation sessions and patient support groups. I attended classes in which medical students learned to look at paintings, and classes in which undergraduates considered the healing power of poetry. I became the client of an art therapist who was also a professor at Antioch University, the only university in the state of Washington, and one of only two in the northwest, that trains art therapists. During my sessions with her I would practice the techniques of art therapy, and she explained the reasoning behind the types of activities she offered me and the logic behind them. And, of course, I took notes on my observations, on my impressions of interviews, and on themes I could see emerging across all of these experiences.

Likewise, I knew I wanted to speak with medical providers, art facilitators and patients, and through my conversations with them I would find that several people mentioned a particularly puzzling or important element of the work, and would widen my participant circle to include other types of people who could shed light on the topic. For example, when speaking to art therapists I encountered a theme of frustration that their work wasn't billable to insurance, and a desire for it to be taken seriously as a form of evidence-based medicine. What we need, I heard them say, was a study that measures the effects of art making in the brain. Once such studies were published, art facilitation would surely become a standard practice. To understand how certain therapies and procedures become standard of care I spoke with hospital administrators and insurance specialists; to understand what a study that measures changes in the brain resulting in art-making activities would look like I spoke with neurologists and physicians.

Anthropology situates local practices in the wider contexts that give rise to and influence them; to understand how art making has come to be a hospital-based activity, I have incorporated elements of bioethics, neuroscience, art history, art therapy, creative writing, music therapy, poetry therapy, palliative care, insurance practices, hospital administration, philosophy and sociology. My goal is to weave together an understand of how a humanistic practice of making art enters the biomedical space of a hospital and to bring together concerns about the nature of suffering, healing and care that arise in natural sciences, social sciences and humanities. We are witness to a time in which the boundaries and intersections between these fields are being examined, experimented with, and crossed. Hospitals are supporting the facilitation of artistic activities in their hospitals, from philanthropic donations in some institutions to core funds at others. How art and medicine come together is a topic of academic inquiry and practical concern.

I'd like to follow my use of ethnography by briefly paying attention to the use of ethnography in the fields I have outlined above. Although ethnography is widely considered a hallmark anthropological method, the contemplation of art and the practice of medicine each have explicit ethnographic components. Close observation has long been bound up in understanding the production of art, and ethnography itself is a medical genre. Understanding how each field practices a form of ethnographic attention to the everyday will highlight tensions within and among these fields, tensions that arise in the practice of art making in the hospital, and that help explain how a poet becomes a member of an advanced care team.

Ethnography In The Study Of Art

Early ethnographic studies were interested in the classification, cataloguing, and function of the aesthetic object, though not all ethnographic objects were appreciated for their aesthetic value. For example, an intricately carved oar was studied more for what it revealed about a culture's systems of transportation and exchange than its aesthetic values (Gell 1998). Museums displayed ethnographic objects with aesthetic properties in dioramas of daily life rather than as art objects, emphasizing function over form. If ethnographic objects were art, they were primitive art, "prior" to the great traditions of the West. There were notable exceptions of anthropologists who did study art, including Firth, Herskovits, and Redfield, though Perkins and Morphy note that "more often than not studies of art were absent where they might have been expected, as in Malinowski's study of the Kula…most anthropologists considered the aesthetic contemplation of ethnographic objects "epiphenomenal" (Perkins and Morphy 2005 5-9).

Sharing a similar trajectory to the field of medical anthropology, the anthropology of art began to robustly develop as a field after World War II, when aesthetics, performance and material culture became integral to the research process of anthropologists. This shift occurred because of changes in British anthropology (similar changes occurred within American anthropology), where there was a "move away from the focus on social relations and analysis of social structures to an increased concern with myth, religion, and ritual" (Perkins and Morphy 2005 9). Anthropologists began to examine the aesthetic object as a container of meaning, perhaps containing symbols but also itself a symbol with various meanings. The renewed anthropological interest in symbolism combined with structuralist, semiotic and linguistic approaches to viewing culture as a system of meaning (Ibid). While I have not attempted to interpret an art object or decode its meaning in the course of my research on art-making in medical institutions, I have listened to the narratives that people share regarding the meaning of the art-making process or the object created.

Examining art as activity, sociologist Howard Becker outlined a series of steps that take place in the construction of an art object or performance: an idea of what kind of work is to be made, the execution of that idea, manufacturing and distributing the materials and equipment, activities that can be defined as "support" (sweeping the stage, etc), an audience to respond to the work, "creating and maintaining the rationale according to which all these other activities make sense and are worth doing", and a supposition of civic order in which people can make art with a degree of stability (Becker 1982, x).

When considering a work of Art with a capital "A", it is important to understand how the construction of a work of art is deeply embedded in local meanings. In art history, an insistence on an understanding of the socio historical context of a work of art became a barrier to art appreciation by people outside of the academy. Art historians claimed that you needed to understand the political, cultural, religious and economic values of the artist's milieu in order to "get" the painting. But this type of art appreciation excluded people without the background knowledge - and cultural and academic privilege that provided this knowledge - and limited art appreciation to an elite group. Today the tone has shifted and people are encouraged to come as you are, come to observe. Observe closely and deeply.

Observation does not happen in a cultural vacuum; you do bring yourself, and your past experiences, to the contemplation of a painting or sculpture, but the idea is that in careful observation over time you can find meaning in the paining, you can describe things that are significant. You can provide a richer, or thicker, description of what you see. This premise underlies a technique of teaching sustained looking through the observation of paintings to medical students via a technique called Visual Thinking Strategies, a technique that studies prove enhances the diagnostic abilities of physicians. The tension regarding who can observe, the learned art historian or the layman, is also present in the question of who can facilitate art-making, the licensed art therapist, or the artist? The professional artist, or a volunteer? Each work today in hospitals, facilitating art making experiences with patients and medical staff. Who is permitted to participate in art activities (namely, the sick, or those who care for them), and who is permitted to facilitate art activities (licensed mental health professionals, artists, or others) are questions that suggest that the universal experience of regarding and creating art is being offered or restricted in interesting ways. How this happens in the medical context is a question this study will consider.

Ethnography In The Practice Of Medicine

The practice of medicine and the practice of ethnography have a close relationship. In fact, ethnography has been described as not just an anthropological but a medical genre. There are several prominent medical professionals who worked to obtain doctorates in anthropology, including Paul Farmer, Arthur Kleinman, and Seth Holmes. Josep Comelles, another scholar who holds an MD and doctorate in medical anthropology, argues that participant-observation and ethnographic writing are qualitative methods that have been part of medical training since the time of Hippocrates until very recently, fading from practice in the 21st century. He states that the attendance by physicians to "the natural environment, local living conditions and how they affect morbidity and mortality, eating habits, and mother and child care in rural and indigenous communities" in their ethnographies reflects a commitment of the medical practitioner to his patient. According to Comelles, the genres of medical topographies, geographies and monographs "should not be approached as part of the history of anthropology, but as specifically medical genres related to medical practice" (Comelles 2000, 41). In his article describing the role of local knowledge in medical practice, he details the quest of doctors practicing rural medicine to obtain an emic perspective of disease causes, treatments and cures, to detail local knowledge, to practice participant observation, and to include first-hand accounts of illness and healing experiences in the 17th, 18th and 19h centuries. Comelles states that the disuse of ethnographic methods by medical practitioners signals the privileging of a clinical gaze and increasing distance in the care relationship between physician and patient (Comelles 2000, 41).

What Will Follow

> Anthropologist to Artist: "You've painted this enticing picture, but I don't have a clear example in my head: how do you *do* art in the hospital?
>
> Artist: "That's a great question, and I imagine that if you ask a thousand

> people you'll get a thousand different answers…But you really have to see it, because so much is lost in translation when it's described in words. It's like trying to read the back of a tapestry.

Come, let us examine the threads of this tapestry. Let us take some time to pause at patient bedsides, hospital conference rooms, secluded nooks with dim lighting, lobbies with high traffic, deserted atriums after sunset, small offices with shelves and boxes overflowing with art supplies, pediatric schoolhouses with brightly colored walls, and drab chemotherapy infusion room, each a space where art making happens in hospitals, to consider the many interesting forms in which art making behavior manifests and how it is valued, how creative engagement can disrupt biomedical logic, how it supports the fundamental activities of healing, and how arts activities support the social role of the patient at the point of death, and beyond death.

The next section of this work, Chapter Two will delve into understanding the nuanced ways in which creative activity is valued in the realm of biomedical care. I will discuss how the evidence used to support the practice of art making in hospitals are multiple and sit in tension with each other. I will consider the evidence that exists in the clinical literature, and why it is valued. What is used as "evidence" that art making activities should continue, and why is evidence of the effectiveness of art activities sometimes eschewed by physicians?

I will examine cases that resist measurement, and consider what that means for how art making can and should be valued. I will consider how art making is funded, and how funding mechanisms are intertwined with clinical evidence.

Finally, I will consider the question that an artist posed, “Where does art stop, and where does medicine begin?”

Chapter Three will consider how the practice of engaging in artistic activity can challenge and disrupt biomedical logic. How does one balance the emotional weight of caring for the ill with the availability of many advanced medical treatments and technologies that can blur the beginnings and endings of life against the truth of human mortality? How does art-making speak to this paradox? A theme that cut across almost all categories of participants was the idea that art making can be a subversive practice that disrupts medical care, and that this disruption can be a good thing.

There are many components of art making that implement a counterweight to the practice of biomedicine, or to biomedical logic. It begins with choice – the choice to participate or refuse disrupts the passive role of the patient, participating disrupts the routine and the boredom of the day, and the act of creating the art can disrupt the architecture of the medical space. Creating art in hospitals disrupts the top-down hierarchy of the medical space. Finally, arts facilitators embrace and celebrate the unknown in their encounters with patients, disrupting the positivist logic of evidence-based medicine that asserts that there is an outcome and we can know it and act accordingly.

The fourth chapter will consider how the practice of art requires skills and relationships that are at the core of healing. Through telling stories and listening to stories, by reading and writing poetry, the empathetic relationship between provider and patient is strengthened. Arts activities facilitate caring relationships, help doctors and patients to navigate uncertainty, and promote practices of reflection and resilience.

The fifth chapter will examine the ways in which arts activities can serve as a validation of life, a validation of suffering, and a validation of care. Many arts projects are undertaken by patients with a terminal illness, and these projects can communicate a person's life and identity, serve as a memorial or legacy object, and continue a person's social role through and after death.

Engaging in arts activities call patients back from the isolation of disease into social communion with others, and can provide a form of social palliation. They allow for others to witness the suffering of the ill person, and to accompany them throughout the course of the illness, unto and through death.

Chapter 2.
Proof of Art: Evidence and Values Underlying Creative Arts Activities

When you work with sick people – or really, anybody - you work with this strange machine of pain, money, death, life everything. – John Blalock, artist

Health care is kind of the big thing that is going to define us as a society right now, it's the point where issues of class and socioeconomic and political views all come together – it's where the rubber meets the road – where policy and decisions meet people's bodies, and that's where artists are going to gravitate. – Eric Avery, physician

When I began listening to the stories of the people who are involved in supporting creative arts programs in hospitals – either by facilitating art sessions, supporting healing arts programs administratively, or by being a physician champion – I became drawn in by the ways that art making in medical contexts speaks to ideas we have about what healing is, and what evidence we need that it has happened; what it means to creatively express oneself when touched by illness, and what benefit that brings; how we think of good care, and how we can imagine better care.

Historically, conceptualizations of what medicine is and what constitutes good care in the United States have taken many forms. As people from different societies and geographies migrated to the US they brought with them a variety of curative therapies that mingled with each other and also the healing modalities of First Nations populations (Packard 1901). The US began as a medically pluralistic society, meaning that many different medical philosophies and practices were available to patients, including hydropathy, homeopathy, osteopathy, botanic medicine, and biological medicine (Baer 2001).

Scientific medicine or biological medicine, which has come to be known as biomedicine, grew to become the dominant model of care in the United States. Biological medicine capitalized on the acceptance of germ theory in the late 19th century and grew in power through the support of industrial capitalists, who appreciated its focus on the individual as the locus of disease rather than the social, occupational or physical environment; "germ theory, while certainly not a conscious creation of the capitalist class, served its interests well by allowing an emphasis on specific cures for specific disease along with a corresponding neglect of social origins of disease" (Baer 2001, 33). Sharon Kaufman, a scholar who writes about the changing medical practices that constitute end of life care, and how extraordinary procedures have now become *Ordinary Medicine* (2015), quotes Daniel Callahan to characterize the cultural nature of health care in the United States: "American health care is radically American: individualistic, scientifically ambitious, market intoxicated, suspicious of government, and profit-driven," (ibid).

Biomedicine, with its heavy emphasis on biology, physiology, and evidence-based practices, has become the gold standard in US medical care (Timmermans & Berg 2003). The biomedical model privileges the clinical gaze, a gaze that dissects the body into parts rather than an integrated system, and emphasizes isolating the cause of disease within the private body rather than considering how that body is positioned within and shaped by social systems (Foucault 1973; Baer 2001). There is much talk today of paying attention to "the social determinants of health", as if health itself is not a social condition. The body is biological, but not singularly so. It is double, triple (Mauss 1973), multiple (Mol 2002). It is double in that it is biological and social, Mauss added that the psychological self makes for a triple self, and Mol found that multiple selves are performed in enactments or social exchanges with others. Health and illness are shaped by cultural beliefs, and constructed through social practices.

Medicine is enacted through social roles. Foucault has written that the doctor's role is to observe the disease process, the patient's role is to reveal. "Doctor and patient are caught up in an ever-greater proximity, bound together, the doctor by an ever-more attentive, more insistent, more penetrating gaze, the patient by all the silent, irreplaceable qualities that, in him, betray – that is, reveal and conceal – the clearly ordered forms of the disease" (Foucault 1973, 17). Patients are made to give up their "irreplaceable qualities" through exams, imagings, and laboratory analyses. Physicians are meant to look at this data and to understand disease processes and determine next treatment steps. Despite the positivist framework of biomedicine, which, simply put, holds that objective science can reveal a true or correct course of action, the reality of caring for people who are ill is much messier.

Take, for example, the decision to begin a treatment. If there are several options, how does a doctor choose the "best" one? The scientific literature often contains conflicting recommendations, a person may have multiple illnesses that complicate a course of treatment, or the person may not agree to a course of treatment for various reasons. Attention must be paid to the individual, to the "person who has the disease" (Osler) yet biomedicine is becoming increasingly standardized. Physician intuition carried greater weight in earlier decades, and doctors drew upon their experience and "gut" to determine patient treatment. Now, uncertainty about patient care is largely met with evidence from research trials. Outcomes, risks and benefits are predicted in tidy percentages. The evidence shows a statistically significant shift in patient outcomes based on a tested intervention, or perhaps it is only the likelihood of a shift, and doctors face a variety of pressures to prescribe treatment accordingly.

Evidence-based medicine has exploded. It is a descriptor, a movement, a mandate. There are research centers and journals devoted to evidence-based medicine. The field is now deep enough that there are graduate degrees offered in evidence-based healthcare. The thousands of research trials conducted each year provide outcomes of tested interventions that need to be assessed for clinical application, for which other centers and journals and professional positions dedicated to "translational science" provide counsel. The outcomes of these trials become evidence, and this evidence changes how doctors think about what procedures are to be prescribed. And, importantly, evidence is used to create policy that shapes or constrains physician behavior.

The fact that creative activities that are individually tailored and contain treatment goals which are often multiple and difficult to measure, or contain no treatment goals at all, are finding a home in a biomedical realm is interesting indeed.

How creative activities are performed, how they are valued, and how they intersect with biomedical logic are questions that deserve careful attention, and that this project sought to answer.

How have creative activities become co-located with medical practices in hospitals? What do we think that they do, and what do we want them to do? How do we know they "work", and what does it mean for an arts activity to be effective? Are these types of questions, questions about efficacy and evidence, questions we want to ask of a creative experience?

For there will be the arts
and some will call them
soft data
whereas in fact they are the hard data
by which our lives are lived
- John Stone, Gaudeamus Igatur

Evidence In Tension

Arts professionals that facilitate creative activities and the doctors that support them have different perspectives on the necessity of evidence. They come from professions that embrace different logics: the standardized, evidence-based positivism of biomedicine sits in tension with the ambiguous and individual modalities of arts professionals. But when each speaks about the value they see in artistic activities that take place in hospitals, they intersect with and borrow the logic of the other. Artists and art therapists spoke to me of the latest advances in brain science, of neuroplasticity, how the brain can change when exposed to different experiences; they told me a study that could measure a change in the brain of a patient who participated in an arts activity is their next hoped for advance in the field. When describing their own work they also spoke of intangible benefits from art making; but in speaking of the future of arts activities in hospitals, they largely spoke of scientific rigor and measurement and proof.

Most doctors I spoke with, though steeped in the world of evidence-based medicine, were surprisingly not as keen on finding proof or evidence to support art in hospitals. The doctors had various levels of involvement with creative activities that corresponded to their views about the necessity of evidence. Doctors who supported, but did not actively participate, in arts programs in their hospitals did speak about the need for evidence to connect biological healing processes to participation in arts activities. Their personal experience with patients who participated in creative activities suggested that patient health was improving. "Anecdotally, do I see a difference? Yes." However, they were cautious about making statements that expressed certainty about these effects. "It would be really hard to pull that out in the absence of a study that really looked at that, but my *sense* is that it does," or "I can't prove it, but I think that it does."

Other physicians, who were more involved in an arts activity themselves, were more open about attributing a healing benefit to an arts activity.

> I do some poetry with my patients. It's not for everybody, you know, but some people just love to write, and it's a very healing thing. I find that their depression, the way they deal with their illness, is improved using poetry. - Neurologist, poet
>
> Oh yes. I've seen from my own experience of being a patient and writing poetry in response to those experiences that a poem really does afford some specific benefits in relation to the sense of healing.
> I think in particular the way that poetry really can locate us in the physical body, in the rhythms of the body, in the conversational rhythms of our

> minds and our internal dialogues – I think that when one's body feels uncertain or feels like it's betraying us, that very visceral quality of poetry can really be quite powerful and reassuring and that kind of point of intrusion perhaps back into one's own body. That is one way I find poetry in particularly valuable.
>
> And we have had some studies from the biomedical realm that suggest that poetry, because of its rhythms, may help regularize or synchronize bodily rhythms in people who meditate or who recite poetry.
> - Dr. Campo, Internist, poet

These doctors could speak to specific healing effects of participation in creative expression– depression, regularizing bodily rhythms – based on their own experiences; they used their own stories as evidence. Arts professionals echo the power of first hand encounters with creative practices; one arts professional told me "my wish would be for the doctors here to see this themselves. Because *then* they'd get it."

The doctors who said they would need evidence to talk about *clinical outcomes* from arts participation told me that they didn't need any such evidence to say that art *should* be in their hospital, citing a moral reason for the programs. "We offer [opportunities to participate in arts activities] because it's the right thing to do." When I explained that some arts professionals are interested in conducting research studies that would provide evidence of clinical effectiveness, they were quick to tell me that that was the wrong approach. Neurologists I spoke with about the feasibility of such a research study said measuring an effect from an art treatment would be difficult to design because of the complexity of isolating the effect of the art making from other factors that contribute to healing such as medication and time. Others said such measurements were not necessary, and perhaps even not appropriate. "You can't measure it. Because of course – that would ruin it." One palliative care doctor said that the value of art making does not need to be, and shouldn't be, expressed by evidence.

> I don't think I would really want to try to measure it. The ways that we have to quantify those things are so crude. I think [an arts activity] has its own intrinsic value that speaks for itself. I believe in it, and I don't necessarily want to or need to quantify that. To reduce it to the type of entity that can be quantitatively compared seems to me, that's a little bit missing the point.

Evidence is not one thing. There are multiple ways physicians and artists speak about it: as the outcomes of clinical trials, as a patient story, as a personal experience, and as unnecessary in the face of a moral good. Yet the currency of the medical field is clinical evidence, and artists want to trade in it.

Body Of Evidence

"There's a very, very big branch of medicine that ties immunology to emotional output…there's a strong connection between the immune system, even to the point of altering white blood cell counts, and emotion." – Neurologist, poet

Trials have been done to provide evidence that art activities have a therapeutic benefit. Art therapists find that engagement in artistic activities fosters emotional expression and increases optimism (Council 1993; Machioldi 1993; Hogan 2001; Hill 1948). A review article that examined studies of arts activities in the psychooncology literature listed a number of improvements in mental health (Geue et al 2010). While the effects of art on the brain are just beginning to be researched (Bolwerk 2014), the effects of emotional expression and optimism on other *clinical* outcomes have been found.

Emotional expression and optimism are reported to have important immunological and healing benefits. Segerstrom and Sephton (2009) found that having "optimistic expectancies", or being optimistic, affected cell-mediated immunity (CMI). Cell-mediated immunity is an immune response in which the body releases immunological cells, such as T-lymphocytes and macrophages, to respond to a threat in the body, or antigen. Their study found that the immunological response to an antigen in the body increases when a person's sense of optimism for the future increases. (ibid, 2009). The authors state that this study "is the first evidence that expectancy change correlates with immunological change", and "supports the validity of psychological interventions to improve immunity and health" (ibid, 453).

Illness is recognized to be stress-inducing, and chronic illness is a stressor that has effects the social and physical self. "Chronic stressors…pervade a person's life, forcing him or her to restructure his or her identity or social roles" and are "associated with suppression of both cellular and humoral measures" (Segerstrom et al 2004). The link between stress and wound healing is strong, both in humans and in animals. Namely, those who are stressed heal slower. It is thought that "stress may impede healing directly via the neuro-endocrine and immune systems" (Glaser & Kiecolt-Glaser 2005; Weinman et al 2008). Building on research that found that psychological interventions can improve immunity, and that emotional disclosure is correlated with decreased visits to the doctor, Weinman's team designed a study to test the effect of emotional disclosure on wound healing (Weinman et al 96, 2008). Participants were divided into two groups; each group wrote for twenty minutes for three consecutive days. One group, the experimental group, was encouraged to write about "a traumatic and upsetting experience in their life…to delve into their deepest emotions and feelings about this event" ibid). The participants in the other group, the control group, were asked to write about time management, and to focus on details but not emotions. Both groups returned in seven days to receive a four millimeter skin biopsy on the inner part of the upper arm of the non-dominant hand, and all were given a standard bandage. They all came back again three times, one, two and three weeks after the biopsy, to have their wounds measured. The results were significant. Those who wrote about emotional experiences had wounds that were eleven percent smaller than those who wrote about time management. This has implications for surgical procedures in hospitals, suggesting surgical patients should be offered the opportunity for emotional expression. Other studies have found that stress-reducing pre-operative interventions can have beneficial effects on "pain, mood, and length of hospital stay" (Johnston and Vogele 1993), and could be a worthwhile pre-operative intervention. The authors conclude, "The emotional disclosure intervention is brief and low in cost and is therefore a promising intervention" (Weinman et al 2008, 100).

Another study utilized a health survey to gauge the impact of Arts-in-Medicine programs on an adult hemodialysis unit. They found that after six months, participation in the Arts-in-Medicine program activities correlated to less weight gain, greater serum carbon dioxide content, greater phosphate levels, and a tendency toward less depression, along with improved social function and bodily pain (Ross et al 2006). Other studies have found that creative engagement correlates with reduced cortisol, heart rate and blood pressure, and increased optimism (Christenson 2014) and that journaling improves outcomes for people with diabetes and hypertension (Delamare 2014). The evidence that creative activities change clinical outcomes is growing. What effect it will have on the position of arts programs in hospitals remains to be seen.

Resonant Frequencies: Some Things You Can't Measure

Music is as powerful as any medicine. - Oliver Sacks

In the research literature, evidence supports the contention that the opportunity to participate in creative activities provides a distraction, helps patient cope and comply, normalizes the hospital space and equipment, and provides procedural support. Helping someone through a difficult illness or painful procedure often means doing many of these things at once, and arts facilitators speak of holding multiple goals throughout a session. Some benefits that creative activities provide have been documented, as demonstrated in the studies above. But, it is important to note, some things don't easily lend themselves to measurement. One music therapist, whom I'll call Joe, keeps a professional journal in which he records his sessions with patients: what their condition is, what technique he used to facilitate improvement, and what the outcome is. Joe told me about a story that he logged into his journal as “tracer session”, or an important example of the possibilities of medical therapy. In this tracer session, music therapy worked to avert the need for a medical procedure. This type of session is hard to classify. Since a procedure was avoided, it was not quite procedural support. Is it an example of promoting patient compliance? Helping a patient cope? Providing distraction? Providing a type of cure?

Before I describe the tracer session, I’d like to tell you about Joe. His story is a story of the potential and power of music: of listening to music, of making music, and of creating the instruments that make music. It’s about how each can wound and heal, and the story of how one man navigated his way through each practice, unlocking the different potentials of music.

Joe grew up in honkytonks and taverns in southern Maryland in a family that loved music. His uncle played pedal steel guitar. He says music is what helps him survive adolescence. “I came to music and recognized that there's this thing I can escape into, and when I come out, it's better. It somehow delivered me to a better place.” He later went to guitar school, and built a nylon string classical guitar, a flamenco guitar, and an electric bass guitar. As he talked about making musical instruments his voice took on a rich tone, his passion evident. His description of crafting a guitar has its own lyrical quality. “You sand down the wood, and then sand it finer, and finer. To know when it's done you can tap on it, and at the moment when you get a tone back is when you know you've sanded it enough. If you don't sand it enough when you're tapping on it it's just got like a thud sound (he taps on table to show me), but there's a certain point where you start hearing that the tone sustains when you tap on it. One of the teachers showed me that you can sing into it, and if you just go like this (he slowly breathes a sustained tone) you can find the resonant frequency of the wood. And when you sing the tone it will reflect back from the wood, it will sing back to you. It made me realize that the music is in this stuff before you even put it together and put the strings on it and make the frets and organize -like oh this is a scale, and this is how your supposed - that's all culture, right? That's all cultural stuff. What this culture decides is how you organize music. But the *music*, which is more fundamental, is actually in the materials, it's in the…" He leans forward as he tells me, "It's probably in the *tree*."

Joe's experience with of benefitting from the intangible qualities of music has led him to work with patients. Joe is a professional musical therapist, pursuing training in NMT (neurologic musical therapy), and works in a large urban hospital. Sometimes, especially noteworthy sessions stand out as exemplars of how music therapy functions, and Joe highlights these in his notes as tracer sessions, as I described above. One tracer session that Joe shared with me is as follows.

> So here's an example of one that happened just a few weeks ago. There's a kid that's six years old, he had a sudden cardiac arrest. He just dropped. Totally unexpected, no previous history, no heart problem, just like *boom*. He had a brain injury following that because his heart stopped, an anoxic injury. And it took him a while to recover.
>
> My first sessions with him were really about trying to [provide some] comfort for the family because they wanted music,

music was really meaningful to them. The little sister was there so I'm trying to find ways she can be involved, singing with him, that sort of thing. When patients are very first emerging from a neurological injury, there are therapy techniques like musical sensory orientation training, when you're just trying to stimulate any kind of response, any kind of orientation. Visual engagement, any kind of participation. So that was my initial goal with him. And those sessions were kind of mixed. I got the comfort piece happening no problem, but he was really still not quite emerging in those early sessions I had with him.

I didn't see him for several days, and some spontaneous recovery happened. I come back, and he's walking and talking. Just like that - boom. But when I go in, he's really anxious, he's really scared. And I couldn't figure out why. Mom tells me, I think he's going to have to get another IV. And he's *not* happy about this at all. Mom says, can you please stay? So I start playing for him a little bit. I didn't really want to get in to having him play instruments because I was anticipating the nurses would have to come in and do the new IV. So they came in and they put the numbing cream on, they put some saran wrap over it. Every time the door opened and the nurse came in he starts fidgeting around. As soon as they leave he just looks at me (Joe models an eager, pleading look) and looks at the guitar and I say, should I do some more? And he's just like oh, yeah.

And in the meanwhile he has another IV that's in. So the nurses are coming in and they check and they go over and they mess with the machine a little bit and they go back out. And then two of them come back in and I'm like okay, here it goes. And this is more of a medical approach in music therapy, it's called procedural support. And it's basically providing alternate focus for their attention while they get the procedure, you know, and helping them to recover more quickly afterwards. So that's kind of the full scope of that particular kind of intervention.

So I'm thinking that's what we're gonna do, right? The nurse goes over there and messes with the machine, and says some things to mom, and says some things to the other nurse, and they take off their stuff and they go away. And meanwhile this child is just sitting there, and all of a sudden his face becomes relaxed and drowsy, and then he's asleep. And I just keep playing, I just keep playing for a little while, keep fading, keep getting quieter, keep slowing the music, and then eventually the music just dissolves.

He is completely out. So I get up and go to the mom and say, "I thought we were going to put an IV in?" And she said, "I think you cured him. He was so anxious. The nurse said that they think he was

> so tense that the IV wasn't working; they thought it had blown out, and they were going to replace it. But once he just relaxed and calmed down, it started working again."
>
> And this has happened numerous times. The kid is really anxious or in pain or whatever, and there's a medicine flowing through them, but they are somehow holding on to the pain. And then once they are able to relax – oh! It's like it all just hits them, and they are out. And this is what happened to this kid. So you'd better believe that was a tracer session to me. I put that in my journal: "music therapy averts medical procedure!"

When doctors speak about measurement ruining what they describe to me as "the magic" of creative experiences, they are referring to sessions like these – sessions in which an intangible benefit has occurred that is unique to the patient and the artist, the relationship between them, and the moment. This session resists dissection, reduction to a formula or protocol, and standardization. And they are speaking from experience: evidence-based medicine has impacted a physician's ability to provide this type of personal care. Both physicians and patients complain of an increasing "cookbook" approach to medicine, and of less time available to truly listen to and come to know a patient. It has also reduced physician authority and creativity: the more evidence exists, the more doctors feel compelled (and *are* compelled by structural forces such as insurance reimbursement policies) to follow it (Kaufman 2015).

When doctors speak of not wanting a randomized trial that would document clinical benefits of procedures such as this tracer session, of not wanting to subject such a session to the "crude" measurement tools we have available today, they are also speaking of not wanting the consequences that come with claiming that a practice has evidence. Healing, in the various was described above, does not always follow each session with an arts professional. I wonder if the option of a “null outcome” in these sessions, or of holding no specific treatment goal, has to remain a possibility in order for the unexpected moments of healing to happen. In this time of arts activities increasing in US hospitals, arts professionals are largely free from external metrics to follow their intuition and to adjust to changing circumstances in each encounter with a patient. Professional autonomy may be something, if evidence leads to standardization of arts activities as it has led to the standardization of other aspects of patient care, arts professionals stand to lose.

Some Things You Shouldn’t Measure

There’s a wonderful film from the 1980s; it was called Buffalo 66. It stars Christina Ricci and Vincent Gallo. She wants to be his girlfriend; and everything he does she likes to put meaning into. And he says, “Can’t you just think of this as spanning time? We’re spanning time. We’re just spanning time.”

And I love that phrase. Our artists are to be present and span time with you; and that’s … and whether you’re the staff, whether you’re the family, whether you’re the patient, spanning time is really good. And so many people who are hospitalized have no family, or they haven’t been touched for a million years...No one’s taking the time to hear them and listen to them. That’s what artmaking does, right? It allows you to span time. – Arts professional

The phrase we all know is “spending time”, and it’s easy to think that’s what the character meant, the actor’s unique accent rendering it “spanning”. But exploring what it means to span time yields rich interpretations. According to Merriam-Webster, one of the definitions of span is “the full extent of something end to end”; another is “the extent, stretch, reach, or spread between two limits” (2003). Spanning the distance between normal daily activities and threatening medical procedures, between making a decision and undergoing a treatment, between shifts in identity from before to after diagnosis, is indeed, as the arts professional said, "really good". It is more than good – it is a necessary component of care, and of healing. Sometimes patients have to endure treatments that take a long time, and that are boring or difficult to sit through. “Time is measured in not only objective, standardized units, but in sociocultural terms” (Klitzman 2007). In Klitzman’s study of the different perceptions of time patients and doctors hold, he interviewed fifty doctors who became patients and asked them to reflect on their different personal and professional experiences of time. He found that doctors described waiting as inevitable, while patients described waiting as suffering; “a person waiting is a person suffering” (ibid, page 149). Spanning time is an embodied practice of care that is the staple of act of championship. Having a supportive person span the time with you makes a significant different in a patient’s disease and treatment experience.

Other in-patient procedures require long periods of sitting and waiting, such as receiving a dose of chemotherapy through an IV. One adult patient described a treatment room as being bare and beige, with about six brown oversized armchairs. When receiving chemotherapy, patients sit in these chairs with a pillow behind their backs and a blanket across their laps. People who are receiving dialysis respond in different ways. "As a patient, it’s interesting how people react to being in a group at all, without the art therapy. Some people hide under a blanket the entire time, and don’t say anything to anybody; others make eye contact and say hello." The medical center where this patient received chemotherapy offers "Integrative Health" modalities, including art therapy. One or two days a week, the art therapist comes by the chemotherapy room. If a patient chooses to make art, the art therapist will roll over a hospital table that he has filled with art supplies, and patients choose the ones that appeal to them. In this context, the activities are able to be completed in a single session, and can be as detailed or simple as the patient chooses. The patient I spoke with was an artist who chose to work with new materials that were a bit challenging to craft a small project. I asked him about his interaction with the art therapist, and if the therapist focused his comments on the work. The patient replied that sometimes the art therapist makes comments such as "I like the direction your work is going", but the conversation wasn't exclusively focused on the art project. "Since this takes a few hours, we talk about other things. We make small talk, he's a nice guy and he's easy to talk to" (Adult oncology patient). In essence, the therapist was “spanning time” with the patient.

Sitting with patients during, the act of accompanying, used to be part of the work nurses performed (Nursing Standard 1987). Sitting at the bedside is still considered best practice (Malouf 2014), though nurses face increasing administrative demands that reduce their availability to sit with patients. . Patients feel the loss of companionship, and the isolation that going through an illness and treatment entails. A woman who works to facilitate the entrance of artists into hospitals speaks about how much positive feedback she receives about bringing art programming into hospitals.

> Participants [have] started to come to me and say, “I wish I had this when I was in the hospital, because that’s when I need it. Chemotherapy takes six hours, by the time I got there and then waited for my blood and then they put a line in. And sometimes my sister came with me, but she couldn't stay the whole time...or, 'I couldn’t look at the television anymore or the fish tank,' or some woman would say, “I was in bone marrow transplant in isolation for three months, and I could have *really* used the photography project to work on there.

So the opportunity to participate in a creative activity helps to distract patients from the boredom or discomfort of their treatment or illness experience. In this distraction, artists and patients are "spanning time" together, and this companionship is a form of care. It is a form of relational care, but also it is the care the nurses used to provide. "So the artists are there, and they are “taking care”—I’m putting that in quotes—of patients in a wonderful and beautiful way, but they’re also doing the work of nurses … quite frankly, it’s the artist sitting with somebody and looking at somebody and having a conversation with someone that really helps the staff."

She goes on to say that many times staff request that an artist work with patients because it makes their job easier. “Sometimes it’s because the patient has expressed a desire, but more often than not it’s because the patient is being difficult with the staff, [or] uses the call button. And then that patient needs a distraction or a diversion or an intense experience that will take their mind off of whatever it is the nursing staff cannot provide.”

Spending time with patients, averting a medical procedure – these aren't the therapeutic goals that arts professionals hold, but they are able to happen because of the unscripted and unstandardized nature of arts sessions.

I have outlined two examples of meaningful benefits that arise from facilitating creative activities with patients. I have suggested some reasons why clinical trials might not be the best way to obtain evidence. Some arts professionals are themselves conflicted about wanting to produce clinical evidence. They understand the limits of how evidence is produced, but they also understand how it circulates.

> We both know how poorly studies are done. But the abstracts all look *great*. Then you look back and you say, "Oh, I've got 12 people. Really? And two of them were unavailable for the pre-test, and four of them didn't take the post-test. We don't need this. Let's throw that study out the window. But, no, let's keep it because it only proves what I already know. Still, I do attach that study to every funding request, because people love to see studies.

Research evidence is closely connected to funding. Insurance providers that use a fee-for-service payment model pay for itemized services that a hospital provides. Many are critical of the model, saying it incentivizes hospitals to provide more services, rather than better care (quantity over quality). And this is what physicians describe as their worry, that measurement and its promise to improve quality will in practice do the opposite.

The question of clinical evidence has a close and somewhat circular relationship with how healthcare is funded. In the application of biomedicine, scholars have described a strong link between research outcomes and funding. A procedure gets funded because the outcomes of a trial are used as evidence of an effect, and insurance providers want to fund things that "work" (Kaufman 2015). Industry also funds trials, meaning that the production of what counts as evidence in these cases is fundamentally skewed by profit motives. A health services scholar I met with to discuss how treatments or technologies become standard of care told me that the relationship between evidence and reimbursable procedures is not quite that straightforward; there are multiple paths for a treatment to become standard of care. There is the path of efficacy: you build a better mousetrap, and it gets widely adopted. It makes money before the use value (clinical outcome) is evident. There is the path of shifting cultural and social norms, as happened with digital mammography, where both clinicians and patients advocate for it despite unclear evidence. And there is the path of using marketing effectively, both by lobbying in political arenas and by doing academic detailing in individual clinics, to get a practice or technology adopted, and then reimbursed.

Many art therapists told me that, as mental health professionals, they would like their services to be reimbursable by insurance. The services of their peers in non-medical settings typically are, but none of the hospitals that I spoke with charge patients for the services of artists, nor do they want to. So, then, how are arts professionals who work in hospitals funded?

Funding hospitals arts programs

In every place we come in in a different way. Sometimes it's the medical director's wife who happens to be an artist herself. Sometimes it's the social worker. Sometimes it's an angel who's worked with a family of a former patient, or the family of a patient who might have been in our workshop program here, and says, "Oh, my God, I was in the hospital. I can't believe the creative therapist was there too. That's amazing."
- Arts professional

Arts programs at the hospitals I studied are funded by several different mechanisms and each funding structure is hyper local, specific to the individual way each hospital operates, and to the individuals at each hospital. Some arts programs raise their own money, by selling small objects that patients make, such as holiday cards, to support pediatric programming that would otherwise be unfunded, like patient camps. One hospital used the money from a coffee cart to fund two full time arts professionals. Some artists are funded by the hospitals' core fund, though this is rare, and hospital administrators prefer to reserve this money for medical equipment and other capital costs. Hospital administrators weigh many things when choosing how to allocate funds, and look for ways to stretch hospital dollars. There are many philanthropic donors who would like to fund a program that provides aesthetic engagement to people in hospitals, but purchasing a new piece of medical machinery is less compelling. In fact, as described above, doctors and hospital administrators told me that they viewed philanthropy as the appropriate funding mechanism for creative arts programs. When I posed the question that I heard voiced by art therapists to administrators and doctors, they were sympathetic to the lack of full-time stable positions at hospitals, but they were alarmed by the idea that hospital arts programs would be reimbursable by insurance, that patients would have to pay a fee for these services. Doctors and administrators who champion arts programs at their institutions work to keep the programs free and accessible to all patients. They do this in many ways, the most common being by building philanthropic relationships with local donors.

> I'm happy with the idea that we're not asking the insurance companies to pay for this, we're not really even asking the medical hierarchy here to pay for it. We're going out to the community, finding a likeminded individual who has the means and having her say, "I believe in this, I'll donate the money."
>
> I think that revenue stream for me is more authentic than trying to take something that really has benefits I believe can't be measured and then try to measure it so that you can have a metric that will speak the same language as the quality improvement people here or the insurance company or whatever."
>
> – Palliative care physician

A Different Kind Of Evidence

Hospitals administrators have a different perspective on the value of arts programs and what benefits they want them to provide. One hospital administrator in a large urban city told me that her number one focus is to make sure that patients have access to the types of experiences that will help them in their cancer treatment, but she is also aware that it reflects well on the hospital.

> You know, honestly, I think a lot of people see it as a competitive edge, because the level of service that is available within our community is very good, and patients have choices, really good choices. There's some great providers, and some people feel like oh, if we offered this, it would give us a little bit of a competitive edge.
>
> People come to these organizations, I believe, for a cure. They want to be cured. They're not coming for art therapy. But if it's all equal in their mind, perhaps if they see a robust program that has other choices to assist them or their family member through the process, then they elect to come here. So there's also a business side

> of it as well as an emotional side or supportive lens.
>
> – Hospital Administrator

The art therapist who works in this hospital speaks of being approached by the administration for stories that could generate positive publicity internally among donors. “Actually, this week they wanted some patient quotes, they wanted patient stories. They said today at a meeting said they wanted a story, a very impactful story that would convince potential donors how important [the art therapy program] is. I’ve had those requests before and I’m always on the fence about this because I would never stop a therapeutic relationship to ask for a testimonial in the middle of it, to say ‘Tell me how this is helpful again?’ Yet many arts professionals do provide stories to help promote their work. The anecdotes and stories that arts professionals are asked for are a different type of evidence from that of research trials, and one that hospital administrators find valuable to promote the attention their hospital gives to the patient experience.

At other times, it is the art itself that provides “evidence” for donors. The art patients produce may be featured in hospital newsletters or other media. Patients, their families, and their care team take pride in having their work recognized. One art therapist told me: “Some of my patients have produced really amazing things that have gotten publicity both in the hospital and publicly. Even though that hasn’t been my intention with my therapy, it’s been really meaningful.”

Potential donors may be shown images of the art, or be invited to see it on display. Walking through some hospitals in the south, the northwest, and the east coast, I saw patient art on display in various contexts. Poetry written by children was printed on expensive paper and mounted behind glass. Felted yarn creatures crafted by adults were mounted on a blank board in the manner of a taxonomic chart. Individual drawings were hung on with metal clothespins on wire down halls, and large murals were on display in lobbies. I was drawn in by these displays. Patients and their family members and visitors stop to look deeply at them, often taking pictures. These projects are evidence of some level of attention to holistic care and to the patient experience, and a story of "good care" is one donors want to be a part of.

Ian Cion, the director of the Arts in Medicine program at MD Anderson in Houston, Texas, spoke about the reception of his latest art project, a life-size dragon whose scales were created by over 1,300 patients, family members, and medical staff over a period of nine months. His approach, involving the entire hospital community over a length of time, is not the usual approach to art making in the hospital, which is usually done in one session, in small groups or at the bedside. The project had an impact on the hospital community, and the unveiling of the finished dragon became an important event. Ian says "It was one of those really crazy, wonderful things. At the unveiling the president of MD Anderson came. We got a lot of positive response. We posted it to our like MD Anderson social media page and it got 60,000 visits. It was really good."

In addition to the publicity the unveiling of the project garnered, a story about it was published on MD Anderson's CancerWise news page and a WOUB documentary was made describing the Arts in Medicine program and Ian's work that has been screened at medical centers and universities across the country. Ian recognizes a positive shift in the attention being given to hospital art programs, and also recognizes that there is room for that attention to deepen. Hospitals are happy to take credit for the good work that is happening on their campuses, but garnering institutional support is still a barrier to continuing or expanding the work. In our conversations, he told me about the struggle of artists in hospitals: how they see the many therapeutic, sociopersonal, physical, and economic benefits of their work, but how they feel that the potential of creative engagement is overlooked. "We're still on soft money. No matter how many successes we have in the arena, we're still in a time in history of the field that I don't think the full value of what we're doing is totally understood." Ian articulated what many arts professionals feel: that work is undervalued, that evidence is needed to prove value, and that proven value will lead to more steady and secure funding. Ian sees this moment of uncertainty as an exciting time, when arts professionals have freedom to define and frame their work outside of the biomedical context. He spoke of the challenge of needing to "speak the language" of medicine to communicate its value while also staying true to art's location outside of the medical world. Next I will discuss another method of communicating value, the evidence that comes from first-hand encounters.

Seeing Is Believing

The most compelling evidence, arts professionals told me, is the personal experience of the program. Skeptics need to see it. One of the arts professionals that used this technique to grow a hospitals art program from one that had a part time volunteer to one that now employs multiple artists and an art program director is Todd Frazier of Houston Methodist. Houston Methodist's arts program has grown to be quite robust. It is credited for playing some part in employee satisfaction scores, which have earned it a ranking it among Fortune magazine's "100 best companies to work for" seven years in a row (houstonmethodist.org). The hospital has a very strong commitment to making aesthetic experiences available to patients, staff and visitors in the hospital environment. During my conversation with Todd Frazier, a renowned composer, non-profit leader and the Director of the Center for Performing Arts Medicine at Houston Methodist, he told me that arts care is part of the "Methodist Experience", part of the spiritual care experience. We were sitting in the large and airy Crain Garden, a pianist playing near us on the long black grand piano to our right, water flowing through a beautiful fountain of a boy riding a dolphin to the left. Todd spoke of the interconnectedness of medicine, religion and art, embodied in the figure of the Physician-Priest-Artist, "a combination that has been with us since the beginning of medicine". This combination does have a rich history; I will discuss this connection further in chapter four.

The Center for Performing Arts Medicine has carved its niche by providing care to performing artists. He walked me up to Dr. Stasney's office, who is the founder of CPAM, and entering the waiting room I had to pause for a second to take in the rich emerald green wallpaper and stuffed ornate couch upon which a patient was waiting. Dr. Stasney has provided medical care to opera singers, public speakers, and pop singers, and other performing artists, and large playbills hung in gilt frames on the walls.

In addition to providing care to artists, the hospital provides the opportunity for patients to experience the arts through regularly scheduled music performances, a concert series, rotating art installations, and interactive art projects. I was interested in Todd's path, how we went from a consultant to a part time staff person to an integral part of the hospital's identity and branding. What was his strategy, I wanted to know? How did he convince the hospital of the value of providing aesthetic experiences for staff and patients? He echoed a refrain I had heard from other arts professionals and art therapists: "People need to physically see it to get in. Once they see it, then they ask how much does it cost". He told me that he was hired full time because they could see that the programs really made a difference in patient satisfaction, and the philanthropic situation bloomed: "Arts & Medicine" these are two of the strengths of Houston, and you're really bringing them together in a program like this." The program was a differentiator, one that helped brand the "Methodist Experience". At Texas Methodist, the programs are targeted to and enjoyed by staff and patients alike.

Staff satisfaction translates directly into patient satisfaction. A 2009 white paper written by the a business research and education firm, the Forum for People, Performance Management and Measurement, "The Relationship Between Employee Satisfaction and Hospital Patient Experiences" contained a literature review on health care employee satisfaction. "An empirical analysis that shows a direct and positive relationship between the satisfaction of employees and the quality of the patient experience in a major urban hospital." This finding is not news to health care professionals. "Those organizations who recognize this will find themselves with a competitive advantage as the health care industry continues to change and evolve over the next few years. Some believe that technology is the answer to increase efficiency, reduce costs and improve the quality of care within the U.S. health care system. While technology provides the framework for creating an organization that will thrive, it is just one part of a total strategy…Acknowledging the *personal* nature of care delivery will result in happier employees, patients and financial stakeholders" (Mossburger 2014). According to the Americans For the Arts Study, staff make up forty percent of the participants in hospital arts activities. I heard large artworks that had been constructed by many hospital staff at Texas Houston, and I saw how activities that were designed by patients also welcomed staff.

Nurses are often the staff members who join in creative arts activities. In one session I observed, an art table was set up in a hospital hallway outside of patient rooms. Nurses often walked by, and several stopped to comment or join in for several minutes. One nurse began using the art materials, asking questions about how to achieve certain effects, and completed two projects. As she worked, she said, "This is my stress buster. Oh my goodness this is great. I'm going to quit my job and do *this*." The direct experience in the activity quickly convinces the medical staff who participate in it that such programs are worth keeping, and expanding.

But its not just direct experience with art making (experiencing it in the environment, or engaging in a creative arts activity themselves) that affects nurses and other medical staff – they also benefit indirectly through the benefits experienced by their patients. When the patients are able to participate in art activities, and have improved morale and decreased pain, nursing morale improves too. There is also a practical reason nurses want their patients to participate in arts programs. Nurses benefit from freed time and attention while patients are working with arts professionals, especially from "difficult" patients, who need their attention. An arts professional told me, "And what I sell them on is that this helps them. Oncology nurses, in particular, are *incredibly* burdened…It really has to do with how much documentation is required on every patient. They are at the nurse's station and at the computer *so* much instead of actually interacting with the patient, so the artist…really helps the staff."

Economies Of Art: Art, Hospitals, And The Marketplace

Could you tell me why do hospitals want artists? Why do they think they need an artist in their hospital?

Well, nobody thinks they need anything. The hospitals don't ever think that. What they think is: how can this program either save me money, make the workload easier on our staff, or bring in higher patient satisfaction, of course.
The bottom line … well, it is money for the hospital.
- Arts Professional

The value that arts programs bring often lay cost-savings next to clinical evidence, if available, and patient stories. Having programs that foster creative expression is good for the hospital, for all of the reasons the arts administrator outlined: reduced burden of medical staff, increased patient satisfaction scores, increased staff morale, and a very real benefit to an institution's bottom line.

Christenson, a doctor whose writing on the therapeutic benefits of the arts is prolific, outlines numerous ways in which the arts benefit medicine and public health. He describes the personal, professional and relational benefits to physicians and patients from integrating the arts into healthcare: "opportunities for greater patient understanding, improved patient comfort and treatment, results, and enhanced clinical skills, personal enrichment, and resilience in medical practitioners" (2013). Although he doesn't explicitly highlight the economic benefit of art in medicine, the examples he pulls from the literature demonstrate a significant potential for cost-savings. Christenson describes a study that found "[a]dding music therapy as a procedural support decreased the need for sedation, reduced procedural times, and reduced the number of staff necessary during the procedures. When the cost savings related to adding music therapy were extrapolated to the number of such procedures conducted throughout the United States, it was estimated that this simple intervention could save 2.25 billion dollars per year (Wood 2008)" (2013).

Because arts programs are entering the realm of biomedicine, and because hospitals are located in the marketplace, they appeal to the issue of cost.

> While health care would seem like a service industry, it is still a business venture that comes with the same, bottom-line concerns that other industries face. Doctors and hospitals are under economic pressures that force them to find ways to lower their expenses or increase revenue by providing more services. (BlueCross BlueShield of Kansas).

Traditionally all US hospitals were non-profit, but in the 1980s the number of for-profit hospitals grew (Mann 1998). As of 2015, there are 5,686 registered hospitals in the United States. 1,060 are for-profit (AHA 2014), meaning they are responsible for generating a profit for their shareholders. Not-for-profit and government hospitals also feel economic pressure due to rising malpractice insurance premiums, high professional salaries for doctors and nurses, and patient demand for "the latest medical technology" (BlueCross BlueShield). It would seem that engaging with the logic of cost-effectiveness makes a powerful argument to support a program or intervention, but I was told that is not the case. A health services scholar at a top university informed me that the weakest argument is the one for cost-effectiveness. He illustrated his point with the example of smoking cessation. "If you look at cost effectiveness of many things we do, it's not there. If you look at the cost effectiveness of things like smoking cessation, which is quite high, we don't do it." Many smoking cessation programs have a strong counseling program, and "there is a limit to what you can bill for in counseling people"; it's not highly profitable. The more profitable a therapy is, even if there is a lack of strong evidence, the more likely it is to get applied.

Those who study healthcare note, "the marketplace thwarts the social good of medicine" (Kaufman 2015, 79). Hospitals are meant to serve people at their most vulnerable, including the most vulnerable. Prioritizing cost and efficiency means attending to numbers and outcomes, and this type of framework makes valuing and giving good care difficult. Creative activities and their related practices of care are not efficient. And they resist the measurement model of biomedicine. But that does not mean we cannot attend to qualities of care, or ask what good care for patients looks like without needing evidence from an RCT. Ingunn Moser, a Norwegian scholar of technology and culture, uses the context of care practices with dementia patients in nursing homes to show how we can still think of something as good to do without having to measure it:

> If we turn to dementia care practices on their own terms, we learn that these have nothing to do with proving that they are good or cost-effective. Instead practice revolves around the double aim of finding ways of acting, and creatively *improving* this action and interaction in and as part of daily life, and thereby also improving the daily life and condition(s) of the patients (2011, 278).

Attending to the question of *how we care*, and how we can *improve* the care we provide has more promising implications for patients that asking *what evidence* we have that a certain practice has a certain outcome. Asking how we care allows for attention to relationship, opens space for the practice of tinkering, and brings us outside the logic of biomedicine into the logic of relationship and care.

Conclusion

Arts activities are used in various capacities in US hospitals, and arts professionals, physicians and hospital administrators provide different types of evidence of how they work, why they are valued, and how the benefits from these activities should be framed. Research outcomes, patient stories, anecdotes, personal experience, and patient and staff satisfaction scores are various kinds of evidence that professionals who do and support arts programs summon to explain their value. The different types of evidence sit in tension with each other. Arts professionals are interested in producing evidence that has credence in the biomedical model they work in, doctors prefer that arts activities be external to bureaucratic measures of quality and cost, and many hospital administrators are interested in how stories from these activities can pull on the heartstrings of donors and generate positive publicity for the hospital. In these many ways, art making finds a way to exist next to and inform the work of biomedicine. An arts professional I spoke with said he didn't see the desire for clinical evidence of biological benefits from some arts interventions and the protection of the intangible benefits of others as incompatible. His goal was to have both present in the hospital. Artistic interventions that had demonstrated efficacy could be offered to patients alongside other physical and occupational therapies, reimbursable by insurance, and for cases when the benefits of artistic experiences are meaningful in non-clinical ways, philanthropic support could be used.

One artist said the question he kept returning to was: "where does art stop, and where does medicine begin?" As explained in chapter one, and as some of the quotations in this chapter show, the divisions between the practices of making art and doing medicine aren't as firm as we may like to think. Arts practices are involved in the administration – or aversion – of pharmacological therapies. They change hospital environments, morale, and relationships between patients and staff. They span time. Biomedical logic doesn't fully acknowledge all of the ways biology and social practices meet, and evidence from a randomized trail would not foreground this important intersection. In this chapter, my project has been to show how the different types of evidence are used to demonstrate the benefit of art making programs; and the priorities that the use of different types of evidence highlight. By laying out the different values we place on practices of care, we can more carefully consider what evidence we will ask of care practices.

In the US medical model, the benefit of patient therapies is usually framed as supportive of biomedical goals. The next chapter will examine how creative activities disrupt the logic of biomedicine, and in so doing, makes space for alternative possibilities of care, and of engaging with the unknown.

Chapter 3: So How Can We Change the Room? Creative Arts Activities as Moments of Disruption

The Art of Medicine

Sometimes medicine is referred to as an "art". When people speak of the "the art" of a certain craft, such as the art of weaving, or the art of bonsai, they are usually using the definition of art that means the skilled execution of that task. It is interesting to me that when doctors and therapists referred to the "art of medicine", they weren't speaking about the skilled execution of diagnosing and prescribing – they were speaking about the art of attending to human relationship. "There's a lot about medicine that, as much as you want to find the randomized controlled trial that digs down and tells you exactly what to deliver at the right time and at the right dosage on the right schedule, man - there's so many variables that go into that. Sometimes it's the way the nurse is able to get the kid to take the medicine at the right time, you know? It's many different things" (Music therapist). Understanding what the illness experience is, the nature of suffering, and how healing works requires a lens broader than biomedicine's focus on pathology. Because biomedical science hones in on the corporeal causes and details of disease, for healing of a person to happen the standard protocol of disease treatment *needs* to be paired with activities that attend to the patient-person as a social being, not merely biological. The music therapist continues, "And that kind of human element is in some ways what I ascribe as art. I think of art as part of how we relate to each other, how we are kind, and respectful. That to me is art." It's about skill, about intuition, the difference between being just an ordinary average doctor, and one that's really good. As experts in clinical education have shared with me, the skills of a "really good" doctor are skills that are notoriously difficult to teach in class. In fact, medical students usually come in with energy, empathy and passion, and lose these at the second year of residency, suggesting that immersion in the world of biomedicine itself is the thing that turns potentially really great doctors who treat whole patients into, to borrow Frenkel's (2008) description of the medical paradigm, really great mechanics who fix broken bodies. Some medical schools are beginning to disrupt the standard biomedical paradigm.

The University of Alberta is once such medical school. It offers an Arts & Humanities in Health & Medicine (AHHM) Program. When Dr. Tao was a medical student at the University of Canada, she created a video exploration of the concept "art in medicine" as a final project for an elective in the AHHM program. In her description of the project she writes, "As part of their Hippocratic oath, medical students pledge to remember that there is 'an art to medicine as well as science.' The aim of this project is to explore the views of medical students, residents, staff and faculty members in the Faculty of Medicine & Dentistry at the University of Alberta regarding the meaning of the phrase 'the art of medicine.'" Dr. Tao asked fifty people in the halls of the university, doctors, professors and medical students, to speak about what 'the art of medicine' meant to them.

The question elicited halting phrases and pauses, before participants began to define it by what it is *not* – it is not an algorithm, not logic, not strict scientific facts or cut and dry knowledge. "There's so much intuition, and witchcraft to medicine" one student says. "There are no straightforward patients. You can't always have an answer or an explanation, you can't predict what's going to happen to someone", another one explains.

Then the participants begin to speak about what it *is*. In their words, the art of medicine is:

> Communication, more than just asking, but how you will ask, the art of delivering a message. The subtleties – what you say, but also your demeanor, and how you interact.
>
> Being able to relate to the person. Treating only the physical part is not enough to make a person healthy, treat the person as a whole, not just on the basis of disease.
>
> Humanistic. Compassion. You can't be a doctor without remembering that you are a person as well. You're made of the same stuff your patients are made of.
>
> Trust, respectful relationship. All of the things that are happen after the technology is over. Patient's care about the person looking after them, not just the science looking after them.
>
> Trying to figure out who the patient is in front of me as a person. Trying to find some sort of common ground between science, healing and suffering.

The above quotes speak to the art of human relationship. Trained in scientific medicine, these medical students and professionals have a sense that the patient, and the doctor, matter as social beings.

Anthropologists have examined how biomedical care intersects with the body social. Julie Livingston, whose work has been recognized by a MacArthur Fellowship or “Genius Grant”, studied cancer care in Botswana. Her book *Improvising Medicine* highlights the nature of improvised medicine on an oncology ward, and “the intensely social nature of pain” (2012, 119). Contrary to Scarry’s assertion that pain is “an individually held experience”, Livingston invokes Asad’s view that pain is a social relationship: “Sufferers are also social persons and their suffering is partly constituted by the way they inhabit, or are constrained to inhabit, their relationship with others” (Asad in Livingston 2012, 121). Through witnessing pain, voicing the pain of silent sufferers, and through laughter, oncology patients and their caretakers relate to each other in the social space of the ward. In a context in which biomedicine is practiced and pharmaceutical palliatives are largely unavailable, suffering is immense. Livingston describes cancer without oncology as “obscene”. Tumors grow until they break through the skin, creating rotting wounds. Family members of advanced cancer patients are overwhelmed by the physical care needs, the pain, the stench of their wounds. When the latter becomes extreme, some patients are moved to a small house on the edge of family property, or to the hospital. Social isolation is paired with geographical separation. When new nurses train at the country’s only oncology hospital, they have to learn to suppress their nausea as they clean rotting flesh on sentient bodies. With time they learn to be near, to see, and to respond (sometimes to joke) with their patients. Being near these patients, responding to their suffering, and calling them into a social relationship, into a form of community, Livingston contends, is a form of palliation. By embedding an individual isolated by disease in the context of a social relationship, suffering is lessened.

Because there aren't pathways in the standard practice of medicine that support relationship, standard biomedical logic needs to be disrupted. Many people I spoke with, artists, physicians, and patients - used that very word: "disruption". Other participants spoke about the ways in which creative engagement subverted biomedical practices, and though they may not have explicitly labeled it as disruptive practices, the activities functioned as such.

In this chapter I examine how the logic and practice of art making works to subvert key aspects of the logic and practice of biomedicine. This chapter will explore how the artist's social role as an outsider who challenges the status quo is enacted in a medical context. In my interviews, artists, physicians, and hospital described their discomfort with the biomedical model of patient care. They stated that they saw their work of bringing art-making into hospitals as a way to contradict the passive patient role, disease experience, the hospital's architecture, institutional hierarchy, and the positivist logic of evidence-based medicine. This chapter will explore how they understand their work to get a better sense of the value, use and function of art in the medical space.

Artist as disruptor

In my conversations with artists who work in hospitals, I noticed a connection between the role of the artist in hospitals and the topic of disruption. Many of the artists I spoke with, including physicians who strongly identify as artists, stated that the role of the artist is to push back against reductionism by manifesting the individual, to relate to the patient as a whole person, to be comfortable with the impossibility of certainty by celebrating the unknown, and to decenter the hierarchical power structure of the hospital by centering the patient.

The role of the artist in society is described in a rich body of anthropological literature (Gell 1998; Perkins and Morphy 2006; Meyers 2004; Price 1989). Rubén Gaztambide-Fernández, a professor at the University of Toronto Institute for Studies in Education who is interested in the curriculum of artistic education and how it helps young artists understand their role in society, writes about the social role of the artist as manifest in "three theoretical conceptions: the artist as Cultural 'Civilizer', the artist as 'Border Crosser', and the artist as 'Representator'" (2008). Gaztambide-Fernández connects these conceptions to "disparate and contradicting assumptions about culture" (ibid 233). In other words, what we think is the role of the artist is bound up in what we think happens, or *should* happen, when the public audience engages with works of art. As a Cultural Civilizer, the artists' "role is to provide great works of beauty that contribute to the civilizing project of modernity". The task of the artist as border crosser is to "see through social structures and develop cultural products that transgress social borders" (ibid 246). The artist as "Representator" is less concerned with controlling the social meaning and impact of a work of art. Influenced by the discourse of cultural populism, the "Representator's" artistic works "are representations of larger struggles of meaning and identification, and therefore, their significance lies not on their value as works of art or their ability to trigger consciousness, but on how audiences engage with them to represent themselves" (ibid 248). In other words, the role of the artist as "Representator" is to create a work audiences can engage with and in which they can see their own experience represented.

Artists work in hospitals in many capacities, and can enact each of the aforementioned artistic roles. Artists who donate art or conduct an on-site performance fulfill the role of Cultural Civilizer. Environmental art and art as part of the built environment of the hospital is a rich topic of inquiry, and many interesting texts on these topics have been produced (Komiske 2005; Domke 2009, among others). In my study I examined the artist not as the creator of a specific product we name "Art", but as a facilitator of creative experiences for hospital participants. These conceptions of who the artist is *outside* of the medical institution are meaningful because they travel into the social world of the hospital. In speaking to artists, art therapists and doctors I heard the role of the artist being described as a hybrid of a border crosser, in the sense that they transgress institutional hierarchies, and Representator, in that they facilitate works in which participants can choose to represent themselves. What I heard repeatedly about the way artists function in the hospital, the value they bring, was the way their status mirrors that of patients (also-outsiders), their ability to look at, witness and see patients, and their willingness to enter into relation with patients.

A case of disruption

Artists embody variations of these social roles in the hospital, though their position vis-a-vis the institution may require them to modify or adapt their social role. One artist I spoke with worked to transgress social and architectural borders within the hospital, preferring to do it from a position outside of the hospital bureaucracy. "I've done a bunch of things – worked for non-profits, worked for the American cancer society, started Oncology Youth Connection, also worked as an employee for the hospital as an Artist-in-residence. I find the best way though, is to work as an independent outside artist contracted by the hospital. If not, I will work in whatever handcuffs you give me. But I find that my purpose is to undermine the structure of the hospital. You can't do that from the inside."

The same artist spoke of the fluid nature of his role, and how it lies in stark opposition to the defined roles of other hospital personnel. "All of the people in the hospital are there to do something to the patients. They literally have a job title that says their personal title – I am the aid, I'm here to aid you. No one says I'm here to do something that has no purpose. And that is the main job of the artist."

One of the things this particular artist does is to transform, or disrupt, the architecture of the patient's room. Because John worked as a nurse before he became a professional artist, he provided a unique insight into the power and limits of the artist.

> When you call yourself an artist it gives yourself the authority to do things that no one else can do. I understand that for instance in oncology there are certain things you can't do. Maybe you can't leave the room - so how can we change the room? I'm an artist I'm not confined to this medical paradigm – in

> fact, it's my job to challenge that, to invert it. This came out of political movements in the 1960s such as Dada – challenging authority was the job of the artist. That's really the zeitgeist that we've always taken on.
>
> The stuff that we would do is hilarious. Some of them I won't' tell you because we're on the record. I started coming in and doing projects with my patients on the weekend when there was no admin around. We always worked on nightshifts because we'd have the place to ourselves, writing songs, doing absurdist decoration. One of the reasons I've been able to stretch this is because of my background as a nurse – once you've done something once you can do it again. And I won't break the rules – I won't even accidentally break the rules –I've been involved in writing the rules, so that gives me an "in".

John's quote speaks to the productive tension inherent in his position as a current artist-former nurse. The artist's identity as an outsider allows him to bypass the rules other medical staff have to abide by (i.e. challenge institutional authority), while also making him subject to institutional rules that other medical staff can bend (i.e. as a non-medical hospital employee, certain areas are off limits, at least until the administration goes home).

Often patients who are hospitalized for an extended period of time are at times too sick to make a choice to participate in an art activity, or don't want the pressure of producing something. "Patients sleep through the projects; most don't even remember the projects. Their job is to breathe and sleep." Some arts lend themselves to passive engagement; music therapists can play music by the bedside, poets may read aloud. But facilitators of interactive art activities have to find unconventional ways to "perform" an art activity for the patient. In these cases, the artist "can make an experience, and [the patient] can experience it." John, an artist who espouses the philosophy of social practice, describes how he facilitated a "passive art project". Working with a teenage girl who was in reverse isolation, meaning that she was isolated not because she had a contagious illness that could infect others, but that the drugs from her transplant operation had compromised her immune system and she needed protection from everyday germs, including those of her much loved pet cat, John designed a way to have her "experience" a cat through art. He posted a call for cat pictures to social media; he received over 20,000 photos of cats and empathetic messages. While she was sleeping, he built a tent fort around her bed with hospitals sheets, staying true to his desire to use the existing materials of the space. He projected the pictures of the cats onto the sheets; he played cat sounds on a stereo in the room. "She woke up to the sound of purring."

John follows the lead of patients creating or facilitating art projects or art experiences. "I see those types of [sessions] as the type of art work that I want to make. I don't care if that's pretentious or not pretentious…When you're working with patients, the philosophy is that whatever they think, is best for them is best for them. Not what YOU think is best for them, but what they think is best for them. If [creating something to be distributed on social media is] what they want, let's address that, let's treat it like a type of art form". By facilitating a passive art experience for a patient, John broadens the scope of what art at the bedside can look like. In examples like the one above, the art is transitional, in the moment, and based upon the patient's preference to see her cat. "The artist is the instigator, the participants have the ownership, and the project is simple." In projects such as these, conception, creation, experience, and observation are all part of the art experience. "There's many different layers, there's no way to tell what is the art."

When creating passive art experiences for patients, John is not doing what an art therapist or what many hospital artists see as their work: facilitating a *patient*'s creation of an artistic project. Doing art *for* patients is often a taboo. But John points to an important patient benefit to consider:

> One of the things we found that was very obvious - or that seems completely obvious after the fact – when they are very sick or undergoing treatment they do not need or want art. When jumping into the trenches our instinct is to go to the sickest patient. That was one of the reasons why I started to develop the passive art projects.
>
> One of the assumptions that I railed about was wrong in that we think that they want to create the art. But they actually expressed a lot of desire for and interested in experiencing art produced by someone else. The purist idea of Social Practice is that the artist is the instigator alone – why be strict about that? Let's do some art for the patient, that's what we're good at. And let's make it purposeless.

John's conception of the passive art experience highlights an important insight: patients may not want always want an active role in art production. This has a parallel in the mainstream conception of patient autonomy, which holds that patients should be in charge of medical decisions. But this is not always the role they want.

Disorientation and isolation

Arthur Frank, a medical sociologist, writes that illness is a disorienting disruption, including the loss of a destination map that had previously guided a patient's path. After being de-centered by an illness diagnosis, patients struggle to find meaning, and to create a new vision of their future (Frank 1995). One patient spoke to me about how the sight of an art therapist's cart mimicked her disorienting experience of illness diagnosis.

> Her art cart has wire baskets, so you can see everything from the side. So it's really friendly in that way. Lots of color. One of the big things for me was being in this beige room, this super low-stimulus environment. Everything is just like institutional beige or white. So just looking at that cart I was like, ahhh...a little bit of chaos, but contained. Kind of mirrors the experience I'm in. Getting a cancer diagnosis is like super-chaos. Like the feeling that your life came apart. So just that little bit was good.

The echo of the chaos felt familiar, and the containment of the chaos made it safe for this patient to engage with the creative experience.

When hospitalized, the disorientation of an intense illness experience is paired with a feeling of isolation. Artists who conceptualize themselves as "outsiders" use their knowledge of social isolation and outsider status to identify with patients who are also feeling isolated from their previous selves, homes, professions, families, and communities.

> I didn't really know until I started working in a hospital, especially in the critical setting, how real isolation can be, how a person going through an extreme clinical or medical crisis, how different they can feel, and how long they can feel that difference. And one thing I really *know* is that the artists feel that way a lot of times too, and one of the things that artists do here is show that it's cool to be an outsider. Historically, culturally, that's what people admire about artists: they do it their own way. And so when I saw that that state existed for both kids and people who are going through an extreme crisis and people who are artists, I felt like, well, there's a bridge there. It was almost a natural fitting.
>
> And I haven't heard a lot of people talk about that, but like I think that's one of the values of having artists in a clinical setting:

> that people see you when you walk into that room and a) they're excited that an artist has walked into their room, because artists are kind of cool, and b) there's a deep…even with little kids there's a deep sort of unconscious understanding that you're on the level. You get them. You get what they're going through, because you can see. As an artist, that's part of your job description: *seeing* and *feeling*. And so those two things are also a pretty compelling reason why artists are useful or helpful in a clinical setting." - Ian Cion.

"Seeing and feeling are elements of relationship. One thing that we have learned in psychology across time is how important relationships are. So the relationship between the child and the artist becomes a very close one," said Dr. Copeland, clinical professor and chief of the Behavioral Medicine Section of the Division of Pediatrics at M.D. Anderson (retired) when describing Collidescapes, one of the projects Cion facilitated. This example highlights the need for social relationship to be connected to biomedical cure, a concept I will discuss in greater detail in chapter four.

Choice and recognition

The US hospital is an institution with a rigid power structure. The hospital management, such as the dean and administrator, are at the top. Following them are the specialist surgeons, specialists, doctors, nurses, and medical students. The patients have the least amount of power, perhaps not even an agent, who is doing, but a person to whom things are done. Patients who have suffered a brain injury or who have cognitive difficulties have even less agency or ability to enact their wishes. When a creative arts facilitator attends to, recognizes and relates to such patients, he or she is doing the work of subverting the hierarchical structure of the hospital. They are centering the patient.

Art group was scheduled from six to eight in the evening, but when we arrived the door to the all-purpose room was closed. Orena opened the door, wheeled in the cart, and informed the handful of people in the room that art group was starting. There was a strained silence. A family conference was taking place, and the conversation was tense. We set out a few supplies on the table, and then Orena said we would come back in a few minutes.

We stepped outside and Orena took the opportunity to give me a few instructions, the same ones she tells her art therapy interns. She discouraged asking questions, or talking to patients. “If they ask you questions, you can answer, but direct the conversation back to them. Don’t talk about yourself too much. It’s an art,” she told me, “and you get better at it with time.”

The doctor and family members walked out, and we began setting out the supplies: magazines, paper, postcards, art clippings. A woman with an unsteady gait walked in, wearing a wide belt around her waist that was buckled in the front, loose ends dangling. I thought at the time that the belt was to help her keep her balance when walking, but I later learned that “transfer belts” are belts with hand-grips on each side, and are worn by stroke victims or other patients with trouble moving without help to allow caregivers assist them in ambulation, or in moving them in and out of chairs and beds. Several other women came in wearing similar belts. One came in in a walker. Orena welcomed each warmly, and began making small talk, asking them about their day. We were in the rehab wing on the hospital, and these patients are recovering from illnesses or injuries such as strokes.

They sat around the table, and Orena explained the purpose of the activity: to make a collage magnet. She passed around a sample, and the women expressed approval. To make the magnet they would first select pictures or pieces of paper, then compose them on a one by two inch square of cardboard, and use a glue stick to attach the images to the cardboard. A piece of plastic was placed on top, and then foil tape was placed along the four sides. To finish, an adhesive magnet was glued to the back. These magnets could be placed on refrigerators or other metal surfaces in their hospital rooms or homes.

This was a physical rehabilitation group, and some of these women were recovering from strokes or other injuries that made activities with fine motor skills challenging. These simple steps would require patience and assistance from Orena to complete. She broke each step into small tasks: choose two to three pictures or pieces of paper. Use whatever textures or images make you pause, or have a reaction. You don't need to analyze the reaction. The women began leafing through the images, and a soon each woman had a small collection in front of her. The next step was to compose the chosen images and textures on the cardboard square. This required some images to be cut out, or paper to be torn, or small pieces to be carefully placed on a small surface. Orena encouraged the women to do as much as they could. To those who asked for help, Orena offered choices that allowed them to direct her every move. You would like this picture cut? Tell me where to begin and where to end. You would like it placed on the cardboard? Should it be under this piece that's already here, or on top? On the left or the right? Later Orena told me that for this group, her goal is that they can engage in the art activity regardless of skill level. She helps every woman to complete her magnet. "From a humanistic standpoint, every time we finish something, we complete a goal. We increase self-esteem. Completing is very important for these women, and the self-esteem gained from completing this small project has ripple effects, it helps them accomplish larger goals."

Orena recognizes each woman as a social agent capable of meaningful decision-making and action. Medical anthropologist Janelle Taylor writes about the relationship between recognition, caring and dementia, and the multiple weights of recognition. A common question asked to familial caregivers of dementia patients is, "does she recognize you?" Recognition is so very nuanced, and this phrase is often troubling. Taylor uses the French philosopher Ricoeur's analysis of the meanings of recognition, which contains three "moments in a dialectic that begins from recognition as identification (of things), moves through self-recognition, and finally concludes with recognition by an Other" (Taylor 2008, 314) to explore the possible ways we acknowledge and bestow recognition. The question of whether or not a person with dementia recognizes a family member refers to the first moment – and speaks to the ability of a "sovereign self". Taylor is more interested in the third moment, "when the subjects is granted social and political recognition by others" (ibid). Watching Orena work, I saw the moments of recognition play out. These women were patients in a large highly ranked urban hospital that served a large area, some of them many hours from home. Their geographic location and status as stroke victim isolated them from social participation in their families and communities. By asking their preferences, encouraging them to make choices about those preferences, and by listening and enacting those choices, Orena is granting them "'recognition' as fully social persons and members of a community" (Taylor 2008, 315).

As the example with Orena shows, the patients in the art group have agency to determine their artistic vision, they are active, and they are making choices, however small. Mol defines good care as a series of small choices that are made in continuing conversation with one's doctor. These choices are revisited over time to ensure the patient's hopes and ways of life are still being attended to. Accompanying the patient through a series of smaller choices is an example of a different logic, a logic of care. The 'logic of care' is contrasted to the 'logic of choice', in which doctors would present the information about the risks and benefits of a treatment, and then allow the patients to choose between several options on their own. But how did the logic of choice become one of the logics of biomedicine?

Choice as disruption

When the National Commission for the Protection of Human Subjects of Biomedical and Behavioral research met at a conference center in the Belmont Estate in Maryland, their charge was to develop "basic ethical principles" that govern research relationships and interactions with human subjects, protecting people who take part in research studies. The principles the Commission outlined, respect for persons, beneficence, and justice continue to provide ethical guidance for research and for medical practice to this day. The first principle, respect for persons, has been operationalized as respect for patient autonomy; that is, respect for patient choice. "To respect autonomy is to give weight to autonomous persons' considered opinions and choices while refraining from obstructing their actions unless they are clearly detrimental to others" (Belmont Report 1976). The Western medical tradition, which traces its beginnings to Hippocrates and his creed, "Do no harm," has long provided doctors a guide in thinking about how they provide care. The patient's role during when receiving biomedical treatment has largely been a passive one, with little ability to take an active role in making decisions determining her care. The principle of patient autonomy allows patients to make decisions regarding their therapies, surgeries, and treatment regimens. There are voices expressing concern that the logic of choice undermines the caring relationship that medical practitioners have with their patients (Mol 2008, Gawande 2014), but the idea that patients should be active participants in making decisions about their care continues to guide medical practice today.

In the medical art therapy literature, too, the choice to participate or not is often cited as one of the ways that art making in the medical context respects patient autonomy. Patients can't say no to disease progression, or to catheters or blood draws or other uncomfortable or painful procedures, but they can say no to the art therapist, they can decline to participate in the activity. And many do. One patient describes making art with the art therapist who comes into the chemotherapy infusion clinic and states that in the past year he's been there, he's only seen a handful of people take the therapist up on his offer to make something creative. A poet describes being turned down as part of every day she spends in the hospital. The opportunity to exercise one's autonomy in saying no to a hospital-based activity is important service art therapists offer. A volunteer who does art at the bedside with pediatric patients told me that "hospital patients experience limited control over what happens to their bodies and who enters their rooms, and from our first knock to our parting question about whether to leave the door open or closed, we offer children the choices about our presence in the room, our movements, and our activities." If patients do decide to participate, they are given a choice in which activity to participate, what materials to use, whether or not to explain or discuss what they have created, and how the art made will be displayed, stored, or destroyed. Exercising these choices allows patients to be active in making decisions about and participating in their creative care.

Other professionals who facilitate art making in the medical context see a more complex thing happening when patients exercise choice. They see a patient's ability to choose as a disruption of the patient's "sick role" (Parsons 1982). Parsons, a sociologist, understood the sick role itself to be a form of deviance, in which a patient is relieved of normal social and professional roles due to a professionally diagnosed illness. A patient's excuse from everyday duties comes on the condition that the patient make an effort to get well, and to follow a doctor's prescriptions and treatment regiments (ibid). In biomedical care, patients must follow the physician's lead, and be compliant. In hospital art making, art facilitators follow the patient's lead. One artist described that patient art projects must be about "not what you think is best for them - but what they think is best for them." By choosing an activity that has potential therapeutic value, patients are not only exercising the choice to say yes or no, they are making a choice about *the kind* of care in which they would like to participate.

"Disrupting the psychology of the architecture"

The architecture of hospitals has changed over time, yet several questions regarding the challenge of housing bodies have remained: what are the risks and benefits of privacy, how to minimize harm from the hospitalization, and how to keep bodies visible to an overseeing authority? The first hospitals have origins in religious temples or monasteries in Greece, Egypt, Sri Lanka and India. During the Roman Empire secular hospitals served military populations. The modern hospital contains elements of a design that is believed to have originated in Florence, Italy and had a design similar to the long naves found in churches in the 1400s: long rectangular wards from which patients could see, and be visible to, the central altar. Modern hospitals retain a similar design with multiple patient beds in long rooms in view of a central nurses station. As wards became larger, some containing over 100 beds, their conditions deteriorated; they were "dark, poorly ventilated, unsanitary, and often located adjacent to other wards with infectious patients" (Gormley 2010). Reforms were enacted by Florence Nightingale and others that kept the multi-bed layout of the ward but increased light, fresh air and ventilation by lining the beds up along walls that contained interspersed tall windows (Richardson 2010). With each set of reforms, patient privacy increased. In the 1950s, hospital rooms in the US were still being designed with two to four beds. Thompson and Golden's 1975 book, cited in Gromley, contained a quote by a hospital planner who predicted in 1962 that semi-private rooms would be outdated in five to ten years, yet it wasn't until 2006 that the Guidelines for the Design and Construction of Hospitals stated that "In new construction, the maximum number of beds-per-room shall be one unless the functional program demonstrates the necessity of a two-bed arrangement" (Gormley 2010). In most large urban hospitals in the US, patients are in private rooms. In this way, individuals have privacy, not from their medical teams, of course, which may enter at any time, but from other patients.

The changing architecture of the hospital signifies an important shift in how physicians view the body, and how it can remain subject to a medical gaze (Foucault 2003). The logic of such architecture (and the revealing gowns necessary to wear inside of it) requires that the patient’s body be on eternal display, ever subject to observation, while the patient's social personhood is obscured. There have been shifts in hospital design connected to patient satisfaction (or, money) and nursing efficiency (that is, time).

John sees the artist's social role as providing a way in which to disrupt not only the limits of a patient's "sick role", but as a way to disrupt the logic of a hospital's architecture. He told me he is not afraid to reinvent the architecture of the patient's space. He turns patient's hospital room into a camera; he turns hospital sheets into a projection theater. He transforms the meaning of a doorway.

> When you have a protracted disease it shrinks your worldview. Children's drawings from a refugee camp in Africa show a worldview that is very limited. They are just drawing the building in front of them, just a square, not lions or dragons, and you see that in the hospital.
>
> So we build a camera. I have a kit I have and we build it in about 30 min. It was designed so that you couldn't position it to take a picture like you normally would, like right in front of you. You have to set it someplace in the environment that is not in front have you. Their job was to look for a place that the camera is interested in. Let's expand, and then expand again.
>
> Now they are looking around the room, from different perspectives, and then from the perspective of the camera. It's using the image as confirmation of this idea. You think that oh – it would look like this from over there and then you see the picture and you are like oh shit THAT's what it looks like. You can think something or act it out but when you see a photo you can prove to yourself that is true.
>
> And what that does is expand the room. We can't change you or take you out of the room, so let's change the room. How can we change your perspective? What is the door? Is the door going to be pain? Somebody I don't want to see, someone I do want to see. There's a terror built into the psychology of the hospital room and this work is to disrupt that.

Patients John worked with faced with the uncertainty of a diagnosis of a disease that may or may not be curable. Their long-term futures were uncertain, and their days in the hospital contained many moments of uncertainty. Disrupting the room that was often their treatment space, and so a source of pain, provided a way for patients to re-construct their room, their treatment experience, and their agency, even if only in the context of the art project. It allowed them to express certain aspects of their illness experience with certainty. At times John's patients conceived of artistic expressions that became public, and others were able to witness their portrayal of their illness experience.

Frank has written that illness is a call for stories, its experience demands recounting (1995). But, arts professionals said, talking requires language, and language means that the brain has begun to move the sensations and emotions that make up experiences, especially traumatic experiences, from the right side of the brain where sensory perceptions are experienced to the left side of the brain where language happens. But when people are living in the traumatic state of illness, they may not have language to express their emotions, their questions, or their pain. In addition, biomedicine contains language and uses language in a way that distances doctors from patients, and patients from their disease. Art, then, John told me, can be "a way to blow off steam, a way to engage. A way to touch something that's too hot. Words are terrible, language is terrible, it fills us with fear. Art is a way to let us talk about it. Letting the subconscious take over, let other processes take over." Engaging in creative activities gives patients – and medical staff – an opportunity to express their experience with illness. After the sensations are expressed, they can begin to be named in a language that is not biomedical. Once they are named with a new language, they can be communicated in a new language, and acted upon in a new way.

Creating an Alternate Orbit

Walking through a hospital and encountering compelling artwork is at once rare and becoming more common. Many hospitals have non-descript landscape paintings hung on walls. As mentioned earlier, views of nature landscapes have been linked to faster healing times for surgical patients. Other studies have cautioned against abstract art or portraits that could be ambiguously (or threateningly) interpreted, and unfortunately this has resulted in large amounts of boring art on the walls. One patient described a piece of art that was on the wall in her room:

> It must have been from some sort of office supply store for medical spaces. It was just so bland. It was totally non-anything. It was horizontally hung, and could be read as a landscape, but it was just these vague lines. It had like a third field or something, with contour lines that could be hills. And some kind of bluish open sky feeling, but not *really* a sky. That's something that I think is missing in hospitals – a sense of place in hospital art.

People crave knowledge of, and interaction with, their environment. "I know that there's a growing and compelling literature on the value of aesthetics in the clinical context; and what we haven't touched on nearly enough is the role of being able to participate in your environment," Cion told me. Cion conceived of and facilitated a long-term, large-scale art project that restructured, if not the architecture of the hospital, the way people moved while near the art. It let people participate in their environment while calling them into social relationship with patients, providers, and the entire hospital staff.

While conducting this research, I was given many hospital tours of artwork displayed in rehab centers, blood draw rooms, patient rooms, waiting rooms, patient consult rooms, private physician offices, staff lunch rooms, public lobbies. I was taken in by artistic scientific images of nerve cells blown up on canvases, of framed letter pressed poetry, of delicate glass sculptures, of saturated photographs, of carvings, of paintings, of welded steel structures, of beautiful polished wood. After observing a piece of art in a hospital, I would find a seat nearby and watch how other people in the space engaged. Not very often, someone would stop and contemplate an image or object. Some were noticed if a person had a reason they had to stay in the space (say, an image in a waiting room, or in a room for blood draws), but they were not compelling enough that other people would walk into these spaces just to see the artwork. People walking through hospitals spaces were on their own pathways, navigating their private trajectories.

There was one piece of art I saw that made nearly every passer-by pause. In a long byway in MD Anderson, between the pavilion and the elevators that will lift you to twenty-flour floors, rests a 9-foot dragon whose scales were hand drawn by over 1,300 patients, family members, doctors and hospital staff. Sitting in a nearby chair, talking to Ian Cion, the artist who conceptualized it and facilitated its completion, I watched people who happened by stop to look at it. It takes a moment for the handmade-ness of it to sink in. The frame is made of the humble Popsicle stick, supported by cardboard and wire. The scales are many-hued, and contain prayers, songs and memorials in 7 languages. People walking by slow down, get closer, look, and read. An older couple a floor above us peered over the half wall on their floor and asked for directions: how could they get down to see the dragon? Ian directed them to the elevators, and then over to the dragon. When they entered the space, they walked around the dragon, taking photos of each other. As Ian stood up to take a photo of both of them with the dragon, I saw another group of people approaching. A young family with a small child just beginning to walk stopped at the dragon; the little boy wobbled up to the dragon and babbled up to it. Elementary school-aged children nearly stepped on the hand-made paper flowers at its base, trying to get a closer look. People in scrubs sat in chairs near the dragon, talking on the phone, quickly eating a salad, or just watching.

They lookers were stopped, they were summoned, they were pulled in. Hailed. Interpellated. Althusser, a French philosopher, uses the idea of *hailing,* or *interpellating,* to understand how ideology hails and identifies individuals as subjects of the state. This process happens as an at-once call and response, that both marks the freedom and the subjugation of the individual. Ideology hails the subject: it performs the call. As a subject, a person exercises their freedom by responding to the hailing, and yet in their response they acknowledge the nature of their subjugation: they are both free to respond, and they *must* respond. Althusser ends his essay on the Ideological State Apparatus (ISA) by pointing out that these power dynamics are not "natural", but must be produced and reproduced every day in both in the structures of the ISA and in the consciousness of individuals (Althusser 2001).

The notion of interpellation and the reproduction of subjugated subjects has been taken up by scholars of critical media studies to understand the relationship between media and its viewers (Horkheimer and Adorno 1982). They argue that mass media interpellates viewers as passive subjects, who receive "reoccurring tropes and predictable story lines which only serve to further stultify them" (ibid in Nguyen 2015)." We see that viewers are hailed by this constructed art piece, this bright paper dragon. They are summoned, and they respond. How can we understand the work of interpellation in this context? How does interacting with this art piece constitute the viewer's subjectivity?

When doing art bedside, Ian spoke about inverting the top down environment that exists in US society, and is reproduced in US hospitals. "The hospital's *such* a top/down environment for patients. To create a break in that is important to me." When Cion discussed the way people at the hospital interacted with the dragon, from conception to construction to display, he spoke of a type of disruption of the passive subject. Through designing the large-scale, long-term art project that resulted in Okoa, the dragon, Cion was conscious of disrupting this hierarchy, and disrupting experience of receiving and participating in cancer care. One of the ways this disruption happened was through the interpellation of the site of construction, the art table.

> We set up this art table, and people would start stopping by and working. It was a very high traffic area. A lot of patients and some families were stopping, but so were staff people, and they would ask, "Oh, we can do this too?" Most people thought it was for kids. Most people didn't think adults were working on it; and so they

> were really surprised, whether it was adult patients or adult family members or staff members that they were allowed to participate because they'd come to expect art was something for the kids. That was really fun, because people were like, "Oooh … " and all of a sudden they're getting their inner child flared up.
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> And then, of course, they sat down and started drawing and said, "Oh, my God, this is so relaxing. Oh, this is so good for you. Oh, I'm coming here every day on my lunch break. And, sure enough, people did. We had people sitting down in like full scrubs doing it. We had high-level physicians and hospital administrators coming down and doing it; and it became this *thing*. Everybody was into it. And then everybody was anticipating, "When is this going to be done?" They were excited from beginning to end about it.

Describing the way people in the hospital were recruited to participate in the art project, Ian describes how people were summoned, or hailed, by the art table, and by the emerging dragon. In responding to this summons, they were not acknowledging a form of subjugation, or reproducing the hierarchical power structures in the hospital. They were participating in a creative community separate from the hierarchical milieu of the hospital. Creating this long-term large-scale work opened a space for people to act as agents, as advocates, as witnesses, as members of a community. By responding to the summons, subjects shed their individual and situated selves; by engaging in the creative process, art participants at once created an object that expressed their individuality, and affirmed their status as members of a community. This community was not other patients, as it often is, but other witnesses of and participants in the suffering that illness and treatment produces.

This type of art project was unique among the art projects that I observed, or that I spoke about with artists, in the sense that it was a large scale, long-term public art project containing scales that were individually created elements. Cancer treatment takes time, as does constructing a dragon. As I've described above, hospital art projects are usually structured so that they may completed in forty-five minutes, and are individually created, kept, and displayed. Arts facilitators, both art therapists and artists, have stated the goal in such projects is completion. "When we finish, we need to have some type of finished project. Need to get the dopamine bump. If you don't get the bump you don't have that change. The goal is that in forty-give minutes is to have that change. You can tell my medical background – that's not the way an artist would talk about it, but that's what they are doing." The construction of this dragon was designed so that the individual scales could be completed quickly, in forty-five minutes or less, but the scales were glued on to the frame of the dragon over a period of months.

> People really liked to see it emerging. And so then I said, "Ok, well, so let's do it where you can build it all on site, because it increases the enthusiasm about the emerging niche of it, the fact that it is changing, that it is growing, that people can come back and see *change*." And so one of the things that's always been compelling for me about large-scale, long-term public arts in the hospital is that people get to experience like a long-term goal, and they get to *see* something happening over time that is in parallel with their cancer care, their long-term clinical situation, so that we have another long-term goal set in to motion.

The other thing this type of project does locate an individual as a member of a community. As the scales were added, participants could see how their words or images were in dialogue with other members of the hospital community who were also participating in crafting scales for the dragon.

The dragon project decentered the hospital hierarchy. It altered the experience of people walking through the physical space of the hospital atrium in which it was assembled, and it disrupted the architecture of the ideology of subjecthood. It also disrupted the architecture of cancer treatment.

> "And the other analogy that I like to make is that when you're diagnosed with like a serious medical situation like cancer, your whole life starts to revolve around it; and so if I want to create an alternate orbit, if I want to create something that has a heavy enough pull to pull some of your life back out of that orbit of that disease, then the thing has to be hefty; it has to like have a *weight* to it, like a spiritual weight, something that's compelling enough that all of a sudden it's just going to reclaim something, or help you reclaim some of that identity, some of that selfhood, and some of that interest."

The dragon's weight is achieved through size (it is both taller and longer than a human being) and through symbolism. The name of the dragon, Okoa, means rescue or protect in Swahili. The dragon journeys down a river, similar to how patients journey through their cancer treatment. The weight is also achieved by the scale of the whole to its parts. The small scales, individually drawn by doctors, nurses, parents, siblings, patients, staff, layer and layer to make up the dragon. People who participated in the project can easily find their chain of scales, but they also see those scales embedded in a larger whole. Their individual scale is embedded in a community.

As discussed earlier, new construction codes in the United States mandate that hospital rooms to be private. In England, private rooms are available, but come with a list of pros and cons that are presented to patients (Pennington and Isles 2013). Among the cons is “no one to see you when you fall” and “loneliness”. Social isolation of illness and medical treatment are social facts, and have consequences. Being pulled into social community provides a benefit that mitigates these consequences. It doesn’t physically disrupt the architecture per se, but by summoning a patient out of their single room into community, the isolation of the patient is disrupted.

Embracing the unknown

This chapter speaks of how bringing creative activities into a hospital can produce a type of disruption of biomedical logic, institutional hierarchy, and institutional space. For this final segment, I am going to share how artists described the act of creating to be in itself a disruption of the type of “being-in-the-world” (Heidegger 2010) that biomedicine fosters. A disruption of how we relate to uncertainty and the unknown. For positivist science/evidence based medicine, the unknown is something to be fought against. Uncertainty is inefficient, unscientific and uncomfortable for practitioners of biomedicine. For some artists, the unknown is something to be celebrated, uncertainty something to be embraced.

The artist brings this comfort and engagement with the unknown into his interactions with patients. Ian Cion, who facilitated the construction of Okoa the

Dragon at MD Anderson, spoke with me about how creating art in a hospital setting prompts multiple layers of engagement with the unknown. There is the act of confronting and engaging with a blank page, which has an unknown outcome and takes courage. There is the act of making meaning of an illness diagnosis, whose trajectory, treatment and outcome may be unknown. This type of engagement also takes courage. Finally, there is the act of facing the ultimate unknown, death.

> There are very rigid and strict protocols that patients have to follow when they're going to treatment. They *have* to do what they have to do. And the clinical setting is very specific and very different from any other setting in a person's life. And so one of the things that the artist brings, one of the things that I do strategically when I make art with people is that I try and embrace and celebrate the unknown.
>
> Making art is just the act of leaping into or making something, of confronting the blank page, and that it is a direct and courageous confrontation with the unknown. And so even that simple act of courage, I think, can have rippling effects in a person's life. And so this idea for me that one of the things that the artist brings to the table is a celebration of the unknown; it's not chaos per se; it's more like embracing the unknown and realizing that within the unknown is the discovery of magic, of self, of capacity. But, in order to discover those things, you have to have courage. And, hopefully, by getting people in the habit with the simpler things like, "OK, I'm going to make a drawing." Hopefully that can, over time, build one's capacities to embrace the unknown and prepare you for the more difficult or more serious encounters with it.

Cion stated that the encounter with the unknown is part of the social role of the artist.

> I think that's part of the deal as well; and I think that that's also part of the archetype of artists' DNA is that there is a certain element of fearlessness in the artist. You have to embrace a life that is oftentimes misunderstood or underfunded or on the fringe, or all of those kind of things that are associated with the art or the artist. It's not the starving artist, but it's the notion that if the artist is willing to go out into the unknown.
>
> I think that that's something that we bring to the patients: that

> the unknown can be a positive thing. And I think that that's something the hospital administrators recognize. about earlier; the sympathetic relationship between the artist and the patient, how there's a certain sense of simpatico in there.

A pediatric palliative care doctor spoke with me about how he was inspired by the courage of his young patients, and the limits of medicine to provide courage. "I'll take credit for their pain relief, but I certainly wouldn't take credit for their courage." When a patient is in a hospital setting in which cure and care lie in technological and pharmaceutical treatments, and when those treatments hit their limits, doctors speak about their lack of tools, both at their disposal in the practice of medicine and in their training, to provide a way for patients to confront the unknown. In fact, many of them say that it is they who learn from their patients about how to navigate uncertainty and face unknowns.

Artists are invited into hospitals. They are paid through philanthropic donations, or, more rarely, their salary comes from the hospital's general fund. They have offices within the institution. Their emails and business cards bear a hospital's address. Hospital administrators often hold up the art programs available at the hospital or examples from the projects that were completed as symbols of the institution's attention to the whole person. One of the questions that I wanted to understand in my conversations with medical and arts professionals was why hospitals are increasingly inviting artists to work within their walls if some of the work they do subverts or disrupts the architectural interpretation, procedural routines, and social practices of biomedicine? One arts professional suggested that it is precisely *because* art making provides an alternative, and necessary, framework through which to understand what it means to be a human who is ill and who suffers that it is being brought to intersect with the Western model of medicine.

> "Medicine knows it's not perfect, and it knows it needs help, and there's a long history, and a willingness on medicine's part, to look to the arts and to look to other field for help. It knows that it's both an art and a science, and it knows it relies on creativity and forms of healing that are beyond science, and it will acknowledge that. You know, why would a healthcare system want something that's going to subvert it? Well, because it knows it's not perfect, you know? It knows it needs that.

As I began analyzing the interviews I conducted with arts professionals, hospital professionals, and patients and family members, patterns began to emerge in the stories I heard. At the end of subsequent interviews, when I heard an echo of the pattern, I would discuss my analytic framework with my interviewee to see if he or she agreed or found places of difference. Interviewees would offer important tweaks or clarifications, but all agreed with the high-level analysis of how art functions in medical spaces: to support biomedical care, disrupt biomedical logic, and extend the practice of healing from scientific medicine into "something beyond".

The creative activities that took place in hospitals were not easily categorized into three distinct functions: when the different people I spoke with described their experience with art in the medical setting, their stories flowed through and between each of them. An arts-professional who facilitates Visual Thinking Strategies with providers saw her work clearly addressing the first two functions in my framework, and offered a way to think about what "something beyond" could mean.

> In some respects, my work addresses the actual care. In some respects, it's learning to look, like take in the

> information. That's an actual skill that you would use on patients.
>
> On the other hand, it's also subverting some big expectations around a story, and knowledge that are at stake in the patient-doctor relationship, and are at stake in academic environments.
>
> And then a third thing that I think my work is doing that may be isn't in your framework, or that I'm striving to do, and this might be where I'm using art as a springboard, trying to do other things beyond art, like bringing in the clinical reasoning toolbox or things like that, has to do with a metacognitive understanding of what it means to provide care.
>
> Like giving them a refresher - oh, the skills involved in care are both a science and an art, and we're going to break them down even further than we did in medical school. And we're going to get into not only the skills themselves, but also what it means for people to provide care and to have good care provided to them.

The question of what it means to provide good care is an important one. The next chapter will consider the nature of good care, how treating and living will illness requires a "narrative contract" and how doctors and patients use creativity to navigate the places between suffering and hope, and to move forward despite uncertainty and unknowns.

Chapter 4: At the Root of Healing
How the Practice of Art Making Highlights the Skills That Are Fundamental to Healing

This work is an exploration of how and why art and medicine are coming together in US hospitals. Because US hospitals are structured by and enact the positivist logic of biomedicine, I have looked at how the logics of art-making – which are highly personal, subjective, open to the unknown, and which embrace uncertainty, intersect with the logics of biomedicine – which are impersonal, positivist and objective, and which drive toward certainty. I have asked people involved in creative activities in hospital spaces, those who facilitate the activities, participate in them, or support them in other professional capacities, why it is important for art to be co-located with medicine, how art is done in medical spaces, and what benefits arise from the intermingling of the two. I have learned that creative activities are valued in ways that exist in tension with each other, that they provide a necessary disruption to some aspects of biomedical care, and that they do something "beyond" the practice of biological medicine. It would be simple to say that biomedicine is focused on treating the body, and so the "something beyond" that making art offers is a healing of the spirit, as if a clean dichotomy between body and spirit existed. I have heard people say that, yes, but I have heard things that point to a broader conceptualization of the individual and of the act of healing. In fact, creative engagement fosters the elements that fundamental to healing: mystery, relationship, narrative, empathy, resilience and reflection.

There is much that is unknown in medicine. For all of the drive toward certainty and predictable outcomes, healing is still a mysterious process. To "heal" or "care for" someone, body and spirit, involves being "in relation" to them. What I mean by that is that relationship and connection are important components of caring for those who are ill. Scholars of medical ethics describe relationship-centered care as a way to enlarge conceptions of care. Relationship-centered care defined by Dr. Mary Beach and Dr. Thomas Inui is "care in which all participants appreciate the importance of their relationships with one another" (2006). In this chapter, I explore how creative engagement encourages a specific type of relationship in which both physician and patient are humanized, story is attended to, and empathy is built. I will also examine how engaging in creative activities is an important form of self-care for providers, promoting reflective practice and provider well-being.

There is an inherent tension in the positivist logic, or assumptions that structure the practices and values, of biomedicine. The idea that we can know things with certainty is contradicted in every case in which symptoms do not point to a specific diagnosis, in each body in which disease does not respond to treatment, and even in the scientific literature in which the evidence from various randomized controlled trials suggests conflicting courses of action. In the high-acuity environment of a hospital, this tension is amplified by financial pressure, and by the need to do things quickly. It is often not possible to take time to consider options, or to take time to wait and see. Biomedicine enacts efficiency through reductionism; specifically, the patient is reduced to their pathology. Explaining this to me, one doctor said, "You are no longer Dr. Gray, the anthropologist. You are the hip replacement in bed 3." In the biomedical framework, the many unknowns that are manifest in the intimately personal experience of disease and illness are not welcome. "The only real specialty in medicine that's trained to be comfortable with the unknown," he continued, "is primary care, because 50% of what we see is undifferentiated symptoms. So we get very good at saying, let's just wait and see what happens. But, you know, in a very high-pressured hospital environment the drive is for certainty. You have to image it, you have to test it, you have to get the diagnosis, you have to get them *out*."[2].

Healing symbols

Medical research is concerned with supporting biomedicine, and with providing evidence that can direct a course of action. It is concerned with understanding which inputs have predictable outputs. To put it another way, if Patient X is administered Y medication, Z outcome can be expected. As discussed in previous chapters, the gold standard of measurement that exists today is the randomized controlled clinical trial, which is designed to control all variables except one – the medical intervention – so that the effects of that specific intervention can be measured, and replicated. Yet there is something called the "placebo effect" which muddles the ability to product sure outcomes. The placebo effect refers to the fact that people get better when they are given a pill that they think is medicine, but in fact contains no medicine. What is fascinating

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[2] See also Rhodes 1995 for an important discussion regarding the practice of "emptying beds" in an emergency psychiatric unit.

about the placebo effects is that there is a physiological outcome that occurs when patients *think* they have received a medication, when they were only given a sugar pill. This is a problem because it means that what people *think* about the medicine has strong effects *in the body*; in some cases as strong as the medicine itself.

The ideas that surround the placebo are so strong that the most rigorous treatment trials conceal which group has the placebo and which group has the treatment from both the participants receiving the treatment and the scientists administering it in what is known as the gold-standard of evidenced based medicine, the double-blind, randomized controlled clinical trial. Evidenced-based medicine calls for more trials to provide more evidence to provide more direction in prescribing treatment whose outcomes can be predicted. Yet it seems that understanding the nature of healing may not lie in more tests or in more trials that can move us closer to a type of certainty, for two important reasons. One: researcher bias, flawed study design, and "the high rate of non-replication" impact what we can claim to know for certain from published studies (Ioannidis 2005). Two: the body defies certainty. And the body exists in social relationship.

It bears repeating that though certainty is the goal, the process of healing ill bodies is uncertain. As several doctors told me, there are many things that we still don't know about how healing happens, about how medicine does or doesn't work in the body. We don't understand why what people think about a medicine influences its efficacy. The power of symbolism is evident in the fact that the placebo response is so powerful, and is empirically measurable and observable (Frenkel

2008). Claude Levi-Strauss wrote that symbols are effective because the psychological reality they represent corresponds to an organic physiological reality (Levi-Strauss 1963). Oron Frenkel, a philosopher and a physician, draws upon a 2002 article by Moerman & Jonas, an anthropologist and doctor duo, to investigate what they termed the "*meaning response"* to "more appropriately capture the way people are responding to meanings associated with placebos given certain situations, not to placebos themselves" (ibid, page 66). The placebo, and its situated, constructed context, contains a multiplicity of symbols: of cure, of hope, of science and progress, of efficacy.

Dr. Jack Coulehan, a physician whose poetry investigates the symbolic nature of medicine, spoke with me of the power of the symbolic affect of medicine, and the lack of understanding of this symbolic affect. "When you look at the whole realm of symbolic healing, if you take everything we do in medicine, all the drugs and everything, let's say none of those had a physiological effect – people would still find them beneficial. Because we live in a world of symbols, and they would work because they hold symbolic value…and we just have a teeny understanding of how [the placebo] works".

Symbols have a powerful effect on healing. The interpretation of symbols depends on the shared cultural understanding of the symbol, and also of the positionality of the person interpreting the symbol. For example, the symbol of the doctor's white coat can signify competence and skill to someone who has had positive encounters with physicians, promoting confidence in and adherence to medical advice. The same symbol may connote dominating or even manipulative authority to another, prompting distrust and disregard for medical recommendations or refusal of medical treatment. How people understand the symbols that are ever-present in their care experience impacts their reception of care, and so impacts their healing.

There us a rich body of work that examines the connection between symbols and healing in traditional healing rituals and in Western psychotherapy (Levi-Strauss 1963, Dow 1986, Kleinman 1988, Prince 1980, Kirmayer 1993, to name a few). Kirmayer states that "the talking cures of psychotherapy consist of a thousands small turns that repair, restore and mend the damaged, locate new possibilities or carry the sufferer forward into a new situation (1993: 161)." I heard this many times: that the power of engagement with artistic activity lay in its ability to open up new possibilities of self-conception and being. Disease may be located in the body, but illness is socially constructed and requires social engagement. Dr. Arthur Kleinman devised a set of eight questions designed to elicit a person's understanding of his or her illness. This widely cited and used interview guide contains queries such as "What do you think has caused your problem? What do you think the sickness does? How does it work?" Without understanding a person's social and symbolic world, a doctor cannot be an effective healer. The medical ritual must make use of symbols and acts that have meaning to the patient for it to be effective.

Dr. Coulehan recognized that practices and systems that hold symbolic meaning for everyone involved in medical care – patients, family members, medical staff – are not well attended to. They are not well understood. "Unfortunately, we don't know enough about them to make them predictable, the way we do with antibiotics." Another physician who is a published poet, Dr. Rafael Campo, also spoke with me about this topic, saying, "we are unfortunately so limited in our understanding of how the mind and body interrelate as it relates to healing." Dr. Campo was especially interested in how symbols present in poetry facilitate the sharing of experiences between people, how they joined people. He saw the expression of an individual experience of illness by the poet, the recognition of it by the patient, the recognition of the poet and the patient's experience by the doctor, and the connection established between expression and recognition as a healing process.

> When we create in an artistic expression of what we feel internally, we are offering that symbol or that representation that joins us and one that is uniquely healing.
>
> People say oh, poems, what's a poem going to do that helps somebody? That's just kind of nonsense. There's a kind of a cynicism about what we don't understand that I think is itself sadly very limiting and really is part of how we again distance ourselves from our patient…When we refuse to participate in the ritual or to share the symbol, we're also refusing that potential for healing as well, and probably in a sense are harming our patients that way.

By refusing the ritual of allowing the patient to tell their story of suffering while deeply listening, and by maintaining distance from the patient story, Dr. Campo describes how physicians are also creating distance from their own story – that they, too, will one day be wearing a hospital gown wanting the doctor in the white coat to attend to them, to attend deeply. By using poetry to bridge the gap between medical knowledge and the human experience, he links treating disease with caring for the person; or, as he explains it, he does the work of healing. Anthropologists (Kleinman 2006; Livingstone 2012, among many others), philosophers (Mol 2008; Frenkel 2008) and other physicians (Verghese 2010; Gawande 2014; Byock 2012) have written about the connection between entering into relationship with patients and healing. Illness is embedded in individual and social narratives. These narratives contain symbols that carry meaning and influence action. Illness narratives need to be summoned and heard before medical treatment takes place, and healing practices should align with the patient's framework of illness.

Participation in mystery

As stated above, the paradigm of biomedicine is concerned with solving problems. Modern medical education creates doctors who are experts at solving problems. In this paradigm the diseased body is conceptualized as a problem. Oron Frenkel, a medical philosopher, writes that the body might instead be viewed as a mystery. Frenkel cites the philosopher Gabriel Marcel[3], who delineates the difference between a problem and a mystery. Marcel writes, "A problem is something which I meet, which I find completely before me, but which I can therefore lay siege to and reduce. But a mystery is something in which I am myself involved, and it can therefore only be thought of as a sphere where the distinction between what is in me and what is before me loses its meaning and initial validity (Marcel 1949, 117)." Building upon this, Frenkel states,

> Viewing the body as a broken machine is to view it detachedly as a problem. In this light, the proper action is to find the appropriate tool or technique, such as the proper medication for a particular disease. As novices, we at first find ourselves radically involved in the clinical theater

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[3] Marcel's work is known as "Christian Existenialism". His work still generates a relatively small stream of scholarship. But "Marcel's influence on contemporary philosophy is apparent, for example, in the work of Paul Ricoeur, his most famous student", whose work on "detour and return" echoes Marcel's thoughts on "primary and secondary reflection" (Stanford Encyclopedia on Philosophy).

> from which we must learn to disengage, taking on the objective comportment we are trained to prioritize. Marcel implores us not to problematize and seek technical solutions, but to approach the mystery that lies before us through participation.

According to Frenkel, when engaging in solving a problem, the solution does not depend on the identity of the questioner, but lies in a technique or technical solution. It is important to note that any person could use the technique with the same result. When facing a mystery, the identities of the people who approach it matter. Indeed, technical solutions will not solve a mystery. Mysteries require full participation of the questioner. Yet deep participation is antithetical to biomedical care. Doctors are not trained to intimately connect with their patients; they are taught to practice detached concern "to protect themselves from burn-out as they care for one suffering person after another under great time constraints" (Halpern 2001). Frenkel cites Merleau-Ponty to talk about being *with* other people (detached concern) as opposed to being *beside* them (practicing empathy). Frenkel's argument is that people attribute meanings to situations and interactions, and that these meanings can influence the effect of medical treatments (called the meaning-response when applied to the placebo effect). Because this meaning response is real, measurable, and influential, and because it is enacted through our bodies, Frenkel shifts our understanding, away from the mechanistic view of the body and its processes, toward one that allows for an understanding of embodied meanings. Frenkel is interested in how physicians, through skillful participation and through empathy, can facilitate a "meaning response" that is healing. To repeat Marcel, "a mystery is something in which I myself am involved" (1949: 117). Framing the body as a mystery requires personal participation from the physician, a type of participation that is not typically supported in biomedical culture. Dr. Campo stated:

> I think one of the biggest problems with medicine these days is that we are so removed from our patients and their experience of illness and forget that we're going to be them someday. We have not yet figured out a cure for our mortality, so all of us will be patients someday and I think there's a fear of recognizing that, that keeps us from really identifying with our patients when they're ill.

A patient is not isolated in illness – we all hold "dual citizenship, in the kingdom of the well and in the kingdom of the sick" (Sontag 1978). Physicians, too, will one day become patients. This is hard news to bear, but facing it can open the possibility of a deeper practice of relating to a patient. Bringing one's self into participation with an ill patient, Frenkel states, is the practice of a good doctor, who, I would add, is practicing good care.

A relational practice of care

Mol's text, *The Logic of Care,* explores what good care is, and how it gets done. She argues that care involves a relationship over time. When one cares, one doesn't seek a finite answer about how to treat, or lay out options for a patient to choose; rather, one engages with the patient to visit and revisit decisions about life quality and care. She uses the concept of "tinkering", making fine adjustments over time and in joint consultation, to describe what an ideal patient-care provider relationship looks like. But ultimately, the logic of care is a logic of relatedness. "The logic of choice assumes that we are autonomous individuals. The logic of care is attuned to people who are first and foremost related…Nobody acts all alone. Who bakes your bread? Who removes your rubbish bags? The logic of choice is concerned with individuals who wish to be free.

The individuals who figure in the logic of care would die if they were left alone. They owe their very ability to act to others" (Mol 71-72). They exist in relationship to care-ers.

Tinkering with a problem over time and entering into the mystery of relationship foregrounds connection to a patient, their values, and their illness story. A critical aspect of being in relationship is attending to story. Abraham Verghese, a Stanford doctor who places great weight on the intimate rituals between patients and doctors, is a staunch proponent of listening to the patient story. He described the shrewd attention Sir Joseph Bell[4] paid to the details of his patient's story in his 2010 TED talk. Sir Bell discerned the patient's place of residence, mode of employment, family status, and morning route by a quick assessment of her shoes and clothing. Dr. Verghese appeals to the audience to imagine what other level of detail he might discern when he examines her physical body, and contrasts that to the rushed ritual of modern medicine. He has coined the term "iPatient" to give name to the modern practice of examination in which the patient is examined in absentia, through the lab results and corporeal data that is relayed to a computer around which physicians gather to consult.

> The iPatient is getting wonderful care all across America. The real patient often wonders, where is everyone? When are they going to come by and explain things to me? Who's in charge? There's a real disjunction between the patient's perception and our own perceptions as physicians of the best medical care.

Dr. Verghese suggests that the current medical standard is not the best care for patients. He speaks about how he has incorporated into his own practice of caring for difficult patients with complicated chronic conditions what can be considered a model of better

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[4] Sir Joseph Bell was Sir Arthur Conan Doyle's teacher, and his inspiration for the character of Sherlock Holmes.

care. Verghese describes it as a "method where I invited the patient to tell me the story [of their illness] for their entire first visit, and I tried not to interrupt them. We know the average American physician interrupts their patient in fourteen seconds. And if I ever get to heaven, it will be because I held my piece for forty-five minutes and did not interrupt my patient." After the story is heard in the first visit, the second visit is spent doing an "extraordinarily thorough exam" in which his ritual of attentive touch moves from pulse to hands, to nailbeds, to eptrochlear node, and continues. Many patients state they have never been examined in such detail before, and he laments this lack of attention to the patient body as a shameful lapse. Deep attention and human touch are part of the ritual of healing. A doctor's thorough touch symbolizes attention and concern, which make a patient feel cared for and secure. Withholding touch can result in a missed diagnosis, and Verghese tells a tragic case of missed opportunities to diagnose palpable cancer tumors because a patient wasn't touched during her years of medical care. He tells the audience, "Ladies and gentlemen, that is not an unusual story. Unfortunately, it happens all the time." Verghese concedes that in some cases, touch might not be "necessary" for curative care in cases where the disease is understood at the molecular level. But to patients, Verghese says, it "matter[s] deeply." Touch is part of the ritual of examination, it symbolizes attention and care, and it conveys a message that patients long to hear: "I will always, always, always be there. I will see you through this. I will never abandon you. I will be with you through the end."

Hospitals and stories

There is a reason that story and medicine go together, several doctors told me. Hospitals are a place of stories. Much writing that happens in the hospital, such as chart notes and patient reports, focuses on plot, the sequence of events and outcomes: this was described, that treatment ordered, this lab result obtained, that diagnosis made, this treatment result, that outcome. When reading such charts, doctors learn what happened, then what happened next. Little of the patient's character is captured in hospital writing. But, Dr. Danielle Ofri tells me, "character is always more interesting than plot." She made this statement while explaining the genesis of the Bellevue Literary Review at her hospital. Bellevue hospital is the oldest hospital in the United States, and it is home to the first, if not the only, literary magazine to be published out of a hospital. I was interested in the intention and vision behind the Review, but founder and editor-in-chief Dr. Ofri stated that its conception had "some accidentalness to it." It grew out of medical student writing; specifically, from her desire to hear more about character than plot in patient history notes her students were writing.

> I am certainly interested in who they are as people, because I find them intrinsically interesting. Whether that's my own quirk, or the fact that the writer side of me is interested in character. Character is always more interesting than plot. So I want to know where they came from, how they came to America, who is in their family, what they do, what their hobbies are, I'm just interested.

When Dr. Ofri was working as an attending, she would read the clinical histories that the medical students write, that describe the "chief complaint, history of present illness, past medical, past surgical, social, physical, labs assessment. After you read the first fifty, they are all the same, and they are kind of dry. I got bored out of my mind, reading those notes." So Dr. Ofri asked students to write a different type of clinical note.

"Just tell me the patient's story. Ask the patient - what is it like to have diabetes? And write that down. So I started to get some interesting collections, kind of nice little essays." A colleague of hers was also collecting medical student writing inspired by patients.

> Independently, unbeknownst to me, we got a new chair of medicine. And one of the things he instituted on the inpatient medical ward is that students had to write a thousand word medical essay, which you know, for English majors is nothing, but for medical students - 1,000 words, god almighty!
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> But it could be on anything, physiology, philosophy, ethics, as long as it was inspired by a patient. And so he was ending up with all these interesting student essays, but it was two different parts of the medical school. And so a colleague said you two ought to get together. And so we did, thinking well, maybe we'll make a student publication, with all these great essays. And as we spoke about it, we said, we think there is a larger interest in this.
>
> So we started the BLR, put out some calls for submissions, and we got a thousand submissions, we were swamped. From people - mainly *not* medical people - just writers and people, a few doctors and nurses. But I think the issues of health and healing really touched everyone. You can get by in life and never need a lawyer, but you'll never escape being part of the medical world, you or your loved ones. We all have thoughts, anxieties, and vulnerabilities.

The journal receives many submissions from doctors now, and several doctors have described the admissions process to me as quite competitive. The journal, and its home in a public hospital, conveys the message that stories need to be told, and heard, as a necessary part of practicing and partaking in medical care, for physicians and patients alike.

The narrative contract

I have laid side-by-side two arcs of the same circle: telling one's story is an important part of the illness experience, and listening to story is an important part of patient care. Many people I spoke with acknowledged this, but there is still the problem of how it gets done. Trust needs to be built, empathy expressed, genuine interest in one's illness experience expressed. Dr. Campo enters into a "narrative contract" with patients, in which he shares and promises to receive story.

It often begins with a poem, such as the following one by Thom Gunn.

The Man with Night Sweats

I wake up cold, I who
Prospered through dreams of heat
Wake to their residue,
Sweat, and a clinging sheet.

My flesh was its own shield:
Where it was gashed, it healed.

I grew as I explored
The body I could trust
Even while I adored
The risk that made robust,

A world of wonders in
Each challenge to the skin.

I cannot but be sorry

The given shield was cracked,
My mind reduced to hurry,
My flesh reduced and wrecked.

I have to change the bed,
But catch myself instead

Stopped upright where I am
Hugging my body to me
As if to shield it from
The pains that will go through me,

As if hands were enough
To hold an avalanche off.
-Thom Gunn

Dr. Campo, who is a poet and a physician, like John Keats, like William Carlos Williams, writes poetry and practices medicine. But I was connected to him because he combined art and medicine in his daily practice - he uses poetry *with* his patients. I pondered this as I prepared for our interview. Did he write poems with patients in his office? How much time did that take? Was there room for attending to illness? I was interested, yet less open to the idea than I imagined I would be. I am entrenched in the biomedical paradigm of bodily disease as mechanistic failure, even as I name it, even as I struggle against it. Still it persists. If I went to the doctor's office with a serious illness, I would want a cure. I would be afraid, and I would want my fears allayed by treatments that could secure years and lay them before me. But what if -- the "if" so very hard to entertain -- what if I couldn't be offered a sure cure? What if the path ahead was uncertain? I would want to be seen. When I am called in to the exam room, when I hear, "the doctor will see you now," I want the doctor to *see* me now. But amid rushed schedules and signatures and forms, how is space created for truly “seeing” a patient? How does engagement with creative activities intertwine with medical care? One of the questions that led me to this research topic was a simple why, and how. Why were artists in hospitals? Why were art and medicine being combined? And how exactly did that happen, how did it work? I have spent the past five years observing how visual art, music and poetry are being used in hospitals. I have heard, and seen, and witnessed the way that creative practices transform the clinical experience for patients, family members, and staff. But I hadn’t seen, and couldn’t yet imagine, how a doctor used poetry with a patient during a twenty-minute office visit. How could that be time enough for either poetry or medicine?

Because patients sometimes know of Dr. Campo’s interest in poetry, they often spontaneously bring poetry to him, saying, "I thought this might help you better understand what I'm going through.” There are also times,” Dr. Campo tells me, where he will initiate the exploration of poetry when a patient receives a new diagnosis. He doesn’t write the poem with the patient, or, as I had imagined, even read it aloud. He includes the poem as “one way of knowing” among other medical literature, and allows the patient to respond to it.

> What I will often do is bring in materials from different kinds of ways of knowing about the illness. I'll bring to the appointment some patient education materials, I'll bring in maybe an article from a biomedical journal, and then I'll also bring narratives.
>
> I'll bring some poems or maybe a short excerpt of a story that in some way relates to the patient's new health condition. And it really does surprise me that when folks come back for their next visit or when I hear back from them in another way, through a letter or some other context, that it's not the review article from the New England Journal that they want to talk about. It's usually the

> poem – 'That poem by Thom Gunn really was just too useful to me as I was thinking about what I'm facing with this, now that I have HIV.'
>
> This also sometimes in very practical ways helped me understand aspects of my patients' lives that I didn't fully appreciate. I've shared poems with patients and learned that they are not literate, and can't read the poem, and yet when we read the poem together, they can still experience some of the power of that.

His colleagues will ask, doesn't it slow you down, this attending to poetry? How do you start to talk to someone who is newly diagnosed about a poem about cancer? It must bring up all these feelings? His answer speaks to the importance of relationship in building trust, and how the initial investment in trust can help make patient visits more efficient over time.

> You know, [bringing up feelings] is actually part of the point. Because it ironically makes me even more efficient because through the sharing of these kinds of deeper narratives, there's trust that develops that I would say short circuits all of the kind of throat clearing and the kind of "here are the 20 questions I'm supposed to ask about what you're experiencing."
>
> And we're starting each time we meet or each time I visit at the bedside at a much more intimate place together that I don't have to go through the 20 questions, half of which are not really going to give me useful information about what's going on anyway, and that frankly, I think a lot of docs use almost as a way to sort of silence the patient.
>
> I actually think when we do that, we're saying we really don't want to hear the patient's story, where this, by establishing this kind of a narrative contract with a patient, I'm saying in many different ways, I want to hear your story. I want to know – tell me really what's going on. What's at the heart of this?

A poem that recognizes the lived experience of a serious diagnosis let's patients know that they are seen, truly. And that their experience will continue to be seen and cared about by their doctor. This assurance helps patients reveal themselves even more to their doctors, an important turn in the doctor-patient relationship. Many patients don't share all of their concerns with their doctors, leading to misdiagnosis or delayed diagnosis. They don't want to be a bother, or be seen as a nuisance by their doctors. Or the doctor will interrupt them on an average of 12 seconds after they speak (Rhoades et al 2001). By using a poem that communicates understanding of the patient's experience of illness, and by then listening to the patient's story, Dr. Campo is able to hear, and address, patient concerns.

Another physician, a neurologist, also spoke to me of using poetry to enhance the practice of medicine, in this case by teaching a class titled "the Healing Power of Poetry".

Walking the Dog
John Wright

She weighed 300 pounds
fat and high sugars were killing her, I thought.
So, I thought

So I gave her a puppy with dark curly hair.
Nothing else had worked.
Walking the dog twice a day, I thought

Might persuade, might motivate.
She was pleased with my prescription.
She laughed, she rocked from side to side.

She lived for 12 years, hugging that little black dog
While her lean husband walked it faithfully twice a day

"What's this poem about, really?" Dr. Ginsberg, a neurologist and a poet, explained his use of the poem. "The poem is about a physician who despite the fact that he knew his patient was dying of diabetes never abandoned her; he kept seeing her, and he kept seeing her until she died." As mentioned above, Verghese stated that the most important message that his ritual of touch and of deep examination conveyed was the message of a physician abiding. “I will not abandon you… I will be with you through the end”. The ongoing relationship patients had with their family doctors several generations ago has been fractured now by specialization and fragmentation of care. Each part of the body has a specialty branch of medicine that attends to it, but the humanity of the patient resists compartmentalization. Abiding with the patient recognizes that they are whole, rather than a collection of problems, and that they are being cared for as a whole entity.

> It’s a wonderful thing to bring students back to the realization that with all the fancy technology that we have, the human brain has not changed in 10,000 years. We’re still reliant on sitting down face to face and having a conversation, and listening to people – listening carefully to what their belief systems are, what their cultural systems are…you have to understand what people believe and you have to honor that belief.
>
> So this “Walking the Dog” poem is a marvelous poem because it kind of tickles the students and then we really talk about what’s the import of it…when I taught my students in my office, I always taught them about the relationship that they were building with a patient and family, and that if they were going to ignore that, they would do a tremendous disservice to the patient.

This poem is an example of being in relationship with one’s patient. In it, the doctor is practicing relationship centered care, in which “the patterns of meaning and relating are co-created continuously throughout the communicative encounter” (Shapiro 2009). Throughout her illness, the doctor continued to be engaged in her care, and in her story.

The poet/physician who taught this class used poems as examples of how they portrayed healing encounters. He also instructed students in different types of verse: sonnet, sestina, haiku, and free verse. He wanted his students to experience the healing power of creating poetry. He told me that he wrote poetry himself to reflect on moments of suffering that he witnessed or personally experienced, but didn’t have time or space to consider them when they happened. Other physician poets, such as Dr. Coulehan, affirmed that reflection is an important component of creative engagement.

> You know, when I teach medical students, let's say I'm teaching with poetry, I make the point that I don't expect them all to be poets. I don't expect them all to write short stories, I don't expect them all to even paint or make music. People have different ways of developing their subjectivity and their empathy. What I think the commonality is, that is crucial for any medical person, is reflection, a reflective practice. - Jack Coulehan

Maintaining empathy

Patient art, poetry, music and literature gives providers a new way to "see" the patient experience, and listen to their stories. The power of seeing the patient experience through art was described to me by a surgeon. Surgery is a practice of seeing the patient in a unique way – seeing the body in a way that allows cutting into healthy tissue, muscle and organs, wounding the good to cut out the bad, and is a practice that takes an immense amount of training. The training promotes the cultivating of a tough exterior, of being able to make important decisions on one's own, but comes at a cost. Dr. Dawson is a surgeon whose book, *Forged by the Knife,* details her residency experience, which she describes "consisted of a series of spirit-cursing episodes". About 15 years after completing her surgical training, she began to examine her experience of becoming a surgeon, one of the only black female surgeons in the United States, as an experience in which she was initiated into the field of General Surgery, even as she was excluded from many aspects of this largely white, male profession; "I had not recognized residency as a process of socialization, an initiation into a secret society – and I had been alien enough that the cloak of socialization had never totally covered me" (Dawson 1999, 18).

When I met her, she had been practicing general surgery for over 30 years, specializing in breast surgery at a large urban hospital. I asked to be connected with her because she was described to me as a doctor who was interested in the art services available to patients at her hospital, who personally led patients down to the art therapist's office. She greeted me with a warm smile. Sitting in her office with light coming in the windows behind her, she described to me why she found this work so valuable.

> We get a lot of training as physicians in how to protect ourselves from the emotional impact of what we do. It's a different way of feeling the patient experience, because obviously I experience it in a very conceptual way most of the time, talking about things. And so seeing the way that patient's expressed their experiences in art, I don't know, I don't even have words for it!

She explained that seeing patient art doesn't directly impact the way she provides care, her comment "you can't be sobbing in the office" alluding to the mandate to practice detached concern, but it does connect the physical disease process with the emotional.

> You bypass all the intellectual stuff and it has a big emotional impact…it's really the leaping over the intellectual right into the emotional space. And I don't do that much at work."

With seeing the patient experience comes understanding, with understanding comes empathy. Empathy is both a feeling and a skill. It is that combination of skill and emotion that is so hard to teach in medical schools, that the majority of students come in with but that is so hard to preserve in medical education, an education whose courses and clinical practicum strip it from residents (Dawson 1999). Dr. Ofri spoke about the fear and vulnerability inherent in the illness experience for both patients and doctors. Patients come in to the hospital "scared to the soles of their feet", and through participating in a creative activity, such as writing, "art can recognize" that experience. Being present in the moment, and aware of the emotions of self and others, works to foster empathy for a patient's illness experience and help physicians with their own fear.

Dr. Ofri doesn't go as far as to say that art assuages grief and suffering, but that they recognize and validate that suffering.

> "I think for patients, there's a lot of fear going on. I think we are scared, and we should be. We're sick, and our bodies are doing things we aren't in control of, or our minds, or there's a lot of fear and vulnerability. And I think that art and literature and music can do a lot to...I'm not going to say assuage that, but to recognize and validate that.

The recognition of a patient's experience does not assuage the fear or the pain, but the validation is so important because it is an act of recognition and witnessing. The authors of the creative pieces, and the physician or member of the care team that selected them, speak through the art to the patient. We see you. We have been where you are now. Or we will one day be in your shoes. And we are here with you in your moment of fear and uncertainty.

By creating art, doctors learn to practice empathy for themselves. During residency empathy drops off. Residency is a very stressful time. Dr. Breuner, a faculty member who mentors residents at a large pediatric hospital, spoke to me about how she sees art and medicine coming together, and the conversation turned to the connection between art and empathy, and how difficult it is for physicians to maintain empathy. The night before our interview, a meeting on medicine and humanism was held at a faculty provider's house, and 15 residents attended/were there. Residents, she explained to me, are having it *rough.*

> Residents…these are all interns. I'm sure you remember from like from *ER* or *Grey's Anatomy,* whatever show you watch; they start out as a first-year, second-, or third-year; so they are coming out of medical school after four years of college and four years of medical school, and whatever in between, and then suddenly starting this three-year *ridiculous* amount of training. And this is the time empathy drops. And it's because they get like not a lot of sleep and they're overwhelmed, because there's so much they have to know and do and take care of…And, oh, by the way, if they're wanting to have children now because they've delayed for a long time having children, they have *them* during their residency. So it is a very, very challenging time.

This training does produce incredible clinical skills. But the problematic question for those who teach young doctors is how to provide the skill training while maintaining empathy?

> But then the other side of that is that you have these *incredibly* trained, educated people that know when someone's sick just by looking at them, and know what to do, and so there's a positive to it. But what we are trying to do as faculty is try to generate empathy within the trainees during a time when clearly empathy drops, and it's challenging to flip that, to figure out: what do they have in their own life that they can use to help themselves, or even help how they take care of patients?

This "time when clearly empathy drops" is a time of intense pressure for young doctors as they learn to practice medicine in a for-profit system that exploits their labor. Medical training often focuses on how to help doctors build resiliency during this period, rather than questioning the hospital structures that make providing care for patients so difficult. Young physicians must learn how to treat and care for people who are coming in for broken bones that will heal as well as for people who are in their last moments of life, and this also requires a type of personal resilience. Arts activities for physicians are usually framed as ways to promote the personal resilience that is necessary to provide good medical care, but it also serves to support the institutional structures such as quick bed turnover and long hours for residents that harm new doctors.

Dr. Breuner asked the residents what creative activities they engaged in that were meaningful to them.

> And not one person in this room of like fifteen or twenty residents and trainees didn't have something that they did: cooking, crocheting, music, like me playing the fiddle, or writing or poetry, or even art itself, like painting or drawing. Everybody had something that they did. And then they said right away, "I wish I had more time to do that."

One of the things that was discussed that evening was how crayons were ever-present in this pediatric hospital, and that perhaps they could ask patients to draw something meaningful with them. "And so then one of the people that was there said, "Well, *you* should get the kids to draw family—their family—and where they are in their family. "Where are they in relationship to the nuclear family, and that's kind of important because that informs like their own self-worth." Dr. Breuner took this one step further, to ask the residents themselves to draw their own family, and their place in it.

> And so then I said, "I'm going to challenge you guys to do this too.
> Because the more you actually can figure out where you are in your family
> by either making your mark or drawing it, the more you'll be able to help
> someone who's stuck in their situation."

But this challenge wasn't just about understanding the location of the self, to empathize with the familial position of the patient. It was about trying to do something that is hard, that you are not an expert at, and forgiving yourself for not being that expert. And then transferring that forgiveness to your patients.

> The more you can forgive yourself for not necessarily being good at the art you want to do, the more you'll be able to forgive your patients for *not* doing what they said they were going to do or that you *told* them to do, or making choices that may not be healthy. If you can like work on forgiving yourself for doing stuff like that, that you'll be better at working with patients at *their* level as opposed to top-down.

Engaging in creative activity brings us into the present moment (Malchioldi, public talk). Being present in the moment, attending to self and other, fosters relationship. Attending to the self that provides care requires attention, deep listening, and empathy – activities and skills that when transferred in relationship to a self that receives care, results in a deeper relationship, and a better practice of care.

That moment that you will revisit in your nightmares

The medical professionals and students I spoke with described the intense difficulty of witnessing human suffering without social support during their residency. Their medical training was competitive and difficult, and lengthy. After completing their BA and any science classes required for medical school, students take the medical college admissions test (MCAT). Students then undergo intense competition to be accepted into medical school. Admission is so competitive that each student applies to an average of fifteen medical schools (AAMC 2014). Most medical schools matriculate between one hundred to two hundred students each year, and the well-ranked schools receive between 6,000-10,000 applications for these spots - an acceptance rate of about three percent in the best case scenario, and less than one percent in the most competitive cases[5]. Medical school lasts another four years. The first year consists of basic science courses requiring intense amounts of memorization. Gross anatomy, described to me as an especially challenging class, is also taken during the first year, and includes long hours in the "cadaver lab". In this lab, students learn the "wonders of the human body from the cranial nerves, brachial plexus and mediastinum to the femur, humerus and orbicularis oculi muscle in your eye" (Divitia 2010). There are several moments in medical training in which empathy drops. One medical student wrote about his experience of anatomy lab:

> The act of dissecting cadavers sets me apart from 99% of my family, friends, and peers. Never is that more evident than on the phone with my mom trying to describe my day. I often will say that anatomy lab was "good" or "pretty uneventful today," because I just don't know…how to say anything else. I guess you have to be there to explain what it is like to hold organs in your hands, to physically follow the path of nerves down the arm, or to spend hundreds of hours cutting apart another human's body.

The second year of classes focuses on clinical diseases. After the second year of medical school, students take the first part of their licensing exam.

During the third and fourth year of medical school, the last two years, students begin to really practice medicine and see patients. They do clinical rotations through different medical specialties (pediatrics, dermatology, psychiatry, etc.) in which they become members of a medical team. A medical team consists of an attending (senior doctor), residents (doctors in training) and interns (first year residents) (StudentDoctor.net). Those interested in medical education have been trying to

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[5] Out of 49,480 applicants, 20, 343 students matriculated, meaning that about forty percent of medical student applicants were accepted into one of the universities to which they applied.

understand why it is in the third year of medical school, right when medical students begin seeing patients, empathy drops.

Students become remarkably skilled. Yet they are not just learning how to diagnose and treat the human body, they are learning what has been described in many texts that discuss medical education as “the hidden curriculum.” The hidden curriculum teaches students that medicine is a business, and they must take certain actions to maximize profit (such as not spending too much time with patients, discharging patients as soon as possible), yet they must also learn to “unsee” this curriculum and the medical culture that embraces it as “just the way things are” (Taylor and Wendland 2015).

After completing medical school, students take part two of their licensing exam and apply for residency. Residency lasts between three to five years, and residents practice medicine under the supervision of an attending physician. Residents then take the final part of their licensing exam, and become licensed physicians (Divitia 2010)

This training is intense. In addition, medical students are on-call and sleep deprived, poorly paid, and expected to deal with challenging situations. One medical student who was mid-way through her third year told me how difficult it was to be thrust into the world of illness and human suffering: “You’re waiting for that one moment that you will revisit in your nightmares.”

In addition to the burden of providing care for others, medical residents pay a high personal tax. Medical residency”, a 3rd year medical student told me, “is so difficult. “It seems like some of the purpose is to break you down as a person. If you don’t have a really strong sense of self, it’s easy to feel like you’re a complete failure, have nothing to contribute.” During the third year medical students can work upwards of 80 hours a week (though many schools limit the number of hours they are allowed to be scheduled to work to 80) and are expected to do much of the “scut work” (labor that has no educational value) of the hospital. During this period of intense training and pressure, residents do not have time to reflect or process their experiences attending to human suffering. The lack of ability to reflect takes a toll.

Space for reflection

In my interviews with doctors, I asked about their experience with art and medicine. I didn’t ask about their experience with medical education, unless their art experience occurred during their medical education. Yet every doctor I spoke with told me about tragic encounters with human suffering during residency that challenged their ability to make sense of it, and challenged their ability to cope. In fact, many mid-career professionals I spoke with shared that the moments they marked as turning points in the way they thought about or practiced medicine were from experiences had during residency. They told me that medical residents are dealing daily people experience the deepest traumas: pain, incapacitation, fear, death. They described the constant experience of revolving traumas with no time to reflect or catch your breath as unique even among other professionals that experience trauma semi-regularly. For each of them, their experience with art helped them deal with these experiences at the time, or provided a way to reflect on it later. One doctor shared the following memory of her residency, which I will share with you in its entirety:

> When I was in my residence training, I was in the emergency room and I was ending a shift where I'd been there overnight taking care of patients. It was early morning and these two patients came in. They were both having CPR in progress, so they were dying patients. And both of those patients died, but one of those patients, his wife followed him into the emergency room. She was there, and they had a young child.
>
> What a horrible moment, and like I'm the person who was responsible for sitting down with his wife that early morning and let her know that her husband had died. There was a social worker there as well. That's a weighty thing to have to tell anybody. I mean, other people probably are wounded by their jobs too – policemen, firefighters, you know, medics – all sorts of people who deal with really tragic things occurring within their work, and yet your job is to be a caretaker or a care provider or even just a caring person in that moment. You're going to have to distance yourself a little bit from what is tragic in order to provide support to somebody else who is experiencing a bigger tragedy.
>
> And the thing reason that I tell that story is that in the process of trying to resuscitate him, some of the blood got on my pants, and I went home after my shift and took them off and put them on the washer and I went to bed. Most pants with a bloodstain on them, it has to be taken care of, otherwise those pants are never going to be useful again, right? So sometime I'm going to have to take care of that. I left those on my washer for a month. And probably the only reason is because dealing with that stain is also dealing with that whole emotionally filled moment, you know?
>
> And– there's not much time, you need to move on, there's more patients to be taken care of, there's not the time that people give themselves or take for themselves or are allowed to sort of deal with those kinds of moments, you know.
>
> And I think that there's some value of art in the environment that helps with that. If I look up and I see something that's beautiful or that means something . . . It's funny, there's a piece of art in one of the hallways of [the hospital I worked in], and for whatever reason, that art is very meaningful to me - for all of my training that I went through, that painting somehow resonated with me and it means a lot to me as becoming a physician, and it has nothing to do with medicine at all. It's a field of Queen Anne's lace that's been painted, and it means a lot to me…And I think it's just serene, it just looked like calm, and there were so many times when my training was chaotic – [the hospital I worked at was] a place where you are dealing with a lot of stories that have difficult scenarios to solve, there's a lot of social problems and all those things. And that just seems like serenity to me.

This doctor's story speaks to many things: the difficult conditions residents work in, the tragic moments they are witness to, the work they must do to be a care provider, and a 'caring person' to others, the lack of time they have to take care of themselves, the way that an encounter with a piece of art can provide a moment of serenity. This story describes how amid the turmoil of attending to illness and injury with care, the simple act of observing art can provide a moment of stillness. The next stories will examine how doctors find quietude and resilience in an ongoing engagement with creative activity.

Dr. Ofri was one of the keynote speakers at the 2013 Society for Arts and Healthcare conference. Not surprisingly, her talk noted the importance of metaphor and story in "both critical clinical thinking and humanistic patient interaction" (SAH 2013). I contacted her after hearing her speak, intrigued about connection she saw between literature and medicine – *why* were the coming together in this hospital? I was also interested in *how* she joined the art of writing and the practice of medicine in an institution. Many doctors write creatively about their professional experiences. Medical literature is a rich field. Medical humanities programs have a decade-old foothold in many medical schools. But the *BLR* is uniquely situated – a journal published by a hospital, containing stories and poems that deal with the issues of illness, suffering, healing and death. Professionally, she is both a doctor and a writer. Attending to stories is an important function of both roles. But there is a personal element too, one that involved a difficult experience during her residency. Dr. Ofri was doing clinical work with no plans to be a writer. When she gave herself permission to take time away from academic medicine, the need to describe and share her experiences filled the space.

> Writing was not in my plans at all. I was an MD PhD student. I was going to do round work and clinical work and writing wasn't on the horizon. I began to deviate from that path during the fall of my internship year. A very close childhood friend died of a sudden cardiac arrest at a young age from a congenital heart condition. And I remember the shock of that period and also we were knee-deep in HIV. I remember even the day of the funeral I was trying to leave early because to get to grand central station I had to get a

> central line in and I could not find his veins and this guy was just covered it Kaposi sarcoma and I was so angry that he was alive and that my good friend was dead.
>
> I think it was starting then that I began to wonder what I was racing towards. I have been doing you know academics my entire life I hadn't taken any time off in fact I sped up, I had skipped a year in high school, I'd entered college early I did an MD/PhD program and now residency and I never have taken a step away.

Ofri explained that she experienced a "saturation of death", from the loss of her close friend in her personal life to the prevalence of HIV loss in her professional world. After Ofri completed residency, during a time when many medical students are applying for fellowships that include further years of specialty training, depending on how many a medical student does, she decided not to do a fellowship after residency and planned to travel internationally, "working temp jobs wherever they need a doctor."

> And I remember that my supervisors were so against this. I mean to the one they said it was a terrible idea. I would lose my connections I would never get back to academic medicine. I remember I went spoke to a social worker that was part of the medical center, and she said, you know? I think they're jealous. And that just clinched it for me. I said I'm out of here.

Dr. Ofri stepped back from full time medical practice. She worked small shifts. She travelled for weeks in Central America, reading books in Guatemala.

> And that's when I first felt the compulsion to think about the experiences I've had in medical school and residency period." I think I realized while they were happening they were incredibly powerful and I should be thinking about them but I couldn't do it. I think I was too close to the emotional ground and I needed to be away.

When Dr. Ofri returned to New York, there was a hiring freeze at Bellevue Hospital and there were no full time positions available. She took a sixty percent position when it "unfroze", an arrangement "which I'd never considered, but I needed a job so I took it." One day she picked up a writing brochure. She decided to take writing classes on her day off and stayed with it. "And when a full time offer came up I turned it down. And to this day I preserve sixty percent status so that I have time for writing." Dr. Ofri has published four books, and is a frequent contributor to the New York Times.

The field of medicine is increasingly providing opportunities for medical students to engage in creative activities. A 2015 study examined the impact of art making on medical students. It found that there were "instrumental, humanistic and advocacy-oriented implications of art-making" (Cox et al 2015). The authors concluded "art-making can play a valuable role in medical education by providing a means of making sense of, and learning foundational information and concepts in medicine. Creative expression through artistic means also provides learners and practitioners a means of exploring their emerging sense of professional identity and clarifying their value" (ibid). This study shows that there is both a clinical benefit to engaging in art, and a personal one. The clinical benefit of art engagement is usually explicitly named in course descriptions; instructors of such courses can speak eloquently about how a certain type of creative engagement can make you a better clinician, but in the same conversation they wanted me to know that they found the personal benefit students received to be just as, if not more, compelling. After all, a doctor is not a strict technician, applying generalizable formulas and using tools to achieve outcomes; she is attending to human illness, which means attending to the narratives patients construct around illness, and the meaning they make from it.

Courses in which medical students hone their clinical observation skills by observing and discussing paintings, also known as Visual Thinking Strategies courses, is billed in a top US medical school as "enhancing diagnostic acumen". The instructor of such a course met with me, and explained the ways in which students learned and practiced diagnostic skills (this has been discussed in greater detail in Chapter 2). At the end of our conversation, when I asked what benefit she hoped students got from her course, she did not speak about clinically correct diagnoses, but about resilience. She began by describing the difficult journey of medical students.

> A lot of time the students are tired, it's a stressful time of their life, they're dealing with the first exposure to patients, the first time doing clinical exams, touching people's bodies, interacting with people in an intimate way in which you haven't had experience like that before. [When doing VTS] I like the idea that maybe we are contributing to their sense of well being in that environment and allowing them to sort of maintain connection to their humanity, who they are.

The hospital context anonymizes patients – it truly strips them of their individuality. Physicians also learn to anonymize themselves in patient encounters.

> One of the things we bring to art when we view art is our past experience – we don't do that when we counsel patients. Sometimes we do, but like the patient interaction is much more – it's supposed to be patient centered, it's about them, it's not really about me.

And yet the physician's self is invariably summoned when confronting the suffering of another person. The art experience provides a space in which medical students can reflect upon their subjective experience, and acknowledge their humanity.

> But when I look at this dog attacking this person, I think about the time a dog bit me when I was a little kid. If [engaging with art] gives them some time to sort of reflect on their own past experiences as part of the interaction with the art and part of their growth as a doctor, then I would feel that was worthwhile.
>
> We do a whole session where we look at nudes. We'll see these very sensual paintings and I watch medical students describing it in a very clinical way. We are trying to get them to reconnect with what it's like to be a human and that nakedness is part of humanity.

The doctor who teaches the Visual Thinking Strategies class spoke with me about how engaging with art can be an experience that strengthens resilience and provides coping strategies for students while they are in medical school, and also when they become practicing physicians.

> So I think the one thing that is really helpful, or I'm really excited about – the theme of resilience and escaping from the rigors or the demands of medicine, both mentally and emotionally. This experience may teach you in that sense to handle all of that and remain calm, you know, and like some of the stuff is pretty big stuff.
>
> And I think with art, that interface really allows them to feel their humanity again, and that feeds back into their resilience of being a professional. Burnout of physicians is about like losing yourself along the way, and disconnecting yourself as a human. And so my hope is that they help heal those connections.

The thing that makes an art experience as facilitated in a VTS class a way to teach students clinical skills as well as be a form of resilience is how the arts discussions call forth subjective interpretations. How the sensibility of the medical student as a culturally situated individual matters. How she can use that sensibility to connect with others. How detailed observation can provide in depth knowledge of a scene. And how, when that scene is enscripted on a human body, the physician can read details that lead to a more accurate diagnosis.

One of the things that physicians are taught, tacitly and explicitly, in medical school is how to practice detached concern. "Detached concern" means they can view the suffering of another from a detached perspective. The story I shared earlier about the young medical resident who had to tell a wife that her husband had died one early morning knew that "you're going to have to distance yourself a little bit from what is tragic in order to provide support to somebody else who is experiencing a bigger tragedy".

Surgeons have a negative reputation among patients (and some of their colleagues) for being cold-hearted. One surgical student described how surgeons learn to practice detached concern in an online forum for medical students:

> To be good at procedures and surgeries, you will need to distance yourself from your patients. Every time you make a cut with a scalpel, you cannot think of the pain. Same thing when you staple the patient's scalp shut, giving a shot, do a shave biopsy, or whatnot. You cannot think about it from the patient's point of view.
>
> Or else you may not do good work. I still remember when I used a metal blade (lancet) to prick patients' fingers for diabetes day. Every time I manually pricked their fingers, I just kept imagining the pain. So after pricking 5 patients, I stopped and let the nurse do it. Safe to say, I didn't do a good job that day.
>
> Emotional detachment is vital for doing procedures. But after a few years in a detached state, you may very well lose the ability to relate. Surgery and OB/GYN doctors didn't get their negative reputation for nothing.

This student makes clear that emotional distance is a skill his education stressed was a skill physicians must acquire. A surgeon I spoke with in the beginning of this study also told me about the importance of detached concern in the moment a surgeon first meets a patient, a moment I didn't realize carries great emotional weight for a patient.

I didn't know that on the path to receiving a cancer diagnosis, a patient sees their familiar family doctor for an initial complaint – a bump that won't go down, a feeling of unwellness. If the doctor is concerned, she will send the patient to a specialist for a test, and the patient will undergo a diagnostic procedure. After the test confirms they have cancer, they must take action, which usually means surgery. And so the surgeon is the first medical professional a cancer patient sees after their diagnosis. The surgeon will explain the option or options available, describe the procedure and lay out what to expect. During this appointment patients are in shock, emotional, and vulnerable. Physicians practice detached concern to insulate themselves from the raw emotions the patients display. “You don't think about it, you just do it. I think that we really are taught to put a barrier around ourselves emotionally when dealing with patients. Because you can't be sitting in the exam room sobbing, obviously. [The practice of detached concern] is instilled from the time you are a medical student, until at some point you may or may not wake up and think, oh, I'm experiencing all this stuff, but I'm really not.”

If you’re “really not” experiencing the sadness of witnessing suffering in the moment, when do you experience it? When do you sob, as a physician? While writing this manuscript, the image of a physician bent over and crying in a parking lot after a young patient’s death garnered an emotional public response, going “viral”. People shared the image on their Facebook walls, linked to it on Twitter; news articles commented on it. One doctor wrote an article that examined the breadth of the response to that image (Wible 2015). Dr. Wible cited the need for patients to see the empathy of their physicians, to know that they, too, are heartbroken by the unexpected death, by the suffering of their patients. But, she continues, the culture of medicine does not allow physicians to express grief. Dr. Wible cited another doctor who wrote, “We are never formally trained to deal with loss.” For all of the clinical training physicians get, they acutely feel the lack of skills to deal with the constant witnessing of suffering and loss.

The way medicine is practiced in US hospitals, with its emphasis on efficiency, moving from patient to patient as quickly as possible, doctors do not have time to acknowledge or express grief. Referencing that image, another doctor writes, “The part most people fail to realize, is that this man now has to compose himself, walk into another person’s room, and introduce himself with a smile and handshake to the next person.” Because medical instructors can’t change the logic of biomedicine, the logic they know will damage the young students in their class, they hope to provide them with an experience that enforces resilience[6].

Dr. Ofri's latest book is titled *What doctors feel: How Emotions Affect the Practice of Medicine*, and it examines the difficult consequences of the emotional damage experienced by medical students. In it she states,

> Much has been written about what doctors do and how they frame their thoughts. But the emotional side of medicine - the parts that are less rational, less amenable to systematic intervention - has not been examined as thoroughly, yet it may be at least as important.
>
> One might reasonably say, *I don't give a damn how my doctor feels as long as she gets me better*. In straightforward medical cases, this line of thinking is probably valid. Doctors who are angry, nervous, jealous, burned out, terrified, or ashamed if they can still treat bronchitis or ankle sprains competently.
>
> The problems arise when clinical situations are convoluted, unyielding, or overlaid with unexpected complications, medical errors, or psychological components. This is where factors other than clinical competency come into play." (2013, 1)

Dr. Ofri's text examines how these emotions, particularly shame, guilt and fear, affect the physicians and the patients they care fore. She presents intimate cases of individual doctors, whose crises during the practice of medicine were solitary experiences, further rendering them without social recourse to address it. Dr. Ofri also examines evidence of how the emotions of physicians affect the clinical outcomes of patients.

> There is…a growing body of evidence to suggest that burned-out and emotionally fatigued doctors commit more medical errors…A seminal study by the Rand Corporation followed twenty thousand patients and their doctors for two years…These were patients with ordinary chronic illnesses – diabetes, hypertension, heart disease, and depression – not acutely ill patients in the hospital…One of the most intriguing findings of the study was that patients were much more likely to take their prescribed medications when they were cared for by doctors who were satisfied with their jobs and lives. This is one of the first studies that directly linked

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[6] Another individual solution to a structural problem.

> doctors' inner feelings (as opposed to their concrete actions) with improved medical outcomes in patients (60).

Practicing detached concern is supposed to buffer physicians from burn out. Yet it seems clear that the practice of detached concern does constitute good care, and does not achieve good medical outcomes. Dr. Francis Peabody, in a commencement address to Harvard medical graduates, told the young doctors in 1926 that "The secret of the care of the patient is in caring for the patient" (Ofri 2013, 212). It is not just acceptable to feel care, empathy and concern for your patients; it is the way to practice good medicine.

It is important to know that detached concern has not always been the way medical students were taught to interact with patients. "It's quite interesting when you look historically at what medical educators say about psychological, emotional, virtue based life in medicine," Dr. Coulehan said. "If you look at the older physicians, Gregory, Osler…people in the 19th or 20th century, what they all write is that it's important to maintain your tenderness and your sensibility, you have to be cautious not to develop coldness of heart. And they use the heart metaphor a lot. And they talk about how medicine makes you susceptible to this coldness of heart or this hardness. You have to fight against it." Dr. Coulehan went on to explain that in the mid 20th century there was a shift in how medical students were taught.

> This all got turned on its head. And people stepped back and said, you've got to develop toughness, You've got to develop clinical distance, you've got to be detached. It all got turned on its head.
>
> And what I'm saying is hell – that's easy. It's easy to become detached – that's no problem at all. That just happens naturally. What we need to work on, in medical education, is the ability to stay connected.

Staying connected is has been described to me as the key to avoiding provider burnout. And engaging with art, doctors tell me, is an important way to retain connection. Dr.

Coulehan, again: “I think creative writing is one way, certainly not the only way, to help maintain the sensibility, tenderness.”

To sigh and exclaim and lament

Anton Chekov, Misery excerpt

Just as the young man had been thirsty for water, he thirsts for speech. His son will soon have been dead a week, and he has not really talked to anybody yet... . He wants to talk of it properly, with deliberation.... He wants to tell how his son was taken ill, how he suffered, what he said before he died, how he died.... He wants to describe the funeral, and how he went to the hospital to get his son's clothes. He still has his daughter Anisya in the country.... And he wants to talk about her too.... Yes, he has plenty to talk about now. His listener ought to sigh and exclaim and lament....

> I think about Chekov's story Misery, which opens with a quote, "to whom shall I tell my grief?" I don't know if you know this story but it's a story about Iona, the sledge driver, he's driving a late night taxi in the snow on a February night with all these drunken party revelers. But his son has died and he really wants to tell the story. He tries several times but nobody wants to listen. And the whole night goes by and no one will hear his story. So at the end of the shift, when he's back in the barn, putting away the horse, he tells his story to his horse, who listens patiently and respectfully, and he's told his story. And I think there is a compulsion to tell a story. Even if there's nobody listening or commenting back.

Dr. Ofri shared this story with me, explaining why she was compelled to tell the stories of what she experienced as a doctor. She told me that “For academic medicine, a lot of writing is about the urge to tell the story. To share and reflect upon the experience of what it means to practice medicine.” For another doctor, a neurologist and a poet, the act of creative writing was also about the need to make sense of what he witnessed. The hard stories don’t end in residency.

> Dehumanization described in med school continues during the practice of medicine so I began to use poetry as a tool of retrospective reflection. I'd go through these extraordinary experiences and not know how to deal with them emotionally, and have no outlet really to talk about them.

Like Verghese, he uses the latest in medical technology, but also laments how it has affected the patient-physician relationship. "As technology has woven its way into the structure of medicine and health and the care of people, there has been an even greater dissolution of the emotional bond between physician and patient." Like many other doctors, he is troubled by the norm of practicing detached concern. He is looking for an alternate way to relate to patients. "Poetry has been a way for me to remain connected to the feelings that I have about patients."[7] In one of his poems he writes about his close connection to a young patient he is treating. How they read together each afternoon before the child falls asleep and the doctor injects the chemotherapy. "There is no way to prepare/for the time I arrive/and he is not there."

Dr. Campo spoke with me about the deep emotions that treating seriously ill patients elicit for a physician, and how creative engagement can help process these feelings by surfacing them, naming them, becoming aware of them, and validating them.

> From the caregiver's, side we recognize how frightening this is for our patients, but also for us. We look at our patients and we see ourselves. And maybe we're in denial about that, but we're not immune to our patient's suffering. So this gives us a way to recognize and validate our own fears. And our own sufferings. Certainly caregivers have a lot of stress and beliefs and unrecognized trauma that doesn't get recognized in many places, and art can be a way to do that.

When I would approach people to ask to interview them for a project on arts and

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[7] Now that has extended actually to a therapy using poetry, the National Association of Poetry Therapists exists and you can actually get a certification as a poetry therapist. (AG)

healing, they would often ask me how what I mean by "art". I explained that I was leaving the definition very open, interested in how they defined it for themselves. I wanted to follow the lead of the people who practice creative activities in hospital settings, not ask them to fit a pre-conceived definition of art that I had. I did find that Dissanayake's definition of art as something fundamental that we *do* rather than a final created product seemed to encompass everything I heard and saw. As Dennis Dutton frames Dissanayake's argument, "there is an authentic-biologically given, and not entirely culturally constructed-human nature which underlies art and other aspects of our lives, and we ignore it at our peril-either for survival or for our understanding of art." Dissanayake writes that Homo Aesthetics tends to:

> recognize an extra-ordinary as opposed to an ordinary dimension to experience; to act deliberately in response to uncertainty rather than follow instinctive programs of fight, flight, or freeze in place; to make important things (such as tools, weapons, and transitions) special by transforming them from ordinary to extra-ordinary, often in ritual ceremonies; and to have a capacity to experience a transformative or self-transcendent emotional state.

Creating art, transforming ordinary moments and objects into the extra-ordinary, is what Dissanayake argues has contributed to our biological survival these past 4,000 years. It is an act that defines our humanity. The act of creation can happen alone, with no intended audience, but more often music and visual art and poetry are crafted through engagement with others and are meant to be performed or witnessed by others. An act of creation requires presence and attention, to self and often to others. It requires attention to story and emotion and experience. It creates space for reflection, and requires participation in the mystery of the self. Earlier, Frenkel stated that when participating in the mystery of the body, who a doctor is personally matters, and she must bring her self into engaged relationship with those she is helping to heal. The vulnerability and courage that creating art summons, and the deep attention to self and other that creative activity requires, are also the elements that are at the root of healing.

Chapter 5: The Final Common Pathway
How Creative Activities are Present at the End of Life

For there will be days of joy
For there will be elevators of elation
    and you will walk triumphantly
    in purest joy
    along the halls of the hospital
    and say Yes to all the dark corners
    where no one is listening
For the heart will lead
For the head will explain
    but the final common pathway is the heart

Gaudeamus igitur.* Therefore, let us rejoice** 1 Kings 3:16-27
John Stone

The tension of the human condition

In Chapter One I told the story of learning that a poet was a member of a palliative care team. I was surprised and intrigued to learn that artists are working closely with medical care teams at many different points in medical care and at the end of life. Critically ill patients and their care teams have to make many decisions about which care options to pursue, and the answers are often not clear-cut. I spoke of the difficulty of navigating the unknown, for patients and for physicians, in my previous chapter, and examined how engaging in creative acts can promote reflection, attention to story, and engaged care. In this chapter I ask: how can artistic practices enlarge our understanding of care for the social self after the physical self has died. Doing this work, I come across a resounding tension again and again: our bodies, that move us through the world, will one day fail. The joy of being alive is tempered by the fact of death. Medicine can only postpone, and often lengthens, this inevitability.

Photographing the beginning and the end

And sometimes, there is not even time for medicine. Death happens to those newly born, to those not yet born. And though pregnant mothers in distress are rushed to the hospital, and though in some cases life can be found and supported, in other cases there is nothing biomedicine can offer to save life. These are especially difficult situations that happen more frequently than most people realize. 15-20% of pregnancies end in miscarriage (Layne 2003), and 1% of pregnancies end in stillbirth. Put in real numbers rather than percentages, out of 6 million pregnancies a year in the United States, about 600,000 pregnancies in miscarriage (more than the number of people who will die from cancer this year), and about 24,000 babies a year are stillborn (10 times as many as those that die from SIDS) (Cancer Facts & Figures 2015; CDC). US hospitals, caught up in the narrative of success and triumph lying in a biomedical cure, and death being a shameful failure, are not good at providing care for people at this time (Layne 2003)[8]. This is a sensitive situation in which the inclusion of an artist in the hospital setting provides a model for what good care can look like.

Photographs document moments in time, and they are constructed through choices the photographer makes about framing, exposure, editing, among various other

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[8] I want to add more here; have requested *Motherhood Lost* from library.

details. In US hospitals, photographers are being invited to create portraits of infants with terminal conditions, or who have been born still. These photographers are coordinated by a number of local or national non-profit photography organizations. Now I Lay Me Down To Sleep (NILMDTS), which connects "photographers volunteering their time and services to families that are experiencing the death of an infant," offers photography services nationally. This organization has photographers in many cities across the country. To provide a quick sense of distribution in major urban areas, there are twenty one photographers in Los Angeles, six in Chicago, twenty-eight in Dallas, twenty-three in Seattle, and thirty-two in the Washington, D.C.

I was not attending to art that is not created *by* patients or medical staff in the hospital at the beginning of this project. But after listening to artists describe how they work with very, very ill patients who are not able to actively participate, such as the young girl with a weakened immune system and the cat project discussed earlier, I became interested in how artists produce art in hospitals *for* patients. I heard one photographer who used to work with NILMDTS speak at an event about the way he did his work, and noticed that he described his work as a practice of care. I approached him, and he agreed to speak with me about his work.

I arrived at his apartment on a cool day. He took my jacket while I admired his art collection and modern furniture. I noticed that he had items laid out for me to see on a table, and my eye was immediately drawn to the larger than life portraits of infants. The infants were beautiful, softly lit, perfectly formed. I would learn later that infants who are stillborn are often physically marred by the birth process, scratched or bruised because they were not active participants in their exit from their mother's body. The beauty that I saw was a product of his labor, and his desire to "give a mother an image of her baby that showed he looked like inside of her."

To get this image, the photographer had to do substantial work in the hospital, work that called for skills beyond professional knowledge of shutter speeds and aperture settings. He told me that he often paused on the outside of the door – not knowing what the scene on the other side would be.

When you know there is a grieving mother who has just lost a child on the other side of the door, how do you enter the room?

This photographer entered the room focused on connection. "I had all my equipment with me, which I put down as I got inside the door, and then went usually to the mother's bedside to try to connect". He spoke about the importance of hands. Touching hers. Using his to delicately position the baby, gaining the trust of the family. "I took such care with those tiny little babies – and it's frightful. Some of them are very leaky, they're bleeding. So the care of and treatment of that little thing was the most important thing that I could do in that room, and showing them care, love respect in the way I treated their baby." By attending to the care of vulnerable bodies by carefully situating his own, this photographer practiced a form of embodied care.

Philosophy professor Maurice Hamington introduced the concept of embodied care into philosophical considerations of human morality and social ethics in his widely cited 2004 text *Embodied Care: Jane Addams, Maurice Merleau-Ponty, and Feminist Ethics* (Hamington 2004 2, 4). In this book, Hamington argues that morality is enacted through the body as it facilitates caring imaginations, or the ability to know and empathize with a little-known other, and caring habits, or the practices of attending to an other. Phillip, the photographer, employed a caring imagination as he considered the current and future emotions and contexts of the families he worked with. Through his body, he demonstrated caring habits that demonstrated deep attention to the "psycho social context" of the infant and families and the context of the environment in which he was working, and in which the photographs would be displayed (Hamington 6).

Validation of physical and social life

Phillip told me how he posed the baby for photographs. "You never touch the baby without their permission – continuing permission, as in 'I'm going to move the baby now, is that all right?' He was conscious of his photographs being more than documentation of biological life. He constructed a social being independent of their medical context. His long-sleeved black corduroy shirt would sometimes double as a backdrop for his photographs. He brought a long black cloth he would have the nurses hold "to cover up all of that hospital equipment". By photographing a child that would never go home, or be shown off to visitors, he was validating that a life was lived, and had value.

> So then after you go shoot and bring these things home and see how much work you've got to do, you have to try to figure out how to tell the most sensitive story the family has ever had in a meaningful, beautiful way that will touch them, that they feel they can share. Because what I've heard over and over again is that these images validate this little life, regardless of how brief it was.

The photographer's labor of care provided an image that has social value. Families shared the images with other family members, showed them at memorial services, or displayed them in their homes. Through photographic images, the parents were able to introduce that child to other members of their social network. The photographs created a social reality that could last beyond the physical death of the body; a reality that acknowledged that the child was a member of a social group, and was a social being.

Validation of suffering and care

The photographs validate the life of the child, and they validate the suffering and care of the family. The suffering of the family took place in the semi-private environment of the hospital room. The photographers are invited in, either by the family or by the medical team, and the family signs consent forms before the photographer enters the room. Still, some environments were difficult to navigate. "Some of them don't want to see the baby, but yet want photographs. And then there are ones that want to spend the whole night there and day with that baby before they're separated from it forever." In our conversations it became clear that knowing how to enter the space, interact with different family members in various emotional states, and create images that will function as validation and memory requires a familiarity with suffering, and a sensitivity to it. "Not everyone can do this," he told me.

The photographer described various family scenes and levels of engagement. Young mothers might talk and joke with their friends while he photographed the baby in the next room; in another scene, family members of a recent immigrant couple filled the room and anointed the baby with shea butter as he photographed.

> Some people have no idea what to do in this situation, so everything is a stress and a strain, and a lot of times the fathers were there and would not get close to me nor would they get close to the baby, and couldn't hold the baby or touch the baby or look at the baby. So you were dealing with that.
>
> Sometimes you were dealing with a whole series of people who really wonder what in the hell is this man doing here? It's not always a welcoming environment, a lot of times it's not, so you're trying to do the best you can and capture stuff for them after the fact when they are healthier emotionally than they are at that time when you're there.

His primary goal, he told me, was to validate the social relationship between the mother and the child.

> My goal is always to involve the mother in the photographs. I can't tell you how many times the mother would say, "no photographs of me." And so I would accept that. I would say, "Well, maybe in a little while you'll at least let me photograph your hands holding the baby." And a lot of times, by that time I had been there an hour or 45 minutes, they would say, "it's okay, I can be in it." That was my goal.

Even if the mother didn't consent to being in the photograph, he would try to photograph the mother's hands holding the baby, or touching the baby. By carefully constructing these images of connection, he validated the social relationship of the mother and child. And he recorded and validated acts of maternal care, that later became proof of care. The mother often won't remember the details of those short hours, he told me. She will later wonder, "Did I touch my baby? Did I cry?" She will wonder if she performed maternal acts of care.

> Because I think the mother is so raw during the whole time I'm there, that they don't remember what they did. They don't remember if they wept, they don't remember if they touched the baby, they don't remember.

> And I think that's what these images speak to the most, is that I *did* care, I did see, I did hold. It's validation to her that that bump she carried around for some time was a living breathing thing for a time, and she held it.

These photographs are markers of social recognition of the child, social relationships of the family, and serve as a legacy of the child's life. NILMDTS shares their vision for this work on their website: "Our mission is to provide remembrance photography to those families whose infants will never leave the hospital to have the opportunity for professional portraiture."

Professional portraiture for infants is becoming a cultural norm for US families who can afford it. Families can arrange for the services of an experienced infant photographer; these sessions can cost between several hundred to several thousand dollars, and typically involve poses that highlight the small size and flexibility of newborns. Other photographers do lifestyle documentary photo-shoots of the new family in their home. Some photography organizations send a photographer to local hospitals on certain days of the week, to offer their services to parents who may not have thought to book a professional infant portrait session, but gladly accept the services.

Professional child portraiture began with paintings of the Christ child and other holy figures in the 12th century. In the 13th century portraits of children and images of children as angels began to emerge. In the 1500s, a moment Philippe Aries notes as "an important moment in the history of feelings" (1962), portraits of contemporary children were created; that is, it was not only holy or royal children that were memorialized in art. Children of painters, merchants and others were depicted. As income increased for many families and as child mortality began to decline, more families commissioned portraits documenting the childhood of their little ones. The 1500s also marked the beginning of the development of a middle-class ideology of childhood, which held that childhood was a special time worthy of celebrating and protecting (Cunningham 1995).

When the process of photography was developed, families paid to have photographic portraits made. In Victorian portrait photography of children, mothers would stand with their children during the process of creating the photograph, but then be scratched off of the photographic plate (Riches 2014). Or they would be hidden behind a draped cloth or curtain, the cloth masking the social relationship of care that sustained the children. In the photographs that Phillip constructed, the social connection is emphasized, validated, and recorded.

Parents sometimes have a troubled relationship with remembrance photography. Once social worker that worked with families who lost children to cancer explained that they often would not even open the beautiful digital images when they arrived, not wanting to remember their child in the context of illness and hospitalization. Parents whose children never left the hospital place a different value on the images of their children. They may take time, a year or longer, to look at the images, but when they do open them, they invariably are grateful for the images. One mother wrote to the photographer, admitting that at the time he was photographing her baby, “I didn’t want you there”. But after taking the time to grieve, and then view the images, she found an incredible value in having them, in grieving with them, and in integrating her experience of loss, and her child’s memory, into her life. She wrote the photographer a letter explaining this, and thanking him for his work; he described this letter to me as a very meaningful possession.

Remembrance photography functions to demonstrate that all lives, however brief, are woven into a social fabric. Their passing is noted, marked and remembered. The photographs serve as a legacy of the child. When families display and interact with the images, they preserve the child's social role as an important member of the family.

Legacy Matters

> I get to experience some of the brightest days at the end of their lives. And then the art remains for their families and it becomes a part of their memorial service. The art remains in a way that their other treatment doesn't. – *Art therapist*

Memory, legacy, and the social, emotional and familial bonds that continue past death become the subject of some hospital art that is created at the end of life. Some nursing scholars describe the process of creating art when very ill as legacy making. Legacy making is a process tightly joined with action and memory; it involves the creation of an object for the purposes of remembrance. The definition of the term "legacy" changes depending on the context and person using the term. There are legal definitions of the term that include financial gifts and tangible items that are stipulated in a last will and testament. Prominent political figures might erect of a physical structure to bear their name, such as the practice of US presidents to create libraries that define and display their legacy. Inspired by the use of the word by hospital artists, when I refer to an art object as "legacy art" in this text, I mean something *created* for a specific person, either by or of the person who is dying, with the intention that that object serve as a *reminder* of a person who died. It is usually created by the person who died herself, although, as the case of the remembrance photographer illustrates, legacy objects can be created by others to serve as memories. The creation of a legacy object is important and deeply fulfilling to patients and their families.

For patients who have no medical treatment options left available to them, engagement with creative activities can function to ease suffering; they can be a form of social palliation. The product of those creative activities can, and often do, become legacy projects. Through the act of creation, a patient can move between the passive "sick role" to the active role of creative agent. A patient's ability to participate in something creative allows his families to witness him succeed in non-medical contexts. A pediatric palliative care doctor spoke of public performances children gave in his hospital; "You know, it's hard to even describe the kind satisfaction that those patients get from being able to perform in that setting, and their families get the opportunity to hear them and have the children be recognized in that way." The memory of a performance, the created object – these become a patient's legacy. Many patients use their sessions with a creative facilitator to create something specifically for the purposes of being remembered; or of continuing to be "present" at meaningful life moments.

Kϋbler-Ross sees the acts of "completion" and "affirmation" as important elements of a good death (1978, Tribby 2009). Creating an object that embodies how one wishes to be remembered by loved ones is a desire shared by many terminally ill patients. Knowing that one's life was meaningful in one's social world and that one will be remembered after one has died is of universal importance to the dying (Green 2008). Research conducted by a medical team as part of a longitudinal study of families after the death of a child from cancer found that taking an active part of one's memorial, or legacy, has significant spiritual, social and medical benefits for the patient (Foster et al 2009):

> Results showed that after the legacy-making intervention, participants' sense of dignity, purpose, meaning, and will to live increased, whereas suffering and depressive symptoms declined. In another study, adults living with advanced cancer reported being concerned about how they would be remembered, and the creation of a legacy was universal to all participants (Coyle, 2006). Creating a legacy appeared to be a significant component in the adjustment process for these adults.

The types of legacy-making projects that children engaged in in the hospital in Foster's study were creative projects that involved the use of art. One sixteen-year old boy crafted a cement stepping stone inscribed with a message for each member of his family. A thirteen-year old girl made paper flowers for her family and friends. Foster's analysis found that though legacy projects were both intentional and serendipitous in nature, those that were intentional were more meaningful for the families as they grieved (2009).

Dr. Coyle, a nurse who works in the Pain and Palliative Care Service at Memorial Sloan-Kettering, conducted a study on the work of living with advanced cancer. She found that individuals worked to orient themselves to the disease and maintain control, to search for and create a system of support and safety, and to find meaning and create a legacy (Coyle 2006). She found that "creating a legacy was a task undertaken by all of the participants", though each had their own definition of what constituted a meaningful legacy. Regardless of the form, what was most important to each patient was the assurance that they would be remembered.

> The concept of leaving a legacy is perhaps not bound up so much with generosity as it is with desire for continued existence in the future—the creation of a view of themselves for posterity incorporating evidence of their own value, of a certain significance of their existence, and a justification for how they

> lived and what they did. Creating a legacy appeared to form a bridge for the participants between existence and nonexistence, and for that reason was an important element in the adaptive and adjustment process of these terminally ill people.

The idea that one continues as a social being after death echoes the argument that professor emeritus of religious studies Dennis Klass makes in *Continuing Bonds* (1996): death is not the end of a relationship, it is a transformative event that marks a new kind of connection with the deceased. A discussion about how one wishes to be remembered, and the creation of a memorial object via a legacy project can serve as a 'linking object' that connects those who remain with those who have passed. When they are actively involved in the creation of a legacy the dying feel more relived, at peace, and report less pain (Foster et al 2006), and the project holds deep emotional significance for those who receive it.

Hospital artists work with many patient populations and facilitate a wide variety of art projects, as I have described in this text. It is worth noting that nearly every artist I spoke with, regardless of the main patient population with which they worked, described a legacy project they helped facilitate. Sometimes a doctor suggested that they work with a terminally ill patient on a legacy project, sometimes the legacy project was initiated by the patient. As I listed to the stories of how patients with a serious illness approached art, I noticed that the projects functioned in three main ways[9], and that each object may contain more than one function: 1) a type of art communicates a person's life and identity; 2) a type of art that is intended to serve as a memory for specific family

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[9] Patients also create art that expresses their current emotions, which may involve deep fear and sadness, during art sessions in which they also create legacy art. Because this art is not intended to be given to someone for the purposes of remembrance, I have not included it as an aspect of "legacy art".

members and 3) a type of art that continues a person's social role, allowing them to be "present" through the art for different life events.

One art therapist described a project in which a patient communicated her identity through an art project.

> I worked with a patient who had had some recent bad news – she was at the end of her treatment and that's as far as it was going to go. The art that came out of that really spoke to the identity that she was proud of and the identity that she as sad of losing.

A similar project was created by an elderly patient who had ovarian cancer who crafted a book of illustrated poems as a memoir for her friends and family.

> She was eighty-nine, had ovarian cancer. She knew she'd eventually die of it. She created a series of poems and then art to go with the poems, and created a book to make for everyone in her life and [it was] it was like her summary kind of, of her life review poems.

Other examples illustrated how patients created art that was meant to serve as a memory object. One art therapist at a hospital in the South spoke of being referred by a physician to help a patient who had a terminal illness create a memoir for her daughter, a project that was deeply significant for her.

> I was able to facilitate an oral historian, record the story, the transcribing process, the design of the book. She has been so motivated to do that, so incredibly motivated. Because it's important to her and important to her daughter.

A therapist at a west coast hospital also shared with me an example of a father who created legacy art to serve as his memory for his young daughter.

> I once worked with a man - male patients are rare here, I do see some of them, but mainly it's women. He made several things. When he was

> dying I was able to go to his house with the social worker and bring him all his art, and we talked about how these are going to be for his child, something for them to have that he made - certain pieces, especially. He had a daughter who was about a year old when he died. Some you can kind of tell would be private and some would be paintings that he'd want the child to have. So they weren't just legacy pieces for their own life review and like what I'm leaving behind, but these ones were like directed right to the kids.

Another example is of a mother who created such a legacy object *with* her daughter. They were both involved in creating the art. The therapist described facilitating these sessions deeply moving.

> I had another mom in here who brought her child in and they made art together, fully aware - she and I had talked before, "so she can have these when I'm gone, these pieces." Those are hard, like I'm sitting there like I am right now - sitting with them and looking at her, looking at her, watching Mom look at the daughter and just going ooh, I know what they're doing right now, she's just soaking it in, and they're making this piece that will be for the daughter's book, to have this art book of her mom.

Mothers diagnosed with HIV in Uganda also created memory books for their children. It is very important for children to have a sense of familial history, and these books serve to ground children in their family lineage, while also giving them important information about their mother's health, experience of illness, and memories of their children (Plan USA).

The same art therapist described her recent work with a patient to create an extensive legacy project that would serve to enact her social role and maternal relationship with her young son.

> She was by trade a therapist herself and had a private practice, and then when she was in her mid-30s was diagnosed with a really rare esophageal

> cancer, like a random thing you don't expect someone to get. She came to art therapy, like I said, about five times. The last time I saw her she was inpatient because she had just had a stent put in her throat to open it up again, and she was doing great.

The art therapist was with her when her surgeon entered her room to speak with her. She asked him to return at a later time, not wanting to miss her opportunity to create with the art therapist. "She didn't want me to leave. She requested that he come back later. She wanted her time." She had planned to create pieces that would serve remembrance items for her family, and especially for her son.

> She had a twelve-year-old son. He was nine when she was diagnosed, and she had made him recordings, audio recordings. She had made him cards and letters for every significant event. She said, "I may or may not be there," because she still was thinking I could have a couple years.

In this story, the cards the patient created served to continue her social role as a mother after her death. Knowing she would be physically absent from many milestones mothers celebrate or mark with their children, such as birthdays, holidays, graduations, weddings, etc., she created ways for her son to experience her thoughts and wishes for him on those occasions.

She died suddenly before she could complete them.

> I was all set to see her again the next week and then she unexpectedly died. She had a rupture and it was just so horrible. The thing you don't want, the death you would wish upon nobody, about twenty-four hours of acute everything and then just suddenly going.

The patient's death was both anticipated and unexpected – this is commonly the case for patients in US hospitals (Kaufman 2005). This therapist described the work of the work of creating legacy art by patient to remain after her death even as she underwent medical procedures to prolong her life as a "parallel process"; she was living in a dialectic.

> She didn't call herself dying, but she was doing this really important parallel process that I identify with a lot of different patients, which is they're hoping to live the longest, fullest life they can, but they still have to prepare for death, and they really don't know. We talked a lot about preparing. The art became the next step for a legacy project.
>
> I was so pleased that she was doing these things, but she openly talked about death too. She also made some drawings and collages that were very personal about what scared the shit out of her, basically and what were her worst fears, but also her hope and strength building. And those weren't for him.
>
> She created these little miniatures - these weren't technically for him, but kind of were, she knew she was making them kind of for the family, so invariably her art became the continuation of the legacy work.

Patients have to do a lot of work in this parallel process. The impending death is a trauma that patients use art sessions to acknowledge, and to address. They acknowledge their fears and their hopes. And they create things that represent them in the moments they will not be able to be a part of. They create things that can be daily reminders of them.

These examples of the legacy work undertaken by patients facing death acknowledge that it is a taxing form of labor that patients make great effort to undertake, despite the need to expend large amounts of emotional and physical energy at a time when they are often exhausted (Foster 2009, Coyle 2006). In the case studies I have described from the literature, the patients struggle to decide for themselves what constitutes a meaningful legacy project, and there are no institutional programs or staff that engage the patient in this process. Patient art-programming does not, in most cases, explicitly aim to assist in the creation of a legacy, though it legacy projects are supported when initiated by the patient.

Given the real emotional, physical and spiritual benefits of engaging in legacy work, desires for legacy should be addressed as part of empathic and palliative care. Despite the acknowledged benefits of an open and empathetic discussion of legacy, discussing the terminal nature of illness is painfully difficult for many physicians, even those who care deeply about offering patients the opportunity to discuss end-of-life issues with their family; indeed, such physicians are loathe to begin such conversations with their own family who may be facing decisions about end of life care (Gawande 2010). Yet physicians sometimes refer patients to hospital artists and art therapists to create a legacy project, and patients find these projects worthwhile. Perhaps it is time to consider whether or not such opportunities should be available to all patients?

Securing the opportunity to participate in a legacy project for all patients is an exercise in medical ethics. As discussed in chapter three, the first principle in medical ethics is respect for patient autonomy, which means that the adult patient has the right to refuse or choose their treatment provided they are mentally competent (of sound mind and body). Patients can choose to refuse heroic life-saving measures such as CPR or advanced cardiac life support by employing a Do Not Resuscitate order. Patients may also create a living will in which they can express their wishes regarding receiving intubation, ventilation, or artificial nutrition and hydration. In these ways the medical community respects patient autonomy only in regards to the body, the physical self. Patients also have social selves that will be affected by disease, treatment and death. Given that being remembered by loved ones is a desire shared by many terminally ill patients, and that some patients value the opportunity to participate in legacy projects and consider how they will continue as social beings through and after death, it is reasonable to assume that such an opportunity can be understood as “good care”. Giving patients the opportunity to participate in such a project provides a more holistic view of patient autonomy, extending autonomy beyond the body, and recognizing that though life may be present in the body, it is maintained and validated through relationships with others.

Care ethics, as discussed by Marian Verkerk at the University Hospital Groningen, offers us a way to enlarge our view of patient autonomy by incorporating respect for relational autonomy. Patient autonomy as described above is about respecting a patient's independence, even though many medical procedures the patient chooses to accept during advanced care make them ever more dependent on medical equipment and on their relationships with medical staff. This form of care emphasizes patient independence in the form of choice (she chose x or y procedure) and renders invisible the increasing intimacy that each procedure entails or causes, thereby distancing the patient from her caretakers. "To understand the value of care itself, it is therefore necessary that we rethink the human condition as interdependent" (Verkerk 2001, 291). People, and specifically people who are hospitalized as patients, exist in relation to others. Care ethics is a critique of the ideal of independency as key to human agency but still holds the moral value of autonomy. Instead of fundamentally individualistic, care ethics develops a "relational account of autonomy" (289). Relational autonomy acknowledges dependence on others, who might include, in the case of the terminally ill patient, family, loved ones, and the medical care team. Dependence has a negative connotation, and relational autonomy seeks to rewrite the definition of what it means to live as a moral agent in relationship to, and with, another. Verkerk writes that "dependence on the help of others is often humiliating in a society which prizes independence. Susan Wendell therefore pleads for the ideal of interdependence (Wendell 1996). She states that we should question our cultural obsession with independence and replace it with a model of reciprocity" (2001, 291). Relational autonomy offers us an alternative way to conceptualize the doctor-patient relationship. Rather than one-way or passive/active, the relationship between the patient and her medical care team should be reconceptualized as a relationship of interdependence.

Enlarging our view of the doctor patient relationship as interdependent does not decrease patient autonomy; rather, patient autonomy is enhanced. Care ethics is still concerned with autonomy "as the moral capacity to make one's own choices in life" (Verkerk 2001: 291). Autonomy in this sense is exercised in order to "monitor one's conduct and determine whether or not it is in accordance with one's true self. An autonomous agent asks questions such as 'Can I take responsibility for this or that action while retaining my self-respect?'" (Verkerk 2001:191). Legacy work not only provides patients with the opportunity to reflect on how they have answered this question in the past, but how they will answer it in the future when they must make difficult decisions about what aspects of advanced medical care they will pursue or accept.

The studies discussed above have shown that an important concern of terminally ill patients is how they will be remembered by loved ones. The examples of legacy art projects that were shared with me also reflect the desire of seriously ill patients to create objects that will represent their memory. Engaging in creative activities that can become legacy projects, has numerous positive emotional, social and physical benefits for the patient as well as the patient's family and friends.

Such projects are sincerely valued by patients and their families (Kelly 2012). Legacy work is a way for terminally ill patients to address and make meaning of the disruption of social self. Ars Moriendi, 13th century booklets on the art of dying, the procedures of dying a good death, used to instruct families, doctors, clergymen and the sick on what to do, say, hope for, and pray for at the time of death (Beaty 1970, Bertman 1998). Today we have no such cultural script when it comes to death and dying (Green 2008), and words are hard to find. In fact, many greeting cards in the United States expressing sympathy for a loss due to death contain phrases such as "there are no words" or "words cannot express…". In the descriptions of how families valued legacy art created by their patient, knowing the item was intended for remembrance found that having the item made grieving easier (Coyle 2006, Foster et all 2009). In fact, one of the most beneficial effects of legacy making for families is just this: it helps loved ones focus their grief; a legacy project, in effect, gives them a sort of "cultural script" of how to grieve and how to use linking objects to promote continuing bonds (Klass 1996).

Furthermore, maintaining the social being of the deceased through ritual and memory is part of the healing process for their loved ones. Without having participated in legacy work, families often create such a ritual or memorial after death on their own, but report that having discussed it before death with their loved one provides deep comfort and peace (Foster et al 2009). Dr. Rafael Campo described how poetry can be used by those who are dying, and those who mourn their passing, as a way to retain connection.

> The way poems – and again, I always think of them as kind of last words, in a sense – what they can do that is really transcendent. And I also think too the poem or the journal or those last words that people who have died leave us are a way of in a sense attaining immortality – those words, those expressions of those people's souls persist, they live on after death. So I think in an important way, poetry can defeat dying, can defeat death. It doesn't prevent physical death, but it can transcend

> that kind of sense of loss that can be so painful for the people left behind. And that person can still be present in his or her words, and that I think helps tremendously.

Social suffering, social solutions

A counter-narrative to biomedical conceptions of illness as disease located in an individual body is conception that examines illness as a social experience. Arthur Kleinman discusses the difference between disease and illness, placing the patient as the dominant actor in his or her experience of living in an ill body rather than acknowledging the doctor in his or her role of diagnosis and treatment as the primary agent. Kleinman is concerned with how the patient suffers, and how that suffering, and the alleviation of suffering, are guided by cultural roles (2006). People are not sick individually, they are ill in relation to others. Biology, society, and kinship meet in the body: biologic processes move us through the world, relationships of care sustain us, and social structures influence the opportunities we have to act, to seek care. When a body falls ill it is not only the body's biology that is affected, but the relationships and social structures of which that embodied self is a part. When a body falls ill, there are not only biological explanations – care given or withheld, social structures that provide or deny access to pain relieving medications and therapeutic drugs also affect the course of illness. A person's illness is frequently produced by social structures, often ones of extreme inequality such as those Livingston describes in her account of the cancer epidemic in Botswana (2012). Illness is experienced in social relationships, affecting familial, friend and professional roles. Illness is lived, suffered, treated and borne by a sick person who is embedded in various social networks. When a person is pulled into networks of treatment, out of public life into the hospital space, out of home into a treatment room, out of agentive social roles into the passive sick role, a person is isolated physically, geographically, and socially. If disease is embedded in a specific body, but illness is an experience lived through social relations, how to care for the whole person? If medical institutions are facilitating programs in which patients make art as a type of holistic palliative care, how does art-making function as a practice of care?

Social pain, social care

Engaging in creating activity in hospitals functions to mark the patient as a social being, enter the patient into a social network or networks, and by affirming the whole person as one who is able, social, creative and productive, do the work of palliative care. The artist who creates large-scale communal projects at MD Anderson, Ian Cion, believed that he was brought into the hospital because the administration valued his communal approach to arts facilitation.

> I was interested in collaborating, in community-based arts programming. And by "community," I mean like setting up groups, getting people to come together, patients and family. And that was also distinctive in terms of the programming that they had in the past. I was really interested in involving the whole family, and involving the parents, involving the siblings, or figuring out how by not involving the parents—by involving the kids—and how that would impact the parents as well as caregivers. I think that they saw the value both for the patients and the families and the institution, but also for the message of caring that it would convey.

Not all creative facilitators I spoke with facilitated community projects. Yet many of them spoke of how they saw community form between patients who created art, and patients and their families or sometimes even care teams when they discussed the art.

Rafael Campo described the creation of poetry as a way of building community.

> Poems are a very primal call to community. I think in the larger fractured world in which we live where people are so alienated from one another and are really disconnected from community in a broad sense, poetry can be this wonderful call to rejoin the human experience. Whether it's writing in a group of people living with illness who are expressing what they're feeling and what they're seeing in the form of poetry – that sort of ritual of formal language and joining in that circle of shared experience through the poem is also really I think pretty unique to poetry.
>
> When we think of performative language and we think of the healing rituals of Native American people, for example – there are many traditions of using performative language to heal in this community sense. I think that poetry does have this really unique quality of joining us, both publicly in a healing gesture and then also internally helping us to feel solace or maybe the kind of catharsis that is also really part of getting well.

Art making in hospitals, through large-scale projects that are open to the hospital community, or through small workshops or activity nights with a few patients, is a social, integrative process that pulls patients out of the isolation of their rooms into a community of others. Because they are in the hospital to receive treatment for an illness, many patients are also managing a great deal of pain. Some scholars, such as Julie Livingston, state that being in community with others can work to alleviate pain. Let us take a moment to consider how social integration works to address pain as a form of palliation.

In contexts in which palliative care is not available, such as the treatment of cancer in Botswana, patients experience severe pain and suffering. Pain relieving drugs such as morphine are not accessible, and patients bear excruciating procedures like bone marrow aspirations, suturing, and chemotherapy, in silence, but their pain is closely observed and named by others as part of care.

Elaine Scarry writes of pain as excruciatingly individual, as annihilating the social self. Livinsgton (2012) writes that conceiving of pain as social, understanding pain as a relationship (Asad, in Livingston 121), is more helpful to understanding pain and palliation in the Botswana context. When pain is shared, as it is by those who are connected intimately to sufferers who massage the aching midnight body, the individual self is not annihilated but affirmed. When pain is voiced by nurses in a hospital who murmur *"botlhoko"*, the Tswana word for pain, in deep empathy as a severely painful aspiration procedure is performed, the self is seen and heard though it may be silent. Jokes are made that allow patients, nurses, doctors and a visiting ethnographer to laugh together. When laughter is shared in spite of, or because of, extreme pain, the self is restored to its social context. Geertz (1973) writes that the ability to share a joke is emblematic of one's deep immersion in a culture. When a patient and his or her caregivers or medical care team laugh, the person in his or her entirety is incorporated into the social milieu; the person is deeply embedded in his or her social scene.

Laughter, then, can be understood as a type of palliative care that relieves the pain of isolation by reaffirming the social situation of the patient in the context of cancer care in Botswana. In medical institutions in the United States, the production of art in relationship with others can also be understood as palliative. Being in community with others affirms or re-affirms the social self of the one who suffers and in so doing, relieves the suffering. In various contexts, when the social self is seen and recognized, when suffering is voiced, and when the self is integrated in social networks, the whole person experiences healing. This happens in creative activities in medical institutions. Art production supports recognition and integration – practices of care that mitigate isolation and relieve pain – and that allow patients to make meaning of physical and social suffering.

Palliation as accompaniment

When the last breath leaves the body,
do not think I am dead . . .[10]

The Yolmo, ethnically Tibetan Buddhists who make their home in Nepal, carry out practices of accompaniment to that they believe help ensure a good death, accompanying their loved one "in the process of dying, up to the 'mouth' of death itself" (Desjarlais 2014). A Yolmo lama, a religious figure, will often be requested by the family to read from the Bardo Thos Grol (Tibetan book of the Dead).

> The texts make clear other dimensions of a person's existence, beyond the pain and futility of dying itself. The coarseness of dying is steered into something sacred and transformative. When heard, the texts emit a semantic, syllabic, and emotional fullness which stands in contrast to the sparse banality of dying. They couch the singular intensity, the lonely thusness, of the person's cessation within an expansive spatial and temporal landscape.

In the United States, there is not a similar ritual of accompaniment at the time of death. And most US deaths – over seventy percent -- take place in US hospitals (Kaufman

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[10] From "Shifting, Not Dying." Translated from Nepali by Temba D. Yolmo and Robert R. Desjarlais (in Desjarlais 2012).

2005). Music therapists, among other creative facilitators who work with terminal patients in US hospitals, are asking, “How do we make a good death happen? How do we make you comfortable, preserve the quality of life, how do we make a good death?” This music therapist sees such questions being attended to in a hospice. A 2013 survey found that sixty-nine percent of responding pediatric hospitals had a palliative care team, but not quite 30% offered home visit services, or a separate place to receive hospice care (National Hospice and Palliative Care Organization 2015, 7).

> There isn't a place for them to go that's separate...every unit is about something- the surgical unit, the medical unit, the intensive care unit, the cancer care unit....unless you have a place that is designated where that's going to happen, it's going to happen kind of amongst everything else.

Another music therapist spoke of how music can be a form of accompaniment at the time of death. When families requested it, she would play in the room of a patient who was close to death. She described sitting in a chair in the corner of the room, softly playing her guitar. “That’s something that I actually really enjoy about music – a patient doesn’t have to be fully engaged in it, they can be passive, they don’t even have to be conscious. It’s nice to give that aura over the room. It can help people quiet down.”

The examples from the Yolmo and the music therapist show that aural accompaniment at the time death is near is an important form of care that can be offered whose effects go beyond what biomedicine can offer. It reaches the patient, the patient’s gathered friends and family, and medical team, and by reaching includes them in a community of care for the patient and for the process of dying.

On Accompaniment

Accompanying someone through the “sparse banality of dying” in a hospital can be a brutal process for those who attempt it. Palliative care or hospice teams administer large doses of pain medication, and the patient may be so deeply sedated that they lose consciousness, their breath slowing until it stops. But sometimes pain is not fully masked, and the patient cries out. Or the body is not calm under sedation, but wracked by seizures or tremors. The last breaths may be labored. For the loved ones attending to the patient at this time, the suffering is communal. The patient suffers, and so do those who witness the suffering. People do sometimes want to look away, or leave the room. Under these circumstances, witnessing is a moral act.

> One of our most difficult duties as human beings is to listen to the voices of those who suffer...these voices bespeak conditions of embodiment that most of us would rather forget our own vulnerability to. Listening is hard, but it is also a fundamental moral act; to realize the best potential in postmodern times requires an ethics of listening. I hope to show that in listening for the other, we listen for ourselves. The moment of witness in the story crystallizes a mutuality of need, when each is *for* the other. (Frank 1995, 25).

Communal witnessing is enacted by, and creates, connections of care. Physicians can choose to enter in to these connections, can choose to witness the pain of patients as well as treat it. Rafael Campo spoke about the obligation physicians have to not only witness the pain of their patients, but to “share in the experience of bearing it.”

> Pain does demand that we witness it and that we try to articulate it, and certainly not do what we typically do in allopathic medicine which is to distance ourselves from it and to just try to cover it up with a medicine – that's not to say we shouldn't try to relieve pain with analgesics, but I think sometimes that's all we care to do, that's all we know how to do.

> There are those many instances where pain medication doesn't take the pain away, and rather than averting our eyes from that experience of suffering, I think we're really obligated to be present at it and really, in the way that poetry does, share in the experience of bearing it.

When biomedical options reach their limits, or fail to work the way we hope they would, or cannot relieve suffering, the examples of those who create with and for and about patients offer us a model of care that can be called “good care”, and that can be an aid to a good death: embodied accompaniment, and empathetic witnessing.

Chapter 6: Conclusion

Imagine that you have decided to get that nagging pain that you have felt for the past two months under your ribs investigated. Your doctor is not overly concerned by your symptoms of fatigue and low fever, suspecting a seasonal cold, but orders a diagnostic exam to rule out a more serious condition. The exam reveals that the condition is in fact quite serious; you have kidney cancer. Your prognosis is uncertain. You are scheduled for more imaging, a surgery, and then chemotherapy. You must take an extended leave of absence from your job. Your spouse works longer hours and also takes over household duties, visiting as much as possible in between. Friends and family visit too, but there are still long hours in each day in which you are alone. You have always loved music, and during your second hospitalization your oncologist suggests that a music therapist join the medical team. The musician joins your doctors as they consult with you during their rounds, and knows about what treatments you are undergoing. During particularly unpleasant or painful parts of your treatment, he plays music that you find soothing, and you are able to relax, to manage the pain without the opiates that make you itch and leave you feeling foggy.

During the times when you feel well enough to want to do something, he comes in and shows you how to play a few notes on the violin, which you used to practice in junior high school. He brings a small laptop with software that lets you record your playing, and add other sound elements. You wouldn't have called yourself tech-savvy, but you find you enjoy it. You look forward to the days when he visits you. In between sessions, you play the song you find you are composing, and think of other elements to add. You start to really like the song, and you can tell it's improving. The nurses begin to request it when they come into your room. They tell your doctor about it and she asks to hear it; she shares that she too plays a stringed instrument. Your medical consultations now often involve a quick discussion of pieces you both enjoy. You find that you feel freer to ask questions about your treatment, and to share your concerns. You notice that the quality of her listening has changed, and you feel more deeply heard. The musician arranges for you to record your song onto a CD, and the list of people with whom you'd like to share it is longer than you anticipated.

Or perhaps you enjoy keeping a journal, or you used to before life got so busy, and you are visited by a poet who guides you in crafting descriptive sentences that lead to a series of poems. Or it could be you have never touched a paintbrush in your life, but an artist asks if you would be interested in exploring painting one morning as you lay in bed for the third straight day, weary of boredom. You find the simple exercises she suggests interesting, and begin to pick up technique and style. You find yourself enjoying the act of composing images for loved ones; you find that your days have stretches of enjoyable and meaningful activity.

These scenes are composed of descriptions shared with me from the few examples I encountered of artists integrated into medical care teams. They portray what medical care could be like for more people if artists and art therapists were more uniformly integrated into the medical care team in more hospitals, especially for patients with serious chronic conditions. Throughout this work, I have offered a critique of the biomedical paradigm and the logic that supports it, highlighting the ways in which creative activities point to gaps in care practices or suggest alternative ways of conceptualizing care. In this final chapter, I would like to suggest a vision of what a re-framing of the purpose and practice of medicine could be. I have cited Atul Gawande's critique of current medical care practices and his vision of a better care model several times in this work, and I return to it again here. "We've been wrong about what our job is in medicine", he writes in the epilogue of *Being Mortal* (2014, 259). "We think our job is to ensure health and survival. But really it is larger that that. It is to enable well-being." Well-being is not something to be attended to outside of the medical system, but within it.

There is at times a division of labor in the types of care that happen in the hospital. To generalize, the work of the doctors is to diagnose and treat the body, while other types of care professionals such a social workers and therapists generally address the psychosocial aspects of disease. In an example I heard that represents one end of the spectrum of ways that doctors approach their work, a doctor was dismayed by a crying patient and called in a social worker, to avoid engaging in the pain, fear or sadness that the patient expressed. But on the other end of the spectrum the doctor listens, and engages, and refers a patient for a creative arts activity, not to avoid engaging in emotion, but because the doctor senses that this type of activity would be an important way to care for and support the social and emotional experience of illness. I use the example of the arts professional who is integrated into the care team not to suggest that such a division of labor is appropriate and that doctors don't need to engage with patients emotionally – they still should. And it is not to suggest that doctors must facilitate art experiences – this need not be a part of their expertise. But I do suggest that doctors should recognize that art experiences, along with other "integrative" or "holistic" services are an essential part of caring for a patient. Physicians can make the opportunities available for patients to participate in creative activities through referrals, and learn from the work patients do in these sessions. It also suggests that a doctor engage with the facilitator of the creative experience in a way that he or she learns more about the ways in which a patient is processing that experience through the arts, such as by inviting the artist to accompany the care team or to make notes about patient progress in patient charts.

My study has shown that the will to offer patients opportunities to participate in art experiences exists in US hospitals. In some hospitals arts facilitators operate on the margins of medical care, not interacting with physicians or other members of the care team; in other hospitals they accompany doctors on rounds and make notes in patient charts. As I have studied the different ways arts practices and medical care are coming together, I have been interested in values. Why is it that hospitals value artists and want to include them?

In this study I examined the institutional logics that bring together creative arts activities and biomedicine in US hospitals. I asked how art gets done, how it functions, and how it is valued. I limited my study to art activity that required active engagement within hospital walls, but I learned that sometimes patients want to passively participate in an aesthetic experience, such as the young girl receiving cancer care who woke up to find her hospital room transformed into a stage that celebrated the cat that she missed during her illness. I spoke with artists and art therapists who facilitated creative activities, patients, family and staff who participated in them, and scholars, physicians and administrators who supported these activities. I learned that some arts facilitators see their role as facilitating the work of the patient and do not collaborate with patients or alter their artwork. Other artists use their professional skill to create with and for the patient. In addition to the types of arts facilitation that are practiced, I also learned that the categories I used of participant, professional or facilitator are not discrete - often a participant might have multiple roles, such as a doctor who is both a physician and a poet, and who facilitates creative encounters while treating patients.

In addition to conducting nearly seventy interviews, I observed and participated in art sessions. I also attended seminars, grand rounds open to the public on topics of wellness and creativity, went to hospital chaplain teas, attended classes that connected art and medicine, and shadowed artist and art therapists during their day. I typed up my fieldnotes, transcribed my recorded interviews, and analyzed and coded the data. I discussed the themes I saw emerging with scholars supporting my work, with research participants, and with colleagues, refining them based on this valuable input.

So after all of this, why is it that we need creative activity to be joined with medical care? I echo the argument that biology, society, and kinship meet in the body: biologic processes move us through the world, relationships of care sustain us, and social structures influence the opportunities we have to act, to seek care. I build upon scholarship that posits that engaging in creative activities is a basic human activity, and one that has long played a role in our biological survival. Art has had a place in healing before and during the origins of scientific medicine. Through its affiliation with various political and corporate ideologies, the practice of scientific medicine has become structured to reduce a person to his pathology for purposes of diagnosis and treatment, obscuring the social construction of health and illness and limiting the types of healing that can happen. Through a for-profit model that requires new doctors to work inhumanely long hours completing both mundane hospital tasks and responding to the tragic moments of human lives while moving bodies out of beds as quickly as possible, medicine injures both its practitioners and its patients. Because we express self and community through creative activities, it is not hard to believe that we heal and restore body, self and community through creativity as well.

I argue that the engaging in creativity during illness speaks to our understanding of the human experience: what the connection is between body and self, and what kind of connection we want with others in moments of great pain and suffering. It challenges our perceptions of which kinds of claims are "true", or hold the types of truths we value. Art questions our response to uncertainty. It fosters the skills of deep attention to story, maintaining empathy, and being in relationship with an other, the same skills that are fundamental to healing. It allows us to imagine, create and preserve personhood by validating and continuing the social selves of those who die.

Other scholars who study the practice of biomedicine have also written about the need to reconceptulize patient care. The present study is in dialogue with anthropological conceptions of care, and offers the lens of creativity to enlarge conceptions of the type of care that is possible in hospitals, to include the performance of an aesthetic skill or experience for patients, the invitation for patients to express themselves creatively, and the public display and dialogue with created works. It joins conversations about the social construction and limits of scientific knowledge, and offers different ways to conceptualize what might count as evidence of healing. Finally it adds to our understanding of the type of care that is possible at the end of life, and what types of activities might be included in a good death.

The practice of Arts in Medicine is becoming a discipline in its own right, arts professionals told me. One artist spoke of a conversation he had with one of his mentors, a palliative care physician who told him that in the 1960s, in the early days of palliative care, the field was undefined and best practices were just emerging. Palliative care doctors had to defer to other types of doctors in determining what constituted good care for critically ill patients, and were not commonly employed by hospitals. Now, the vast majority of hospitals employ palliative care physicians. “Hospitals are not required to have artists yet,” he told me. “But they will be.”

There are several tensions that remain unresolved in the field of Arts in Medicine. One such tension concerns the question of whether mental health credentials should be required to facilitate art making activities with patients, as art therapists largely maintain, or if people who are not licensed mental health professionals can also facilitate creative activities. Who gets to decide this is not quite clear, as hospitals do employ both therapists and professional artists. The professional organization that organized much professional discussion on this topic, the Society for Arts and Healthcare, has supported the practice of various types of patient and staff art making opportunities, although the association has recently dissolved after thirty years. The National Organization for Arts in Health is currently forming its board, and I will be following how this issue is addressed. As I have described in previous chapters, scholars such as Ellen Dissanayake maintain that art making is a basic human activity. As such, it is an activity in which all hospitalized people should have the opportunity to participate. Licensed art therapists do excellent work with patients in hospitals, but I do think that the opportunities for patients to participate in art activities should not be limited to sessions with art therapists.

There is also the question of how we measure what we value, and whether the frame of evidence-based medicine is useful or appropriate to apply to art making activities. I would like to suggest that future research on this topic incorporate the patient experience, and not only biological or clinical outcomes, to capture a fuller picture of the impact of these activities and to orient the research toward outcomes that are meaningful to patients and other participants. I also advocate for more research that looks at the impact and value of long-term communal art projects in the context. It is interesting to note that such projects are increasing (they were the more recent ones a hospital had done, or were a "new" mode of arts activity artists and therapists were experimenting with) and deserve attention in future studies.

I have looked at arts activities in US hospitals and not primary care or outpatient settings for a very specific reason: a serious illness that requires hospitalization often requires the re-crafting of the narrative of one's life, and one's future trajectory, as described by Arthur Frank (1995), and arts activities can help form this new narrative. There are arts activities that pass the time, and activities that help rehabilitate impaired motor or sensory processing skills that are important to patients and staff but do not necessarily involve a re-evaluation of the narrative self. The art making activities that I learned about that are especially meaningful to participants are the projects that explore, express and validate personhood. In the context of end of life care, these activities are not only meaningful to the patient in their end of life care, but also to loved ones who carry and continue the social bonds that bind them to the deceased patient (Klass 1996).

These activities strengthen one’s courage in the face of the unknown, provide relief from pain, and strengthen and preserve social relationships. Investing in these types of arts activities should be a priority for every Arts in Medicine program.

This discipline and practice is indeed growing, and the opening vignettes I crafted suggest how the integration of artists into healthcare teams could become a new mode of patient care. Considering how and why hospitals invest in and support art making activities is an invitation to more deeply reflect upon what types of care promote patient healing. I argue that it is essential to understand the evidence and logics that underlie creative arts programs, along with how they are valued and how they function, to understand how they serve as a model of a “better” type of care to both those in need of healing, and those who heal.

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