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'Healthcaring': Learning to Resist the Logic of Letting Go through Arts-Based Curriculum in a Student-Run Free Clinic

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‘Healthcaring’: Learning to Resist the Logic of Letting Go through Arts-Based Curriculum in a Student-Run Free Clinic

by

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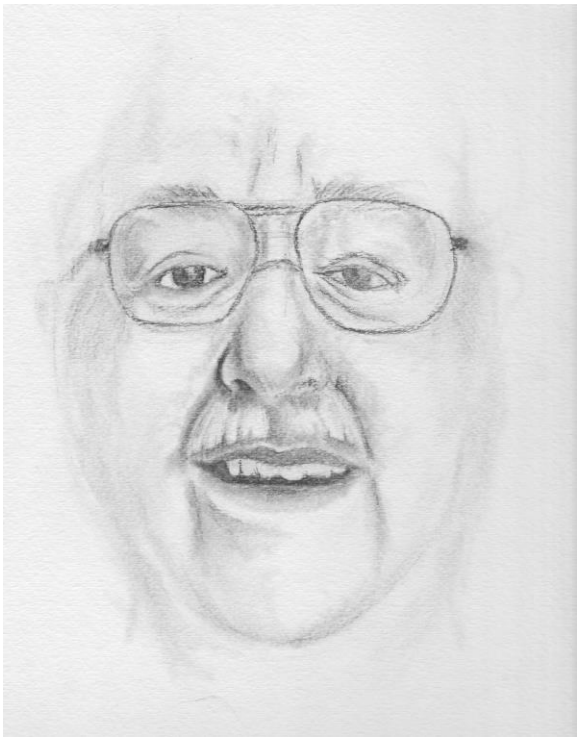
Dedication



To my dad.

A thinker and a dreamer whose curiosity was contagious.

Thank you for always believing in me.

I love you.

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This work exists because of the help of many people. My advisor, Jerome Crowder, has supported me through this process for the last three years and facilitated opportunities for me to develop and explore arts-based curricular interventions. He and my amazing committee, Eric Avery, Robert Beach, Lori Earnshaw, and Arlene Macdonald, have helped push this work forward through their insights and encouragements. And I am grateful to mentors not on my committee who have had important roles in my education and development, including Paula Summerly, Joan Nichols, and Susan McCammon. I have also been financially supported through the generosity of the Institute for the Medical Humanities (IMH), the UTMB Graduate School of Biomedical Sciences, and The John P. McGovern Academy of Oslerean Medicine. Additionally, this work would not be possible without the mentors and students who helped shaped me as a scholar while at the University of Louisville in the departments of Women's and Gender Studies, the Bioethics and Medical Humanities, and the Fine Arts, especially John Begley, Mary Carothers, Karen Christopher, Stephen Hansen, and Valerie Weber. And a very special thank you to Nancy Nyquist Potter who introduced me to the magic of scholarship and helped me see how I fit in the disorienting world of academia.

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to all my extended family of aunties, uncles, and cousins who gave me love, laughter, and shoes to help me make my way through this process. Throughout the last two years I have also had the amazing support and encouragement of the Parra Pedraza family. The terms “in-law” and “step” seem too insignificant and distant for the relationships I have gained since meeting and marrying my husband. I love you all dearly, especially my amazing step-daughters Sofia, Karime, and Mia— *Ustedes hacen de mi mundo un lugar más brillante.*

And, of course, this work would not be possible without the support and love of my dear husband. Gerson, *te amo mucho. Tu eres la luna de mi cielo— mi mundo y mi vida. Gracias por tu paciencia, tu amabilidad y tu amor.*

‘Healthcaring’: Learning to Resist the Logic of Letting Go through Arts-Based Curriculum in a Student-Run Free Clinic

Publication No._____

Rebecca Amerisa Waters, PhD

The University of Texas Medical Branch, 2018

Supervisor: Jerome Crowder

Contemporary healthcare education does not adequately prepare students for some of the most persistent moral challenges of medical practice in the United States. Healthcare in the US includes practices and policies of exclusion limiting who has access to life-extending and life-saving treatments. This dissertation addresses 1) examples of the structural harms and inequities that pervade the US medical system, 2) their effects on healthcare learners, 3) the free clinic, both historic and contemporary, as a space of resistance, and 4) the need for educational interventions to increase understanding, shape attitudes, and challenge existing biases of those harms in healthcare practice. I theorize the ways in which it has become logical in healthcare practice to “let go” of some individuals who struggle to access care. Looking at the free-clinic movement as a space that has historically rejected this letting go, I argue that arts-based curricula should be an integral part of developing understanding and critical thinking around the systemic failings of the US healthcare system. I show how arts activism frameworks can help learners understand and respond to the structural harms of medical practice. Focusing on the space of the free clinic as a microcosm of the disparities present in the broader US healthcare system, I design an arts-based curriculum that cultivates critical consciousness amongst learners and

enables recognition of institutional injustices in healthcare. An arts-based curriculum grounded in arts activism framings can nurture creative inquiry and critical thinking in our future healers and empower them to combat healthcare inequities and injustice through everyday action. In this pedagogical frame, healers learn that change happens through a never-ending process of individuals recognizing a need and taking action.

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List of Abbreviations

ACA	Affordable Care Act
AIDS	Acquired Immunodeficiency Syndrome
CDC	Centers for Disease Control
CEP	Creative Expressions Project
CGHC	Common Ground Health Clinic
DHHS	Department of Health and Human Services
FQHC	Federally Qualified Health Center
GSBS	Graduate School of Biomedical Science
HOTAC	Holding On Through Art Curriculum
HEP	Humanities Ethics and Professionalism
IMH	Institute for the Medical Humanities
JAMP	Joint Admissions Medical Program
SSRFC	Society for Student-Run Free Clinics
SRFC	Student-Run Free Clinic
UTSA	University of Texas Health Center in San Antonio
UTMB	University of Texas Medical Branch

"I guess I'm just thinking about my own, whatever, part in this. I can say to myself, 'It's the System,' but does that mean I couldn't do anything about *any*thing? To change things? To me, the two things go together. You can't change one thing without changing the other thing."

—Susan Nussbaum, *Good Kings Bad Kings*

Introduction “They Let Me Go”

Illustration 1: They Let Me Go, Amerisa Waters, Watercolor Pencils, 2018.

“They let me go. They let me go.”

This is what a neighbor told me as he recounted having a minor stroke after he was turned away from the hospital without receiving treatment for his high blood pressure. My neighbor does not have insurance or other funding and was not provided access to medication. Everyday individuals like my neighbor are harmed by the economically-driven structure of the US health care system; stories of lung cancer

diagnoses without subsequent follow up because of lack of insurance, stories of patients presenting with advanced illness because they didn't have access to preventative screenings, stories of the lived experiences of health care injustices.[1] My neighbor's experience is not unique and his story is just one of countless stories, told and untold, from individuals whom the US healthcare system has failed—a system that lets millions of individuals go without access to healthcare services.[2] People are not given proper care or are denied access altogether as a result of policies causing higher rates of mortality for those of lower socioeconomic status.[3] Although there are regular technological advances in medical practice, few solutions address the persistent inequities in access to quality care and the difficulties of providing care in such a flawed system. Instead, this system trains learners in the logic of "letting go"— it becomes logical to let some individuals go without access to preventative and life-saving care because they are unfunded,[4] and thus expendable. As discussed throughout the first half of this dissertation, this logical harm results from the accepted inequities that persist in the US medical system, their effects on healthcare learners, and the lack of educational interventions to increase understanding of those harms in healthcare practice. This dissertation articulates and unpacks the logic of letting go and the ways this logic has been structured into the US healthcare system. I argue that arts-based curricula should be an integral mechanism for developing student understanding and critical thinking around the systemic failings of the US healthcare

[1] Prior to coming to Texas I would mostly read about such experiences in blogs or articles but since volunteering at St. Vincent's Student-Run Free Clinic I have heard these stories directly from the individuals who come to clinic seeking help. It is these stories that have inspired me to pursue social justice healthcare education interventions

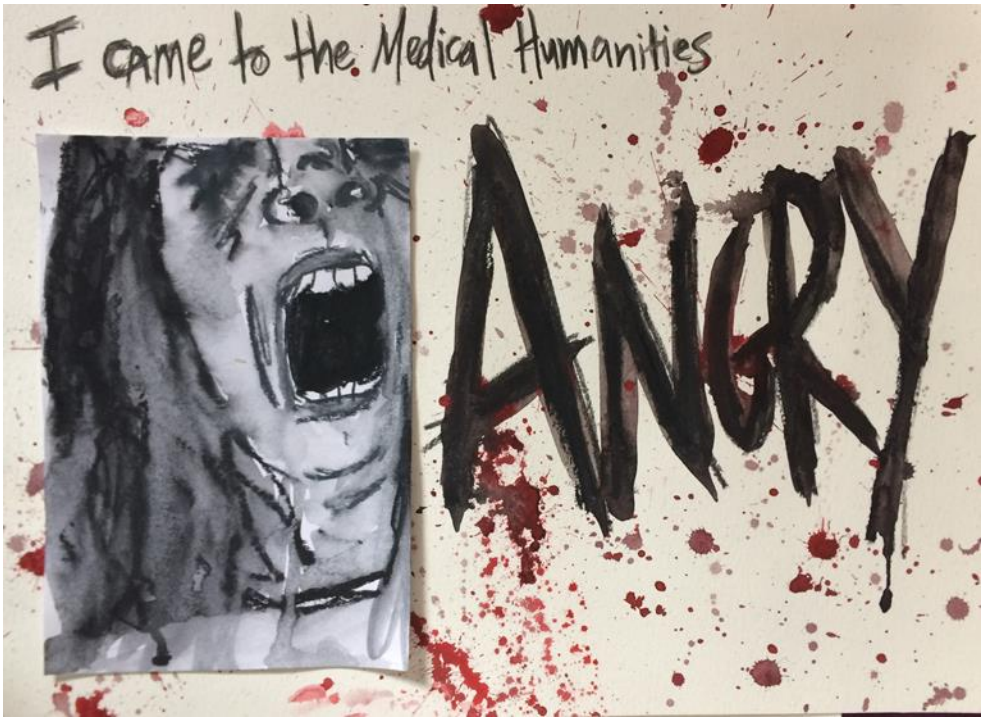
[2] Kaiser Family Foundation, "Key Facts about the Uninsured Population," *Kaiser Family Foundation - Health Policy Research, Analysis, Polling, Facts, Data and Journalism*, September 2016, accessed December 20, 2016, http://kff.org/uninsured/fact-sheet/key-facts-about-the-uninsured-population/.

[3] Benjamin D. Sommers, Katherine Baicker, and Arnold M. Epstein, "Mortality and Access to Care among Adults after State Medicaid Expansions," *New England Journal of Medicine* 367, no. 11 (July 25, 2012): 1025-1034.

[4] The common term used for someone who does not have insurance or the financial resources to cover the costs of healthcare is "unfunded". This term will be employed for the remainder of this dissertation.

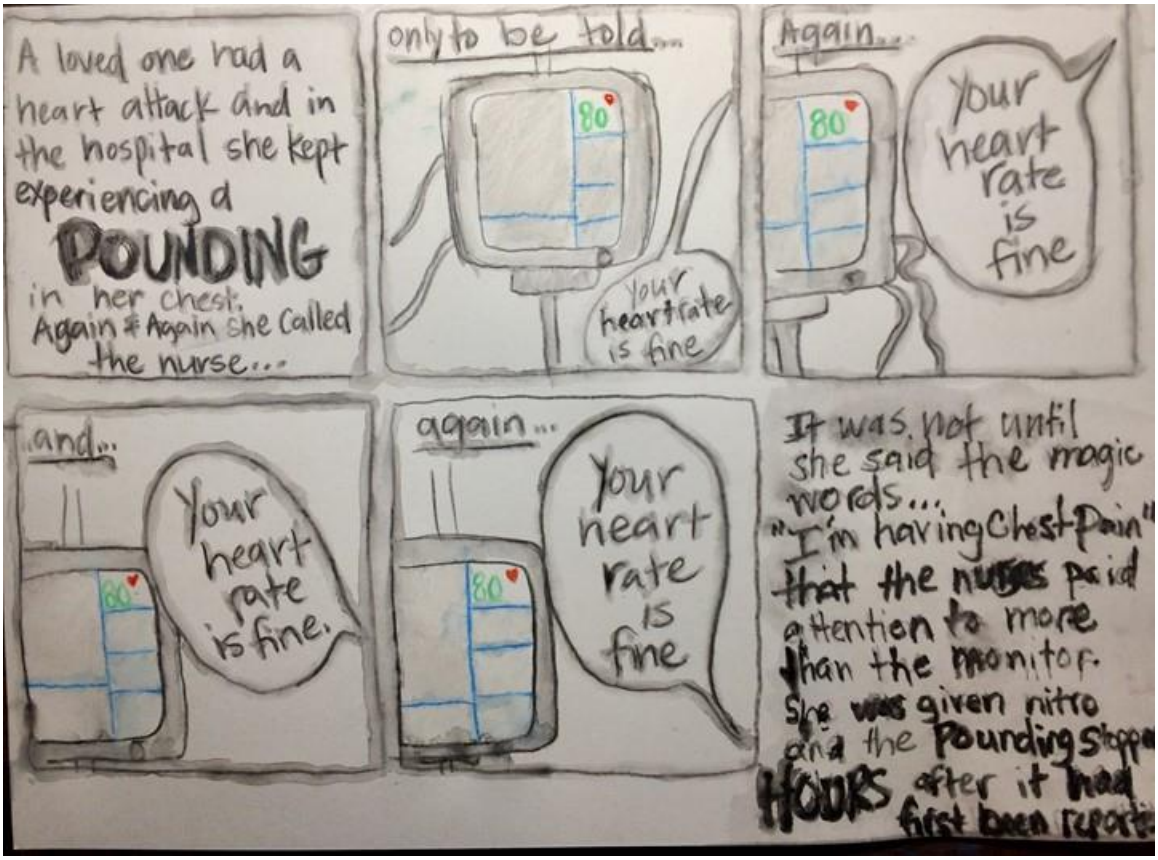
system. Furthermore, I contend that arts activism frameworks are useful for educating healthcare learners to understand, respond to and challenge the structural harms of medical practice. Focusing on the space of the free clinic as a microcosm of the disparities present in the broader US healthcare system, I design an arts-based curriculum that seeks to cultivate critical consciousness amongst learners and enable recognition of institutional injustices in healthcare. An arts-based curriculum grounded in arts activism framings can nurture creative thinking in our future healers and empower them to combat healthcare inequities and injustice through everyday action.

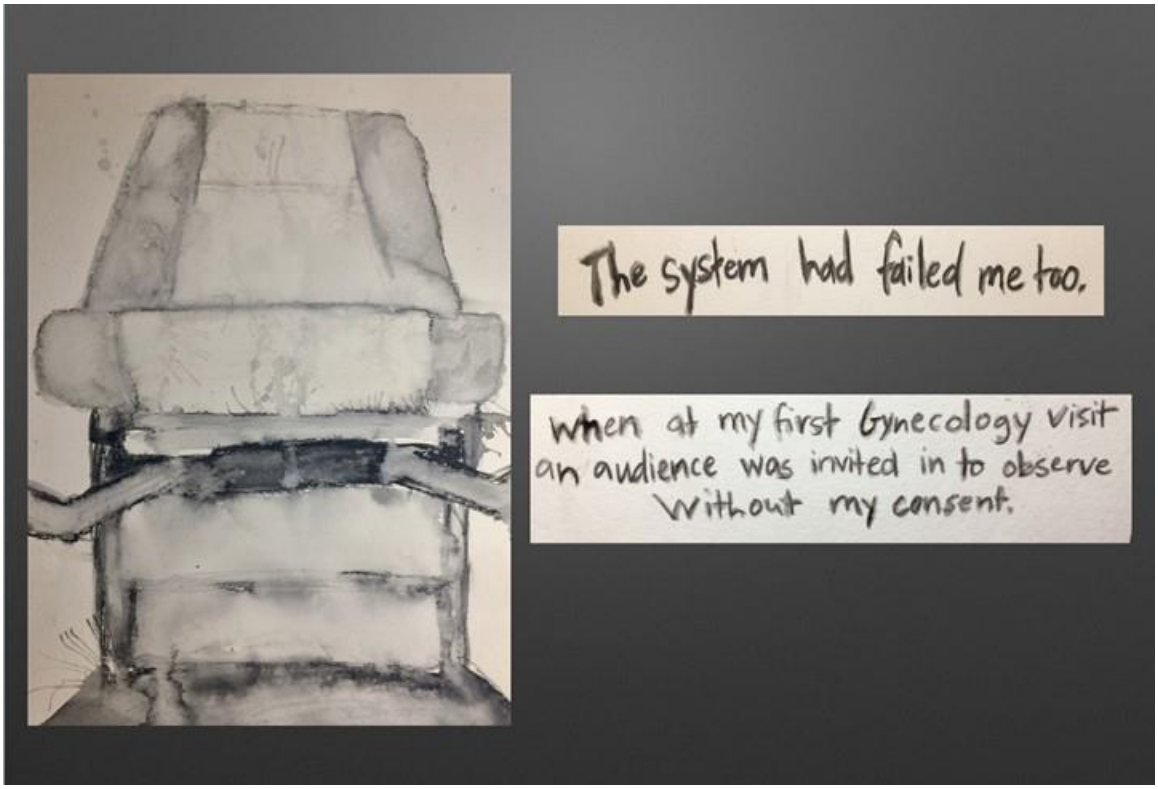
This research is shaped by my perspective as an artist, as an individual who has experienced and witnessed compromised care, as a graduate student who has volunteered in a student-run free clinic, and as a medical humanities researcher and educator seeking to develop curricular interventions for healthcare learners. This project is one that is six years in the making and builds upon the work I began while working on a Masters in Women's and Gender Studies at the University of Louisville. The summer after my first year as a graduate student, several of my loved ones experienced compromised care in healthcare settings. The following year, I began using my research to more fully understand why negative healthcare experiences kept happening to those around me, reflecting on my own encounters with the healthcare system as a patient and as a provider. (I had previously worked full-time as a pharmacy technician.) These experiences resulted in my entrance to the Medical Humanities to be fueled by anger.


I came to the Medical Humanities
ANGRY


The Medical System
had failed my loved ones
AGAIN & AGAIN

It failed when:




The system had failed me too.
when at my first Gynecology visit an audience was invited in to observe without my consent.

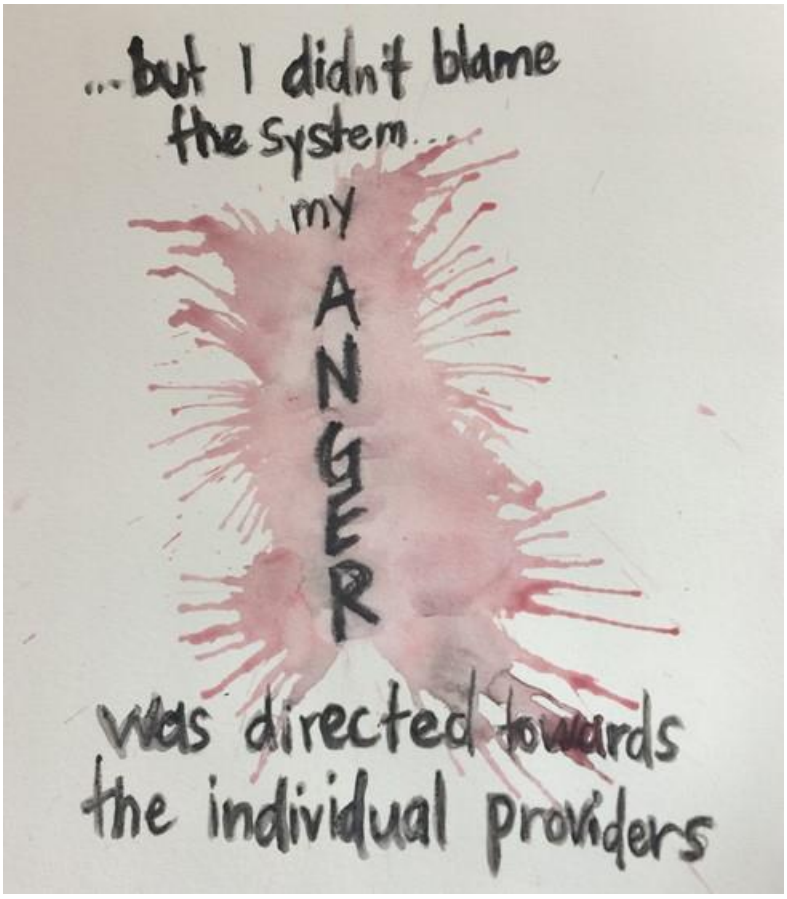

...but I didn't blame the system...
my
ANGER
was directed towards the individual providers

Illustration 2: Medical Humanities Origin Story Series, Amerisa Waters, Watercolor and Aqua Graphite, 2018.

It was in this work that I discovered the structural harm that can shape the actions of the individuals providing care. My questioning led me to pursue a Masters in Bioethics and Medical Humanities and ultimately led me to this doctoral work. I continue this work in an effort to develop and implement solutions for the problems that pervade healthcare experience, access, and delivery in the United States.

My doctoral research has been greatly influenced by my volunteer work as a student director at St. Vincent's Student-Run Free Clinic (St. Vincent's) in Galveston, Texas. In this role, I worked alongside clinical students[5] to manage day-to-day clinic operations, lead primary and specialty care clinics, advocate for patients, and develop and implement educational initiatives for student volunteers. Globally, student-run free clinics are predominantly found in the United States and are the result of the United States's profit-focused system that limits healthcare access. Volunteering at St. Vincent's sparked my curiosity to learn more about free clinics, specifically the origins of the movement and its history. My research uncovered extensive efforts by early free clinics to provide quality healthcare services to those who need them and to resist the letting go of individuals by the formal structures of medicine. St. Vincent's is one such clinic resisting healthcare injustice.

[5] These include medical, nursing, physician assistant, clinical lab science, and graduate students.

Illustration 3: Hope Inside, Amerisa Waters, Watercolor, 2017.

Founded in the mid-1960s[6] by two UTMB faculty, St. Vincent's clinic was a place where individuals could receive confidential and non-judgmental care for sexually transmitted diseases. Students became involved shortly after it started and by the late 1980s, it became a student-run free clinic with UTMB students managing the clinic and overseeing all day-to-day operations.[7] Over the years, the clinic has expanded services to include general and specialty medical services. Today, the clinic operates three times a week and provides primary and specialty care to hundreds of patients every year. In 2017, over 800 individual patients were seen in roughly 2000 patient visits.[8] These included

[6] Barbara Thompson, personal communication, January 17, 2018.
[7] Robert Beach, personal communication, April 26, 2016.
[8] Statistics taken from St. Vincent's Student-Run Free Clinic tracking.

visits for primary care as well as Neurology, Gynecology, Rheumatology, Psychiatry, Wound Care, and Dermatology. There is also a once weekly dental clinic that offers tooth extractions. These services evolved, and continue to evolve, to fit the particular needs that result from limited healthcare access in the state of Texas. They seek to address the specific needs that arise for those living in poverty on and around a small barrier island in the Gulf of Mexico.

My work at St. Vincent's has been transformative. At this clinic, I have witnessed and felt the tensions of a healthcare system that excludes those in need of help. I have both witnessed and experienced the distress of not always being able to help patients who seek care at St. Vincent's. I have met patients whom the system has treated as unworthy of access to care and treatment. I have seen the most caring and compassionate healthcare students and their mentors begin to burn out from working within a system that uses healthcare policy to ration access. It is humbling to have experienced this edge of burnout – to have witnessed these healers struggle to understand the failing healthcare system – to see them blame themselves for the harms structured in this system. Healthcare learners are not taught how to cope but instead are left feeling marginalized themselves as they attempt to interpret the hidden curriculum. According to Anna B. Reisman, the hidden curriculum is "the unofficial rules for survival and advancement. It's a powerful undercurrent that can turn even the most self-assured and altruistic student into an obedient drone."[9] Learners may enter medicine with the goal of helping patients but are at risk of developing moral distress as a result of the pressures of their education system

[9] Anna B. Reisman, "Outing the Hidden Curriculum" *Hastings Center Report* 36, no. 4 *(*July-August 2006): 9

and the failings of the healthcare system as a whole. Witnessing the most pernicious effects of the US healthcare system raised questions: How can we educate students on the complexities of access in the US healthcare system? How can we ensure more students learn how to push back against the ingrained inequities? How can students learn everyday techniques and practices for resisting those injustices in healthcare? How can art help to make this possible? Such are the questions from which this work emerges.

Lessons learned at St. Vincent's form the foundation of this project— a project to better understand how letting people go becomes logical in healthcare practice, and what effects this logic has on both patients and providers. In spite of the negative forces of healthcare education, students often respond with innovative solutions to the constraints of practice to help their patients get the care and treatment that they need. Like the quadruple aim of healthcare, this project focuses on two of the four aims including the need to improve the work life of healthcare providers while also working to enhance patient experience.[10] My research seeks to address the often-ignored structural harms of medicine and to develop a curriculum that will better equip these learners with the understanding, critical awareness, and tools necessary to challenge the system's injustices and to advocate for their patients through everyday resistance and action. I am calling for spaces of art in healthcare education that enable students to slow down and examine the systems in which they learn and work—the water in which they swim—and to question the parts of those systems that cause harm and suffering. This project argues that making art and engaging with artwork can help cultivate more social justice-minded healers.

[10] The other two aims include improving population health, and reducing costs, see Thomas Bodenheimer and Christine Sinsky, "From Triple to Quadruple Aim: Care of the Patient Requires Care of the Provider," *Annals of Family Medicine* 12, no. 6 (November 2014): 573–576.

This dissertation is an interdisciplinary, literature-based study that includes in-depth, critical readings from multiple bodies of literature, including the arts in medicine, spatial and critical social theory, and arts activism research. My contribution to the medical Humanities is putting these diverse bodies of literature in conversation with one another to develop a novel curriculum for the specific space of St. Vincent's student-run free clinic. a curriculum that can then be adapted to other settings. The connections I forge between these bodies of literature help illuminate the injustice present in US healthcare and propose a way out of the logic of letting go through the development of arts-based curriculum. The first half of this work focuses on theorizing the current landscape of healthcare while also examining the history and present practice of the free clinic. For this section I pull heavily from contemporary social and spatial theory in order to provide a more nuanced view of healthcare in the United States.

Critical social theory is a vital component of theorizing the logic of letting go and creating a curriculum that cultivates healers who reject that logic. Zeus Leonardo defines critical social theory as "multidisciplinary frameworks with the implicit goal of advancing the emancipatory function of knowledge."[11] Critical social theory, including spatial theory, illuminates the ways in which medicine and its spaces of care have been formed and shaped by the dominant narratives and framings within society. Healthcare providers often become constrained by the systems within which they work, but within these systems there exists space to resist structural harms. Critical social theory uses its power "to change the pedagogical process from one of knowledge transmission to

[11] Zeus Leonardo, "Critical Social Theory and Transformative Knowledge: The Functions of Criticism in Quality Education," *Educational Researcher* 33, no. 6 (August/September 2004): 11.

knowledge transformation"[12] in order to educate learners on how to resist policies and practices inherent in the healthcare system. It is this kind of knowledge transformation that I seek to evoke through an arts-based curriculum.

Throughout the dissertation I merge the concept of structural violence with spatial theory as a way to elucidate the complexities of the landscape of healthcare. Thinking about space is important— failure to do so can result in individuals being what Sousanis called, "trapped within the borders of their vision. Unable to imagine otherwise."[13] Spatial theory offers a multi-layered and multi-dimensional reframing of space enabling s a re-imagining of assumed boundaries. This more nuanced perspective is important because the ways we imagine and use space construct social and political possibilities, and also influence the meanings that are made in different kinds of spaces. Such expanded vision can enable the ability to transcend the false boundaries that have produced a stunted understanding of space and our relationship to it. This has important implications for medical practice in the ways it helps reveal the relational components of the spaces where medicine occurs.

The first half of this dissertation focuses on theorizing the injustices present in health care today as well as laying out some solutions that individuals have created to address these injustices. In chapter one, "Injustice in Healthcare and the Logic of Letting Go," I pull from critical social and spatial theorists to unpack the logic of letting go in healthcare. Rooted in a dichotomy of worth, the logic of letting go frames some lives as expendable and not worthy of access to healthcare. In this chapter, I lay out the ways the

[12] Ibid.
[13] Nick Sousanis, *Unflattening.* (Cambridge, MA: Harvard University Press, 2015), 24.

US healthcare system is unjust, with harm structured in its practices and policies. I point to the ways in which students and providers get caught in the middle and are taught to accept and participate in exclusionary care.

Chapters two and three focus on the potential for resisting the logic of letting go. In chapter two, "Leaving Omelas— Freeing Healthcare, " I introduce the free clinic movement of the late 1960s. I trace the history of the contemporary free clinic as a historical example of the ways in which individuals in healthcare have rejected its harmful logic. This chapter describes the contemporary free clinic's emergence and the ways in which these clinics have served as sites of resistance. Pulling from spatial theory, I highlight the ways in which free clinics, in practice and philosophy, have functioned as a tactic and the ways in which they have resisted the structural harms of US healthcare. Chapter three, "Free Clinics Today— 'Healthcaring' at St. Vincent's," shifts from history of the free clinic movement to the present-day practice of free care in the United States. I outline the different forms of this current free clinic space and articulate the ways they are similar and different from past iterations. Narrowing in on the student-run free clinic generally, focusing in on St. Vincent's, I discuss the strengths and weaknesses of the care provided in these spaces and their potential for educating learners to resist the logic of letting go.

The second half of the dissertation shifts to explore the ways in which art is useful as a means of educating the healthcare learners in St. Vincent's on the complexities of healthcare practice.[14] I begin in chapter four, "Humanizing Medicine through Arts and Humanities Education— Current Practices and Spaces for Growth, " by providing a

[14] These include Medical, Nursing, Physician Assistant, and Clinical Laboratory Science students.

review of the arts in healthcare literature. Art has been used to nuance healthcare education, refine observations skills, increase empathy, illuminate the lived experience of illness and cultivate space for self-reflection. In the past thirty years, the area of arts in healthcare has exploded with arts-based programs, flourishing across the United States. An examination of the arts in healthcare literature reveals a broad range of practices and programs that utilize art-based interventions in healthcare and health education settings. I utilize this literature as a way not only to learn from the past and current work, but also to identify the gaps that exist in the literature and the current practice. These programs and courses are generally elective and offered in the late clinical years, and are usually focused on individual self-reflection. I highlight the limitations of current practices of arts and healthcare and point to arts activism research as helpful in filling the gap that exists in arts in healthcare initiatives. I contend that although there is important work being done in the application of art to healthcare education to cultivate reflective practice, more is needed to prepare students for practicing in an unjust system.

In Chapter Five, "Activism through Art," I introduce the work being done in arts activism curricula as a solution for the gaps of arts in healthcare work. Art activism curricula focus on educating learners to connect individual experience to the systemic forces that shape them, and thus it lends itself well to underscoring the structural harms that influence medical practice. By building connections between arts activism curricula and art as an educational intervention in healthcare, I make the case for developing an arts activism-influenced curriculum for a student-run free clinic to cultivate more social-justice-minded healers.

The culmination of this dissertation is the development of an arts-based social

justice curriculum for St. Vincent's Student-Run Free Clinic, which will be the focus of chapter six, "Learning 'Healthcaring' in a Student-Run Free Clinic—a Model Curriculum." Focusing on St. Vincent's Student-Run Free Clinic as a case example of a space of resistance, I offer a more intentional social justice curriculum to cultivate social-justice-minded healers in this space. I combine different perspectives from the various bodies of literature to develop this more formal arts-based, social justice curriculum. The curriculum I propose is a series of workshops that are informed by the different perspectives offered by the various bodies of literature highlighted throughout this work. Through this curriculum I seek to facilitate the creative thinking required to imagine new ways of resisting the harms experienced on an individual level, including those which are linked to systemic forces. I contend that art interventions allow for a different kind of engagement with these topics.

The model arts-based curriculum presented here is specifically for St. Vincent's, which I have chosen because of its current function as a site of resistance and as a space that social justice-minded students are already congregating.[15] This curriculum is directed towards the students who enter this space, rather than all healthcare learners, because these students are already doing this work and will become educators for other students and healthcare providers. The curriculum I present here has the potential to be applied in other areas of healthcare at other sites as well as will be discussed in the last chapter.

Certainly, there are educational interventions in place that educate healthcare learners on the structural harms that pervade medicine and the social determinants of

[15] While working at St. Vincent's, I have found that social justice is often a motivation of students who enter that space.

health, but my work is focused on students seeking interventions on an individual level to challenge the macro harms that affect care.[16] The structural violence curricula that do exist focuses on raising awareness and understanding, termed "structural competence."[17] Much can be learned from such programs but they are lacking as they do not recognize art as an important component of educating and addressing such harms. Arts education brings something new into the discussions of individual engagement. This dissertation focuses on utilizing the arts to teach students the problems of healthcare and how to be part of the solution to the injustices that pervade it.

[16] There are many educational initiatives that seek to educate healthcare learners on the structural harms experienced by their patients, but these interventions are generally focused on responding to the effects of such harms rather than on challenging the structural harms themselves. This curriculum takes the form of educating on social determinants of health and screening methods and tools to use with patients. For examples of these see Chazeman S. Jackson, and J. Nadine Gracia, "Addressing Health and Health-Care Disparities: The Role of a Diverse Workforce and the Social Determinants of Health," *Public Health Rep,* 129, no. 1 (January 1, 2014): 57–61; Linn Gould, Elizabeth Mogford, and Andra DeVoght, "Successes and Challenges of Teaching the Social Determinants of Health in Secondary Schools: Case Examples in Seattle, Washington," *Health Promotion Practice* 11, no. 3 (May 1, 2010): 26S–33S; Lori Hanson, "Global Citizenship, Global Health, and the Internationalization of Curriculum: A Study of Transformative Potential," *Journal of Studies in International Education* 14, no. 1 (March 1, 2010): 70–88.; Elizabeth Mogford, Linn Gould, and Andra DeVoght, "Teaching Critical Health Literacy in the US as a Means to Action on the Social Determinants of Health," *Health Promotion International* 26, no. 1 (March 1, 2011): 4–13; Linda Reutter and Kaysi Eastlick Kushner, "'Health Equity through Action on the Social Determinants of Health': Taking up the Challenge in Nursing," *Nursing Inquiry* 17, no. 3 (September 1, 2010): 269–280. There are some initiatives that work to educate on structural harm but these seem to be more focused on awareness than intervention. For examples of these see footnote 7 for examples of this work. While these initiatives are incredibly important, and inform my own work, they are limited in scope. The curriculum I develop is focused on educating learners to be agents of change working to challenge the structural injustices of healthcare in the US.

[17] See for example, Alisha Ali and Corianna E. Sichel, "Structural Competency as a Framework for Training in Counseling Psychology," *The Counseling Psychologist* 42, no. 7 (October 1, 2014): 901–918; Jonathan M. Metzl and Helena Hansen, "Structural Competency: Theorizing a New Medical Engagement with Stigma and Inequality," *Social Science & Medicine*, *Structural Stigma and Population Health*, 103, Supplement C (February 1, 2014): 126–133.; Jonathan M. Metzl and Dorothy E. Roberts, "Structural Competency Meets Structural Racism: Race, Politics, and the Structure of Medical Knowledge," *Virtual Mentor* 16, no. 9 (September 1, 2014): 674; Rebecca K. Tsevat, Anoushka A. Sinha, Kevin J. Gutierrez, and Sayantani DasGupta, "Bringing Home the Health Humanities: Narrative Humility, Structural Competency, and Engaged Pedagogy," *Academic Medicine* 90, no. 11 (November 2015): 1462.

PART ONE

Chapter 1 Injustice in Healthcare and the Logic of Letting Go

> Poverty is not a fact of nature. In a country as blessed with natural resources as the United States, poverty is a consequence of choices we make as a society about how to distribute those resources.
>
> -Sered & Norton-Hawk, *Can't Catch a Break*

Access to health care has long been, and continues to be, a hotly contested issue in the United States. The United States remains an outlier amongst industrialized nations in its failure to provide universal health care to its citizens, with the US healthcare system rooted in a dichotomy of worth—those worthy of access to care and those who are not.[18] For those deemed unworthy, treatable conditions can become terminal diagnoses, and health providers are at the forefront of this denial, both as witnesses and often unwilling accomplices to that denial of care. This denial of care is part of a long history in the US healthcare system. The development of the healthcare system in the US was left primarily in private hands beginning at the start of the twentieth century with governmental programs limited to those deemed worthy of healthcare access, i.e. women, children, veterans, and the disabled.[19] There remains a portion of the population unable to access healthcare in the US and thus denied preventative, life-saving and life-extending treatments. In this chapter, I explore this injustice in US healthcare and an educational system that trains providers to accept and participate in exclusionary care. Using the work of Elizabeth Povinelli, Giorgio Agamben and Lisa Cacho, I outline a theoretical framework highlighting the logic of letting go that is cultivated in US healthcare practice

[18] Kristen Sessions, Amal Hassan, Thomas G. McLeod, and Mark L. Wieland, "Health Insurance Status and Eligibility Among Patients Who Seek Healthcare at a Free Clinic in the Affordable Care Act Era," *Journal of Community Health* 43, no.2 (August 22, 2017): 1–5.

[19] Jonathan Engel, *Poor People's Medicine: Medicaid and American Charity Care since 1965.* (Durham, NC: Duke University Press, 2006).

and identify the way this logic renders some bodies socially dead, making it thinkable that they should not get access to life-extending and life-saving treatments. This logic dehumanizes certain bodies and categorizes them as a moral exclusion from healthcare access. At St. Vincent's we see the individuals who are left out of the healthcare system. The St. Vincent's patient population consists of roughly 800 patients who seek care at St. Vincent's because they are unable to access needed healthcare services in other settings. This population includes, but are not limited to, a range of experiences including individuals working multiple jobs but unable to access insurance benefits, individuals who are homeless or in extreme poverty but not eligible for Medicaid, and individuals with disabilities who are unable to access disability coverage.[20] Utilizing spatial theory, I articulate the ways in which this logic has been structured into the practice of medicine making it thinkable that some individuals should suffer preventable deaths. This renders these deaths expected and normal. I highlight the ways in which clinical students are caught in the middle and constrained and limited by this logic of letting go. The danger ultimately lies in the potential for healthcare learners to be indoctrinated into this system of exclusion resulting in the preventable deaths becoming thinkable.

SOCIAL DEATH

The individuals who are "let go" by the healthcare system become understood as ineligible for personhood with the narrative of personal responsibility functioning as a killing abstraction.[21] These individuals are socially dead and thus no longer eligible for

[20] There is a diversity of reasons that bring patients to St. Vincent's these are but a few examples.

[21] According to Cacho, "the killing abstraction... references the ways in which racialized populations are made unduly vulnerable by global capitalism and neoliberal restructuring, and it refers to the way they are positioned absolutely and necessarily beyond legal recourse" Lisa Marie

even the most basic decencies afforded other populations. According to Lisa Cacho, "the space of social death is a desperate space, overwrought with and overdetermined by the ideological contradictions of ineligible personhood."[22] Social death constructs a logic that renders individuals as lacking social worth, which can result in these individuals being conceptualized as socially expendable and able to let die. Those excluded from healthcare access are rendered as what Giorgio Agamben[23] has termed "bare life:" they can be socially "killed," without being "sacrificed" in any way that would make their death meaningful.[24] These individuals are:

> …perceived as nonexistent or as a nonentity. In this case, harm doing results from unconcern or unawareness of others' needs or entitlements to basic resources, such as housing, health services, respect, and fair treatment. Although harms that result from unconcern or from efforts to achieve one's own goals may not involve malevolent intent, they can nevertheless result in exploitation, disruption of crucial services, suffering, the destruction of communities, and death.[25]

The biological death of individuals let go by the healthcare system is related to the social death that has already occurred. It is in occupying this space of social death that physical death can more easily occur. Social death facilitates biological death when the denial of treatment is justified and when such a denial results in preventable death. The justification of preventable death is made thinkable through a rhetoric of choice and narrative of personal responsibility that frames poor individuals as responsible for their

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Cacho, *Social Death: Racialized Rightlessness and the Criminalization of the Unprotected,* (New York, NY: NYU Press, 2012), 7.

[22] Ibid., 145

[23] Giorgio Agamben, *Homo Sacer: Sovereign Power and Bare Life,* trans. Daniel Heller-Razen (Stanford, CA: Stanford University Press, 1998).

[24] Ibid.

[25] cf Susan Opotow, "Moral Exclusion and Injustice: An Introduction," *Journal of Social Issues* - Wiley Online Library. 1990, Accessed October 10, 2017. http://onlinelibrary.wiley.com/doi/10.1111/j.1540-4560.1990.tb00268.x/abstract, 2

own plight. The narrative emerges in a variety of ways including through social media in the form of memes and blogs, as well as through political discourse.[26] Poor individuals are presented as being unworthy of healthcare as a result of their own failure to follow the instructions for health that political rhetoric insinuates should be common knowledge and their civic duty—they should just get a job and get healthcare.[27] The discourse surrounding access to healthcare and a livable wage is a cautionary tale, positioning an individual who is poor as failing to fulfill the responsibility to be a good citizen.

This linking of healthcare access to employment, rather than to means alone, occurred in the 1940s when "Relatively inexpensive physician insurance guaranteed to the vast majority of working- and middle-class Americans the same access to physician care as the wealthiest American."[28] It is assumed that those excluded from healthcare are framed as having failed to be responsible to make the appropriate choices to get access, but it is this narrative of personal responsibility and the rhetoric of choice that render invisible the reality of the barriers such individuals face. It renders invisible the realities we see at the clinic. It renders invisible the individuals working multiple jobs, none of

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[26] This rhetoric emerges in a variety of ways including on popular news networks such as Fox news, on conservative written and video blogs, politician comments, online polls, and on social media in the forms of memes, tweets, and other postings. For examples see Jason Wilson, "The rise of Tomi Lahren, the media star lampooned as 'white power Barbie." The Guardian Weekly US Edition. September 23, 2016.; Paul Hsieh, "No, The Government Should Not Provide Health Insurance For All Americans." Forbes. Accessed March 11, 2018. https://www.forbes.com/sites/paulhsieh/2016/12/29/no-the-government-should-not-provide-health-insurance-for-all-americans/; Gallup Inc, "Majority in US Say Healthcare Not Gov't Responsibility." Gallup.com. Accessed March 11, 2018. http://news.gallup.com/poll/165917/majority-say-healthcare-not-gov-responsibility.aspx; "Health Care." Fox News. Accessed March 11, 2018. http://www.foxnews.com/category/politics/executive/health-care.html; Phillip Bump, "Jason Chaffetz's iPhone Comment Revives the 'poverty Is a Choice' Argument - The Washington Post." Accessed March 11, 2018. https://www.washingtonpost.com/news/politics/wp/2017/03/07/jason-chaffetzs-iphone-comment-revives-the-poverty-is-a-choice-argument/?utm_term=.554bf8f2c2da.

[27] This narrative emerges in various places in contemporary society. One is through political discourse, which seems more prominent amongst conservative fractions. This also emerges on social media in the forms of blogs, memes, and other postings.

[28] Engel, *Poor People's Medicine*, 15.

which offer enough hours to qualify for insurance that comes with being full time. It renders invisible individuals who are disabled but due to complicated processes have been unable to access disability resources through the government. It renders invisible those individuals who do indeed have insurance but whose insurance comes with unaffordable deductibles or limitations on services covered. It renders invisible the very real barriers to access to care. When I first started at St. Vincent's there was a patient who broke his foot in an accident, which was stabilized in a splint in the ER with a referral given for an orthopedic physician the patient could not access. The patient was unable to receive proper treatment for the break, which resulted in disability for the patient struggling to navigate the complicated process of getting disability benefits.[29] A preventable disability kept him from work and further constrained his ability to access healthcare services.

Through popular media we as a society see the simplification of the complex causes of inaccessible healthcare, but at St. Vincent's students see a very different narrative of accessing healthcare. These learners meet the individuals who are struggling to make ends meet despite working multiple jobs, none of which offer insurance access. There exists a precarity to the system of health access through employment. To begin, there is a shortage of opportunities for employment generally and particularly of opportunities for stable employment that offers access to insurance benefits. Although there exist government mandates of employer-sponsored healthcare through the

[29] This includes the completion of complicated paperwork as well as getting varies kinds of documentation. One part of the documentation is having faculty complete a section of the paperwork. I have witness providers refusing to complete this portion on the justification that they "do not do disability paperwork." My colleagues in medical school have told me this is a response they also hear and witness during their clinicals.

Affordable Care Act (ACA), such mandates do not guarantee access.[30] To bypass these requirements, employers can restrict employees to working part time rendering them ineligible for insurance benefits.[31] This can result with individuals who work at multiple part time jobs with no insurance eligibility. There also exist challenges for those who may be eligible for government programs. For example, those who are disabled might be unable to access disability because of the complicated and confusing application processes.[32] There are insured individuals who have large deductibles or plans without specialty care coverage cannot get the treatment they need. Insurance does not equal access, and access to insurance is complicated, but these realities are rendered invisible through the construction of the "Other." It is a dichotomy of the *us's* with access and the *them's* who failed to fulfill their responsibilities to gain access to healthcare services.

US VERSUS THEM AND DEFINING THE "OTHER"

Lack of access becomes an indicator of bad behavior and irresponsibility; the shaming of this population functions by defining these individuals as a particular Other.

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[30] Formally known as the Shared Responsibility for employers, this mandate states that "certain employers…must with offer health coverage that is "affordable" and that provides "minimum value" to their full-time employees… or potentially make an employer shared responsibility payment to the IRS if at least one of their full-time employees receives a premium tax credit for purchasing individual coverage on a Health Insurance Marketplaces…" see "Questions and Answers on Employer Shared Responsibility Provisions Under the Affordable Care Act | Internal Revenue Service." Accessed March 13, 2018. https://www.irs.gov/affordable-care-act/employers/questions-and-answers-on-employer-shared-responsibility-provisions-under-the-affordable-care-act.

[31] William Even, and David MacPherson. "The Affordable Care Act and the Growth of Involuntary Part-Time Employment." *SSRN Scholarly Paper*. Rochester, NY: Social Science Research Network, August 25, 2017.

[32] Information on the process and application to apply for disability can be found at "Apply Online for Disability Benefits." Accessed March 10, 2018. https://www.ssa.gov/applyfordisability/. The process can be confusing and require either internet access and know-how or access to the social security office. For individuals in Galveston Island, the closest office is on the mainland 25 miles away and upon completing a preliminary search for public transit options did not reveal any options. Even when access to the application is possible there still exist other barriers. Another major barrier is for those who are not eligible for disability because of immigration status. Undocumented individuals are not eligible for social security benefits, even if they have been paying taxes into social security.

The framing of the Other also results in individuals voting against their own interests as was seen with the election of Kentucky governor Matt Bevin. In the 2017 census data, Kentucky reported that 18.5% of the population lives in poverty with 6% of the those under the age of 65 without insurance,[33] which is down from 18.1% in 2010 prior to the ACA's implementation.[34] In 2015, Matt Bevin was elected to the position of Governor in Kentucky after openly campaigning his plan to dismantle Medicaid expansion in the state along with the state's health insurance exchange, KYNECT.[35] In the case of Kentucky, a governor was elected under the promise to strip those who have benefited from Medicaid expansion of their access to health care coverage—those deemed unworthy of access. This debate continues today with the current federal administration, elected after campaigning to end the Affordable Care Act and greatly reduce access to healthcare—greatly reduced it from its already limited access. Those who voted against their own interests were supporting the logic that some people don't deserve healthcare access, though they did not conceptualize themselves as a part of that group because they likely do not see themselves as the Other. The connections of one's own experience with that of the "Other" can easily be missed because it is easy to justify why oneself is entitled to access because one is well-versed in all the complexities of one's own life—the complexities that prevent you from having insurance through a job or enough money to pay out-of-pocket. This Othering strengthens this logic of letting go because even those

[33] "US Census Bureau QuickFacts: Kentucky." Accessed March 12, 2018. https://www.census.gov/quickfacts/KY.

[34] Bowen Garrett and Anuj Gangopadhyaya. "Who Gained Health Insurance Coverage under the ACA, and Where Do They Live?" Urban Institute, December 22, 2016. https://www.urban.org/research/publication/who-gained-health-insurance-coverage-under-aca-and-where-do-they-live.

[35] see "Issues." Matt Bevin for Kentucky - New. http://www.mattbevin.com/issues.

who fall within this group of limited or no access to healthcare come to support policies that further restrict or remove that access for themselves.

This "us versus them" mentality is never so apparent as when someone who believed they would always be an "us" becomes a "them:" when they lose their access to healthcare or their job and lack the resources and social support that would prevent total ruin. From time to time, we have a patient at St. Vincent's who fits into this group. This individual may or may not vocally oppose the ACA, but always seems to resist the help that they need. It can be confusing to see someone turn away from help that will enable them the possibility to get back on their feet. One such example is a woman who came to St. Vincent's seeking healthcare and help. She was living in her car after being laid off from her job, unable to afford gas to go on job interviews, but when we made the suggestion of a local shelter that offers vouchers for gas to get clients to medical appointments and job interviews the women stated she would not go there. The reasoning she gave for not going to the shelter was that it is full of "those people." As a free clinic our budget does not allow for us to give patients money for gas, but the homeless shelter has a program that will cover such an expense for clients. This individual did not go to the shelter that day and seemed set on her decision that she would not. She was not willing to utilize the support services available to her because she did not want to be around "those" people— those who fall in the category of "them" of this "us versus them" mentality. She could not identify with this group who had been let go from healthcare because she could not see the humanity of "those people" despite being so aware of her own. The logic of letting go was, and continues to be, persuasive.

BOOTSTRAPS AND THE NEOLIBERAL DREAM

All of this, the narrative of personal responsibility and the us versus them

mentality, is connected to the problematic bootstrap narrative that is prominent in the US. This narrative suggests that if one wants to improve one's lot in life one just need to work hard and pull oneself up by one's bootstraps. The phrase "to pull oneself up by one's bootstraps" is thought by some to have originated in the 1834 of the Working Man's Advocate when it was used to convey an impossible task.[36] The phrase has since shifted from that of one of impossibility to one that implies that hard work is all that is required to succeed and is used to justify the elimination of social welfare programs and believes it to be okay because it is understood as the responsibility of the private sector/charity. This narrative assumes an even playing field and certain privileges that make such a feat possible. Despite its holes, this narrative persists with the thinking that all one needs to do is work hard to get what they need in life.

The bootstraps narrative is never more present than it is in Texas. The narrative that all that is needed to gain success is hard work renders invisible the complex inequities upon which this country was founded, and in doing so reframes those who do not succeed as the cause of their own failure. Such assumptions are connected to neoliberal ideology as pointed out by Dag Einar Thorsen who, citing notable neoliberal scholars, asserts:

> He or she is willing to accept the risks associated with participating in free markets, and to adapt to rapid changes arising from such participation (Friedman, 1980). Individuals are also seen as being solely responsible for the consequences of the choices and decisions they freely make. Inequality and glaring social injustice is under this perspective morally acceptable, at least to the degree in which such states of affairs could be seen as the

[36] This explanation came up various times and points to see "Why Do We Say Pull Yourself up by the Bootstraps?" book browse. https://www.bookbrowse.com/expressions/detail/index.cfm/expression_number/532/pull-yourself-up-by-the-bootstraps;%20http://stateofopportunity.michiganradio.org/post/where-does-phrase-pull-yourself-your-bootstraps-actually-come.

> result of long chains of freely made decisions by individuals (Nozick 1974; Hayek, 1976).[37]

This narrative was utilized by various Texas politicians as justification for why the state should opt out of expanding Medicaid, resulting in a coverage gap for nearly 2.5 million uninsured individuals nationwide with an estimated 27% of those uninsured residing in Texas.[38] Then governor Rick Perry was vocal in his opposition to Medicaid expansion, asserting that:

> We are not the people of equal outcomes, of quotas, of raced-based appeals or a nanny state. We're the people who say everyone deserves a shot, but success is only the product of hard work and innovation. We're the ideology that is blind of color and solely grounded in a merit system. We are compassionate without being cynical. Government can be a tool to self-improvement, and self-empowerment. Not self-entrapment. These ideals are as old as America, and they will live on as the prevailing sentiment long after we are gone, because they are what make America unique. We will never bend to the social and economic agenda of western Europe. Yet it is an interesting place to vacation, but it is a sorry example of government. We will continue to pursue a uniquely American vision seeded in liberty, personal responsibility, and individuality.[39]

This speech, given March 14, 2013 at the Conservative Political Action Conference (CPAC), pulls on all the elements of the bootstraps narrative— Perry claims that it is with hard work and personal responsibility that individuals get access to healthcare.[40] It is

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[37] Dag Einar Thorsen,"The Neoliberal Challenge - What Is Neoliberalism." *Contemporary Readings in Law and Social Justice* 2 (2010): 188. Citing Friedman, Nozick 1974; Hayek.

[38] Rachel Garfield and Anthony Damico. "The Coverage Gap: Uninsured Poor Adults in States That Do Not Expand Medicaid." The Henry J. Kaiser Family Foundation (blog), November 1, 2017. https://www.kff.org/medicaid/issue-brief/the-coverage-gap-uninsured-poor-adults-in-states-that-do-not-expand-medicaid/.

[39] Rick Perry, "Rick Perry Remarks," Conservative Political Action Conference March 14, 2013 https://www.c-span.org/video/?311495-4/governor-rick-perry-remarks-conservative-political-action-conference&start=1118

[40] On its website, Conservative Political Action Conference (CPAC) identifies itself as "the birthplace of modern conservatism" with the conference identified as a place to "unite the political leaders of the conservative movement with the people who make up the movement" see "US census Bureau QuickFacts, http://cpac.conservative.org/about/

through a meritocracy that individuals gain access. Through this assertion, he implies that those who do not have access have not worked hard enough and have failed to fulfill their responsibility to get access. Since its advent, Medicaid has been infused with this narrative of personal responsibility with social support programs designed and developed keeping in mind a risk of dependency:

> Most reformers were concerned with the danger of "pauperizing" someone who was temporarily down on his luck. They feared creating a cycle of dependence in which the pauper, upon receiving help, lost the will to support himself and his family, and became a lifelong ward of the state—a financial burden as well as a spiritual disgrace.[41]

The justification that welfare services should be restricted "for one's own good" is one that continues to be used. The political reasoning of limiting access to healthcare and other resources is justified as necessary in order to not compromise the character of the country's citizens.

Neoliberalism extends beyond policy and practice and is also a moralistic framing that shapes understandings of what constitutes a virtuous person. Thorsen highlights the moralistic effects of neoliberal influence:

> "Neoliberalism could also include a perspective on moral virtue; the virtuous person is one who is able to access the relevant markets and function as a competent actor in these markets… If a person demands that the state should regulate the market or make reparations to the unfortunate, who have been caught at the losing end of a freely initiated market transaction, this is viewed as an indication that the person in question is morally depraved and underdeveloped, and scarcely different from a proponent of a totalitarian state [see Mises 1962]…[42]

Those who fail to fulfill the neoliberal expectations laid out for them are thereby framed as deviant. It becomes thinkable that life-saving treatment should be denied to those

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[41] Engel, *Poor People's Medicine*, 20

[42] Dag Einar Thorsen,"The Neoliberal Challenge"

individuals who failed to meet the neoliberal expectations laid out for them— it becomes thinkable to let them go. In practice, this letting go takes many forms. It can be individuals with non-emergent conditions being turned away from treatment. It can mean that undocumented individuals with kidney failure lack access to dialysis except in the case of an emergency.[43] This letting go also occurs when patients receive diagnostics when seeking emergency care and are diagnosed with cancer and then discharged and instructed to return when they have funding.[44] Furthermore, when the concept of failure is defined by and rooted in neoliberal ideology it becomes thinkable that human flourishing and survival do not have to be markers of success— profits are success and as long as they are present, human suffering is acceptable. As Elizabeth Povinelli notes:

> Any form of life that could not produce values according to market logic would not merely be allowed to die, but, in situations in which the security of the market (and since the market was now the raison d'être of the state, the state) seemed at stake, ferreted out and strangled… Any form of life that is not organized on the basis of market values is characterized as a potential security risk. If a social welfare program, for instance, can be shown to lengthen life and increase health, but cannot at the same time be shown to produce a market value, this lengthened life and increased health is not a value to be capacitated. Indeed, it is a value to be actively attacked and rooted out of the state and national psyche.[45]

The failure to adhere to neoliberal standards of behavior results in the moral exclusion of the poor from healthcare access— the ultimate message that is conveyed is that there are

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[43] see Laura Hurley, Allison Kempe, Lori A. Crane, Arthur Davidson, Katherine Pratte, Stuart Linas, L. Miriam Dickinson, and Tomas Berl. "Care of Undocumented Individuals With ESRD: A National Survey of US Nephrologists." *American Journal of Kidney Diseases* 53, no. 6 (June 1, 2009): 940–949. Rudolph A. Rodriguez, "Dialysis for Undocumented Immigrants in the United States." *Advances in Chronic Kidney Disease, Socioeconomics, Disparities, and the Kidney,* 22, no. 1 (January 1, 2015): 60–65.

[44] Since volunteering at St. Vincent's I have learned of this practice through individuals who call seeking help when they have been turned away from funding settings. Though we cannot provide cancer treatment at St. Vincent's we do see these patients and work to help them gain access to much needed care. This practice will be discussed in more detail in chapter three.

[45] Elizabeth A. Povinelli, *Economies of Abandonment: Social Belonging and Endurance in Late Liberalism*. (Durham NC: Duke University Press Books, 2011), 22.

situations in which people will die from treatable illnesses.

The US has a history of separating the population into those who are worthy of access and those who are not. In his 1997 article "Enemies of the People: The Moral Dimension to Public Health,"[46] James Morone tracks how morality has shaped US health politics and policy and highlights the stigma such moral framings have thus produced. This moral framing, and the image and stereotypes it produces for US society, positions some individuals as worthy of healthcare and others as not. This framing is still a fundamental part of the structure of and policies governing the US healthcare system. As Morone rightly notes:

> Moral images and stereotypes shape public policy. They help set the political agenda. They can be the difference between expanding social welfare and cracking down on crime, between fighting poverty and fearing the poor, between public health and criminalization. Yet the politics of morality is not analyzed. On the contrary, the dominant model of American politics, the liberal tradition, is organized to dismiss the entire matter.[47]

The US healthcare system continues to employ a moralistic framing to categorize some individuals as unworthy of treatment, including them in a space of moral exclusion. According to Susan Opotow, "moral exclusion occurs when individuals or groups are perceived as outside the boundary in which moral values, rules, and considerations of fairness apply. Those who are morally excluded are perceived as nonentities, expendable, or undeserving…"[48] As a result of healthcare policy, an entire portion of the population has been perceived as a nonentity and thus deemed unworthy of life-extending and life-

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[46] James A. Morone. "Enemies of the People: The Moral Dimension to Public Health," in *Journal of Health Politics, Policy and Law,* 22, no. 4, (August 1997): 993-1020.

[47] Ibid., 994.

[48] Susan Opotow. "Moral Exclusion and Injustice: An Introduction." *Journal of Social Issues,* 46: 1. (1990) 1-20.

saving treatments.

The recent healthcare reform and those states, such as Texas, that failed to expand Medicaid reveal one way that individuals have been deemed unworthy of care. Such a decision results in an entire portion of the population being without access to health insurance coverage, and results in a coverage gap for low-income individuals who do not qualify for the strict Medicaid eligibility requirements (based on income, household size, disability, family status, and other factors) and are also not eligible for savings on a private health plan bought through the ACA Marketplace.[49] The low-income gap results in delayed diagnoses, inability to access treatment, and preventable death. Amongst adults residing in states that expanded Medicaid, the ACA has improved access with reduced mortality and extended coverage, but disparities in access and quality of care persist.[50] Medicaid expansion under the ACA was designed to provide Medicaid "eligibility to nearly all low-income individuals with incomes at or below 138 percent of poverty."[51] After the ACA was passed in March 2010, twenty-six states sued the federal government on the grounds that the requirement to expand Medicaid was coercive and unconstitutional, resulting with states able to opt out of expanding Medicaid.[52] The functional result of this "opt out" is a large population of people who are not eligible for Medicaid and who cannot afford the ACA vouchers— individuals deemed unworthy (by

[49] "How Medicaid Health Care Expansion Affects You." HealthCare.gov. Accessed March 12, 2018. https://www.healthcare.gov/medicaid-chip/medicaid-expansion-and-you/.

[50] Ibid.

[51] Carter Price and Christine Eisner. "For States That Opt out of Medicaid Expansion: 3.6 Million Fewer Insured and $8.4 Billion Less in Federal Payments," *Health Affairs* 32, no. 6 (June 2013):1030.

[52] Ibid.

the state) for healthcare access.[53] According to Rachel Garfield and Anthony Damico:

> ...because the ACA envisioned low-income people receiving coverage through Medicaid, it does not provide financial assistance to people below poverty for other coverage options. As a result, in states that do not expand Medicaid, many adults fall into a 'coverage gap' of having incomes above Medicaid eligibility limits but below the lower limit for Marketplace premium tax credits.[54]

Individuals falling within this coverage gap are framed as lacking coverage as a result of their own moral failings and thus are deemed unworthy of access to life-extending and life-saving healthcare. One sees this through the rhetoric of politicians, the news reporting, and on social media outlets. By presenting the poor as lazy and contemptible, the rhetoric of personal responsibility transforms impoverished individuals from human subjects to objects. The individual needing healthcare is no longer considered human, but is instead transformed into an object of contempt. According to William Ian Miller (1998), contempt "is the correlative of shaming or humiliating others for their failures to maintain group norms."[55] Contempt in the healthcare setting is difficult to identify and challenge as such because of its broad spectrum of expression, and should be understood as a kind of social death that leads to physical death.

LETTING GO

In her story, "The Ones Who Walk Away from Omelas,"[56] Ursula Le Guin asks

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[53] Rachel Garfield and Anthony Damico, "The Coverage Gap: Uninsured Poor Adults in States That Do Not Expand Medicaid," Kaiser Family Foundation Brief (October 19, 2016), accessed November 11, 2016, http://kff.org/uninsured/issue-brief/the-coverage-gap-uninsured-poor-adults-in-states-that-do-not-expand-medicaid/.

[54] Ibid.

[55] William Ian Miller, *The Anatomy of Disgust.* Revised edition. (Cambridge, MA: Harvard University Press, 1998), 216.

[56] Ursula Le Guin, "The Ones Who Walk Away from Omelas," in *The Wind's Twelve Quarters: Short Stories,* (Toronto, ON: Bantam Books, 1976): 251-259.

readers to imagine a utopian world without war or slavery or pernicious hierarchies. She asks us to imagine a world filled with happy people with "A boundless and generous contentment, a magnanimous triumph felt not against some outer enemy but in communion…"[57] Le Guin paints the portrait of a place that seems too good to be true before revealing the suffering that makes the utopia possible: that of a small child locked in a closet in the basement under one of the public buildings. The perfection of this place is dependent upon the dehumanization and misery of a child locked in a broom closet, just as the technological utopian of the US healthcare system depends upon the exclusion of some for advances for others. And just as the child in the broom closet sits naked and scared and covered in sores, crying for help that will not come, there are those in the US in need of healthcare who will not receive it. Though all those in medicine will not face the reality of their Omelas, all those who live in Le Guin's Omelas are required, at some point, to learn of the child who makes their utopia possible:

> They all know it is there, all the people of Omelas. Some of them have come to see it, others are content merely to know it is there. They all know that it has to be there. Some of them understand why, and some do not, but they all understand that their happiness, the beauty of their city, the tenderness of their friendships, the health of their children, the wisdom of their scholars, the skill of their makers, even the abundance of their harvest and the kindly weathers of their skies, depend wholly on this child's abominable misery.[58]

Though this story may seem extreme, there is a parallel story in the current practice of medicine in the US, in which the happiness of some depends upon the suffering of others. While the US enjoys some of the most cutting-edge technologies and treatment options, there are populations who are excluded from accessing these resources. This exclusionary

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[57] Ibid., 255.
[58] Le Guin, "The Ones Who Walk Away," 257.

practice has long been rooted in a dichotomy of worth that distinguishes between those who are worthy of healthcare access and those who are not.

The dichotomy of worth that pervades healthcare is nurtured by a narrative of personal responsibility that posits that health is an individual responsibility. Individuals must take care of their own individual bodies through exercise and eating right, by not engaging in risk behaviors, and by obtaining insurance access.[59] The narrative of personal responsibility is rooted in a rhetoric of choice that frames individuals in this gap as choosing poor health.[60] Narratives of personal responsibility oversimplify the causes and contributions to disease and healthcare access as will be discussed in more detail later in this chapter. Nevertheless, these narratives shape the ways we understand ourselves and the world, as well as the meaning that is attributed to the actions and embodied states of individuals and groups in that world. This narrative is connected to that of the humanist notions of the sixteenth and seventeenth centuries when conceptions of the self were

[59] The narrative of personal responsibility can also help understand the rhetoric around healthcare access that emerges in social media and memes, online blogs, political shows, and amongst politicians. This linking will be discussed more in-depth later in this chapter.

[60] Personal Responsibility has been linked with research on obesity and lung cancer in both scholarly work and in some public health campaigns. For public health campaigns see: "Georgia's Child Obesity Ads Aim to Create Movement out of Controversy - CNN." Accessed March 1, 2018. https://www.cnn.com/2012/02/07/health/atlanta-child-obesity-ads/index.html; Stampler, Laura. "Mayor Bloomberg Defends Anti-Obesity Ads And Then Orders Chicken Soup And Popcorn." Business Insider. Accessed March 11, 2018. http://www.businessinsider.com/mayor-bloomberg-ironically-defends-controversial-anti-obesity-ad-while-in-seamlesscom-headquarters-2012-1; and for scholarly work see: Pearl, Rebecca L., and Matthew S. Lebowitz. "Beyond personal responsibility: Effects of causal attributions for overweight and obesity on weight-related beliefs, stigma, and policy support." Psychology & Health 29, no. 10 (October 2014): 1176-1191. CINAHL Plus with Full Text, EBSCOhost (accessed March 11, 2018); Brownell, Kelly D., Rogan Kersh, David S. Ludwig, Robert C. Post, Rebecca M. Puhl, Marlene B. Schwartz, and Walter C. Willett. "Personal Responsibility And Obesity: A Constructive Approach To A Controversial Issue." Health Affairs 29, no. 3 (March 1, 2010): 379–87. https://doi.org/10.1377/hlthaff.2009.0739.; Buyx, A. M. "Personal Responsibility for Health as a Rationing Criterion: Why We Don't like It and Why Maybe We Should." Journal of Medical Ethics 34, no. 12 (2008): 871–74; Brown-Johnson, Cati G., and Judith J. Prochaska. "Shame-Based Appeals in a Tobacco Control Public Health Campaign: Potential Harms and Benefits." Tobacco Control 24, no. 5 (September 2015): 419–20. https://doi.org/10.1136/tobaccocontrol-2015-052233.

turned outward with an emphasis on individual responsibility to society. Such notions constructed expectations of the ideal citizen whose "overriding concern was to act in accordance with the traditional values of the Roman community."[61] Today the values of the society are rooted in neoliberal ideology that asserts that freedom is achieved and human well-being is improved when there exists free market and trade.[62] As Sue McGregor notes:

> The theoretical assumption of neoliberalism is that the free functioning of the market forces leads to a better utilization and allocations of resources, guarantees a better satisfaction of the requirements of consumption and bigger balance of the foreign trade, and altogether produces higher economic growth and therefore development.[63]

The narrative of personal responsibility is deeply embedded in neoliberal ideology that cognitively differentiates the worthwhile from the worthless through discourses of responsibility and self-determination. It is a shifting in understanding from health as a right to health as a responsibility:

> "The 'right to health' was once understood to be related to enhancing the access of all citizens to health care services for the better treatment of ill health. In contemporary times, however, as the philosophies of the new public health have gathered force, the 'right to health' is rephrased as taking on personal responsibility for one's health by accepting and adopting the imperatives issuing forth from the state and other health-related agencies concerning the maintenance and protection of good health."[64]

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[61] Robert E. Proctor, *Defining the Humanities: How Rediscovering a Tradition can Improve our Schools* (Bloomington, IN: Indiana University Press, 1998), 61.

[62] David Harvey, *A Brief History of Neoliberalism* (Oxford, UK: Oxford University Press, 2007), 2.

[63] Sue McGregor, "Neoliberalism and Health Care," *International Journal of Consumer Studies* 25, no. 2 (June 1, 2001): 82–89.

[64] Alan Petersen and Deborah Lupton, *The New Public Health: Discourses, Knowledges, Strategies* (London, UK: SAGE, 1996), 65.

Those who do not fulfill the expectations set out by this neoliberal ideology are deemed failures with their exclusion from healthcare access framed as justified. Their letting go becomes sensible.

INVISIBLE CONTROLS THROUGH GOVERNMENTALITY

The social death of the individuals who are let go by the healthcare system occurs as a result of these new forms of control through governmentality.[65] Judith Butler asserts that:

> Govermentality operates through state and non-state institutions and discourses that are legitimated neither by direct elections nor through established authority. Marked by a diffuse set of strategies and tactics, governmentality gains its meaning and purpose from no single source, no unified sovereign subject. Rather, the tactics characteristic of govermentality operate diffusely, to dispose and order populations, and to produce and reproduce subjects, their practices and beliefs, in relation to specific policy aims.[66]

Governmentality asserts power not through a state exerting total control, but rather through the production of citizens who regulate their own behavior while also surveilling and policing that of others. Individuals are called to busy themselves with projects of self-improvement, with the discourses framing healthcare access as one's responsibility to manage and maintain one's own health. The debates over expanded healthcare coverage provide a "warning" for what not to become, and simultaneously instruct individuals on self-regulation as well as on the regulation of others. Opposition to the ACA is partially ideological and framed around the belief that only those who are worthy deserve healthcare. This opposition can run deep with some individuals resisting resources that they associate with those who are unworthy of access. This mentality

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[65] Judith Butler, *Precarious Life: The Powers of Mourning and Violence* (New York, NY: Verso, 2006).

[66] Ibid., 52.

manifests as the individual who refused the resources for homelessness because of not wanting to be around "those people." Another way this manifests is as a refusal to have insurance if it means having it through the ACA. At St. Vincent's I received a phone message from a woman seeking help for her husband who was told he might have cancer during an emergency room visit. We got the patient in to be seen at St. Vincent's and through the course of trying to find resources to get the patient access to further diagnostics and treatment discovered the possibility for him to sign up for the ACA. When informed of this opportunity, the patient expressed reluctance to sign up stating that he did not support the ACA and that it was a conscious choice to not have coverage under it. Despite the fact that signing up would afford him access to the much-needed healthcare, he hesitated to sign up because of political and ideological beliefs against "Obamacare." His behavior was shaped by a form of governmentality. He self-regulated by resisting signing up for the resource that would give him access to potential life-saving treatment. The political rhetoric surrounding healthcare reform seemed to overpower the patient's own need for treatment. The patient eventually decided to sign up for the ACA and had insurance within a matter of weeks.

Governmentality is a power of invisibility where "not only is law treated as a tactic, but it is also suspended in order to heighten the discretionary power of those who are asked to rely on their own judgments to decide fundamental matters of justice, life, and death."[67] Judgments are made concerning access to healthcare but are not framed as the life and death matters that they represent, but instead are framed in terms of personal responsibility and other political ideologies. This conceptual shift results in individuals

[67] Ibid., 54-55.

voting against their own interests as was seen with the election of Bevin in Kentucky—where those benefiting from Medicaid expansion voted for someone who campaigned that he would reverse that policy. Rather than voting to keep access to healthcare, individuals make decisions in line with their self-understanding as "subjects" of a political party and the ones thriving in that party.

The logic of letting go, and the political debates that support it, frame individuals in terms of their "outsiderness," and as examples of non-citizens. According to Jonathan Inda, post-social, or anti-citizen technologies "deem the exclusion of certain anti-citizens to be unavoidable, and endeavor to regulate these individuals and sectors of society… through operations that seek to contain the threats they and their actions pose."[68] This emphasis marks particular individuals as not fulfilling the responsibility required to be a good, responsible citizen, and instead connects those existing in the uninsured space as doing so because of bad choices. Their lack of access is linked to personal choice, as well as a failure of personal responsibility, and therefore becomes a matter of ethopolitics. Inda defines "Ethopolitics" as "fundamentally a politics of life. It is concerned with how persons comprehend themselves and manage their existence. It emphasizes treating one's life prudently as a kind of rational planning enterprise – one that requires constant work on the part of the politic subject."[69] This ethopolitical framing results in the existence of the uninsured body becoming evidence of a person's poor management of his/her own existence. If some are no longer valued as a result of the failure to live up to societal expectations of personal responsibility, it then becomes justified to exclude them from

[68] Jonathan Xavier Inda, T*argeting Immigrants: Government, Technology, and Ethics* (Malden, MA: John Wiley & Sons, 2008, 19-20.

[69] Ibid., 24.

the systems of society. The uninsured body thus becomes a state of exception and thus allows for the exclusion of this population by a system that is supposed to help.[70]

STRUCTURAL HARM

The acceptance of the logic of letting go by healthcare providers and workers is often not conscious or recognized. Healthcare space is structured in such a way to perpetuate the logic of letting go—with this logic deeply embedded and structured into its spaces enacting a form of harm against patients and providers. The term "structural violence" was originally coined by Johan Galtung who expanded the definition of violence to include more than just direct, interpersonal violence. Galtung nuances understandings of harm by distinguishing that which has been committed by a specific actor from that which is not caused by an actor but harms nonetheless. According to Galtung:

> In both cases individuals may be killed or mutilated, hit or hurt in both senses of these words, and manipulated by means of stick or carrot strategies. But whereas in the first case these consequences can be traced back to concrete persons as actors, in the second case this is no longer meaningful. There may not be any person who directly harms another person in the structure. The violence is built into the structure and shows up as unequal power and consequently as unequal life chances.[71]

As previously discussed, there is a long history of unequal life chances through practices of exclusion. The spaces of healthcare education and practice emerge from a long and complicated history of inequities and injustice that continue to influence their present-day iterations. According to Paul Farmer, structural harm is suffering that is structured "by

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[70] see Giorgio Agamben, *Homo Sacer: Sovereign Power and Bare Life.* Translated by Daniel Heller-Roazen. 1 edition. (Stanford, CA: Stanford University Press, 1998).

[71] Johan Galtung, "Violence, Peace, and Peace Research" *Journal of Peace Research* 6, no. 3, (1969), 167-191.

historically given (and often economically driven) processes and forces that conspire-whether through routine, ritual, or, as is more commonly the case, the hard surfaces of life— to constrain agency."[72] They are produced and structured as a result of the complex history of medicine that has been filled with practices of using marginalized bodies as tools for knowledge building or excluding them from access to care. Within medicine, harms occur even when there is no specific actor directly harming another person. These harms are indirect but no less pernicious. This can be seen when patients fail to have access to healthcare services; there is not a person who directly inflicts harm on another but the individual is harmed nonetheless. Paul Farmer's work further illuminates this point:

> The term "structural violence" is one way of describing social arrangements that put individuals and populations in harm's way. The arrangements are structural because they are embedded in the political and economic organization of our world; they are violent because they cause injury to people…[73]

These injuries are caused when patients are often only able to seek treatment when their condition becomes life-threatening. This harm is the physical manifestations of the disease with the body succumbing to the pain of cancer, the shortness of breath of COPD, the amputations of limbs resulting from untreated diabetes.[74] Patients without insurance are more likely to receive a delayed diagnosis, which means they are more likely to have

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[72] Paul Farmer and Amartya Sen. *Pathologies of Power: Health, Human Rights, and the New War on the Poor.* 1st edition. (Berkeley, CA: University of California Press, 2004), 40.

[73] Paul E. Farmer, Bruce Nizeye, Sara Stulac, and Salmaan Keshavjee. "Structural Violence and Clinical Medicine." *PLOS Medicine 3*, no. 10 (October 24, 2006): e449. https://doi.org/10.1371/journal.pmed.0030449, 1686.

[74] Paradoxically, while patients cannot get access to the medication and tools used to help prevent extremity amputation due to diabetes they are given access to the amputation surgery through the Emergency Medial Treatment and Labor Act (EMTALA) when the condition has become life-threatening.

diseases that have progressed further and are harder to treat than those individuals with insurance who are able to seek and receive preventative care more quickly.[75] Harm occurs when patients seek treatment and are turned away— the system has deemed them unworthy of care and they have received the news from a healthcare institution that is supposed to help.

Examining structural harms in medicine helps to reveal the ways in which healthcare providers become--often unwillingly—complicit with the suffering of their patients. These providers sometimes cause harm unintentionally as a result of systematic forces constraining their actions. The injuries that result from structural harm are not only experienced by patients and their loved ones. Providers are also harmed when they are coerced into complicity through the institutional policies to deny unfunded patients access to care. The inability to give the care and treatments that their patients need can cause moral distress amongst providers. Worse yet, it can cause moral injury to these providers when they accept and perpetuate the logic of letting go and begin to see their patients as worthy or unworthy of care. Jonathan Shay defines moral injury as a "betrayal of what's right…by someone who holds legitimate authority… in a high stakes situation."[76] Healthcare learners may receive moral injury when they witness their

[75] See Judith Adrien, et al., "Why Are Head and Neck Squamous Cell Carcinoma Diagnosed so Late? Influence of Health Care Disparities and Socio-Economic Factors." *Oral Oncology* 50, no. 2 (February 1, 2014): 90–97. Marisa A. Bittoni, et al., "Lack of Private Health Insurance Is Associated with Higher Mortality from Cancer and Other Chronic Diseases, Poor Diet Quality, and Inflammatory Biomarkers in the United States." *Preventive Medicine* 81, no. Supplement C (December 1, 2015): 420–426. Anthony S. Robbins, Catherine C. Lerro, and Ronald D. Barr. "Insurance Status and Distant-Stage Disease at Diagnosis among Adolescent and Young Adult Patients with Cancer Aged 15 to 39 Years: National Cancer Data Base, 2004 through 2010." *Cancer* 120, no. 8 (April 15, 2014): 1212–1219. Gary V. Walker, et al., "Disparities in Stage at Diagnosis, Treatment, and Survival in Nonelderly Adult Patients With Cancer According to Insurance Status." *Journal of Clinical Oncology* 32, no. 28 (October 1, 2014): 3118–3125.

[76] Jonathan Shay. "Moral Injury." *Psychoanalytic Psychology* 31, no. 2 (2014): 183.

teachers fail to help people, a common reason for entering healthcare professions, in a high stakes situation where the result of not helping can be early death. Education and understanding of the realities of the current landscape of healthcare in the US is generally not offered to healthcare learners. As Farmer rightly notes, "With few exceptions, clinicians are not trained to understand such social forces, nor are we trained to alter them."[77] Often when students do get educated around health disparities, structural harm, and social forces affecting healthcare access and outcomes, they are not educated on how to make changes. This leaves us with a system of providers who understand the complexities of their work but unable to affect outcomes they are forced to address.

UNDERSTANDING SPACE

The ways we imagine and use space construct the social and political possibilities of it while also influencing the meanings that are made in different kinds of spaces. Within healthcare settings, providers and workers are influenced and constrained by the harms that pervade the US medical system with these constraints potentially causing injury to providers. Spatial theory is helpful in making sense of the ways in which healthcare has been produced and structured with such harms in its spaces and everyday practices, shaping the human interactions that occur there. In his seminal work, *The Production of Space*,[78] Henri Lefebvre seeks "to expose the actual production of space by bringing the various kinds of space and the modalities of their genesis together with a single theory."[79] Space does not just exist; it is produced. Likening space to energy, he draws attention to its preface—what comes before space.

When we evoke 'energy', we must immediately note that energy has to be

[77] Farmer et al., "Structural Violence and Clinical Medicine," 1686.
[78] Henri Lefebvre, *The Production of Space.* 1 edition. (Cambridge, MA: Wiley-Blackwell, 1992).
[79] Ibid., 16.

> deployed within a space. When we evoke 'space', we must immediately indicate what occupies that space and how it does so: the deployment of energy in relation to 'points' and within a time frame. When we evoke 'time', we must immediately say what it is that moves or changes therein. Space considered in isolation is an empty abstraction; likewise energy and time. Although in one sense this 'substance' is hard to conceive of, most of all at the cosmic level, it is also true to say that evidence of its existence stares us in the face: our senses and our thoughts apprehend nothing else.[80]

For Lefebvre, space is dialectical, and we interact with the space we inhabit. Lefebvre challenges a flat and linear conception of space by exploding it into three parts. His spatial triad includes spatial practice, representations of space, and representational space. Each part of the triad is a different way of thinking about space and all three parts are interrelated. This spatial triad reveals space as complex and dialogical—these three characteristics interrelate and intersect, engage, and combine to inform one another. The triad resists this tendency to dichotomize and expands our understanding of it to encompass a complex, intersecting, overlapping social phenomenon that informs and shapes experience.

The first part of Lefebvre's triad, spatial practice, "embraces production and reproduction, and the particular locations and spatial sets of characteristic of each social formation. Spatial practice ensures continuity and some degree of cohesion."[81] This can be perceived in the everyday acts and the patterns of social activity and in the everyday interpretation of space. Through this framing, Lefebvre highlights "the active- the operational or instrumental- role of space, as knowledge and action, in the existing mode of production. .. [and] how space serves, and how hegemony makes use of it, in the

[80] Ibid., 12.
[81] Ibid., 33.

establishment, on the basis of an underlying logic and with the help of knowledge and technical expertise, of a 'system'."[82] The healthcare system is one such space that serves the role of shaping the actions that occur there. Robbie Davis-Floyd highlighted this process of the healthcare system, and the space in which it operates, constrains and controls in her work *Birth as an American Rite of Passage* in which she deconstructs and examines the rituals of birth processes in the US medical system.[83] According to Davis-Floyd:

> Hospital delivery as a whole may be seen as a ritual enactment of this technocratic model of birth. Once labor has begun, a variety of "standard procedures" will be brought into play in order to mold the labor process into conformity with technological standards. These various interventions may be performed by obstetrical personnel at different intervals over a time period that varies with the length of the woman's labor and the degree to which it conforms to hospital standards. The less conformity the labor exhibits, the greater the number of procedures that will be applied in order to bring it into conformity. These interventions, aimed at producing the "perfect baby," are thus not only instrumental acts but also symbols that convey the core values of American society to women and their attendants as they go through the rite of passage called birth. Through these procedures the natural process of birth is deconstructed into identifiable segments, then reconstructed as a mechanical process. Birth is thereby made to appear as though it confirms, instead of challenges, the technocratic model of reality upon which our society is based.[84]

Davis-Floyd is drawing our attention to the ways in which the human experience of birthing has been pathologized. It has become dependent upon technological interventions, drastically altering the experience of giving birth. Lefebvre points to the ways in which space is produced, arguing that that which becomes normalized and taken

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[82] Ibid., 11.

[83] Robbie E. Davis-Floyd, *Birth as an American Rite of Passage.* 2 edition. (Berkeley, CA: University of California Press, 2004).

[84] Robbie E. Davis-Floyd, "The Technocratic Model of Birth." In *Childbirth: The Medicalization of Obstetrics* by Philip K. Wilson, (New York, NY: Garland Publishing, Inc., 1996).

for granted thus become logical. With the Davis-Floyd example it is the pregnant body that has become an object to be managed and controlled. This control is exerted through spatial engagements as Lefebvre points out, "…the space thus produced also serves as a tool of thought and of action that in addition to being a means of production, it is also a means of control, and hence domination, power…"[85] The logic of healthcare is one that is dominated and shaped by technology, as Davis-Floyd rightly asserts that the "hospital itself is a highly sophisticated technological factory (the more technology the hospital has to offer, the better it is considered to be). As an institution it constitutes a more significant social unit than the individual or the family…"[86] The default in this space is the technology, with the wants and needs of patients as secondary. You see this at the close of life too, in the ways that death education and end-of-life care access is limited with invasive technological interventions serving as the norm.

The technocratic model of medicine is not always the norm in practice. This model is thrown out when, in the consumer-driven, for-profit model of healthcare, an unfunded patient seeks care. The profit focus shapes experiences in healthcare settings and also controls who has access to such spaces and which treatments in those spaces. The for-profit model of healthcare privileges the economics of the institution over patient care, and thus constrains the choices available to un- or underfunded patients. One way that this occurs is what patients have access to which spaces and when.

It is not only economic influences that shape healthcare practices in the US, but it is also the very construction of the physical space also works to constrain and control the

[85] Lefebvre, *The Production of Space,* 26.
[86] Davis-Floyd, "The Technocratic Model of Birth," 252.

actions and experiences that occur in said space. This physicality is what the second part of Lefebvre's triad, representations of or conceived space, emphasizes. Representations of space illuminate the ways in which physical spaces are constructed to support the ideological framings that influence space. Lefebvre describes representations of space as being "tied to the relations of reproduction and to the 'order' which those relations impose, and hence to knowledge, to signs, to codes, and to 'frontal' relations."[87] Representations of space can be understood as conceptualizations of space and take a physical form such as maps and plans. In the case of the hospital room, this would be the plans for the room and the layout mapped out. The maps and plans of hospitals reveal the ways in which hospitals are constructed for function and medical action:

> …the hospital building was gradually organized as an instrument of medical action: it was to allow a better observation of patients, and therefore a better calibration of their treatment; the form of the buildings, by the careful separation of the patients, was to prevent contagions lastly, the ventilation and the air that circulated around each bed was to prevent the deleterious vapors… The hospital… was no longer simply the roof under which penury and imminent death took shelter; it was, in its very materiality, a therapeutic operator.[88]

Signs and codes organize and shape the interactions that occur in space, and these signs and codes are reflective of the ideology of the space. This can be understood as the ways in which hospital and clinic rooms are designed to maximize function and to also create docile bodies of patients. Davis-Floyd identified this practice within the maternity ward when women were separated from their partners and required to disrobe and put on

[87] Lefebvre, *The Production of Space,* 33.

[88] Michel Foucault, *Discipline & Punish: The Birth of the Prison.* Translated by Alan Sheridan. (New York, NY: Vintage Books, 1995), 172.

hospital gowns.[89]

The ideology that underlies the representations of space is further made clear by Michel Foucault in his work *Discipline and Punish: The Birth of the Prison.* According to Foucault, "an architecture would operate to transfer individuals: to act on this it shelters, to provide a hold on their conduct, to carry the effects of power right to them, to make it possible to know them, to alter them. Stones can make people docile and knowable."[90] Indeed, hospitals are structured to maximize the ability to surveil, and to ensure that patients remain docile and easy to manage. The physical space of St. Vincent's perpetuates this harm but also works to resist it. St. Vincent's House, an outreach ministry of the Episcopal Diocese of Texas, hosts the student clinic. Its building is a beacon of hope for the neighborhood. Brightly painted murals share messages of empowerment, kindness, and compassion imploring individuals to help others.[91] These paintings continue inside with messages of nutrition, imploring individuals to care also for themselves. On each of the entrances, colorful doors welcome visitors to the space self-described as an "A Beacon of Hope, A Place of Healing, For All God's People."[92] The House is indeed a space that welcomes all, but it is also a space that enacts control over patients. A large portion of the second floor of the House is made up of clinic exam rooms that follow traditional medical spaces and thus mimic the same harms of such spaces—spaces of waiting where providers hold primary control. Although the clinic models problematic healthcare structures, healthcare providers do have agency when

[89] Davis-Floyd, *Birth as an American Right of Passage.*

[90] Foucault, *Discipline & Punish,* 172.

[91] see Appendix A.

[92] "HOME." Accessed March 14, 2018. http://stvhope.org/.

navigating such spaces. The work of Michel de Certeau, who takes up Lefebvre's work, helps to understand the possibilities of agency in healthcare spaces. [93]

In his work *The Practice of Everyday Life,* de Certeau pulls heavily from Lefebvre but shifts his focus to the agency and experience of those engaging with space and its containing tendencies.[94] Space is produced and is done so in a way that shapes actions and experiences of those engaging with and in that space. De Certeau's work illuminates different possibilities for living within a coercive system, by framing engagement with space through tactics and strategies. Tactics and strategies are two ways of operating in space and are associated with different levels of access to power. According to de Certeau, "strategies are actions which, thanks to the establishment of a place of power (the property of a proper), elaborate theoretical places (systems and totalizing discourses) capable of articulating and ensemble of physical places in which forces are distributed."[95] Strategies presume a certain level of power and control and depend on the "establishment of a place" and are under the purview of the powerful. In a hospital setting this can be understood as the policies and campaigns of the upper administration; they are the plans that elaborate the discourses of a medical system focused on efficiency, profit, and outcomes. These shape the space and the movement in it, but only to an extent. The ordinary practitioners of that space, whether as providers, patients, or loved ones of patients, occupy a certain level of invisibility to the power forces and thus are able to engage in tactics. Tactics are the ways in which we can resist

[93] Michel de Certeau, *The Practice of Everyday Life.* Translated by Steven F. Rendall. 3 edition. (Berkeley, CA: University of California Press, 2011).

[94] Ibid.

[95] Ibid., 38.

the controls of space. The ordinary practitioners of healthcare space, whether as providers, patients, or loved ones of patients, occupy a certain level of invisibility to the power forces and thus are able to engage in tactics. Tactics are the everyday practices that occur that do not require the same level of power. In the hospital setting, tactics can be used to navigate the often-oppressive system in order to engage with patients in a way that respects their dignity and personhood.

CONCLUSION

The spaces of healthcare can be understood as a geography of power: they are filled with the ideological, political, and economic forces that influence and shape the relations that occur in them.[96] It is the economics of this space that largely dictate the practices here— funding status, insurance limitations, and pharmaceutical influence, for example, help shape and construct the healthcare decisions and practices that occur in these spaces. As outlined in this chapter, healthcare spaces are designed to control and constrain the actions and interactions that occur there, but there are ways that these controls have been challenged with healthcare providers and patients collaborating to create new spaces for care that are focused on a more holistic approach to healthcare that rejects the profit-driven approach to healthcare. The space of which I speak is the contemporary free clinic, which emerged in the late 1960s as a response to perceived injustices in the formal healthcare system. In the next chapter, I trace the history of the contemporary free clinic and illuminate the ways in which it emerged as a tactic for healthcare practice. Those engaging in the tactic of the contemporary free clinic rejected

[96] Doreen B. Massey, *For Space* (London, UK: Sage, 2005).

the logic of letting go and sought to create a space that also rejected that logic. They are exiting Omelas and seeking another way.

Chapter 2 Leaving Omelas—Freeing Healthcare

> At times one of the adolescent girls or boys who go to see the child does not go home to weep or rage, does not, in fact, go home at all. Sometimes also a man or woman much older falls silent for a day or two, and then leaves home. These people go out into the street, and walk down the street alone. They keep walking, and walk straight out of the city of Omelas, through the beautiful gates. They keep walking across the farmlands of Omelas. Each one goes alone, youth or girl man or woman. Night falls; the traveler must pass down village streets, between the houses with yellow-lit windows, and on out into the darkness of the fields. Each alone, they go west or north, towards the mountains. They go on. They leave Omelas, they walk ahead into the darkness, and they do not come back. The place they go towards is a place even less imaginable to most of us than the city of happiness. I cannot describe it at all. It is possible that it does not exist. But they seem to know where they are going, the ones who walk away from Omelas.
>
> -Ursula Le Guin, “The Ones Who Walk Away From Omelas”

In the story of the city of the Omelas, the populace flourishes because of the suffering of one child. That child lives in darkness and in squalor so that others in society may thrive in the sunshine. Members of society rationalize their existence, resting on the belief that the child knows no different and that the suffering of one is a worthy price for the happiness of many. Not all members of this society could accept this truth. Some walked away. Beginning in 1967 there were many who walked away from the “Omelas" - that is, the medical system—in the United States. Such people rejected the logic of letting go. These individuals were both patients and providers who refused to treat or be treated in spaces infused with practices of dehumanization. The injustices of the US medical system persist today, as do those providers who choose to reject the logic of letting go by finding ways to care for patients despite the systems and spatial practices that dominate

healthcare. For those providers who walk away, most still exist as citizens of the produced space of funded healthcare settings, but they do so while also existing in free clinics across the country. The place to which these travel is the over one thousand free clinics that exist across the United States and exist as part of a larger history of the contemporary free clinic in the United States. [97, 98] This chapter traces the history of the contemporary free clinic and its emergence as a tactic of rejecting the logic of letting go. Pulling from de Certeau and Doreen Massey, I highlight the ways in which free clinics have functioned as tactics and the ways in which they have resisted the structural harms of US healthcare.

FREE CARE (AT A COST)

Free healthcare did exist in the United States prior to the free clinic spaces that emerged in the late 1960s. It is important to distinguish these early free clinic spaces because the motivations for creating these spaces are markedly different from those that would come later. In the text *The Care of Strangers,* Charles Rosenberg identified two main motivations for the creation of free healthcare:

> Late eighteenth-and early nineteenth-century hospital advocates felt two kinds of motivation. One was the imperative of traditional Christian benevolence in urban communities already burdened with large numbers

[97] In 2010 Julie Darnell of the University of Illinois at Chicago conducted a survey of free clinics in the US Darnell defined "free clinic" as "An organization was operationally defined as a "free clinic" if it met all the following criteria: being a private, nonprofit organization or program component of a nonprofit; providing medical, dental, or mental health services and/or medications directly to patients; serving mostly (☒50%) uninsured patients; charging no fees or nominal fees of not more than $20; not billing patients, denying services, or rescheduling appointments if the patient could not pay the requested fee/donation; and not being recognized as a FQHC…" Julie Darnell. "Free Clinics in the United StatesA Nationwide Survey | HIV | JAMA Internal Medicine | The JAMA Network." JAMA. Accessed November 12, 2017. https://jamanetwork-com.libux.utmb.edu/journals/jamainternalmedicine/fullarticle/416041.

[98] I use the term "contemporary free clinic" to identify those free clinics that began emerging in the late 1960s as a response to injustices present in the healthcare system. Later in this chapter the contemporary free clinic will be distinguished from forms of free and charity care that preceded them in the US.

> of 'unsettled' individuals needing care. The other sort of motivation grew out of the clinical and educational goals of an elite in the medical profession.[99]

The almshouses and early hospitals of the US functioned as storage facilities for the unsavory individuals who had fallen ill, and also as classrooms in which students and residents learned on the backs of the poor.

In her dissertation, *Shelter from the Storm,*[100] Rebecca Theres Baird clearly delineates the distinction between the contemporary free clinic movement and those spaces of free care in the US that proceeded it. As she rightly notes, a major difference was in the shift from moralizing healthcare, where access was linked with willingness to receive spiritual guidance or access was denied to those who were deemed unworthy, to an emphasis on providing non-judgmental healthcare.[101] Many of the early spaces for free care in the US had moralistic underpinnings that worked to shape the culture of those spaces and the experiences of patients. Such moralistic underpinnings reinforced the dichotomy of worth discussed in Chapter One with different kinds of care made available for the worthy and unworthy poor. The dichotomy of worth resulted in spaces being created to house and store those deemed unworthy. In colonial America, most healthcare consisted of home care, but those who did not have access to such care were relegated to almshouses. Almshouses offered care to individuals who lacked anyone to care for them and the means to afford help or a place to go. As Sidney Watson notes:

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[99] Charles E. Rosenberg, *The Care of Strangers: The Rise of America's Hospital System.* Edition Unstated edition. (Baltimore, MD: Johns Hopkins University Press, 1995), 338.

[100] Rebecca Therese Baird, "Shelter from the storm: the Los Angeles Free Clinic, 1967-1975" (doctoral dissertation, Arizona State University, 2016).

[101] Ibid.

> …public almshouses— also called poorhouses—housed those with disabilities, mental illness, contagious diseases, incurable illnesses and alcoholism alongside children and widows. Rooted in the Elizabethan Poor Laws, this "indoor relief" was the only form of public welfare. Poverty, disability, and illness were viewed as moral failings and almshouses were meant to reform through order and structure.[102]

Almshouses functioned more as a space to store the unworthy poor rather than care for them. Residence in an almshouse was also seen as "a punishment for past economic inadequacy and a deterrent to future imprudence…"[103] The undeserving poor were not worthy of dignified care and instead were housed in humiliating conditions. Such conditions were deemed unfair for those hardworking poor and women and the elderly who might find themselves there because they had fallen ill.[104] By the early 20th century the nonprofit community hospital emerged as a space to care for the deserving poor who did not have the means to afford a bed or did not have family to care for them.[105] With these institutions, the dichotomy of worth became more pronounced as religious motivations to help shape who was able to receive that help. These spaces existed to provide "rudimentary nursing care, religious counseling, and weekly visits by a local physician who could frequently diagnose but rarely intervene."[106] These spaces were not for all in need but instead were created to care for the worthy poor, as Engel notes:

> From the beginning these sectarian institutions defined their missions quite specifically. They were to provide community service and charity care to those in need, but only those who met minimal community

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[102] Sidney Watson. "From Almshouses to Nursing Homes and Community Care: Lessons from Medicaid's History," *Georgia State University Law Review* (Spring 2010): 941 Watson pulls heavily from Charles Rosenberg's work *The Care of Strangers*

[103] Rosenberg, *The Care of Strangers,* 322

[104] Ibid.

[105] Watson, "From Almshouses to Nursing Homes and Community Care" 941.

[106] Engel, *Poor People's Medicine,* 8.

> standards of worthiness. The "deserving poor" was a protean term, but throughout the late Victorian era it generally defined those who had fallen on hard times despite moral rectitude.[107]

The poor without "moral rectitude" were deemed unworthy of charity care and remained in poor houses or in the hospital's overcrowded pauper wards. Alternatively, they were cared for in outpatient clinics and dispensaries that were used to keep the poor out of the hospitals and as a space for student and resident physicians to practice.[108]

Education has long been, and continues to be, a motivation for the creation of free spaces of healthcare. Between 1870 and 1910 "hospitals moved from the periphery to the center of medical education and medical practice."[109] The hospital transformed into a space of practice for learners to gain the skills necessary to become providers with the poor often the ones being used to practice upon.[110] Far from being purely altruistic endeavors, these early free clinics proliferated to provide the educational materials needed to train these future physicians. As Rosenberg writes, "need and social class were still fundamental in determining the likelihood of an individual's serving as 'clinical material'."[111] The use of the poor to serve as clinical material for learners continues, but in the late 1960s another kind of space of free healthcare emerged. This space rejected the dichotomy of worth and its logic of letting go— the contemporary free clinic. The individuals creating these spaces sought to be different from the dehumanizing healthcare they critiqued. Although they had both successes and failures—as will be discussed

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[107] Ibid., 9.

[108] Rosenberg, *The Care of Strangers*; Engel, *Poor People's Medicine.*

[109] Paul Starr, *The Social Transformation of Medicine,* (New York, NY: Basic Books, Inc. Publishers, 1982), 146.

[110] Rosenberg, *The Care of Strangers,* 20.

[111] Ibid., 192.

throughout this chapter—there is much to learn from the work of free clinics.

FREEING HEALTHCARE

In stark contrast to the spaces of free care that preceded it, the contemporary free clinic emerged as a rejection of the formal healthcare system that restricted some individuals' access to care. As Constance Bloomfield and Howard Levy of the Health Policy Advisory Committee note:

> …free clinics have arisen in the wake of the widespread failure of America's traditional institutions: the failure of doctors not only to treat bad trips, but to provide any minimal standard of care in ghetto communities; the failure of hospitals to break down the hierarchy among health workers that fosters poor patient care; the failure of Blue Cross, and now Medicare and Medicaid, to eliminate financial barriers to decent medical care. In sum, free clinics are a response to what has become a thorough-going crisis in the American medical system.[112]

Free clinics emerged as explicit critiques of the unjust structures and practices of the healthcare system in the United States. These places were not only spaces of healthcare but also of a kind of activism that strove to free patients from the political and economic controls of the traditional health care system, as well as to provide a different culture of caring for patients. They sought to cultivate a different kind of space for health caring.

As part of this focus, efforts were made to create healthcare spaces free from bias and value judgments. The contemporary free clinics "… focused on treating the disease, educating the patient, and avoiding lectures or moralistic attitudes."[113] The goal was to create safe spaces where individuals could receive care without judgment. These spaces were created by individuals wishing to provide access for those who did not have it. The

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[112] Constance Bloomfield and Howard Levy. "Underground Medicine: Ups and Downs of Free Clinics," *Ramparts*, (March 1972,): 35–36.

[113] Baird, *Shelter from the Storm,* 28-29.

result was a better experiential quality of care that followed a different philosophy of care:

> The 'Free' in Free Clinic refers more to a state of mind than to the absence of a cashier. Free means an entire philosophy of service in which the person is treated rather than his or her disease; it is an important distinction. In a free clinic the focus is on health caring for the whole person, on providing a service which is free of red tape, free of value judgments, free of eligibility requirements, free of emotional hassles, free of frozen medical protocol, free of moralizing, and last and least, free of charge.[114]

It is not just that the clinical spaces did not require financial payment, but, more than that, they were founded on the belief that health care is both a positive and negative right. All individuals have the positive right to access care while also having a negative right of freedom from bureaucracy, value judgments, and moralizing. The contemporary free clinics were founded on the principle that no matter what the resources, you must treat all patients with respect and dignity.[115] These spaces rejected the conventional healthcare spaces with their structural harms and instead sought to create a different kind of healthcare experience.

WALKING THE CITY

The traditional healthcare setting has been established as a place that only allows certain individuals access to the care provided. The policies are centered on maximizing efficiency, profit, and outcomes often over the good of the patient. This means that some individuals are deemed unworthy of healthcare access and are deemed so based on

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[114] Richard Seymour and David E. Smith. *The Haight Ashbury Free Medical Clinics: Still Free After All These Years, 1967-1987.* Y First printing edition. (San Francisco, CA: Partisan Press, 1986), 36-37.

[115] Gregory Weiss, *Grassroots MedicineGrassroots Medicine: The Story of America's Free Health Clinics,* (Lanham, MD: Rowman & Littlefield Publishers, 2006); David Smith, David Bentel, Jerome Schwartz. *The Free Clinic: A Community Approach to Health Care and Drug Abuse.* N edition. (Beloit, WI: Stash Press, 1971); Seymour & Smith, *The Haight Ashbury Free Medical Clinics.*

funding or socioeconomic status. These strategies shape the space and the movement in the space, but only to an extent. Although so much of healthcare space has been produced and it is thus structured to perpetuate harm and inequality against particular groups and populations, there remains space for the quiet everyday practice of seeking a different way. The founders of the early free clinics resisted the controls of the formal healthcare system. Free clinics worked, and continue to work, to create a different culture of medicine and to provide a space for those rejected and dehumanized by the mainstream health care system. Michel de Certeau's work on spatial theory illuminates the ways in which these clinics navigated the space of healthcare in a way that resisted these controls. The result was a culture of caring that allowed for an attention to the experiential and relational quality of care. Rejecting the logic of letting go, these clinics were focused on providing quality care to patients in a safe and welcoming environment.

The individuals at the forefront of the free clinic movement found a way to resist the structural constraints and harms of the produced space of the medical system and provide for those who had been let go. It was through creative thinking and engagement that this care became possible. De Certeau reveals the ways in which creativity is possible even in spaces that are produced. He pulls heavily from Lefebvre but shifts his focus to the agency and experience of those engaging with space and its containing tendencies. De Certeau unflattens space by revealing the ways in which creativity is possible despite the constraints of its design. He characterizes this as "ways of operating" or the "innumerable practices by means which users re-appropriate the space organized

by techniques of sociocultural production.[116] De Certeau illustrates alternative ways of operating beautifully with the example of "Walking the City."[117] Cities are designed to control and constrain movement with streets and the placement of buildings and parks working to dictate the flow of traffic and therefore people. De Certeau unflattens space by revealing the ways in which creativity is possible despite the constraints of its design.

The free clinic movement functioned as a tactic to resist the constraints of the formal healthcare system. The contemporary free clinics were directly responding to the problem of the hospital becoming dehumanizing for patients and providers alike. As Rosenberg notes:

> Suddenly, it seemed in the late 1960s, the American hospital became a problem. It has remained one. Depending on the critic's temperament, politics, or pocketbook, the hospital appeared a source of uncontrolled inflationary pressure, an instrument of class and sexual oppression, or an impersonal monolith, managing in its several ways to dehumanize rich and poor at once, if not alike.[118]

Within this movement individuals decided that the dehumanizing and exclusionary practices of healthcare were unacceptable. The founders of the first free clinics found different ways to operate. They re-appropriated the techniques of organized healthcare in new spaces that allowed for more individual access despite the constraints of the healthcare system.

THE CLINICS THAT EMERGED

The free clinic movement is said to have started with the Haight Ashbury Free

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[116] Ibid., xiv.
[117] Ibid., 91-110.
[118] Rosenberg, *The Care of Strangers,* 3.

Medical Clinic that opened in San Francisco on June 7, 1967.[119] Hundreds of other free clinics opened in the subsequent years and decades. The Haight Ashbury initially opened as a hippie drug clinic to address the influx of individuals in the area for the Summer of Love.[120] The hippie drug clinics "… focused on providing medical services—with an emphasis on drug abuse treatment—for transient young people. Services typically included detoxification and rehabilitation treatment, counseling, and care for drug-related acute illnesses."[121] The Haight Ashbury later expanded their services beyond this drug-related focus in response to the community they served. They continue with these expanded services today. In a self-published work, Haight Ashbury founders David Smith and Richard Seymour provide a history of the Haight-Ashbury Free Medical Clinic along with a more generalized context of the free clinic movement during this twenty-year period of 1967-1987. The authors provide an overview of the programs and development of the clinic while also providing some information about the national free clinic movement, connecting their own history to the larger movement. They present their challenges and failures alongside their successes, providing a meaningful view of the development and growth of what they credit as the first free clinic of its kind in the country. This provides a history of this particular clinic while also providing information to share with other clinics and with individuals interested in starting a free clinic. This level of information-sharing by clinics is a goal articulated by Dr. David Smith

[119] Weiss, *Grassroots Medicine*; Baird, "Shelter from the Storm"; Niki A. Nibbe, "Beyond the Free Clinics Origin Myth: Reconsidering Free Clinics in the Context of 1960s and 1970s" (master's thesis, University of California, 2012).

[120] Seymour & Smith, *The Haight Ashbury Free Medical Clinics.*

[121] Weiss, *Grassroots Medicine,* 25.

throughout this work and others.[122]

The clinics that followed Haight Ashbury fell into three categories: hippie drug clinics (also known as street clinics), neighborhood clinics (also known as Minority clinics), and youth clinics.[123] The youth clinics "…focused on life education and drug education and counseling and were targeted at high school students."[124] The youth clinics were short-lived and were taken over by the emerging governmental programs for children and teens. The hippie drug/street clinics had a patient population consisting of primarily whites, middle-class high school and college-aged individuals estranged from their families. The focus of these clinics was to treat drug-related addiction and illness in a non-judgmental and respectful environment.[125] The Haight Ashbury is one example of this kind of free clinic. The neighborhood (minority) clinics were generally politically organized around race and ethnicity to meet the unaddressed health needs of these groups. They provided more comprehensive medical services than the street clinics and provided care to individuals of all ages. The patients utilizing the neighborhood clinics tended to be those who were excluded from the mainstream health care system, and these clinics operated primarily out of store fronts and churches and relied heavily on donations to open and operate.[126] The Black Panther Party opened neighborhood clinics across the country to serve African Americans whose health needs were not being met by mainstream medicine. The Black Panther Party Free Medical Clinics (PFMC) will be

[122] Seymour & Smith, *The Haight Ashbury Free Medical Clinics.*
[123] Weiss, *Grassroots Medicine.*
[124] Ibid., 25.
[125] Weiss, *Grassroots Medicine*; Smith, Bentel, & Schwartz, *The Free Clinic*.
[126] Ibid.

discussed in further detail later in this chapter.

THE TENETS OF FREE CLINIC CARE

These free clinics of the 1960s were not only creating access for individuals who did not have access to mainstream medicine, but also rejecting the culture of mainstream medicine:

> The word 'free'… doesn't just mean 'no patient charge per patient visit.' It is almost a socio-political term suggesting freedom from conventional bureaucracy, from making destructive moral judgments, to administer services in a way unencumbered by conventional medical protocol.[127]

For these early free clinic founders, providing health care constituted more than attending to the physical ailments of patients. The clinics functioned under the belief that "health care transcends clinical medicine… [and that] Health services… should be provided for all people within the context of total health—individual, community, and social health."[128] These organizations emphasized caring for the whole patient and thus sought to provide more than just physical care to patients. The Black Panther Party Free Medical Clinics (PFMC) provide an excellent example of that. In her book, *Body and Soul: The Black Panther Party and the Fight against Medical Discrimination,* Alondra Nelson provides a rich examination of the health activism of the Black Panther Party through their free clinics. These clinics emphasized caring for the whole patient including helping them to navigate resources related to housing, employment, and welfare programs.[129] These activities extended well beyond the biological health needs of clients:

> The work of these chapter-based institutions did not end with providing health services. The clinics were exemplars of the Party's commitment to

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[127] Smith, Bentel, Schwarz, *The Free Clinic,* xvi.

[128] Ibid., vii.

[129] Alondra Nelson, *Body and Soul: The Black Panther Party and the Fight against Medical Discrimination*. Reprint edition. (Minneapolis , MN: University Of Minnesota Press, 2013), 5-6.

> the *total* well-being of its constituents. A person entering a Party clinic might also receive help from a "patient advocate" with paying bills or dealing with a problematic landlord; this individual might also be encouraged to attend a political education class in which writings by Fanon and other theorists were discussed. In this way, the PFMCs were sites for social change.[130]

Health activism was not the primary focus of the Party but became an important component of programming that sought to "serve the people body and soul."[131] The Party created programs that attended to the varied needs of African Americans at the time including, but not limited to, healthcare.

The Black Panther Party was not the only organization that worked to provide more comprehensive care to patients. The Berkeley Free Clinic also strove to provide more comprehensive care and services to patients. In her thesis, Nikki Nibbe traces the history of the Berkeley free clinic from when it began as part of the Free Church, or the South Campus Community Ministry, to its present-day practice as a provider of assistance to those in need in the area. [132] Free clinics provide resources to meet the needs of the community, with a focus on crisis intervention. The Berkeley Free Clinic formally opened in May of 1969 with the help of three social work graduate students from the University of California Berkeley: Susan Cady, Ann Heisler, and Ellen Koteen. The three used the starting of the clinic as their fieldwork project while studying social work with an emphasis in community organizing.[133] The social work focus of the early organizers of the Berkeley Free Clinic resulted in an organization that sought to meet more than just

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[130] Ibid., 19.
[131] Ibid., 18
[132] Nibbe, *Beyond the Free Clinic Myth.*
[133] Ibid., 106.

the medical needs of patients. The Berkeley Clinic sought to provide medical and mental healthcare but also assisted patients with housing needs with their emergency housing program. This program established a hotline for those in need to call to get short-term housing (1-2 nights).[134] Housing insecurity would prove to be a common problem for which these early free clinics would provide resources.

Other clinics also sought this broader approach to healthcare, offering unique services to clients. The Los Angeles Free Clinic, for example, "provided… the Sex Information Hotline, which opened June 30, 1975…[and]…was a 24-hour hotline 'staffed by nurses, teachers, psych students, and it was a line where you could get accurate non-judgmental sexual information."[135] The Los Angeles clinic, as others, sought to provide education to clients and patients that was non-judgmental. The LA clinic would even solicit patients to help educate other patients. In a somewhat unorthodox practice, the clinic would have female patients serve as chaperones during gynecological exams and would educate these women to teach other patients about sexually transmitted diseases.[136] Like many of the contemporary free clinics, the LA free clinic sought to not only treat but also to educate and empower patients to help themselves and others. With the broad scope of helping, these early free clinics were engaging in social health, which "as a praxis… linked medical services to a program of societal transformation."[137] These free clinic spaces were the sites of a whole new kind of health caring, which attended not only to the physical condition but also the social.

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[134] Ibid., 92.
[135] Baird, *Shelter from the Storm,* citing an interview with Kelly Hodel in 2013, 115.
[136] Ibid., citing an interview with Kelly Hodel in 2013, 153.
[137] Nelson, *Body and Soul,* 12.

FREE FROM RED TAPE

Another way the free clinics sought to remain free from bureaucracy was through the very conscious and persistent effort to not only remain outside of the governing power of mainstream medicine, but also to forge an environment that did not ostracize those individuals seeking help. These free clinics focused on the human interactions of health care asserting that "The identity of the free clinic system is rooted in the concept of people to people involvement."[138] They sought to cultivate an alternative environment that was more relaxed and more informal in order to increase the comfort of patients, and did so by having physicians wear clothes similar to those of the patients. Also, in these settings the support staff were largely without formal credentials (sometimes former patients and generally community members). Individuals who did not have formal credentials in healthcare were instead trained through apprenticeship in the clinic in order to provide care to patients.[139]

The model of providing care in a more informal way carries with it both benefits and concerns. The informal environment was initially utilized in order to make the clinic more welcoming for clientele that was seen in the early clinics. However, the apprenticeship practices meant that patients received care from individuals with limited training and experience. In spite of this, patients often preferred seeing them to those with formal training who worked in mainstream medical settings. Often, patients would have had previous experiences of poor treatment in the traditional medical system and therefore avoided care in those settings. These early clinics worked to create an

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[138] Smith, Bentel, and Schwarz, *The Free Clinic,* xiii.

[139] Seymour & Smith, *The Haight Ashbury Free Medical Clinics*; Smith, Bentel,& Schwarz, *The Free Clinic*; Weiss, *Grassroots Medicine.*

environment counter to the more formal environment of mainstream medicine.

The Haight Ashbury offers one example of a clinic that cultivated an informal environment in an attempt to make patients feel more welcome. Nurses would wear street clothes and sometimes even go barefoot to help the patients feel more at ease. Additionally, the clinic waiting room was painted and had a couch and mattresses to make the space less formal and therefore more welcoming to those outside the mainstream who would seek care there.[140] The Berkeley Free Clinic also cultivated an informal environment through the incorporation of individuals without professional backgrounds being trained to provide healthcare services. In a sense these individuals are "walking the city" of healthcare and rejecting paths that restrict roles to professionally trained individuals. [141] They were re-appropriating medical space and adapting it to their needs and philosophies. According to Nibbe, The Berkeley clinic "began to pattern their work on China's 'barefoot doctor model'"[142] introducing their volunteers to this model during orientation:

> … the informality of the emergency conditions of the riots that allowed many uncredentialed but skilled volunteers to work at levels they never could have in a professional setting. As successive generations of volunteers went through progressively more organized and standardized trainings, the concept of "lay community volunteers" was combined with a political critique of the profit-mongering professional guilds and corporate service institutions to produce a model vaguely parallel to the 'barefoot doctor' model…[143]

It began as necessity with lay persons stepping in to help those injured during riots but

140 David E. Smith and John Luce. Love Needs Care, (Berkeley, CA: Little, Brown and Co., 1971), 158.

141 de Certeau, The Practice of Everyday Life.

142 Nibbe, "Beyond the Free Clinic Myth," 138.

143 Ibid., quoting "Scottosaurus", 138.

evolved to be a standard of practice. You can see this today with community health workers who serve as liaisons, expanding access through in-house training of clinical volunteers and thereby rejecting what was seen as a system focused on profits and not patients.

Another tenet of the first free clinics was that patients would be free from eligibility requirements, a kind of free from letting go. As free clinics have shifted towards functioning as a point of access for patients who are not supported by mainstream medicine's hole-filled safety net, many free clinics have implemented eligibility requirements for their clinics. Eligibility requirements do afford clinics access to more resources and can help ensure that the resources are being used to support those without other access, but these eligibility standards are generally based on socioeconomic status like those of federal programs.[144] This focus results in free clinics implementing the economic controls that were rejected by the early clinics:

> Many clinics—especially those that were created in the early years—strongly believe that free clinics ought to be available to anyone who seeks services from them. They believe that there may be many reasons that a person would go to a free clinic. Lack of financial wherewithal to pay for private care is an obvious reason, but it might be due to feeling mistreated in the private care system or feeling more comfortable with the staff and volunteers at a free clinic or seeking a specific kind of care offered at a free clinic. Some clinics believe that all of these reasons and others are understandable and that no one should be turned away from a medical care site. For these clinics, part of what it means to be 'free' is, when you are sick, to be free of eligibility requirements, means tests, and questions about personal finances.[145]

The financial eligibility requirements fail to reveal the nuances of why someone might

[144] Weiss, *Grassroots Medicine.*

[145] Ibid., 91.

seek treatment at a free clinic even with insurance or a particular income. Insurance does not equal access as insurance often has expensive copayments or co-insurance payments, high deductibles, and poor or no specialty coverage. It is also important to think about all of the reasons someone might "need" free clinic services that are not related to lack of financial resources. As Weiss articulated, patients may choose a free clinic because of poor past experiences with mainstream medicine and for the quality of interactions possible in free clinics (as discussed above). At St. Vincent's we have seen this with patients who gain Medicare and who express fear or hesitation about transitioning to the traditional healthcare setting. We work with patients to help them navigate the system and work to connect them to care with faculty they have already been seeing at St. Vincent's. Some patients have refused to seek care in the traditional healthcare settings and report bad past experiences in those spaces as their reason. Others have shifted their visits to traditional settings only to return to St. Vincent's after experiencing fragmented care or harmful interactions in those spaces. Eligibility that focuses on a financial determination fails to attend to the fact that just because someone is able to financially access funded health care space does not mean one is able to access quality care or respect and dignity in that space.

CONCLUSION

Creating spaces of dignity and respect for patients is what the free clinic movement focuses on. The free clinic was a space where a different kind of care became possible. The present-day free clinic has the potential to continue the simple, yet revolutionary, foundational tenet that every patient should be treated with respect and dignity. The existence of the space alone is not enough to ensure this care. An understanding of the complex and nuanced history of the way free clinics emerged as

spatial critiques of mainstream medicine is necessary in shaping the experiential curriculum in free clinics. If kept outside of political and economic controls, free clinics are able to be important educators for the students who will later practice in mainstream medicine. They can also serve as a reminder of what medicine can be when its focus remains on its interpersonal nature rather than on the financial interaction. The free clinic has the potential to provide a space for a more humane practice of medicine and for the cultivation of social justice-minded healers. In the next chapter I examine the current practice of free clinics in the US, paying special attention to the model of the student-run free clinic with St. Vincent's Student-Run Free Clinic in Galveston, Texas serving as a case study.

Chapter 3 Free Clinics Today and 'Healthcaring' at St. Vincent's

> …How do you say: No, we do not find inspiration here, but we find a country that is as beautiful as it is broken, and we are somehow now part of it, so we are also broken with it, and feel ashamed, confused, and sometimes hopeless, and are trying to figure out how to do something about all that.
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> -Valeria Luiselli, *Tell Me How It Ends*

The need for accessible healthcare in the US persists with free clinics providing care to 1.8 million underinsured and uninsured individuals every year.[146] It seems that this need will only increase— even as I write this dissertation there are efforts in Washington DC to cut healthcare access even further.[147] The free clinic movement of the late 1960s has left a legacy of caring for those let go from the formal healthcare system. In this chapter I provide an overview of the current efforts amongst healthcare providers, students, and lay persons to do something about the brokenness of the healthcare system. I examine the practices of free clinics in the US and discuss their relationship to the free clinic movement of the late 1960s. I outline the ways these spaces are similar to the earlier iterations of free care and also identify the ways in which these spaces have changed. Focusing on the phenomena of the student-run free clinic (SRFC), I link theory to practice and call upon spatial theory to assist in making sense of the uniqueness of this

[146] Sessions et al., "Health Insurance Status and Eligibility"

[147] "ACA Repeal Debate." Commonwealth Fund, Accessed February 5, 2018. http://www.commonwealthfund.org/topics/current-issues/aca-repeal-debate; "How the Republican Tax Cut Plan Goes after Health Care" The Washington Post, Accessed February 5, 2018. https://www.washingtonpost.com/news/posteverything/wp/2017/11/27/how-the-republican-tax-cut-plan-goes-after-health-care/?utm_term=.e71da662857e.; Lydia Ramsey, "The Senate Just Passed a Tax Bill That Would Strike a Blow to a Fundamental Part of Obamacare." Business Insider. Accessed February 5, 2018. http://www.businessinsider.com/trump-gop-senate-tax-reform-bill-health-care-impact-2017-12.

clinical space and why the free clinic is an ideal site to learn to reject the logic of letting and a place to learn a different kind of health caring. Ultimately, I argue that the special space of the free clinic can facilitate the cultivation of social justice-minded healers.

The free clinics that exist today vary in scope, mission and philosophy, but all work to fill the gaps in the US health care system. These clinics range from federally-funded with a paid staff to those on a shoestring budget run with volunteers and no or minimal paid staff. The different kinds of clinics that exist serve different populations and provide varying kinds of care as a result of their funding sources. In the following sections I discuss the common forms of free and low cost clinics focusing in on strengths and limitations of the student-run free clinic. I begin this discussion with the free and low cost clinics that fall within the category of Federally Qualified Health Centers.

FEDERALLY QUALIFIED

Federally Qualified Health Centers (FQHC) have become an important resource for those medically-underserved populations in the US. According to the Department of Health and Human Services (DHHS), "FQHCs are safety net providers that primarily provide services typically furnished in an outpatient clinic."[148] FQHCs are "nonprofit community health clinics that adhere to federal regulations and receive federal grants."[149] These spaces serve both funded and unfunded patients and have federal requirements they must meet in order to maintain access to the federal monies by which they are

[148] Department of Health and Human Services, "Federally Qualified Health Center" *Medicare Learning Network,* January 1, 2017, accessed December 29, 2017, https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/fqhcfactsheet.pdf, 1.

[149] Michael R. Richards et. al., "Access Points for the Underserved: Primary Care Appointment Availability at Federally Qualified Health Centers in 10 States." *Medical Care* 52, no. 9 (September 2014): 818.

supported.[150] FQHCs are valuable resources that assist in meeting the needs of individuals who have limited access to healthcare services. These spaces provide for those who would otherwise be let go by the system and function as an important care gap.

A major benefit of having the FQHC classification is the access it gives clinics to federal funding. These clinics are not solely dependent upon donations, which can be inconsistent and therefore unreliable. They are also able to pay a staff rather than depending upon a volunteer workforce. This can give clinics more control over who they have as part of their staff, as compared to clinics that depend upon whomever shows up to volunteer.[151] The access to resources has clear benefits for the clinic and its patients, but it also has potential problems as well. In order to receive federal funding FQHCs must report their costs through the form of claims for payment. This means that these clinics are required to function within a market-based, fee for service model of healthcare, and can thus result in these clinics feeling the bureaucratic pressures of a funded setting. The funding of this setting can result in stricter time constraints that result from the pressure to increase reimbursement. Very different from the counter-culture clinics that emerged in the late 1960s, FQHCs today are functioning as part of the formal healthcare system rather than intentionally outside of it.

JOINING MAINSTREAM MEDICINE

Historically, free clinics have operated outside the auspices of mainstream medicine, but in recent years there has been a shift towards incorporating free clinics

[150] See Department of Health and Human Services, "Federally Qualified Health Center," 2-3

[151] When free clinics depend on a volunteer labor force there can be some requests of participants but not in the same extent as of paid employees. At St. Vincent's the volunteers' first priority is school and the clinic functions as an extra curricular activity. This means that during test weeks the clinic are limited for the volunteer who attend clinic and we do not have the agency to make demands on volunteers' time.

under the umbrella of the mainstream medical system and the policies and processes of those spaces.[152] In fact, many of the free clinics that exist today would not fit the definition of "free clinic" as defined by the founders of contemporary free clinics across the US because of the constraints that come with receiving federal funding. One such constraint is maintaining eligibility requirements, which directly contrasts with one of the tenets of the free clinic movement: freedom from eligibility requirements.

Although the implementation of eligibility requirements in free clinics can mean access to governmental resources through grants and other programming, it does not come without potential harms. Eligibility requirements can bring with them important benefits including helping to ensure that the resources are being allocated to those in most need of them. Gregory Weiss identified two common justifications by clinics to maintain eligibility requirements:

> Clinics that use eligibility requirements justify them on one or the other or both of two grounds. First, the clinic wants to make its services maximally available to people who genuinely need the services and would not have access to any services if not for the free clinic. No clinic has too much money. Therefore, if a patient has the means to be seen elsewhere, and is counseled to do so, it would mean greater availability for those without service options. Second, because free clinics rely on volunteers, they want to ensure that only patients who cannot afford private care are seen at the clinic. The concern is that motivation to volunteer, especially by health care professionals, would diminish if they were giving their time and being asked to treat patients who do not really need free clinic services.[153]

Lacking eligibility requirements could potentially mean that a patient with financial resources might fill a spot of someone who has no access to anywhere else. An emphasis on financial means as a measurement of eligibility fails to attend to the multiplicity of

[152] Weiss, *Grassroots Medicine,* 77.
[153] Ibid., 14.

reasons why someone might seek care at a free clinic. As previously discussed, one such reason is the need to seek care in a space that is trusted for those individuals whose trust has been broken by the formal healthcare system. Someone who is no longer able to go to a trusted clinic and is required to go to a place deemed untrustworthy may avoid seeking care when needed, and could incur the same harms of not having access. There is an important argument for having eligibility requirements because of the tremendous scope of the need. There are limited hours in the day and thus limited appointments and limited access to much-needed services. During my time at St. Vincent's, there have been patients with insurance who seek healthcare services from the student clinic. In order to be mindful of the limited resources, the St. Vincent's policy is to not turn away but instead work with patients to get them to a funded setting with which they are comfortable, while still being open to providing care to those who cannot access funded settings because of past traumas or other reasons.

The existence of federal funding does not, of course, mean that care is compromised. Nor does functioning within the mainstream medicine preclude care that strives to embody the same philosophy as that of the clinics of the late 1960s. These spaces of care continue to exist, and just as the clinics that preceded them, they are flawed but nevertheless working towards caring for those individuals who have been let go. This rejection of the logic of letting go can be seen with the example of Common Ground Clinic in New Orleans, Louisiana.

SEEKING COMMON GROUND

Established in 2005 just days after Hurricane Katrina, Common Ground Health Clinic (CGHC) opened in the Majid Bilal Mosque as a response "to the humanitarian

disaster and apparent lack of governmental response, [so] two community activists, Sharon Johnson and Malik Rahim put out a call for healthcare workers to help meet the overwhelming need."[154] Just like their historical counterparts, CGHC opened in response to the failed system which left a city in ruins and its inhabitants without access to healthcare services. This clinic emerged in the wake of thousands of individuals being let go as a result of the catastrophic failure of a system not prepared to respond to the devastation caused by a category 5 hurricane.[155] During a time of great tension in the neighborhood of Algeirs, New Orleans, when there was a military and vigilante presence, it was volunteer medics on bikes who Rahim credits as part of the inspiration to start the clinic:

> It was just about the noblest thing I've ever witnessed in my life, recalls Malik Rahim, a lifelong Algiers resident, local housing activist, and former Black Panther Party member who helped arrange space for the medical workers in a local mosque. It was the street medics who really stopped this city from exploding into a race war, because they were white and were serving the black community at a time when blacks were fed up. Those are the real heroes of this thing.[156]

Along with Johnson, Rahim set out to create a healthcare space in order to provide

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[154] The Rosehip Medic Collective, *Alternatives to Emergency Medical Services,* (Self-Published, May 2011), 19.

[155] Joan Brunkard, Gonza Namulanda, and Raoult Ratard. "Hurricane Katrina Deaths, Louisiana, 2005." *Disaster Medicine and Public Health Preparedness* 2, no. 4 (December 2008): 215–223; James R. Elliott and Jeremy Pais. "Race, Class, and Hurricane Katrina: Social Differences in Human Responses to Disaster." *Social Science Research, Katrina in New Orleans/Special Issue on Contemporary Research on the Family*, 35, no. 2 (June 1, 2006): 295–321; Henry A. Giroux. "Reading Hurricane Katrina: Race, Class, and the Biopolitics of Disposability." *College Literature* 33, no. 3 (July 13, 2006): 171–196; Kathleen Tierney, Christine Bevc, and Erica Kuligowski. "Metaphors Matter: Disaster Myths, Media Frames, and Their Consequences in Hurricane Katrina." *The ANNALS of the American Academy of Political and Social Science* 604, no. 1 (March 1, 2006): 57–81; Neil Malhotra and Alexander G. Kuo. "Attributing Blame: The Public's Response to Hurricane Katrina." *The Journal of Politics* 70, no. 1 (January 1, 2008): 120–135; Raymond J. Burby. "Hurricane Katrina and the Paradoxes of Government Disaster Policy: Bringing About Wise Governmental Decisions for Hazardous Areas." *The ANNALS of the American Academy of Political and Social Science* 604, no. 1 (March 1, 2006): 171–191.

[156] Tim Shorrock. "Where FEMA Feared to Tread." YES! Magazine. Accessed March 12, 2018. http://www.yesmagazine.org/issues/health-care-for-all/where-fema-feared-to-tread.

"solidarity, not charity."[157] "Solidarity" implies working with the community, whereas "charity" can imply bestowing upon. Early charity care clinics were rooted in the belief that there is a duty to help those beneath them, and it is this belief that those who need help are inferior to those able to give is what CGHC challenged. [158] The grassroots organization began small and sought to meet the immediate needs of the ravaged community. It expanded to offer more services receiving FQHC status in 2013.[159] They began a clinic that strove to fill the void left by the storm and the government failure to adequately help.[160] The poor of New Orleans had been let go, and CGHC rejected that letting go.

Today, CGHC provide primary and alternative healthcare services including internal and family medicine, pediatrics, women's services, laboratory services, behavioral health services, and social services. The medicine services are available via walk-in and by appointment to treat "minor medical problems like colds and flu and manageable chronic conditions, such as diabetes and high blood pressure."[161] CGHC clinic began by providing completely free services[162] but has shifted to a sliding scale payment system and accepts Medicaid and insurance after being granted FQHC status.[163]

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[157] "SERVICES." CGHC.org, Accessed March 10, 2018. http://cghcnola.org/services.html.

[158] Chuck Collins, Joan P. Garner, and Pam Rogers. *Robin Hood Was Right: A Guide to Giving Your Money for Social Change.* Hardcover Edition With Paperback edition. (New York, NY: W. W. Norton & Company, 2001).

[159] Michael Patrick Welch, "Common Ground Health Clinic in Algiers Receives Federally Qualified Health Status" The Louisiana Weekly. Accessed March 10, 2018. http://www.louisianaweekly.com/common-ground-health-clinic-in-algiers-receives-federally-qualified-health-status/

[160] Donald C. Menzel, "The Katrina Aftermath: A Failure of Federalism or Leadership?" *Public Administration Review* 66, no. 6 (November 1, 2006): 808–12.

[161] "SERVICES." CGHC.org, Accessed March 10, 2018. http://cghcnola.org/services.html.

[162] Leslie Eaton, "New Orleans Recovery Is Slowed by Closed Hospitals." The New York Times, July 24, 2007, https://www.nytimes.com/2007/07/24/us/24orleans.html.

[163] Welch, "Common Ground" http://www.louisianaweekly.com/common-ground-health-clinic-in-

In a 2013 article in the Louisiana Weekly, former executive director, Meshawn Tarver, is quoted conveying the clinic's commitment to serving all:

> If their insurance doesn't cover all the services we'll still accept them. If they're uninsured we accept them on a sliding pay scale based on their income. If they have private insurance we accept them as well. We are here for everyone.[164]

The clinic is representative of the efforts of individuals seeking to make change in their communities. It illustrates what is possible when individuals work together to respond when the system fails to help those who need it most.

CGHC has not been without problems in its twelve year existence. In 2013, an employee diverted almost 5000 dollars for personal use.[165] Additionally, in 2016, the chief executive officer and chief financial officer filed a lawsuit against the clinic, claiming their unlawful termination after reporting the clinic was not compliant with requirements of the Health Resources and Services Administration (HRSA).[166] Just as the early free clinics, the contemporary free clinics are not utopias and are vulnerable to failures and sometimes even legal indiscretions. These risks should not minimize the potential of these spaces, but instead should serve as a reminder of the need to critically examine the work being done and the ways such vulnerabilities arise. Even with the past failures of CGHC, it nevertheless still serves as a much-needed reminder of the resistance that is possible when individuals collaborate to make change. Another space in which this collaboration for change occurs is the student-run free clinic, but this is also a space that

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algiers-receives-federally-qualified-health-status/

[164] Ibid.

[165] Andrea Shaw. "Common Ground Health Clinic Worker Misappropriated $4,900," NOLA.com, Accessed March 10, 2018, http://www.nola.com/politics/index.ssf/2014/11/common_ground_heath_clinic_wor.html.

[166] "Preston Wright et al. versus Common Ground Health Clinic, Inc. et al." (court document), case 2:16-cv-11623-LMA-JCW, accessed March 10, 2018, https://www.gpo.gov/fdsys/pkg/USCOURTS-laed-2_16-cv-11623/pdf/USCOURTS-laed-2_16-cv-11623-0.pdf

has potential to cause harm. The next sections of this chapter introduce the student-run free clinic and discuss its vulnerabilities to perpetuating the structural harms in medicine as well as the potential of cultivating a space for educating learners to resist said harms.

STUDENT-RUN FREE CLINICS

There is a growing body of literature that shows the trend of free clinics managed and operated by students to help fill the coverage gap while also providing educational opportunities for healthcare learners. Student-run free clinics also emerged in the late 1960s as a space to help patients who did not have access to care. The Society for Student-Run Free Clinics (SSRFC) defines the student-run free clinic as

> …an institution that provides care at no cost to those in our society that may not otherwise be able to afford such services. These clinics are staffed by volunteers seeking opportunities to provide care to populations such as the uninsured and homeless while simultaneously enrich [sic] their education with real-life patient care.[167]

In 2014, the Journal of the American Medical Association reported that the number of medical schools with student-run free clinics has doubled in the last nine years with 208 clinics nationwide.[168] Student-run free clinics are distinct from other free and reduced-cost clinics because, just as the name implies, they are led and managed by student volunteers. Some of these clinics run multiple times per week while others meet once or twice a year. They vary in scope and services based on available resources and the needs of the communities they serve. In areas where access to healthcare exists for the uninsured, these clinics may provide more acute care to patients and function to connect

[167] "Promoting and Supporting the Existence of Student-Run Clinics at Every Health Science Center," Society of Student Run Free Clinics, Accessed March 10, 2018, http://studentrunfreeclinics.org/.

[168] Sunny Smith et al. "Presence and Characteristics of Student-Run Free Clinics in Medical Schools." *JAMA* 312, no. 22 (December 10, 2014): 2407.

them to available resources. Others in resource-limited areas will provide more comprehensive services including primary and preventative care as well as specialty care services.[169]

In addition to providing healthcare services to those who might otherwise not have access, SRFCs also provide unique educational opportunities for healthcare learners. It is in these spaces that students can gain access to direct patient care earlier in their educations, even during pre-clinical years.[170] This can mean patients are exposed to more inexperienced providers. Patients seen in free clinics are more likely to be seen by someone lacking formal licensing required in other settings. In the current models of free clinic, there is supervisory oversight by a licensed faculty member.

The fact that these primary care providers are those that don't yet hold full licenses for practice does not automatically mean that the patients receive substandard care. Although students are learners, they are not faced with the pressures of a fee-for-service system that restricts the amount of time that they spend with patients. They may spend more time with the patient and engage in more meaningful dialogues. This can result in both the time and space to get a more thorough history while also allowing for the patient to be heard in a way they do not necessarily have in other clinical settings. This is particularly important for patients who are members of groups who have been historically marginalized. The opportunity to spend more time with patients can also allow providers to build trust with patients, which is especially important for those who

[169] Observations made from viewing the presentations and posters every year at the Society for student-run free clinic conference 2015, 2016, and 2017.

[170] Brent Simmons et al., "Students who Participate in a Student-fun Free Health Clinic Need Education about Access to Care Issues," in Brennan, Virginia M., ed. *Free Clinics: Local Responses to Health Care Needs*. 1 edition. (Baltimore, MD: Johns Hopkins University Press, 2013).

have been marginalized and oppressed by the medical system. Educating volunteers and providers on the history of health inequities in the US is a valuable way to expand upon this potential for building trust with these patients. As Pellegrino argued:

> Understanding the basis for distrust of health professionals and the health care system is essential. This means paying special attention to building trust, being faithful to promises, and removing any basis for a suspicion of discrimination.[171]

While the emphasis on providing access to quality care persists, there is also a strong emphasis on this being a space that provides educational opportunities for healthcare students.[172] This becomes problematic if it is not managed, as individuals risk repeating the harmful practice of medicine being learned on the backs of the poor.[173]

EDUCATION AND THE PRACTICE OF MEDICINE

Unlike the free clinics that emerged in the 1960s, which intentionally fell outside the auspices of mainstream medicine, today's free and low-cost clinics have transitioned to fall under the umbrella of mainstream medicine. This shift means that these spaces are not clearly defined spaces of healthcare and have the potential to fail in similar ways to the mainstream medical system. The presence of learners in healthcare spaces does not automatically result in compromised or substandard care for patients. In fact, studies have shown that medical student involvement in patient care can prevent medical errors.[174]

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[171] Lawrence J. Prograis Jr, and Edmund D. Pellegrino MD. African American Bioethics: Culture, Race, and Identity. (Washington, DC: Georgetown University Press, 2007), xvi.

[172] See Virginia M. Brennan. ed. *Free Clinics: Local Responses to Healthcare Needs.* (Baltimore, MD: Johns Hopkins University Press, 2013.

[173] Washington, Harriet A. *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present.* (New York, NY: Doubleday, 2006.

[174] see SC Seiden, C Galvan, and R Lamm, "Role of Medical Students in Preventing Patient Harm and Enhancing Patient Safety" *Journal of Quality Safety Health Care,* 15, no. 4, (August 2006): 272-276; Dorothea Adelheid Herter et al. "Effect of Supervised Students' Involvement on Diagnostic Accuracy in Hospitalized Medical Patients — A Prospective Controlled Study." *PLoS ONE*, 7 no. 9, (September 11, 2012): e44866; Roberto Esguerra et al. "The transition to a teaching hospital: Patient satisfaction before

Although there are clear benefits to having clinical students involved in patient care, it is not without its risks. Over the years the culture of medicine has developed to incorporate sometimes competing goals of medicine. The goal of providing quality care for patients is one that can be overshadowed by technological advances and the educational goal of medicine. It is safe to say that most individuals enter medicine with the altruistic motivation to help people. This desire to help people persists but often can become muted due to the assimilation to a system that fails to help everyone. These can also be muted by the magnitude of information and skills students of medicine are required to learn. Although there are pitfalls with healthcare spaces that have education of students as part of their goals, these can be managed and there are extensive benefits for patients and healthcare settings by having students involved in patient care and in initiatives like SRFCs.

Furthermore, the educational focus allows space for engaging students with themes not generally emphasized in traditional healthcare educational settings. There is space for educating students who volunteer in these clinics on the complexities of the healthcare system and its injustices. Within the space of the SRFC, learners are exposed to more of the complexities of medicine:

> Unlike traditional clinical settings in which students train, the SRC is staffed primarily by medical students who function largely as directors of daily and global operations of the clinic, navigating a number of complex

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and after the introduction of medical students." *Medical Teacher* 36, no. 8 (August 2014): 710-714; Patricia Turnbull, and Frances M. Weeley. "Service User Involvement: Inspiring Student Nurses to Make a Difference to Patient Care." *Nurse Education in Practice* 13, no. 5 (September 1, 2013): 454–458; Bruch L. Henschen et al. "Four-Year Educational and Patient Care Outcomes of a Team-Based Primary Care Longitudinal Clerkship." *Academic Medicine* 90, no. 11 *Association of American Medical Colleges Medical Education Meeting: Proceedings of the 54th Annual Research in Medical Education Sessions* (November 2015): S43-S49,

> administrative duties for which in large part they receive little to no training in traditional medical school settings.[175]

This broader range of responsibilities can result in students gaining a much more nuanced understanding of the realities of practicing medicine in a system structured with the logic of letting go. It is in this space that healthcare learners can learn to navigate this broken system, and to challenge it. However, such an education is not guaranteed through proximity to the space. Many motivations bring students into student-run clinics, which can influence how they engage with the complexities of that space.

ST. VINCENT'S STUDENT-RUN FREE CLINIC

The SRFC is a place where healthcare students seek alternative educational experiences, volunteering to provide healthcare to the under-and uninsured individuals in their area. St. Vincent's Student-Run Clinic offers primary and specialty services three days a week to individuals in the Galveston area, with services including Medicine, Psychiatry, Neurology, Dermatology, Gynecology, Rheumatology, and Dentistry clinics. There is an in-house pharmacy that provides short-term supplies of medications to patients as well as a patient assistance team of volunteers who manage the required applications for patients to receive free medication from pharmaceutical companies. St. Vincent's serves as a much-needed health safety net for hundreds of individuals on Galveston Island and in the surrounding counties, with some patients driving as far as four hours to seek care. The clinic is staffed entirely by faculty and student volunteers and is governed by an interprofessional committee, including medical, nursing, physician assistant, clinical lab science, and graduate students.

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[175] Yasmin S. Meah, Eric L. Smith, and David C. Thomas. "Student-Run Health Clinic: Novel Arena to Educate Medical Students on Systems-Based Practice." *Mount Sinai Journal Of Medicine* 76, no. 4 (July 2009): 344-356.

The St. Vincent's student board of directors has historically been composed of fourth-year medical students, first-year physician assistant students, one third- or fourth-semester nursing student, a second-year clinical lab science student, and a graduate student. This year there has been a shift to include medical students of all years as part of the leadership team. The student director's role includes staffing the clinic as well as running and managing it. The student directors also collaborate to train and lead volunteers in the care of under- and uninsured populations on and around the island. During their tenure as directors, student leaders face the realities of a healthcare system that lets individuals go and thus have the opportunity to learn the art of providing care to those the system has abandoned. Students witness such harm when they send their patients to their university, only to return post-surgery without access to the medication they have been prescribed, or when a patient visits the clinic in need of colostomy bags, having undergone surgery but unable to access follow-up care. They learn about it when they receive a call from a patient who has been diagnosed with cancer but does not have the coverage or funds to pay for potentially life-saving treatment. They see examples like these as they desperately work with faculty to secure the treatment and resources these patients need. They fight these harms as they create new programs to fill the gaps in care, as happened when in 2014 students created the dental clinic and in 2016 when they established a Hepatitis C treatment protocol. In 2015, students incorporated trauma-informed education for Gynecology volunteers, and in 2014 students formalized a pharmaceutical assistance team to manage patient applications and increase access to free medication.[176] St. Vincent's student leaders are already practicing social-justice oriented

[176] All three of these examples were student director initiated and managed. Students collaborated to seek grant funding and other resources to expand the access of the clinic.

care, whether through these more specialized programs or the everyday acts of opening and running clinic, answering emails, managing laboratory call backs, recruiting and scheduling volunteers, and seeing patients. Though they will witness the effects of the structural harms of the healthcare system, and are already challenging them, they may not be able to articulate their work as such. These leaders need guidance on the complex multiplicities of healthcare space.

THE MULTIPLICITIES OF HEALTHCARE SPACE

Understandings of the complexities of spatial arrangements of the clinic can reveal the creative potential of these spaces of healing. In her text *For Space* (2005), Doreen Massey writes "about ordinary space; the space and places through which, in the negotiation of relations within multiplicities, the social is constructed."[177] According to Massey, space is a product of interrelations, predicated on the existence of plurality, and a product of relations-between. Through this claim, she challenges the tendency to turn space into time and instead argues for a spatio-temporal understanding of space, in which space is inextricably caught up within time. Massey seeks to bring life back to space and argues that space is better understood as a multiplicity of stories-so-far; and engagement with space is a kind of cutting across a series of stories. This can be exemplified with the physician rounding on patients in the hospital. When a physician enters a patient's room on rounds they cut across time and see only one out of a multiplicity of stories. The linear structure of the physician's schedule does not map-on well to the spatial-temporal relations that occur in the patient room. For a physician rounding on patients, the entering in that space and engaging the patient can seem like one point on a series of points, one

[177] Massey, *For Space,* 13.

patient in a series of many, resulting in the transformation of this space into time. The focus is on the story of the patient's disease, but this is just one story in the patient's life and experience.

In the SRFC, learners are faced not only with the medical needs of the patient, but also with the social needs and life challenges faced by a low socioeconomic patient population. Students are taught the fallacy in writing a script and assuming access at the pharmacy when a patient comes for an appointment and has been without his medication because it was too expensive to fill. They learn the need to look up medication prices and to ask questions about financial security. They learn that for some patients even four dollars a month for a prescription is not viable. Volunteering in the space of the free clinic expands the frame of reference for students. It is here that an individual must leave assumptions behind in order to adequately care for her patients. It is in the free clinic that students can learn of the experiences of worlds different than their own. These lessons are important but not guaranteed in the free clinic setting. Although learning in a free clinic can be a transformative experience for students, it is important to recognize that this space is more than a site of learning. First and foremost, students need to view the provision of healthcare as equal, or higher, in value to their learning. A common motivation to enter the SRFC is to augment one's education. While such a motivation is understandable and education encouraged in this space, it also has the potential to be harmful.

MANAGING VOLUNTEER MOTIVATIONS

There is not one singular motivation amongst volunteers for entering the space of the student-run clinic, and they can range from religious, the desire to help, to benefit

one's own career, required as part of curriculum, or to gain clinical experience.[178] The latter of the motivations, to gain clinical experience and practice, must be managed and attended to because of the problematic historic practice of using poor individuals as learning material for clinical students. SRFCs risk repeating the exploitative practices of the past due to the desire, and pressure, to learn as much as possible in the shortest amount of time. The pressures on students to gain clinical knowledge and experiences can cause students to lose sight of the patients in front of them. Even those seeking more responsibilities at student-run free clinics may be ill-prepared for their new roles in leadership. For most, this will be the first experience where they are elevated in the hierarchy and they may have limited experience with positive role models in healthcare. There is the danger that students might act in ways that were modeled by their potentially abusive superiors in previous experiences, which can inform how they treat junior volunteers and their patients. Additionally, there are many elements of medical education that can lead caring students to occasionally lose sight of something so vital to their practice as healers. When students become too focused on the educational side and lose sight of the patient as person it can result in dehumanizing experiences for patients. I have experienced this particular kind of dehumanization as a patient when I myself became an excellent learning opportunity at my first gynecological exam when I was 18 years old. Without my consent, eight students were invited to come in and observe in order to learn:

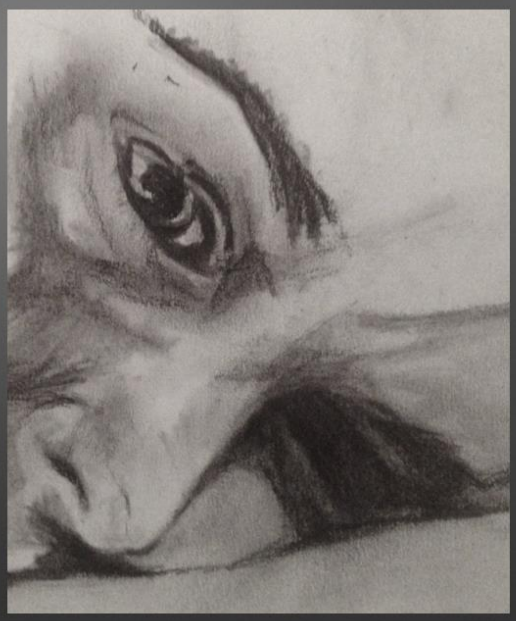
[178] Thomas D. Fletcher and Debra A. Major. "Medical Students' Motivations to Volunteer: An Examination of the Nature of Gender Differences." *Sex Roles* 51, no. 1–2 (July 1, 2004): 109–114.

i was 18. it was my first time at the gynecologist.
when i was in the gown and on the table
the doctor brought in a group of students.

i was told it was an excellent learning opportunity.
i was not asked.

to this day i wonder what the
students learned.
did they noticed my silent tears?
were the humiliation and shame
as visible as they felt?

that shame follows me.



their instrument of science became one of fear and anxiety for me.
to this day it remains a trigger.

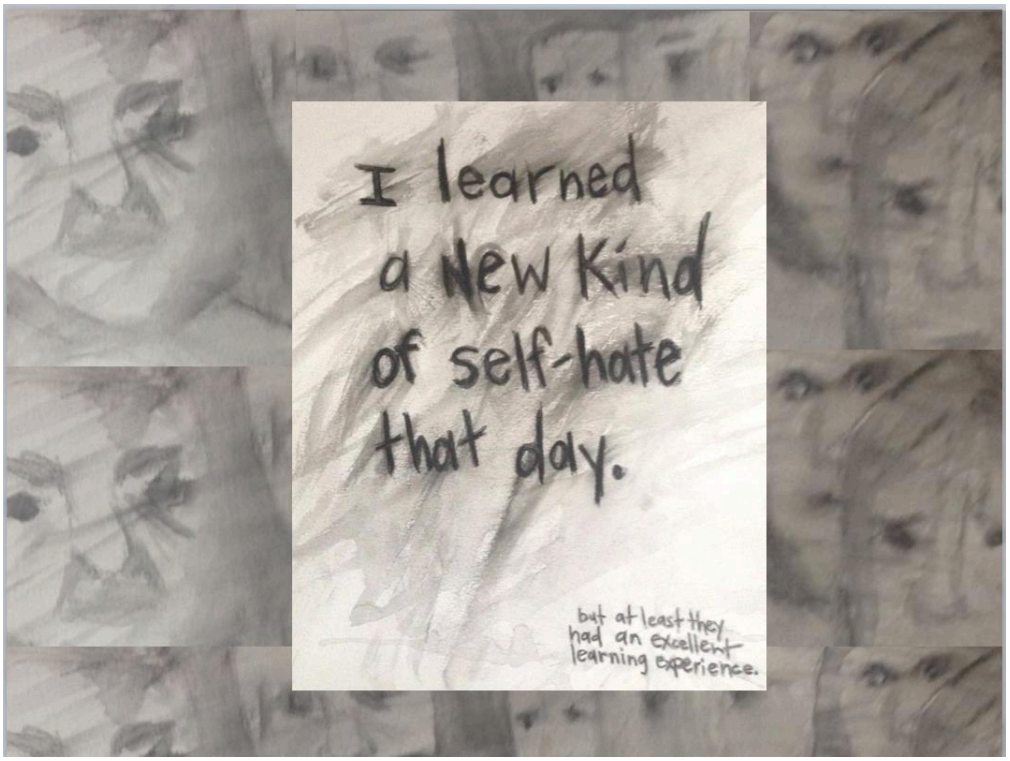


Illustration 4: An Excellent Learning Opportunity series, Amerisa Waters, Aqua Graphite, 2015.

I was no longer a person but instead merely a "great learning opportunity" (illustration four). This experience was traumatic for me and one that has had the lasting effect of anxiety about seeking healthcare services leading me to sometimes delay care. It is necessary for the limitations of healthcare education to be mitigated and attended to as students traverse the spaces of the free clinic.

SHIFTING MOTIVATIONS

Although students may initially enter SRFCs in order to get clinical exposure or to get practice, these motivations can shift once they enter the world of the free clinic. As they become a part of this world they may feel hopeless or confused, but many then try to figure out something they can do to help. During my years working with clinical students,

I have learned that most of them are helpers. In free clinics, learners can gain deeper understandings of the real world problems of medicine with the motivations that keep them in that space shifting away from being education-focused practice. As they are introduced to the logic of letting go, students often seek to do something for those individuals whom the system says they should not help—i.e., the person sitting in front of them. Although this shift can occur, it is not guaranteed. Accordingly, there is a need to develop educational initiatives that assist in educating students on making sense of the system, understanding the work which they are doing, and gaining context on the space they are entering and what it means to provide care in this setting. Students must also be educated on the harms of the system and the ways in which they can challenge those failings.

CONCLUSION

> A changed approach is precisely the goal for the journey ahead: to discover new ways of seeing, to open spaces for possibilities, and to find 'fresh methods' for animating and awakening… It is… about finding different perspectives, and this begins in thinking about seeing…[179]

Regardless of the reason a student might enter a student-run free clinic, there is great room to educate students on the injustices in healthcare, and to have them reflect on their own biases (conscious and unconscious.) Without intentional education, these learners are at risk of perceiving the inequities that pervade healthcare practice in the US as normal and acceptable. There is an urgent need for expanded curricula that educate these learners on the everyday practice of challenging injustice—curricula that empower these learners to act. The arts offer a powerful method for reflecting on current practices and cultivating the creative thinking necessary to challenge these harmful norms of US

[179] Sousanis, *Unflattening,* 27.

healthcare.

Presence in the free clinic is not enough to guarantee that individuals will become more social-justice-minded healers. An arts-based curriculum informed and shaped by spatial theory has the potential to fill the gaps in arts practices in healthcare education. The arts reveal the ways in which structural harm is embedded through the culture and practice of medicine— the ways in which the logic of letting people go is rooted in the history and present practice of medicine. Educating learners through art on the complexities of healthcare through engagement and service in the SRFC can cultivate a practice of medicine that seeks to remove the harm that persist in medicine, one person at a time. Section two of this dissertation will explore the potential of arts-based education in the SRFC starting with an examination of the work already being done in arts and healthcare.

PART TWO

Chapter 4 Humanizing Medicine through Arts and Healthcare Education: Current Practices and Spaces for Growth

> The unendurable happens. You know, people we love and we can't live without are going to die. We're going to die… art knows that. Art holds that knowledge. All art holds the knowledge that we're both living and dying at the same time. It can hold it. And thank God it can because nothing out in the capitalistic corporate world is going to shine that back to us, but art holds it.
>
> -Marie Howe

Healthcare providers are not well-prepared for the everyday challenges they will face in the practice of medicine. They often must bear witness to the unendurable when caring for patients, but the daily effects of witnessing suffering are rarely attended to or acknowledged. Art has emerged as an important addition to healthcare education curricula, nuancing the lessons learned in the clinic and the classroom and providing a place to help hold the suffering that pervades healthcare. Throughout this chapter, I use "engagement with the arts" to describe the practice of looking at visual art, listening to music, watching plays, and other forms of engagement with art created by others. By "engaging in arts practice," I mean active participation in art-making. These approaches will be discussed in further detail in the next section and throughout this chapter. The arts are a powerful method for educating providers on the humanistic elements of medical practice. Art has been used to nurture providers' capacity to care for their patients by enabling them to engage with the experience of illness.[180] It is through the arts that a deeper engagement with the complexities of what it means to be human is made possible,

[180] Thomas R. Cole, Nathan Carlin, and Ronald A. Carson, *Medical humanities: An Introduction* (New York, NY: Cambridge University Press, 2015), 13.

but there remain challenges and spaces for growth within this work.

This chapter provides an overview of the work accomplished thus far in arts in healthcare education. I critically review the various types of programs that currently exist in the US medical and health professions schools, discussing examples of art-based interventions and their benefits for learners and their patients. The examples I offer are by no means exhaustive, but instead are representative of current work in this area. As this chapter will highlight, the existing research and practices of arts-based healthcare curricula focus on the individual but fail to explore the problematic system within which students exist. These programs often focus on self-reflection, self-exploration, improving observational skills, and utilizing art for cultivating empathy. While these are all important components for healthcare education, they are not enough. Within the arts in healthcare literature, there remains a lack of interventions designed to educate health professionals on mitigating the structural harms and injustices present in healthcare practice.

As discussed in the first half of this dissertation, the logic of letting go is woven into the structures, policies, and practices of healthcare in the US. There is a great need for students to understand the complexities of healthcare, and art has the potential to provide a meaningful space of engaging such topics. I contend that it is vital to educate future providers on the realities of providing care in the US healthcare system in order to prepare students to recognize and respond to the structural harms that pervade healthcare. While current arts in healthcare initiatives have much to offer for healthcare learners, they are insufficient to educate learners on the structural complexities and injustices in healthcare practice.

ARTS IN HEALTHCARE: PAST AND CURRENT PRACTICES

The concept of the arts in healthcare education is not a new one. A 2002 study of arts programming in US medical schools showed that over half of all medical schools "involve the arts in the curriculum and over two thirds support extracurricular programs or activities."[181] This trend continues today — healthcare[182] education programs across the US are developing and implementing arts-based curricula not only for clinical students and healthcare providers in the attempt to apply art to cultivate healers.[183] These programs recognize the vast benefits of art for education. Art is thought to assist in the development of healthcare learners, providing students "with a 'simulation' of the wider experience of life" necessary for healthcare encounters, and through "direct participation in the artistic process may help students to explore their own feelings, question them, and develop new ways of thinking."[184] These efforts engage healthcare providers and learners

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[181] Mathew A, Strickland, Cecilia T Gambala, and Paul Rodenhauser. "Medical Education and The Arts: A Survey of US Medical Schools." *Teaching and Learning in Medicine* 14, no. 4 (October 2002): 264–267.

[182] I use this term to refer to medical, nursing, physician assistant, occupational therapy, and physical therapy.

[183] Michael Green, "Graphic Storytelling and Medical Narrative: The Use of Comics in Medical Education," in *Graphic Medicine Manifesto* ed. M. K. Czerwiec (University Park, PA: Pennsylvania State University Press, 2015), 67-86; Cheryl L. McClean, ed. *Creative Arts in Humane Medicine* (Alberta, CA: Brush Education, 2014); Craig Klugman and Diana Beckmann-Mendez, "One Thousand Words: Evaluating an Interdisciplinary Art Education Program," *Journal of Nursing Education* 54, no. 4 (October 30, 2015): 220-223; Arno Kumagai, Kumagai, Arno K. "Perspective: Acts of Interpretation: A Philosophical Approach to Using Creative Arts in Medical Education." Academic Medicine: Journal of the Association of American Medical Colleges 87, no. 8 (August 2012): 1138–44; Paul Ulhas Macneill, "The Arts and Medicine: A Challenging Relationship," *Journal of the Medical Humanities* 37, no. 2 (December 2011): 85-90; Catherine McCabe, Freda Neill, Gary Granville, and Sheila Grace, "Evaluation of an Art in Healthcare Elective Module—A Nurse Education Initiative," *Nurse Education in Practice* 13, no. 2 (March 2013): 113-117; and Mark Perry, Nicola Maffulli, Suzy Willson, and Dylan Morrissey, "The Effectiveness of Arts-Based Interventions in Medical Education: A Literature Review," *Journal of Medical Education* 45, no. 2 (January 5, 2011): 141-148.

[184] Mark Perry et al. "The Effectiveness of Arts-Based Interventions in Medical Education: A Literature Review." *Medical Education* 45, no. 2 (February 1, 2011): 141–148.

in creativity through two main approaches: engaging with the arts in general and engaging in arts practice. In many arts in healthcare programs, students engage with the arts by viewing and responding to works of art.[185] A number of these programs focus on art-making, in which students make reflective works of art, while others utilize both approaches.

These programs exist to pull upon the instrumental and intrinsic benefits of art in order to achieve desired outcomes. In *The Gift of the Muse*,[186] authors Kevin McCarthy, Elizabeth Ondaatje, Laura Zakaras, and Arthur Brooks completed an extensive literature review and identified instrumental benefits of the arts in cognitive, attitudinal/behavioral, health, social, and economic domains. These authors identify links between art and improved test scores, improved self-efficacy, learning skills, health, development of social capital, and economic growth.[187] Within the application of arts interventions to healthcare education, the instrumental benefits have been a prime focus. Such benefits of art include its ability to assist in improving visual observation,[188] its ability to offer another perspective on the experience of illness,[189] or its serving as a method of sharing experiences.

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[185] This can include a variety of kinds including, but not limited to, paintings, literature, comics, or music.

[186] Kevin F. McCarthy, et al., *Gifts of the Muse: Reframing the Debate about the Benefits of the Arts*. (New York, NY: Rand Corporation, 2001).

[187] Ibid.

[188] Alexa Miller et al. "From the Galleries to the Clinic: Applying Art Museum Lessons to Patient Care," *Journal of Medical Humanities* 34, no. 4 (September 8, 2013): 433-438; Sheila Naghshineh et al. "Formal Art Observation Training Improves Medical Students' Visual Diagnostic Skills," *Journal of General Internal Medicine* 23, no. 7 (July 2008): 991-997; Johanna Shapiro, Lloyd Rucker, and Jill Beck. "Training the Clinical Eye and Mind: Using the Arts to Develop Medical Students' Observational and Pattern Recognition Skills," *Medical Education* 40, no. 3 (March 2006): 263-268.

[189] Casey B. White et al. "The Interpretive Project: A Creative Educational Approach to Fostering Medical Students' Reflections and Advancing Humanistic Medicine," *Reflective Practice* 11, no. 4 (September 8, 2010): 517-527.

Art does not just provide instrumental value but also offers intrinsic value for learners. Art has the potential to evoke emotional responses from its viewers. We cry at movies, we fall in love with storybook characters, music can take our breath away — various art forms have the power to move us in a multitude of ways. Music, books, movies, and other types of art can be crafted to evoke emotional reactions from audiences and have the potential as tools to emotionally and empathically educate healthcare learners. McCarthy et al., identify intrinsic benefits of art, more difficult to measure but important nonetheless, including captivation, pleasure, increased empathy, cognitive growth, creation of social bonds, and expressing communal meaning.[190] These same benefits emerge in arts in healthcare programs (though they may or may not be the focus.) One commonly sought-after benefit of these programs is the use of art to cultivate empathy amongst learners.[191] Through art approaches, a different vocabulary to express oneself is made possible. Art enables learners to convey experiences and feelings that words cannot capture.[192] Indeed, it is the intrinsic benefits of art that also work to pull people in:

> What draws people to the arts is not the hope that the experience will make them smarter or more self-disciplined. Instead, it is the expectation that encountering a work of art can be a rewarding experience, one that offers them pleasure and emotional stimulation and meaning.[193]

It is the more intrinsic benefits of art that allow for this exploration of the unsayable and

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[190] McCarthy et al., *Gift of the Muse,* xiii.

[191] McClean, *Creative Arts in Humane Medicine*; Philippa Lyon et al. "An Exploratory Study of the Potential Learning Benefits for Medical Students in Collaborative Drawing: Creativity, Reflection, and 'Critical Looking,'" *BioMed Central Medical Education*, 13, no. 86 (June 17, 2013), 2-10.

[192] Paul Crawford, Brian Brown, Charley Baker, Victoria Tischler, and Brian Abrams, *Health Humanities* (New York, NY: Palgrave Macmillan, 2015), 12.

[193] McCarthy et al., *Gift of the Muse,* 37.

the unknowable: This is what makes the arts a crucial part of humanistic education, which "aims to educate the emotions as well as the intellect, to enhance compassion as well as critical thinking, and to encourage active engagement in public and/or professional life."[194] The use of art engagement in educating future health providers, particularly when supplemented and informed by the medical humanities, is a fundamental component of cultivating healers.

Art allows for a different kind of exploration of the world and the lived experience of being in it. For healthcare learners it can provide a means for leaving the sterile case study and scientific view of medicine, allowing space to explore and more fully understand the complicated and messy aspects of healthcare, which art can relate to viewers in a tangible way. For the remainder of this chapter I will expand on the different functions of art in healthcare education, provide examples of current practices, and discuss their strengths in order to illuminate the ways in which arts in healthcare curriculum should be utilized to better educate providers. Additionally, I will highlight the limitations of these programs and the ways they fail to attend to the experience of working in a system that is structured on a practice of letting some individuals go.

LITERATURE/NARRATIVE AND MEDICINE

Literature provides valuable methods to assist students in making sense of the complexities of healthcare practice. Literature offers a glimpse into the inner lives and experiences of patients and their loved ones, and allows for students to connect with these experiences. Like other arts in healthcare programs, literature and medicine is not a

[194] Cole, Carlin, and Carson, *Medical Humanities,* 3.

recent development. Hawkins and McEntyre[195] assert that literature and medicine "first emerged in its present form as an academic discipline in 1972, when Joanne Trautmann (Banks) was appointed to a position of literature at the Pennsylvania State University College of Medicine."[196] They identify the reasons for including literature in medical school curriculum as being threefold:

> The first concerns the patient: such courses teach physicians how to listen more discerningly to their patients' stories…The second reason concerns the physician: reading and then discussing and reflecting on literature inevitably brings one face to face with one's assumptions, biases, and preconceptions and alerts one to the extent to which these can determine how a text—or a patient's story—is interpreted…The third concerns ethics: literature and literary skills enable physicians to think both critically and empathetically about moral issues in medicine.[197]

Incorporating literature into the education of physicians challenges the simplistic call of medicine to save lives and offers potential for a deeper understanding of the complex and challenging experiences clinicians will face in practice. Through critically reflective engagement with these texts and their characters, among other things, clinical students can attain a more nuanced understanding of the system within which they will work and begin to develop everyday practices to counter the failings of this system. Paired with reflective dialogue, works of literature can allow students to examine the complex experiences of healthcare and reveal the humanness of the harm that occurs in medical space. It can be challenging to discuss the effects of bias on healthcare while simultaneously facing one's own bias, and the use of literature to address can offer a safe space for having such discussions. A dialogue that incorporates literary works provides

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[195] Anne Hunsaker Hawkins and Marilyn Chandler McEntyre, eds. *Teaching Literature and Medicine.* (New York, NY: The Modern Language Association of America, 2000).

[196] Ibid., 4.

[197] Ibid., 4.

the opportunity to engage with difficult concepts in a more tangible way and in a lower stakes environment. Literature engages readers' moral imagination and allows them to "transport…into the lives of others in ways that enhance our empathetic understanding."[198] By providing an intimate view of another's experience, literature facilitates connection and through that connection cultivates empathy. It expands readers' frame of reference and, in a sense, expands what David Perkins identifies as experiential intelligence or "the contribution of intuitively applied prior experience to intelligent functioning."[199] Although this does not enable learners to fully understand the experience of another, it helps them move towards understanding through the insight of a different perspective on the world.

I saw the value of reading healthcare narratives while co-teaching a course for the Joint Admissions Medical Program (JAMP), a pre-medical student internship.[200] The course consisted of two parts: a discussion- and lecture-focused Medical Humanities class that met two days a week and the Creative Expressions Project, an art class that met one day a week for two to three hours. Students were assigned readings in the Medical Humanities that ranged from scholarly articles, book excerpts, poems, memoir excerpts, and blogs. One such reading assigned to students was *No Apparent Distress: A Doctor's Coming-of-Age on the Front Lines of American Medicine* by Rachel Pearson.[201] Pearson's memoir traces her journey to medical school and offers a view into the experience of learning medicine in a system that does not provide access to all

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[198] Cole, Carlin, & Carson, *Medical Humanities,* 168

[199] Perkins, *The Intelligent Eye,* 13.

[200] "JAMP Homepage." Joint Admissions Medical Program, Accessed March 10, 2018. https://www.texasjamp.org/.

[201] Rachel Pearson. *No Apparent Distress: A Doctor's Coming-of-Age on the Front Lines of American Medicine.* 1 edition. (New York, NY: W. W. Norton & Company, 2017).

individuals. In the work, Pearson offers insights from growing up poor and in a family that often lacked access to healthcare along with those from her experience as a medical student and participating in the system that denies access to individuals and families like her own. She allows herself to be vulnerable, revealing her inner thoughts, her insecurities, and her mistakes. In the world of medicine, mistakes are taboo and not openly discussed, but in her memoir, Pearson lays her mistakes bare. She risks judgment from her readers, her teachers, and her colleagues, but in doing so she allows for others to learn from those mistakes.

In the JAMP course, students were assigned four chapters to read as part of the section "Health Disparities and Social Determinants of Health." At the start of class, students were asked to respond in writing to a general open-ended prompt designed to stimulate reflection in major course themes. The point of the reflective writing was to give students the opportunity to spend time thinking about the works before we engaged in the larger class discussions. During class, a number of students connected with the work offering their own healthcare experiences, and those of their loved ones, to the discussions. Others, having not personally had these experiences, were able to learn about them through Pearson's work.

The benefits of student engagement with healthcare experiences through memoir extend beyond formally published works to also include self-published shorter works, such as blogs. For the section on "Stigma and the Moral Dimensions of Medicine," students were assigned the blog post "What Happens when One Fat Patient Sees a Doctor."[202] Written by an anonymous source identified only as "Your Fat Friend," the

[202] Your Fat Friend. "What Happens When One Fat Patient Sees A Doctor." The Establishment, May 2, 2017. https://theestablishment.co/what-happens-when-one-fat-patient-sees-a-doctor-eddd6cd4a252.

blog utilizes the first-person perspective to share the experience of seeking healthcare as an overweight woman. In preparation for the class I pulled research and statistics about fat bias in healthcare expecting naysayers in the class, but to my surprise, there were none. Instead, students engaged in a rich conversation about the dehumanizing treatment the author describes and what that experience must have been like for her. Through her first-person narrative, students were able to go through her journey with her as she tried over and over to get healthcare only to have all of her concerns and experiences ignored with the focus falling only on her overweight body. The discussion extended beyond the woman's experience with other doctors treating her poorly; several slender students also discussed the ways in which this blog made them cognizant of their own body privilege as individuals who fit within the acceptable social standards for body types.[203] The blog made the experience of being fat-shamed when seeking healthcare accessible for those students and thus made that perspective accessible for them to attempt to understand.

Forms of narrative and literature that enrich healthcare education are not limited to non-fiction. Rich and artistically constructed works of literature and fiction offer much to assist in the formation of future healthcare providers. This can be exemplified with programs at the University of Pittsburgh School of Medicine and the University of Virginia School of Medicine. Taught through the University of Pittsburgh Center for Bioethics & Law, "Narrative, Literature, and the Experience of Illness" is a 4th-year medical student elective that offers students the opportunity to "experience and examine the culture and practice of medicine from the perspective of an outside observer."[204]

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[203] These are my own observations of my experience teaching this course in the summer of 2017.

[204] "Fourth-Year Medical School Electives," Center for Bioethics and Health Law | University of Pittsburgh, Accessed March 10, 2018, http://bioethics.pitt.edu/academic-programs/programs-school-medicine/fourth-year-medical-school-electives.

Likewise, the University of Virginia School of Medicine offers their 4th-year students an elective in Literature and Medicine as part of their medical humanities and biomedical ethics electives.[205] On their website they articulate the goals of these electives, including the literature and medicine elective, to:

> (1) cultivate skills of critical and reflective thought; (2) reflect on ethics, values, traditions, spiritual concerns, and professional life; (3) explore the many dimensions and contexts of human experience; and (4) attend to their own formation as professionals.[206]

The University of Virginia's program includes an explicit articulation of the focus on the individual student development through their 4th objective which focuses on the development of the students taking the course. Both of these two programs offer a view into the experiences of patients, their loved ones, and others involved in healthcare through the rich narratives of illness and works of healthcare-related literature. As stated earlier, literature allows learners to imagine another's experience, enabling a more profound understanding of the potential impact of one's actions on another. Such imagination is vital to providing care because clinicians must imagine the multitude of ways that their actions can be interpreted by the patient, family, and other care providers.

Medical and health humanities educators are not alone in finding value in clinical students' engagement with literature. In 2017, a group of UTMB medical students initiated a book club to read and discuss medical and healthcare related memoirs and novels. The group expanded the invitation to include students from all programs, hosting monthly potluck meetings where students discuss works such as *No Apparent Distress* by

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[205] "Electives for Fourth-Year Medical Students," Virginia.edu, Accessed March 10, 2018, https://med.virginia.edu/biomedical-ethics/resources/education/eleectives-for-fourth-year-medical-students/.

[206] Ibid.

Rachel Pearson,[207] *When Breath Becomes Air* by Paul Kalanithi,[208] and *House of God* by Samuel Shem,[209] and *Taking Turns: Stories from HIV/AIDS Care Unit 371* by MK Czerwiec.[210] The students come together outside of the formal space of the clinic or classroom to engage in discussions focused on the experiences highlighted in the different works. For their discussion of *No Apparent Distress,* the author joined via Skype to discuss her work with them and her own experiences with her clinical training. After this particular meeting one medical student described the space as "cathartic" where she had some of her own struggles and fears validated.[211] The space gave students the opportunity to connect their own experiences to those in the memoirs and works of fiction.

Literature in medicine programs allow students to collaboratively consider the complexities of medicine while reading works that illuminate the unseen experiences of medicine. Learners are given the opportunity to look at the experience of healthcare through the lens of fiction, or memoir, and to examine experiences similar to the ones they encounter, or will encounter, in the clinic. When students engage with stories they are given access to different experiences and ways of being in the world, and, ultimately, they are shaped by those stories. As Hilde Lindemann Nelson notes:

> The stories we weave around the acts, experiences, and personal characteristics we care about most . . . allow us to make sense, in our own lives, of moral responsibility, self-interested concern, compensation and

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[207] Rachel Pearson. *No Apparent Distress.*

[208] Paul Kalanithi and Abraham Verghese, *When Breath Becomes Air.* 1 edition. (New York, NY: Random House, 2016).

[209] Sanuel *The House of God,* (New York, NY: Penguin, 2010). Samuel Shem is a pseudonym for Stephen Bergman.

[210] M.K. Czerwiec, *Taking Turns: Stories from HIV/AIDS Care Unit 371*. (University Park, PA: Pennsylvania State University Press, 2017).

[211] 3rd-year medical student, personal communication, October 18, 2017.

survival.[212]

We are all situated in our own experience of the world and thus come to understand it from a particular standpoint,[213] and literature provides a lens into other experiences of the world and in doing so expands our frames of reference. Although reading stories will never allow individuals to fully know the experience of another, they do allow access to worlds and experiences outside of their own. Textual narrative is not the only way to illuminate diverse experiences through storytelling. Comics and medicine, also known as Graphic Medicine, is an exploding field that offers rich opportunities for engaging with the stories of healthcare through image combined with text.

COMICS AND HEALTHCARE EDUCATION

Comics help to integrate experience and can be a rich method of communicating information and understanding of healthcare experiences through visual and textual modalities.[214] This unique form allows for the simultaneous transmission of multiple narratives that makes it possible to examine and convey the complexities of making meaning of diseases, death, and family perspectives. As noted in *The Graphic Medicine Manifesto*:

> Graphic medicine combines the principles of narrative medicine with an exploration of the visual systems of comic art, interrogating the representation of physical and emotional signs and symptoms within the medium.[215]

A more nuanced understanding of the experience with illness, one that acknowledges the

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[212] Hilde Lindemann Nelson, "The Narrative Construction of Personal Identities," from *Damaged Identities: Narrative Repair* (New York, NY: Cornell University Press, 2001), 76-77

[213] Ratliff, Clancy. "Feminist Standpoint Theory." in *Encyclopedia of Gender and Information Technology,* ed. Eileen M. Trauth (Hershey, PA: Idea Group Reference, 2006), 335-340.

[214] MK Czerwiec, "Comics+Medicine: Method, Research, Practice, University of Texas Medical Branch, Galveston, Texas, December 10, 2015.

[215] Czerwiec, M. K., Ian Williams, Susan Merrill Squier, Michael J. Green, Kimberly R. Myers, and Scott T. Smith. Graphic Medicine Manifesto. Penn State Press, 2015, 1.

impact of different perspectives on medical care is made possible through comics. Revealing the multiple truths of health care is vital in practitioner education, because a failure to understand the presence of multiple, sometimes seemingly contradictory, truths can compromise patient care. An emphasis on multiple truths rejects the notion that there is one singular truth and thus allows for seeking to understand difference rather than judging and dismissing it.[216] Comics offer medicine a valuable tool for achieving contextual understandings of the diversity of patient experiences that exist.

The language of comics is able to communicate the various viewpoints of healthcare experiences. Comics use similar literary devices as the more traditional forms of literature but have added impact because of their use of drawings, which provide visual communication and cues for the reader. By encompassing both the visual and literary realms in the transmission of information, comics facilitate the communication of the multiple truths present in health-care contexts and enable understanding through the use of metaphorical techniques, for instance dualism. The use of comics assists in the telling of two narratives simultaneously through the artist's ability to take up dualism. Dualism in comics is the communication of multiple narratives at once.[217] Comics incorporate multiple narratives— visual narratives and written ones— and are thus able to communicate layered meanings in a concise way. The graphic memoir *Becoming, Unbecoming*[218] by Una illustrates the ways in which two complex narratives can be

[216] cf James T. Hansen. "Consequences of the Postmodernist Vision: Diversity as the Guiding Value for the Counseling Profession." *Journal of Counseling & Development* 88, no. 1 (January 1, 2010): 101–107.

[217] Jan Baetens and Hugo Frey. *The Graphic Novel: An Introduction*. (New York, NY: Cambridge University Press, 2014).

[218] Una. *Becoming Unbecoming*. (Brighton, UK: Myriad Editions, 2015).

transmitted simultaneously through comics.[219] In her comic, Una weaves a tale of the life of violence that results from being a woman living in a society that regularly degrades and dehumanizes women, and the tale of being one woman, of many, whose life was radically altered by sexual violence. Dualism is utilized throughout her work in order to tell two narratives of sexual violence: the personal experiences of sexual trauma inflicted against her and the systemic violence and degradation of women that she consumed through news reports and popular culture while growing up in Yorkshire, England. It is these two narratives that she ultimately weaves into a complex story about the ways she learned to lower her gaze and internalize the dehumanizing violence as something of her own making.[220] Una's work has dual value—both instrumental and intrinsic. Throughout her work, Una uses comics to communicate her story along with information about the pervasiveness of sexual assault and scope of the problem and its lack of reporting. Through the showing of the news coverage of the sexual assaults and murders of women in Yorkshire and the showing and telling of her own experience being repeatedly sexually assaulted, she illuminates the ways in which rape culture informs and shapes the understandings of sexual trauma experienced on an individual level. Readers are pulled into the narrative through the vivid images Una creates to convey her experiences. Along with images created specifically for the graphic memoir are images Una created as an attempt to use art to process and make sense of her past. As Una notes:

> When I began drawing, I didn't plan to show the work to anyone, so it is odd to be sharing it with the world now. Many of the earliest drawing will forever remain private, but some of the early, quite abstract drawings are included here. They can be understood as functioning on a more unconscious, symbolic level than the more conventional narrative panels. I

[219] Una is a pseudonym adopted to protect her identity and privacy.
[220] Una, *Becoming, Unbecoming,* 14.

think they communicate something that words, perhaps cannot.[221]

These images captivate readers through their quiet poetry. In one the reader only sees the face of someone being surrounded by darkness, a darkness she also drinks in.[222] Throughout the work, the reader is presented with a rich visual narrative that captivates and forces individuals away from their everyday lives and focuses their attention on a story that has been silenced for so long. [223]

With comics, readers do not passively acquire information, but instead become collaborators in the narratives shared through the printed and visual medium. Certainly, readers of literary texts engage in imaginative work as they read, but in comics the imaginative work is done concerning the action. Comics consist of sequences of still frames and images. The action occurs in the imagination of the reader through the linking of images. The narrative is told through fragments, panel by panel, and the reader is required to connect the panels and do the imaginative work to complete the narrative. This in-between space in comics, between panels, is known as "the gutter."[224] It is in the gutter that the reader's imagination constructs the meaning. Scott McCloud identifies the gutter as the place where "human imagination takes two separate images and transforms them into a single idea."[225] With comics, students are not only given access to the experiences of another, but also are pulled into the narratives as active participants who complete the stories. The reader participates in the telling and construction of the story. In

[221] Una, *Becoming, Unbecoming*, 203.

[222] Ibid., 67.

[223] McCarthy et al., identify this as one of the intrinsic benefits of art— its ability "connect people more deeply to the world and open them to new ways of seeing and experiencing the world." see McCarthy et al., *The Gift of the Muse,* xvi.

[224] McCloud, Scott. *Understanding Comics*. (New York, NY: Harper Collins, 1994).

[225] Ibid., 47.

his work *Understanding Comics,* McCloud illuminates the imaginative work of readers through a comic of a person being attacked by another person with an axe. In the first panel the audience sees the ax held in the air above a man screaming "NO! NO!"[226] and in the second panel the audience is shown a nighttime image of an urban landscape with the text "EEYAA!!"[227] This comic exemplifies the way that imagination of the reader is where the true action occurs, for it is the reader who imagines the moment the axe fell and how exactly it struck its victim. The reader does not only witnesses the murder, but also is a participant in constructing exactly how it happened.

Elisabeth El Refaie pushes audience participation further by making the claim that it is not just the cooperation in closure across panels, but instead:

> …it is the frequent use by graphic memoirists of such rhetorical strategies as metaphor, humor, and intertextuality, which simultaneously demand the readers' active, critical co-operation and which may thus account for the success of some autobiographical comics in evoking both involvement *and* affiliation.[228]

Comics require the reader to connect the panels and to collaborate in the construction of the story, and they connect the reader to the narrative and narrator. It is through visual metaphors and humor that readers are connected emotionally to the protagonist of the story.[229] The affective engagement of readers allows for an empathetic interaction with narratives and a kind of being present with stories that are often silenced, such as Una's in *Becoming, Unbecoming.* This form also helps reveal those stories and experiences of illness that can be hard for those outside of the experience to understand or see. The hard-

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[226] Ibid.

[227] Ibid.

[228] Elisabeth El Refaie, *Autobiographical Comics: Life Writing in Pictures.* (Jackson, MS: University Press of Mississippi, 2012), 206.

[229] Ibid.

to-see is revealed through the depiction of the day-to-day experiences of living with cancer and cancer treatment, as can be seen in *Our Cancer Year* in which Harvey Pekar and Joyce Brabner.[230] This work shares the day to day experience of Pekar's diagnosis and treatment of testicular cancer with the help of images by Frank Stack. The comics depict the realities of hair loss from chemotherapy—loss that includes hair all over the body and not only on the head. It shows the toll of caring in the candid depictions of Brabner reaching her breaking point.

Comics are powerful forms of communication because they are accessible, easy to relate to, and efficient in transmitting information. A program that exemplifies the use of comics to educate healthcare learners is the work being done by Michael Green at Penn State College of Medicine Hershey. Since 2011, Green has taught a course on Comics and Medicine to fourth-year medical students. In this course, students have the opportunity to read a vast array of comics and to also make their own. Green identifies the main aims of the course as:

> 1) to expose students to a set of medically relevant graphic narratives that provoke critical reflection about the experience of illness and the ways patients and their families interface with the medical system; 2) equip students with critical thinking skills for reading and understanding comics that are relevant to medical practice; and 3) nurture students' creativity by helping them develop their own stories into original graphic narratives.[231]

Pulling from the rich Graphic Medicine[232] body of literature, Green provokes critical reflection amongst his students through assigning and discussing medically themed

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[230] Harvey Pekar, Joyce Brabner, and Frank Stack, Our Cancer Year. Philadelphia: Running Press, 1994.

[231] Michael J. Green. "Teaching with Comics: A Course for Fourth-Year Medical Students." *Journal of Medical Humanities* 34, no. 4 (December 1, 2013): 471–76.

[232] Czerwiec, M. K., Ian Williams, Susan Merrill Squier, Michael J. Green, Kimberly R. Myers, and Scott T. Smith. Graphic Medicine Manifesto. Penn State Press, 2015.

comics.[233] The medium of comics provides a unique and powerful window into the experience of another person. The sciences inform providers' understandings of disease in important ways, but the arts can shed light on the experiences of diseases and the multiple types of suffering they can cause. Engaging with the arts can illuminate the complex experience of healthcare—for patients, their loved ones, and providers.

At UTMB, I have collaborated with other instructors to bring comics to the medical school curriculum in the form of a two week intensive minimester course.[234] For the course, I selected titles from the graphic medicine literature to expose students to a broad range of the kinds of work that exist. These works included book-length comics, web comics, and even self-published "zines"[235] that were created by patients, their loved ones, or healthcare providers. The course also included art creation— students learned comics-making techniques through daily exercises and created comics for their final projects. Organized by themes ranging from "the experience of illness" to "power," the course offered comics to illuminate aspects of medicine that students can engage with in a new way—through graphics. For each theme students were provided with excerpts from comics to read and discuss. As a result, students brought their own individual experiences into conversation with those comics students read in the class. Through these exchanges, a diversity of experiences was revealed with students gaining new insights about healthcare experience and practice.

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[233] Green. "Teaching with Comics,"

[234] For syllabus see Appendix B

[235] According to mark Todd and Esther Watson, "Zines are cheaply made printed forms of expression on any subject. They are like mini-magazines or home-made comic books about factory bands, funny stories, sub-cultures, personal collections, comix anthologies, diary entries, pathetic report cards, chain restaurants, and anything else." see Mark Todd and Esther Watson. *Whatcha Mean, What's a Zine?: The Art of Making Zines and Minicomics.* Houghton Mifflin Harcourt, 2006.

THE ART PATIENT— LEARNING TO SEE BY LOOKING AT ART

While literature and comics programs can reveal the diverse experiences of healthcare, there are other initiatives that seek to cultivate learners' sensitivity and to help them become more adept at observing the world around them. As Wrathall writes, "…[art] help[s] by showing us what we don't ordinarily see, indeed, what we may not be able to see at all, but which nevertheless gives content to our experience of the world."[236] Within healthcare education, art can be used as a means of improving observational skills through looking. Observational skills are a vital part of the practice of medicine. Healthcare providers are required to observe and assess. In this programming, the space of the gallery or museum is the classroom where participants look at art not only to learn to see but also to learn an improved way of thinking. As David Perkins observes:

> Looking at art invites, rewards, and encourages a thoughtful deposition, because works of art demand thoughtful attention to discover what they have to show and say. Also, works of art connect to social, personal, and other dimensions of life with strong affective overtones. So, better than most other situations, looking at art can build some very basic thinking dispositions.[237]

Indeed, art does assist in cultivating an ability to see details of life that might otherwise not be seen. To train this kind of seeing, students are introduced to their "art patient."[238]

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[236] Mark Wrathall. "The Phenomenological Relevance of Art" in Art and Phenomenology. London ed. Joseph D. Parry. (New York, NY: Routledge, 2011).

[237] David N. Perkins, *The Intelligent Eye: Learning to Think by looking at Art,* (Los Angeles, CA: J. Paul Getty Museum, 1994), 4

[238] There are art in medicine programs that use the work of art as the point of observation much like the patient would be observed with some programs event calling the artwork the patient or art patient. For example: Craig Klugman, Jennifer Peel, and Diana Beckmann-Mendez, "Art Rounds: Teaching Interprofessional Students Visual Thinking Strategies at One School" *Academic Medicine* 86, no. 10, (October 2011), 1266-1271; Alexa Miller et al. "From the Galleries to the Clinic: Applying Art Museum Lessons to Patient Care." *Journal of Medical Humanities* 34, no. 4 (December 1, 2013): 433–438; S Grossman, J Deupi, and K Leitao. "Seeing the Forest and the Trees: Increasing Nurse Practitioner Students' Observational and Mindfulness Skills." *Creative Nursing* 20, no. 1 (2014): 67–72; Linda Honan Pellico, Linda Friedlaender, and Kristopher P. Fennie. "Looking is Not Seeing: Using Art to Improve Observational Skills." *Journal Of Nursing Education* 48, no. 11 (November, 2009): 648-653.

The emphasis of programs on learning to "look deeply" can be exemplified with healthcare education programs that utilize the museum classroom. One such program is at the University of Texas Health Science Center in San Antonio (UTSA).

In January 2010, UTSA created an opt-in, 3-week program for nursing and medical students who were divided into three groups and participated in three 90-minute sessions at the McNay Art Museum in San Antonio.[239] As part of their curriculum, UTSA uses visual thinking strategies (VTS):

> VTS is a method developed by Abigail Housen… [and was] created as a tool to foster aesthetic development and to assist empathic understanding of others' experience of the visual world through visual art…VTS uses art to assist students in developing critical thinking, communication and observation skills, and participation in group thought processes.[240]

This technique is meant to teach learners to see that which is not obvious and to do so through art. At UTSA students spent time in the museum looking at art and were given different tasks for each of the three weeks during the program. For the first week they had to describe the work, the second week they both described and interpreted the work, and the third week they interpreted the emotional quality of a less representational work.[241] Throughout the three sessions, museum educators facilitated group meetings for students to share and discuss their responses.[242] Such a program offers learners the chance to spend time looking at and reflecting on art while also providing a space for a different kind of conversation with their colleagues outside of the clinical school environment with non-clinical faculty. In a communal setting, students benefit from the diverse

[239] Craig Klugman et al., "Art Rounds"
[240] Ibid., 1266-1267
[241] Ibid.
[242] Ibid.

perspectives of varied responses by different participants. Additionally, these programs have been shown to help cultivate clinical seeing and improve observational skills.[243] Programs such as the art patient offer students the opportunity to develop theire ability to deepen their looking expanding what they see when they examine patients.

Programs that incorporate art engagement provide benefits to participants but are often focused on the instrumental value of art even when intrinsic value is also present. Furthermore, these programs are limited in their impact because they fail to engage students in the rich practice of making art. Art-making in healthcare education programs offers the development of a new way of thinking through creative engagement. The next section offers a closer examination of programs offering opportunities for art creation and creativity in healthcare education and practice.

CREATIVITY AND HEALTHCARE EDUCATION

Creativity is a necessary part of healthcare practice. Healthcare providers engage in creativity, to varying degrees, throughout their work providing care to patients. For example, such creativity manifests in translating the stories of patients, physical exam, and medical knowledge into diagnosis and treatment. However, creativity is also needed when providers work within their roles in a system structured with the logic of letting go. When faced with the dictates of a system— the policies and procedures that shape possible behavior— it can be difficult to imagine actions for resisting those limitation in order to help patients get the care and treatment they need. Creativity is helpful in imagining solutions that resist the injustices and harms of the healthcare system.

Creativity facilitates a different way of seeing and can cultivate a heightened

[243] See Pellico et al., "Looking is Not Seeing" ; Klugman et al., "Art Rounds"

sensitivity that is present-focused enabling a more nuanced engagement with the world. Mihaly Csikszentmihalyi identified creativity as "a central source of meaning in our lives . . . most of the things that are interesting, important, and human are the results of creativity . . . [and] when we are involved in it, we feel that we are living more fully than during the rest of life."[244] The space of creativity has the potential to cultivate an experiential space of being present. This space is not outcome-oriented and is instead allows for the shift to the present moment of creation. Creatively occupying the space of healthcare can assist in the cultivation of meaningful moments.

That which is not always visible becomes visible via art; a propensity that is particularly helpful for assisting providers in developing the capacity to see in a different way. Creativity functions as a valuable space for exploration of the complexities of illness, and engaging in creative expression through arts practice offers space for reflecting on the moments of care. The reflective space of art can function as a process of making sense of the illness, loss, injustice, and death to which providers bear witness.

LEARNING THROUGH ART-MAKING

Art-making is one way that individuals are able to enter into the space of creativity and learn to see and think in new and diverse ways. As Paul Klee so eloquently stated, "art does not reproduce the visible; rather, it makes visible."[245] In healthcare education, art is often used as a kind of reflective practice for learners to make sense of the process of becoming a healthcare provider. Art is not only a method used to achieve

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[244] Mihaly Csikszentmihalyi, *Creativity: Flow and the Psychology of Discovery and Invention* (New York, NY: Harper Collins, 1997), 1-2.

[245] Paul Klee, *Schöpferische Konfession*, (Berlin: Erich Reiss Verlag, 1919) cited in Joseph D. Parry, ed. *Art and Phenomenology.* (New York, NY: Routledge, 2011).

other means, but it is also an experience. Art lends itself well to this function because, as Parry & Wrathall note, "… art is a neighbor to and co-worker with philosophy, and both art and philosophy proceed by directing our attention to our experience of the world."[246] This engagement can allow for a different way of knowing and making meaning of the world in which we live. The kind of knowing made possible via art is one that requires learning through the experiential nature of art. It makes visible that which is difficult to perceive otherwise.

REFLECTING THROUGH ART PRACTICE

As previously discussed, Michael Green at Penn State College of Medicine also incorporates art practice as part of his Comics and Medicine course for medical students. Creating comics allows creative self-expression for students to reflect on their training.[247] His course has produced rich visual narratives that review the complex experiences and emotional responses these students have encountered in their training to date. Some of their comics consider the experience of a family member's traumatic injury[248] while others reflect on the complexities that arise in patient care with "difficult" patients[249] or dying patients.[250] These works illuminate the deeper experiences of these learners as is apparent with Ashley Pistorio's comic "Vita Perseverat."[251] In her comic, Pistorio shares

[246] Joe Parry & Wrathall, *introduction* in Art and Phenomenology. ed. Joseph D. Parry, (New York, NY: Routledge, 2011), 2.

[247] Daniel R. George and Michael J. Green, "Lesson Learned from Comics Produced by Medical Students: Art of Darkness," *JAMA* 314, no. 22 (December 8, 2015), 2345-2346

[248] Lauren Schmidt. "Shadows," Penn State Collection of Graphic Narratives, Accessed March 10, 2018, https://sites.psu.edu/graphicnarratives/2016/08/01/lauren-schmidt/.

[249] Taylor Olmsted. "The Taming of Tina." Penn State Collection of Graphic Narratives, Accessed March 10, 2018, https://sites.psu.edu/graphicnarratives/2016/08/01/taylor-olmsted/.

[250] Ashley Pistorio. "Vita Perseverat." Penn State Collection of Graphic Narratives, Accessed March 10, 2018, https://sites.psu.edu/graphicnarratives/2016/08/01/asley-pistorio/.

[251] Ashley Pistorio. "Vita Perseverat." Penn State Collection of Graphic Narratives, Accessed March 10, 2018, https://sites.psu.edu/graphicnarratives/2016/08/01/asley-pistorio/.

an experience on her Neurology rotation just finishing up for the day when her faculty gives her the option to join him as he finishes things up or to go home. Pistorio immediately points to the power dynamic of medical education through articulating what is obvious to most medical students but not always so for faculty: "In medical school, there really is no "optional" clinical activity."[252] Pistorio reveals her struggle with the activity required of her: to accompany her faculty as he informs the families' of two patients that their loved ones are brain dead. Pistorio reveals her fear through an image of a black hole and her likeness running away from the task. She beautifully illustrates this task by focusing on the details she notices: the beeping and sucking machines, a loved one's stance over her granddaughter, a daughter being held as she breaks down, a father's quiet tears, and a daughter crawling into bed with her mother who has just been diagnosed as brain dead. The daughter is not only the 20-year old in the hospital room; Pistorio reveals the intimate relationship and its dependency with a small child sucking her finger sleeping with her mother showing what is unseen when she draws a small child in her mother's arms. Throughout the comic she makes herself vulnerable, depicting the details of her own struggles with the weight of the encounter through a glimpse at her night at home trying to remove the noises and sights she had witnessed from her mind as well as herself hiding in the hospital bathroom overcome by the loss and waiting to compose herself so she can go home. The comic reveals an intimate view of the suffering in medicine told from the view of a silent learner in the room.

In addition to this intimate glimpse into medical learning, there are also comics that use visual and textual metaphors to make sense of some of the clinical mentors these

[252] Ibid., np.

students must endure.[253] The mentor model of healthcare education, especially in medical school, is structured so that students are mentored by more senior students as well by faculty preceptors. This model of education results in a range of intentional lessons as well as those that are unintentional and hidden—"the hidden curriculum." According to Karnieli-Miller, "The hidden curriculum is the physical and workforce organizational infrastructure in the academic health center that influences the learning process and the socialization to professional norms and rituals."[254] This hidden curriculum can cause harm when mentors model behavior that supports the structural violence and problematic hierarchies already present in the healthcare system. This can be seen in Michael Pitzer's comic "Medical Student: A Tragic Comedy" when the intern is providing tips to the medical student for how to survive the abusive faculty. The student is told "Asking questions is risky! Very, very risky! Ask questions at your own risk! and don't expect an answer, and be ready to run!"[255]

[253] Michael Pitzer. "Medical Student: A Tragic Comedy." Penn State Collection of Graphic Narratives, Accessed March 10, 2018, https://sites.psu.edu/graphicnarratives/2016/08/01/michael-pitzer/.

[254] Orit Karnieli-Miller et al. "Medical Students' Professionalism Narratives: A Window on the Informal Hidden Curriculum". *Academic Medicine* 85, No. 1, (January 2010): 124.

[255] Pitzer. "Medical Student: A Tragic Comedy."

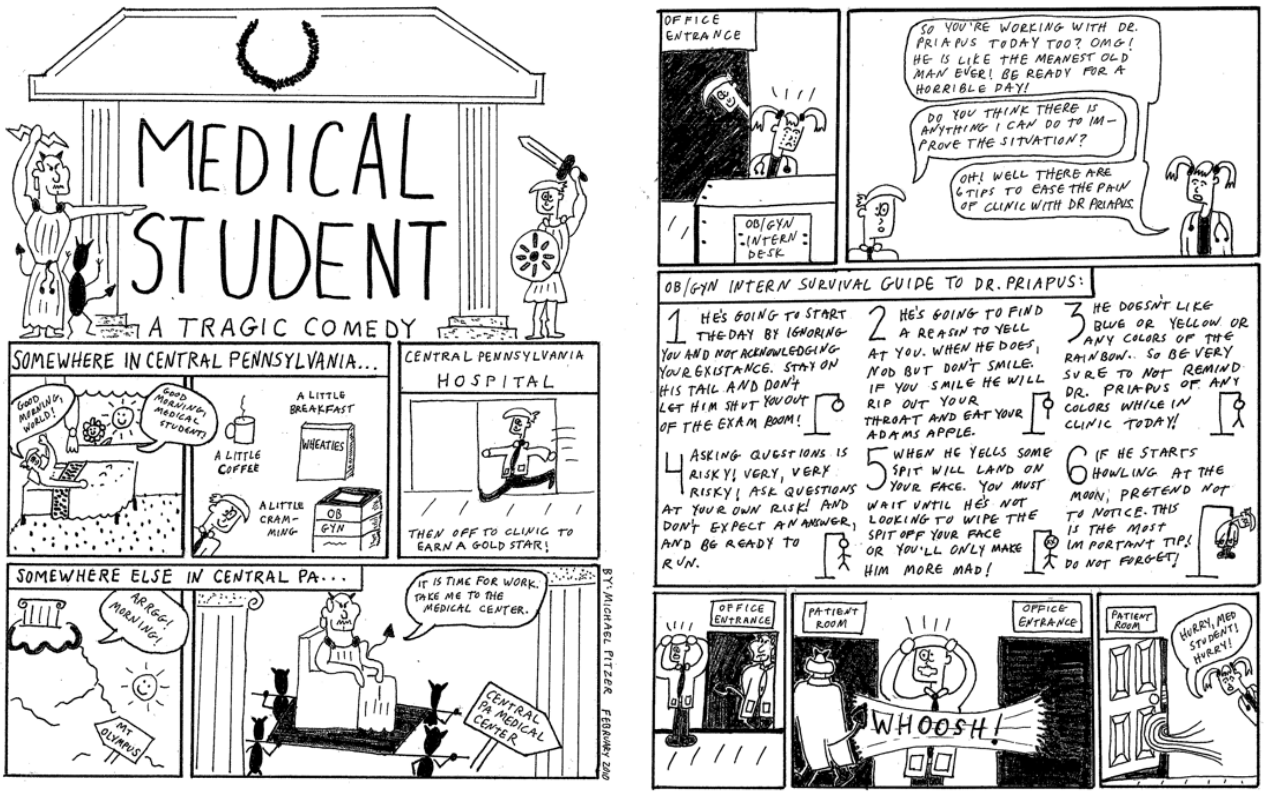

Illustration 5: Excerpt, Medical Student: A Tragic Comedy, Michael Pitzer, 2015. Reproduced with permission. For full comic see Appendix A.

The hidden message is that it is better to be uninformed and not ask questions than to ask the person who is meant to be the teacher, the attending. Furthermore, the message that is received is that this abuse is unavoidable: It is the intern, the medical student's superior, who teaches him these lessons. For these students, creating comics becomes a space of reflection and artistic engagement with their experiences of learning to become physicians. Furthermore, the finished works serve as the foci for discussions around the problematic practices in medicine.

From Reflection to Interpretation

While many arts programs focus on reflection, Arno Kumagai has created a

program to use artistic expression to forge a space of interpretation. Kumagai is a full professor and vice-chair in the Department of Medicine at the University of Toronto and has done much work integrating art and humanities into medical education.[256] He has extensive publications documenting his efforts to move arts in healthcare initiatives beyond the instrumental focus and to engage with the intrinsic value of the arts.[257] In one such projects, Kumagai utilizes a different methodology to move learners beyond individual reflection to connect them with other identities and other world experiences. While at the University of Michigan School of Medicine, Kumagai worked with first and second-year medical students on an art project that paired them with community members who have serious or chronic illnesses.[258] Over the course of two years, the students engage these individuals in conversations about their experiences while also meeting for small group discussions and activities focused on their conversations with community members. Ultimately, students are required to create an interpretative project in any medium to convey their understandings of the stories to which they bear witness.[259] Kumagai has suggested that the engagement with patient stories, and the interpretation of those stories through art, provides unique education for healthcare

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[256] "Vice-Chairs & Senior Advisor | Department of Medicine." Accessed March 19, 2018. http://www.deptmedicine.utoronto.ca/vice-chairs-senior-advisor.

[257] for example see Kumagai, Arno K. and Monica L. Lypson. "Beyond Cultural Competence: Critical Consciousness, Social Justice, and Multicultural Education." Academic Medicine : Journal of the Association of American Medical Colleges 84, no. 6 (2009): 782; Kumagai, Arno K. "Beyond "Dr. Feel-Good": A Role for the Humanities in Medical Education." Academic Medicine 92, no. 12 (2017): 1659-1660; Kumagai, Arno K. "A Conceptual Framework for the use of Illness Narratives in Medical Education." Academic Medicine : Journal of the Association of American Medical Colleges 83, no. 7 (2008): 653-658; Kumagai, Arno K. "From Competencies to Human Interests: Ways of Knowing and Understanding in Medical Education." Academic Medicine 89, no. 7 (2014): 978-983; Kumagai, Arno K. and Delese Wear. ""Making Strange": A Role for the Humanities in Medical Education." Academic Medicine : Journal of the Association of American Medical Colleges 89, no. 7 (2014): 973.

[258] Kumagai, "Acts of Interpretation"

[259] Ibid.

learners:

> The educational result of perspective-taking, self-reflection, and exposure to other identities, experiences and ideas, contributes, I believe, to each student's tacit or implicit knowledge about people, illness, and doctoring.[260]

Kumagai presented some of the work that resulted from this project in his article "Acts of Interpretation: A Philosophical Approach to Using Creative Arts in Medical Education," revealing the medical students' deep reflection and response to the illness experiences they learn about in their conversations with patients.[261] Students not only heard the story of another but connected to that story by interpreting it through art that was shared in an attempt to forge connection and meaning. This meaning is cultivated through conversations between the participants and artists as well as the art and audience. According to Kumagai, "these conversations are *acts of interpretation* in which individuals seek to extract meaning and significance from their interactions with the artwork and one another."[262] Kumagai seeks to move beyond the use of art for instrumental purposes in medical education and toward more intrinsic aims building community through a rich process of story-sharing and art-making.

FINDING "SPACE" IN HEALTHCARE

Art can make possible rich communal spaces for creative expression, and also can offer space for participants to be vulnerable with their colleagues. Both Kumagai and Green make this space available through curricular interventions that allow learners to participate through engaged art practice. In these programs, art-making serves as an experiential intersection of art and medicine. As Eric Avery has articulated:

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[260] Ibid., 1139.
[261] Ibid.
[262] Ibid., 1141.

> Art is, for me, experience in relationship to special images, which simply exist in the world. This relationship of a dependent, non-analytical experience of art does not seem too unlike the experience of being with a patient beyond the analysis of his physiochemical, physiological, and psychological phenomena. This experiential dimension in both art and medicine is the same.[263]

The experiential space of art affords students opportunities to access medicine and their educational experiences in new and varied ways, as exemplified by Creative Expressions Project (CEP), a program at UTMB that utilized art in the curriculum to create a communal space in which students could make sense of experience.

CEP at UTMB began in 2012 as part of the Humanities, Ethics, and Professionalism (HEP) module for the Practice of Medicine Course for rising 2nd-year medical students. This project emerged as a response to the bioethics-focused written assignment for the final project of the course. In an effort to give students other opportunities to engage with the course content, Jerome Crowder and Anne Rudnicki first outlined the course on a napkin and later formally incorporated a creative component to the HEP module.[264] Students had the opportunity to elect to make an art project in place of the required ethics paper. Throughout the 6-week course students engaged in reflective writing, story circle discussions, and art-making to explore their own reasons for entering medicine and on their experiences of medical school. The intention of the art component was to provide a space of creative expression.

In 2014 and 2015 I assisted with two iterations of CEP as a graduate teaching assistant. In this role I drew from my fine arts background to assist with the project

[263] Eric Avery, "Hands Healing: A Photographic Essay," in *Visual Arts and Medical Education,* edited by Edmund D. Pellegrino and Geri Berg. 1st edition. Carbondale: Southern Illinois University Press, 1983, 11.

[264] Jerome Crowder and Anne Rudnicki, Personal Communication, Summer 2015.

development and artistic needs of the students while also working with faculty to respond to reflective writing and run class sessions. CEP gave students the opportunity to reflect, through art, on what it means to be a physician and on their understanding of medicine after one year of study. What resulted was thoughtful reflective writing, rich in-class discussions, and engaging final projects that were displayed at a public exhibition.

CEP also provided a space where students felt safe to be vulnerable, enabling them to learn more about their colleagues. This space of vulnerability is vital but scarce in the often ultra-competitive environment of medical school. As one student noted in their final evaluation in 2014:

> As time goes on in medical school, it is so difficult to become vulnerable. We are pushed to our limit to be perfect even though we are fallible and imperfect just like any other human out there. So putting myself in an uncomfortable situation, where I actually had to perform was incredibly challenging. I had to tell myself that it is okay if I am not perfect, but I can still try.[265]

It is not only the act of making art that holds value for clinical students, but it is also the space created through making art while in the company of others. Making art in communal spaces fostered these more intimate conversations, and a kind of "magic" occurred. Conversations and connections took place between students in ways that did not occur in other settings. Students articulated this in the final reflections. For example, in 2015:

> What impacted me the most from CEP were the stories behind everyone's projects and their ideas for expressing their experiences. It's quite refreshing to see my colleagues in another light, especially that of art and creativity since our lives have been nothing but science and logic for the past year.[266]

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[265] AE, survey completed by Jerome Crowder, Creative Expressions Course responses, 2014.
[266] AE survey completed by Jerome Crowder, Creative Expressions Course responses, 2015.

And another student pointed to the opportunity to get to know her colleagues and the connections made through the course:

> It was great to get to meet such nice and helpful people as well as get to know some of my classmates. The show was incredible. It was awesome to get to talk to people about what they liked in my piece and how they identified with it. Without CEP, it is likely that none of us would ever have had the chance to bring so many people to our art and get such a personal experience.[267]

Students also expressed gratitude for having the opportunity to connect with colleagues they would not have otherwise as well as to share a side of themselves that they do not have space to share in other parts of their education:

> CEP was such an awesome experience. It gave me the chance to focus my energy on something outside of the realm of medical sciences and working on my art proved to be a great stress reliever at the end of my day. It also allowed me to make new friends in my class that I have never had the chance to interact with in the past year. I learned a lot about myself too. I was able to explore my emotions about what is driving me to be a physician on a deeper level than rehearsing interview answers. I was able to bring out another aspect of who I am to peers who only knew me from school.[268]

The space of art illuminated another side of students and allowed for connections that may not have happened otherwise. Art-making lends itself well to the creation of safe spaces where students can expose their struggles as a result from the rich intrinsic values it offers. The cultivation of a space that allows for students to open up and share their vulnerability is not automatic in arts interventions but instead require careful curation by facilitators of these projects. In CEP there was an emphasis on creating a space for students where they would not be evaluated by those responsible for evaluating them in

[267] JL survey completed by Jerome Crowder, Creative Expressions Course responses, 2015.
[268] AF survey completed by Jerome Crowder, Creative Expressions Course responses, 2014.

their other medical school courses. Course facilitators sought to cultivate a collaborative environment attending to power dynamics always present in a graded setting. One way this was done was through adjusting class meetings based on the needs of the students. The course was adjusted to be earlier in the day on Friday as it was the last required activity on their schedule for Fridays. Breakfast was also provided to allow for students to ease stress of the course happening immediately following another required meeting. We worked to start the course with open communication and were mindful to work to honor the students through our responsiveness. The process and experience were designed to create the opportunity to explore the self through communal discussion and art practice.

SPACE TO GROW

CEP, like most arts-in-healthcare programs focused on the individual experience, failed to engage with the ways that structural harms shape and constrain the experiences upon which students are asked to reflect. The larger systemic constraints of the US healthcare system influence and shape medical education and practice, but most arts programs remain exclusively focused on the individual physicians looking inward to reflect on their own practice and to better understand the individual experiences of their patients.

Although these projects focus on the individual experience, there is great potential for adapting this curriculum to move beyond the micro and connect to the macro. This happened organically with one student's project in CEP in 2014. Just prior to the course, student KB spent a month abroad on a global health trip and started the course trying to make sense of the poverty and suffering she witnessed and her sense of being a burden to the community she sought to help. Throughout the course she reflected on her global

health experience and through the reflections sought to better understand her individual role and impact on the country. The practice of trips organized to have students volunteer in low income countries has been termed "voluntourism," which:

> …refers to programmes or trips of a short duration, usually between 1—4 weeks. They may be organized by medical, religious or other organizations and offer health services, which include family medicine clinics, surgical, dental, ophthalmologic or other specialist series, often in temporary 'clinics.' These services are usually targeted at poor or rural populations, and are offered free or at a nominal charge.[269]

Voluntourism is touted as an opportunity for students to gain experience while helping others through an activity that offers them new and different experiences.[270] For KB the experience was troubling, and she used the space CEP offered to make sense of her response to it. After the story circle discussions where KB revealed her distress with the trip, faculty offered her articles that addressed the more systemic problems of such global health missions that bring in unlicensed clinical students and/or untrained volunteers to help local populations. In her project sharing, KB also questioned the general practice of the trip that she took:

> The idea that volunteers, untrained in third world medicine, unfamiliar with the social context or the patients themselves, and often unable to communicate effectively in the local language, can give effective and appropriate medical care seems questionable.[271]

Ultimately, KB created a video digital story in which she paired images from her trip with a poem reflecting on her presence in the Dominican Republic. Her film ended with the insight that her presence, though well-intentioned, caused harm to those she intended

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[269] McLennan, Sharon. "Medical Voluntourism in Honduras: 'Helping' the Poor?" Progress in Development Studies 14, no. 2 (April 1, 2014): 164.

[270] Colleen McGloin and Nichole Georgeou. "'Looks Good on Your CV': The Sociology of Voluntourism Recruitment in Higher Education." Journal of Sociology 52, no. 2 (June 1, 2016): 403–17.

[271] Kathryn Brand, Creative Expressions Course responses, 2014. Shared with consent.

to help:

Something I now see, eyes opened by the sea .
But they also see, good intention polluted by their see.
Because I only see, then simply leave their sea.[272]

In addition to the digital story, KB also created an interactive poem further examining a trip that "spent 6 weeks seeing really terrible situations and were helpless to do anything about it."[273] The interactive poem began with instructions for the audience:

And now that I have left, why do I despair?
This question has plagued me. So what I've learned, I'll share.
Take this in hand- tear free- this is the next part.
Boldly printed, gently bound, so before you start,
know the words are from the heart.[274]

She required the audience to physically tear, and thus cause harm, to the paper, in order to access a poem that she wrote mimicking the harm KB felt she caused on the global health trip. In the poem she expresses the belief that her being there was not needed and indeed was harmful:

My presence in this country was not needed.
In fact, sometimes it seemed my presence impeded
the people from understanding that their lives
have worth, meaning. For the outsider arrives,
saying, "it's my life that thrives.[275]

She also pointed to the structural harms she witnessed while in the hospital:

I say that, but there's something I found lacking:
Medicine, to stop the sickness that's attacking.
Even in hospitals, they are mistreated.
Hands are not washed. Procedures go uncompleted.
Then each day it's repeated.

In her final reflection, K noted the surprise of her colleagues that she critiqued the global

[272] Brand, "See the Sea" Creative Expressions Project. Shared with consent.
[273] Brand, Creative Expressions Course responses, 2014. Shared with consent.
[274] Brand, Interactive Poem, Creative Expressions Project. Shared with consent.
[275] Ibid.

health trips and a reluctance to participate in the tearing off of the poem:

> When I presented my project, it was really interesting how so many people came to it expecting to hear about a positive global health experience, because after they watched the first video nearly everyone would say that it was very "emotional". It was also interesting to see how no one wanted to tear off the second poem. I had to sort of hand it to them and tell them again that they could tear it off. Overall, I think the audience was able to experience my project the way I had hoped. I think that it opened their eyes to a new perspective and view of global health, as the experiences did for me.[276]

More scaffolding is needed to enable students to follow KB's example and explore the structural complexities of healthcare. With gentle guidance incredible insights emerge, but without an understanding of the system, learners will find themselves ill-prepared to respond to and cope with the injustices that pervade the practice of medicine.

CONCLUSION

Art can be understood as an attempt to understand the world around us, and has the potential to engage learners as both viewer and creator. Although the arts can help to nuance understandings of healthcare, there are several crucial areas that remain largely unexplored via existing art interventions. The current research and practices of arts-based healthcare curricula focus on the individual, but fail to adequately explore the problematic system within which these students exist. It is not enough to look inwards and examine the self, and it is not enough to simply become aware of the injustices. Art-based curricula have the potential to address this gap by engaging learners in the structural complexities of healthcare practice. Much can be learned from the arts justice work already being in the form of art activism curriculum, which will be explored in the

[276] Kathryn Brand, survey completed by Jerome Crowder, Creative Expressions Course responses, 2014. Shared with consent.

next chapter.

Chapter 5 Activism through Art

> Without a minimum of hope, we cannot so much as start the struggle. But without the struggle, hope, as an ontological need, dissipates, loses its bearings, and turns into hopelessness. And hopelessness can become tragic despair. Hence the need for a kind of education in hope. Hope, as it happens, is so important for our existence, individual and social, that we must take every care not to experience it in a mistaken form, and thereby allow it to slip toward hopelessness and despair. Hopelessness and despair are both the consequence and the cause of inaction or immobilism. - Freire[277]
>
> -Paulo Freire, *Pedagogy of Hope*

Healthcare education and practice do not exist in a vacuum, but instead are embedded within the complex society in which they are performed. As outlined in the first half of this dissertation, societal norms and biases shape the practice of medicine despite its objective framing. The logic of letting go, and the ways in which it constrains practice, pervade the healthcare system. The structural forces of the medical system often manifest themselves in clinicians' everyday actions, which they learn during the socialization process that occurs during medical education. Arts activism curricula and pedagogy provide meaningful frameworks for educating healthcare learners on the complexities of healthcare practice, and the everyday practice of resisting the injustices they witness and are expected to perform as medical professionals.

This chapter provides an introduction to the arts activism literature and examines the work being done in this field. I provide an overview of arts activism curricula while highlighting the ways this work addresses the gaps that exist in current arts-based

[277] Paulo Freire, *Pedagogy of Hope: Reliving Pedagogy of the Oppressed.* (New York, NY: Bloomsbury Academic, 2014), 3.

healthcare programming and curricula. I look at the social theory that informs these practices and provide examples of projects by individual artists as well as social justice-focused art educational courses. I offer an analysis of the ways in which this work can be applied to arts-based healthcare education interventions to educate learners on the structural complexities of healthcare. This work offers a novel means of cultivating creative thinking and engaging students in active learning around healthcare injustice and health disparities to improve healthcare practice. Arts activism inspired, arts-based healthcare curricula can, I argue, better link theory to practice. I conclude this chapter by suggesting the specific space of the free clinic as an ideal starting point to develop arts-based social justice curriculum for healthcare students.

ACTIVISM ART

Art has been, and continues to be, a powerful method for initiating social change.[278] With the current social and political landscape in the US, activism through art

[278] for example see Nato Thompson, *Seeing Power: Art and Activism in the Twenty-First Century*. *Brooklyn, NY: Melville House), 2014; Beverly Naidus, *Arts for Change: Teaching Outside the Frame.* (Oakland, CA: New Village Press), 2009; Marian Liebmann, Rachel Lev-Wiesel, Rachel ORourke, Lani Gerity, Dan Hocoy, David Gussak, Anndy Wiselogle, et al. *Art Therapy and Social Action: Treating the World's Wounds*. Edited by Frances Kaplan. 1 edition. (London, UK: Jessica Kingsley Publishers, 2006); Tom Borrup, and Robert McNulty. *The Creative Community Builder's Handbook: How to Transform Communities Using Local Assets, Arts, and Culture*. (Saint Paul, MN: Fieldstone Alliance, 2006); Thomas Vernon Reed, *The Art of Protest: Culture and Activism from the Civil Rights Movement to the Streets of Seattle.* 1 edition. (Minneapolis, MN: University Of Minnesota Press, 2005); Maxine Greene, *Releasing the Imagination: Essays on Education, the Arts, and Social Change.* 1 edition. (Princeton, NJ: Jossey-Bass, 2000); Michael Shank, "Redefining the Movement: Art Activism." *Seattle Journal for Social Justice* 3 (2004): 531; Josh MacPhee and Erik Reuland, eds. *Realizing the Impossible: Art Against Authority.* Oakland, CA ; Edinburgh, Scotland: AK Press, 2007; Nina Felshin, ed. *But Is It Art? The Spirit of Art As Activism.* Seattle, Wash: Bay Press, 1994; Mira Schor, Emma Amos, Susan Bee, Johanna Drucker, María Fernández, Amelia Jones, Shirley Kaneda, et al. "Contemporary Feminism: Art Practice, Theory, and Activism—An Intergenerational Perspective." *Art Journal* 58, no. 4 (December 1, 1999): 8–29; Mary Stone Hanley, Gilda L. Sheppard, George W. Noblit, and Thomas Barone, eds. *Culturally Relevant Arts Education for Social Justice: A Way Out of No Way*. 1 edition. (New York, NY: Routledge, 2013); Gregory Sholette, *Dark Matter: Art and Politics in the Age of Enterprise Culture.* (New York, NY: Pluto Press, 2011; Pablo Helguera, *Education for Socially Engaged Art: A Materials and Techniques Handbook.* (New York, NY: Jorge Pinto Books Inc., 2011); Martha Rossler, *If You Lived Here: The City in Art, Theory, and*

is an exploding as a means to challenge the injustices that pervade this society. As Marit Dewhurst[279] notes, arts activism, also known as social justice art,[280] is the process of "creating works of art—from murals and plays to photographs and spoken-word poetry—that question, challenge, and strive to directly influence existing conditions of inequality and other injustices by engaging various communities in social transformation."[281] This practice is not new, but instead has been a powerful force for challenging injustice and seeking change. As Rebecca Bray notes, "…throughout history the most effective civic actors have married the arts with campaigns for social change, using aesthetic approaches to provide a critical perspective on the world as it is and imagine the world as it could be."[282] In the US, the influence of art activism has been extensive and has helped shape a multitude of social justice movements from the civil rights movement to the feminist movements to anti-war movements.[283] Through song, painting, posters, installations, performance, and other creative mediums, artist activists reframe and illuminate social issues and concerns as a method to seek change.

Art activism emphasizes community and interaction as an integral part of its purpose, and its practice falls primarily outside the traditional spaces of the art of

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Social Activism : A Project by Martha Rosier. Edited by Brian Wallis. (New York, NY: New Press), 1998; Nicolas Lampert, *A People's Art History of the United States: 250 Years of Activist Art and Artists Working in Social Justice Movements.* Reprint edition. (New York, NY: The New Press, 2015).

[279] Dewhurst is the Director of Art Education and Associate Professor of Art and Museum Education at City College of New York. She has done extensive work as an educator developing social justice art pedagogy and education programs. see "Marit Dewhurst." Accessed March 20, 2018. http://maritdewhurst.com/.

[280] Marit Dewhurst, *Social Justice Art: A Framework for Activist Art Pedagogy* (Cambridge, MA: Harvard Education Press, 2014).

[281] Ibid., 9.

[282] Rebecca Bray, "Why Artistic Activism?" Center for Artistic Activism (blog), April 28, 2017. https://artisticactivism.org/2017/04/why-artistic-activism/.

[283] This is by no means an exhaustive list. Art activism has been a part of movements throughout history.

museums and galleries.[284] As Boris Groys notes, activist artists:

> …do not want to merely criticize the art system or the general political and social conditions under which this system functions. Rather, they want to change these conditions by means of art—not so much inside the art system but outside it, in reality itself.[285]

Through collaborative creation or audience engagement, arts activism "is about the artistry of social consciousness grounded in human interaction. It represents an innovative use of public space to address contested issues of sociopolitical and cultural significance allied with systems of power and control."[286] Activism art questions societal injustice and structural violence. It seeks to blur the boundaries of power and challenge the hierarchies that contain the capacities of those caught in them.[287] This use of art for social transformation can be exemplified with the Guerrilla Girls, an artist collective that has challenged the patriarchal art world and fought for space within it, using art as its weapon.

The Guerrilla Girls is a collective of feminist activist artists who "believe in an intersectional feminism that fights discrimination and supports human rights for all people and all genders."[288] The group is made up of anonymous members who participate in art actions to challenge social injustice. The group began in 1985, when it deployed art action to highlight the lack of women artists in galleries and museums. For this event they

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[284] Lampert, *A People's Art History of the United States*

[285] Boris Groys. "On Art Activism" E-Flux Journal #56 (June 2014) Accessed January 11, 2018. http://www.e-flux.com/journal/56/60343/on-art-activism/.

[286] Karen Frostig, "Arts Activism: Praxis in Social Justice, Critical Discourse, and Radical Modes of Engagement," *Art Therapy: Journal of the American Art Therapy Association* 28, no. 2, (July 27, 2011): 51.

[287] cf, Nina Felshin, ed. *But Is It Art? The Spirit of Art As Activism.* (Seattle, WA: Bay Press, 1994), 10.

[288] Guerrila Girls. "Guerrilla Girls." Guerrilla Girls. Accessed March 10, 2018. https://www.guerrillagirls.com/open/.

wore gorilla masks and hung posters near art galleries and museums. These posters "combined a statement directed toward the underrepresentation of woe in the art world with bullet points supporting evidence of gender discrimination below, with specific mention of galleries, exhibitions, and art valuations."[289] The event was meant to bring visibility to the art industry's patriarchal culture and to shame those individual galleries and museums that perpetuated that discrimination. The Guerrilla Girls created a movement to demand equality using art and continue to engage in these actions today.

Art activism interventions, such as those by the Guerrilla Girls, seek social change by creating work that engages audiences with stories and truths of individuals and communities different than their own. Art lends itself well to this function because, as Dewhurst notes:

> Art's ability to communicate ideas, where words alone might not suffice, opens up useful ways for disenfranchised or oppressed groups of people to interact with and potentially impact, the world. These activist forms of art offer opportunities to engage with concepts that may be otherwise challenging to explain, such as issues of identity, oppression, or freedom. Activist art can communicate ideas about both individual and community experiences to a wider audience; it can make public that which has been ignored, silenced, or otherwise kept from the public conscience.[290]

Art activism can illuminate that which is difficult to see or comprehend—or that which has been willfully ignored. This transformative function is powerfully illustrated with the diverse AIDS art activism that emerged beginning in the 1980s as a result of the US government's negligence in its response to the AIDS crisis. This silencing motivated collective art interventions such as the AIDS quilt, with art activism instrumental in

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[289] "The Guerrilla Girls Biography, Art, and Analysis of Works." The Art Story. Accessed February 2, 2018. http://www.theartstory.org/artist-guerrilla-girls.htm.

[290] Dewhurst, *Social Justice Art,* 7

giving voice to those lost to the pandemic, whom so many, including the government,[291] refused to recognize.

THE AIDS QUILT

To forget a name is in effect to allow death to have the last word.[292]

The first cases of acquired immunodeficiency syndrome (AIDS) were reported in the US in 1981,[293] when the Centers for Disease Control (CDC) issued a warning in the *Morbidity and Mortality Weekly Report,* after several severe cases of pneumonia were reported in young, homosexual men.[294] Because the ensuing epidemic disproportionately affected gay men, the disease, and its impact, was ignored; President Reagan would not publicly acknowledge it until 1987.[295] This refusal to acknowledge the crisis not only led to the collective forgetting of thousands of AIDS victims, but also to the failure to allocate research funding towards AIDS prevention and treatment. The disease, largely affecting gay men, thus became understood as a disease of the "Other," because, as Susan Sontag notes:

> With AIDS, the shame is linked to an imputation of guilt . . . It is not a mysterious affliction that seems to strike at random. Indeed, to get AIDS is precisely to be revealed, in the majority of cases so far, as a member of a certain 'risk group,' a community of pariahs. The illness flushes out an identity that might have remained hidden from neighbors, job-mates, family, friends. It also confirms an identity, and among the risk group in the United States most severely affected in the beginning, homosexual

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[291] Kyra Pearson, "How to Have History in an Epidemic" in *Remembering the AIDS Quilt, ed.* Charles E. Morris III, (East Lansing, MI: Michigan State University Press, 2011), 263-264.

[292] Peter S. Hawkins,."Naming Names: The Art of Memory and the NAMES Project AIDS Quilt." *Critical Inquiry* 19, no. 4 (1993): 752.

[293] "HIV and AIDS --- United States, 1981--2000." Centers for Disease Control, Accessed February 3, 2018. https://www.cdc.gov/mmwr/preview/mmwrhtml/mm5021a2.htm.

[294] Mirko D. Grmek, *History of AIDS: Emergence and Origin of a Modern Pandemic.* (Princeton, NJ: Princeton University Press, 1993).

[295] Pearson, "How to Have History in an Epidemic"

> men, has been a creator of community as well as an experience that isolates the ill and exposes them to harassment and persecution.[296]

The disease affected a portion of the population who was already perceived as being wrong in their very existence and thus the pandemic largely affecting this population was met with indifference.

The concept for the AIDS quilt first emerged in response to this devastating silence. When Cleve Jones, an American LGBT and AIDS rights activist, heard that the death toll from AIDS in San Francisco had reached one thousand, he wanted to provide a visual representation of the individuals lives lost. Jones sought to "name names" in an effort to ensure that those dead and dying from AIDS would not be forgotten.[297] To do so he asked individuals attending the annual 1985 Harvey Milk march to each make a placard with the name of someone they knew who had died from AIDS. The placards were hung on the facade of the federal building in San Francisco during the parade to provide a visual illustration of the scope of the human loss.[298] This project quite literally gave voice to those individuals the government and much of the general public would like forgotten.

The AIDS Quilt, originally called the NAMES Project Quilt, was formally organized on June 21, 1987 and displayed the following week at the San Francisco Lesbian and Gay Freedom Pride Parade.[299] The project was motivated by the desire to memorialize the individuals who lost their lives to AIDS while also to challenge the

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[296] Sontag, Susan. *Illness as Metaphor and AIDS and Its Metaphors.* 1st edition. (New York, NY: Picador, 2001), 113.

[297] Hawkins,"Naming Names," 756.

[298] Ibid., 756.

[299] Ibid., 757-758.

indifference and inaction that was further exacerbating the loss.[300] Each panel represented the life of an individual life, with some lives represented multiple times, and were stitched together to represent a map of the AIDS crisis:

> …the quilt is incorporative, pieced together from every state like a cultural map of the AIDS crisis. The juxtapositions of seemingly disparate lives demonstrate that AIDS—a crisis of the social body—reveals the interconnectedness of peoples' lives in a seemingly individualistic society.[301]

This work created a space to memorialize those whose very existence was erased, and would eventually name tens of thousands of individuals who died from AIDS while also recognizing the hundreds of thousands who could not be named.[302] The project quickly expanded its reach beyond the San Francisco community when it was displayed in the National Mall in Washington, DC on October 11, 1987 covering a space the size of a football field with 1,920 panels.[303] With this naming, the devastating loss caused by AIDS was attended to and supported in ways it had not been before the display. The Quilt toured in twenty cities and through this raised $500,000 for AIDS organizations.[304] Studies have shown that the AIDS Quilt not only helped raised money but also resulted in increased information-seeking and decreased social distance.[305] This example of collaborative and community art made AIDS more relatable to the general public and in turn was both a public memorial to the lives claimed by AIDS, while also calling for

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[300] Pearson, "How to Have History in an Epidemic", 263-264.

[301] Steven James Gambardella. "Absent Bodies: The AIDS Memorial Quilt as Social Melancholia." *Journal of American Studies* 45, no. 2, (201)1: 219.

[302]Charles E. Morris III,, ed. *Remembering the AIDS Quilt. East Lansing*: (East Lansing, MI: Michigan State University Press, 2011), 3.

[303] Gambardella, "Absent Bodies"

[304] Ibid.

[305] C.S. Knaus and E. W. Austin. "The AIDS Memorial Quilt as Preventative Education: A Developmental Analysis of the Quilt." *AIDS Education and Prevention : Official Publication of the International Society for AIDS Education* 11, no. 6 (December 1, 1999): 525-540.

action to address the unjust distribution of resources, research, and interventions to fight this pandemic.

PERFORMING ACTIVISM

The AIDS Quilt was one example of many activist art projects that emerged in response to the AIDS crisis, aiming to educate the general population and advocate for research and resources. In 1985, Larry Kramer, LGBT activist and co-founder of the Gay Men's Health Crisis, published a play documenting the HIV/AIDS crisis in New York between 1981 and 1984. *The Normal Heart* provides a visual narrative of what many gay men experienced at the beginning of the AIDS crisis in New York.[306] The play works to merge the public and private experiences of the early AIDS crisis, during a time of government inaction and when acquiring AIDS meant almost certain death. Kramer had acquired the reputation of an activist who was "always screaming,"[307] and the text is an example of employing writing to scream for social change in the face of injustice.

The play both educates viewers on the macro impact of AIDS and facilitates an emotional connection to those who were directly impacted by it. The physical set of the play constructs a visual argument using quantitative data regarding the AIDS epidemic and calls for viewers to respond via action. "The walls of the set, made of construction-site plywood, were whitewashed. Everywhere possible, on this set and upon the theater walls too, facts and figures and names were painted, in black simple lettering."[308] The data inscribed on the set include the number of AIDS fatalities, the amount of

[306] Larry Kramer, *The Normal Heart,* with an Introduction by Andrew Holleran and a Foreword by Joseph Papp, (New York, NY: New American Library, 1985), 19

[307] Andrew Holleran, "Introduction," from *The Normal Heart*, au. Larry Kramer (New York, NY: Penguin Group, 1985), 23.

[308] Larry Kramer, *The Normal Heart,* 19.

contributions made by the mayor, as well as other information that painted a picture of the AIDS epidemic's larger impact. It humanized the enormity of the tragedy by juxtaposing the actors' performances against the statistics displayed on the stage. In addition to data regarding the epidemic, audiences also witness stories of the individual lives impacted by AIDS. The narrative form within *The Normal Heart* presents the experience of AIDS in a way that facilitates an individual emotional connection to it, making it relevant to audiences beyond the communities most affected by it. *The Normal Heart* and the AIDS Quilt both connected audiences with the individuals affected by the disease but kept their distance from the material and bodily affects of AIDS.

SEEING THE VOICELESS

So say the wise fools:
Until the voiceless are heard
Everyone suffers[309]

Artist/activist Sue Coe focuses her work to give voice to stories and experiences that have been silenced. One way she gave voice by creating images of the faces of AIDS. Coe grew up in a working-class family in England before receiving a scholarship to attend art school at the Chelsea School of Art in London. At the Chelesa school Coe studied illustration, a medium she hoped would offer more opportunities for job security. During this training she came to understand the importance of creating images that would engage her readers, pulling them into the work.[310] This focus on images would shape her

[309] Sue Coe and Judith Brody, *Bully!* (New York, NY: Thunder's Mouth Press, 2004).

[310] "All Good Art is Political, Käthe Kollwitz and Sue Coe Current Exhibition at Galerie St. Etienne," Galerie St. Etiene, Accessed February 1, 2018, http://www.gseart.com/gse-pages/Current_Exhibition.php.

work as a "graphic journalist,"[311] and her preferred method of working, she reflects, "is to choose a topic, or have it choose me, and research it and do it well over a decade."[312] A theme throughout her work is the importance of raising awareness and visibility of populations suffering unjustly to improve their situation. Coe's art also functions as journalism, reporting on injustices to her audience, often having the final work displayed in a gallery and sometimes in book form.[313] The work she has published in book form cover issues such as animal rights, apartheid, and US politics and inequities.[314] In 1994 she expanded her work to include AIDS activism when she visited Galveston, Texas as part of a UTMB initiative to record the AIDS pandemic and to make it more visible.[315]

Coe has commented that she uses art "to help serve justice and highlight the oppression that is concealed."[316] In Galveston, Coe collaborated with physician/artist Eric Avery to attend rounds, bearing witness to patients' suffering and creating a visual record of the local impact of AIDS. The portraits she composed during her time at UTMB are compassionate depictions that focus on the individuals suffering from AIDS as well as

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[311] Coe uses this title to identify what she does with her work, see "Uncertain Intimacy: Sue Coe's AIDS Portfolio at Pomona Art Museum." KCET, October 21, 2014. https://www.kcet.org/shows/artbound/uncertain-intimacy-sue-coes-aids-portfolio-at-pomona-art-museum.

[312] "All Good Art is Political, Käthe Kollwitz and Sue Coe "Current Exhibition at Galerie St. Etienne," Galerie St. Etienne, Accessed February 1, 2018, http://www.gseart.com/gse-pages/Current_Exhibition.php.

[313] Ibid.

[314] Coe and Brody, *Bully!*; Sue Coe, *Cruel: Bearing Witness to Animal Exploitation.* First Edition edition. (New York, NY: OR Books, 2012); Sue Coe, *Pit's Letter.* First Printing edition. (New York, NY: Four Walls Eight Windows, 2000); Sue Coe, *Sheep of Fools. (*Seattle, WA: Fantagraphics Books, 2005); Sue Coe, *Paintings and Drawings.* First Edition edition. (Metuchen, N.J: Scarecrow Press, 1985); Sue Coe and Holly Metz. *How to Commit Suicide in South Africa.* (New York, NY: Random House Inc, 1984); Sue Coe and Alexander Cockburn, *Dead Meat.* 1st edition. (New York, NY: Four Walls Eight Windows, 1996); Francoise Mouly and Judith Moore, *X.* Reissue edition. (New York, NY: New Press, 1992).

[315] AIDS, Visual. "Allied Against AIDS: Sue Coe's AIDS Portfolio." Visual AIDS. Accessed February 1, 2018. https://www.visualaids.org/events/detail/allied-against-aidssue-coes-aids-portfolio.

[316] quoted in "All Good Art is Political, Käthe Kollwitz and Sue Coe Current Exhibition at Galerie St. Etienne ," Galerie St. Etienne, Accessed February 1, 2018, http://www.gseart.com/gse-pages/Current_Exhibition.php.

those treating it. The resulting work demands the attention of the audience, which corresponds to Coe's intention:

> People think they can choose to be indifferent…the filter of art is a useful veil to present the reality. It opens up a chance to have a dialogue where the viewer asks questions and is more open to the challenge of change.[317]

Indeed her work did help lift the veil through the complex pairing of emotive images and descriptive text. Her time at UTMB resulted in the series *The AIDS Suite,* breathtaking images and texts that captured the lived realities of AIDS.

Coe returned to UTMB in 2006, her visit sponsored by physician David Paar through his work with TDCJ Correctional Managed Program. Coe again worked with UTMB artist/physician Eric Avery who had been working in the Carole Young Facility for HIV positive women. Sue was invited back to UTMB to draw women as he interviewed them. The result was AIDS-related series *Through Her Own Eyes*. Coe created these AIDS-related series to challenge the invisibility of the AIDS crisis and to seek change through raising awareness because she believes that "if people know the fact, they'll change the system."[318] Coe's AIDS work reveals the human faces of the pandemic, shedding a compassionate light on the realities of the disease that had so long been kept private.

Artist/physician Eric Avery, integral in bringing Sue Coe to Galveston to serve as a witness and reporter of the AIDS crisis, also created AIDS-related artwork so as to cultivate new ways of seeing the disease and those affected by it. His work provides a meaningful example of the kind of engagement, communication, and conversation made

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[317] Ibid.

[318] quoted in "All Good Art is Political, Käthe Kollwitz and Sue Coe Current Exhibition at Galerie St. Etienne ," Galerie St. Etienne, Accessed February 1, 2018, http://www.gseart.com/gse-pages/Current_Exhibition.php.

possible through social content art. Avery graduated with a Bachelor of Fine Art from the University of Arizona before earning a medical degree from UTMB, completing a residency in psychiatry in New York City. After completing his Psychiatry Residency, Avery's first job in 1978 was a 3-month position as an Artist in Residence with the Department of Medical Humanities, Hershey Medical Center, Pennsylvania State University. After Penn State Avery worked in Indonesia and Somalia and upon returning to the United States, he stopped practicing medicine completely for 11 years, to concentrate full time on becoming an artist.[319]

It was in 1992 that Avery returned to the practice of medicine after his friends began die:

> When my friends began to die from AIDS, in 1992, I returned to the practice of medicine, joining the UTMB Department of Psychiatry and also became an Associate Member of the IMH.[320] Ron Carson negotiated my return to UTMB, protecting time for me to make art about what I did as an AIDS psychiatrist. From this "space", I began to grow my art/medicine practice. I'd gotten to know Sue well during my break from medicine and with an established Texas art career, and an academic psychiatric practice, I could practice medicine in the art "space" and call it art/medicine as an extension of the medical humanities.[321]

At UTMB art remained integral to Avery's work and practice throughout his career in psychiatry as he sought to merge the worlds of art and medicine. He continues his art practice in retirement.[322] Ultimately, Avery's overarching activism was to illuminate the fact that visual art and medicine both belonged as part of the traditional Medical

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[319] Eric Avery, e-mail communication, February 26, 2018.

[320] The Institute of Medical Humanities at UTMB.

[321] Eric Avery, E-mail communication, February 26, 2018.

[322] Email communication Eric Avery, MD on January 31, 2018; Eric Avery, "DocArt.com - Who Is Eric Avery?" DocArt, Accessed March 10, 2018. http://docart.com/EricAvery.html.

Humanities. Avery's work emphasizes the intersection of art and medicine through activist-oriented performance art that aims to render the private space of the clinic in the public space of a gallery. In "Healing Before Art: Public HIV Blood Testing"[323] he brought HIV testing into the gallery space in an effort to demystify and normalize it.

Illustration 5: Healing Before Art: Public HIV Blood Testing, Eric Avery, Studio Installation of "The Stuff of Life",3" x 6' sheets of linocut blood wallpaper and "HIV Condom Piñatas" round 8½" HIV woodcut spheres, 1993, Image by Eric Avery, MD and is shared with permission.

[323] Eric Avery, "DocArt.com - Healing Before Art: Public HIV Blood Testing," DocArt, Accessed March 10, 2018. http://docart.com/actions/1994Actions.html.

Illustration 6: Sue Coe having her HIV test done in a 1994 NYC installation and art/medicine action. I only have BW photos. Her blood drawer was Phillip Muskin MD, Image by Eric Avery, MD and is shared with permission.

The work created a space for education and he sought to show aspects of AIDS through his art. His work illuminated one of the ways art can save lives:

> If you believe that information can lead to change, then bearing witness is the narrative function of art and serves a social purpose. If one person, after seeing one of my art actions, were motivated to change an HIV risk behavior and did not get HIV, then this would be my evidence that art can save lives. Art can also give hope.[324]

Avery's "Healing before Art" illuminated an area that was very much taboo and contributed to the effort to make education around HIV prevention possible. Although Avery does not identify as a political artist and did not explicitly seek to challenge or change power structures,[325] his art did work to demystify the processes around

[324] Eric Avery. "DocArt.com - The Art and Medicine of Eric Avery, M.D. - Political Prints and Paper Making." DocArt. Accessed March 10, 2018. http://docart.com/bibliography/politicalprints.html.

[325] Email communication with Eric Avery, MD on January 31, 2018.

HIV/AIDS. Avery worked to create a new space for art and medicine and continues to create art to educate but also to transform individual ideas and perceptions. Indeed, it is these interventions that lead to larger social change.

SEEKING CHANGE ONE INDIVIDUAL AT A TIME

The visual advocacy of AIDS activism artwork extends beyond installations, paintings, plays, and prints to include the widespread distribution of educational comics. In the 1980s, AIDS comics emerged as a method for educating broad populations on prevention and symptoms of HIV/AIDS through pamphlets and comic books.[326] Generally focused on education, these mass produced works were meant to reach as many people as possible in an effort to spread information on the etiology of the disease, focusing on the way it spread, its symptoms, and how it might be prevented. AIDS comics were sometimes targeted at particular populations to educate and encourage preventative behavior. For example, *SIDA No Se Quita (*"AIDS, Once You Get It, It Doesn't Go Away") a comic aimed at Latinos, was created by Adriana Batista of the Gay and Lesbian Services Center of Orange County, California along with four Mexican artists[327] The comic used humor throughout to satirize cultural taboos about sex while also providing important information about the disease, local resources, tips for safe sex, and free coupons for HIV testing.[328] During a time when HIV/AIDS was largely ignored, the creation of comics that not only acknowledged non-normative sexual practices but also offered information on safe ways to engage in those practices was indeed a radical

[326] Maury Forman and David Horsey, eds. *Cartooning AIDS Around the World*. First Edition edition. (Dubuque, Iowa: Kendall Hunt Pub Co, 1992).

[327] "California: AIDS Comic Book Aims to Reach Tough Audience." TheBody.com. Accessed February 1, 2018. http://www.thebody.com/content/art21444.html.

[328] Ibid.

act. Gay individuals were let go through the inaction and silence that were the dominant responses to HIV/AIDS. The very existence of these comics communicated that these lives were worth protecting while also communicating some acceptance of the sexual practices that were otherwise portrayed as deviant. The medium of comics offered an accessible way to disseminate information to both targeted and general populations.

Comics have long been utilized to educate populations on taboo and stigmatized subjects through small press or self-published comics known as Underground Comix.[329] Underground Comix first appeared during the turbulent 1960s in the US with the 1968 with the publication of the first *Zap* comic by Robert Crumb. Crumb's first issue of *Zap* initiated an explosion of small press and self-published comics covering an array of counter-cultural, taboo, and satirical topics.[330] Many of these early works included incredibly sexist and misogynistic depictions of women. In response, two groups of California women cartoonists "reacted against the sexist treatment of women in underground comix by deciding to produce a comic that would deal with real female sexuality."[331] The first comic in this genre was created by Joyce Farmer and Lyn Chevely (who used the pseudonym "Chin Lyvely"). The first issue of their underground comix *Tits and Clits*[332] published in 1972. The other group consisted of ten women cartoonists

[329] Patrick Rosenkranz, *Rebel Visions: The Underground Comix Revolution.* Reprint edition. (Seattle, WA: Fantagraphics Books, 2008).

[330] Ibid.

[331] Trina Robbins, *From Girls to Grrlz : A History of Women's Comics from Teens to Zines.* First Edition edition. (San Francisco, CA: Chronicle Books, 1999), 88.

[332] Although *Tits and Clits* was created as a critique of the misogynistic comics of the time, its visual satire was sometimes thought to be perpetuating the objectification of women and at times accused of being pornographic. This seems partly the result of the critiques being subtle with the imagery similar to some of that in the Underground Comix they were critiquing. The name was intended to be a subversion of the focus on "tits and ass" of these earlier underground comix. This subversion was not always recognized with some feminists groups taking offense to the work. See Robbins, *From Girls to Grrrlz.* Despite these

in San Francisco who formed the Wimmen's Comics Collective. The first issue of their *Wimmen's Comix was* published just three weeks after *Tits and Clits*.[333] The comics created by both of these collectives were intended for adult consumption. According to Farmer, the idea for *Tits and Clits* "was to do something radical based on 'sex from a woman's point of view.' This meant talking about birth control, abortion, menstrual blood, odors, wet spots, men…"[334] Indeed, each comic cultivated space to share narratives of sexual and female embodiment that were not welcomed in the mainstream. These comics continued to be produced for over a decade and became a space for women to share experiences and imaginings on menstruation, rape, abortion, mothering, sexual experiences and fantasies. These works rejected the notion that sexual pleasure and desire are masculine traits and instead cultivated a space for female sexual pleasure to be normalized. These comics challenged the injustice of narratives that frame women as passive virgins or sexual objects and instead offered a space for the rich exploration and celebration of women's bodies and pleasure.

Part of the effectiveness of comics is their ability to share complex experiences and stories in a concise manner. This can be illustrated with another AIDS-focused comic, *AIDS News* a comic produced by the People of Color Against AIDS Network (POCAAN).[335] As noted in its introduction, this comic sought to challenge assumptions and educate its readers on AIDS while also working to humanize those with HIV/AIDS:

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shortcomings, the comic did provide a space for women to convey the thoughts and experiences that were silence in other forums.

[333] Robbins, *From Girls to Grrrlz*, 88-90

[334] Joyce Farmer, "Introduction," in *Not Your Mother's Meatloaf , Miller, Saiya, and Liza Bley. Not Your Mother's Meatloaf: A Sex Education Comic Book. (*Berkeley, CA: Soft Skull Press, 2013), 7.

[335] Leonard Rifas and Mark Campos. *AIDS NEWS.* First Edition edition. (Seattle, WA: People of Color Against AIDS Network, 1988).

> This comic book is designed for you and your friends to get information about AIDS, to use in educating each other and the adults in your lives. It is crucial that you have the facts. Only you can decide for yourself what to do. We all need the ability to respond to this disease without hysteria and blaming, to work together to care for people with AIDS, and to protect ourselves and our loved ones from this fatal disease. We hope this book will help.[336]

The comic not only provided valuable public health and information about HIV/AIDS, but importantly, it stated what needed to be said: that those with AIDS deserved care just as any other patient. *AIDS News* reinforced this message in its pages through simple images showing the newly diagnosed being embraced instead of shunned.[337]

AIDS art activism, like all the works discussed above, engaged in the radical act of saying that those living with and dying from AIDS matter, are loved, and deserve help, challenging and revising the embedded structure that asserted AIDS patients were deserving of their illness. They all focus on changing ideas and, as Modrizadeh notes, "Social change happens when ideas change, and ideas change when education prepares the ground for new ideas to take root."[338] It was through reshaping understandings and ideas about HIV/AIDS that these varied kinds of art engagements worked toward social change.

ILLUMINATING INJUSTICE

Art activism functions as a lens that illuminates new ways of seeing, thus facilitating discussions around injustice. The work of Chilean artist Alfredo Jaar demonstrates the ways in which art can spark conversations about injustice and challenge

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[336] Ibid., np.

[337] Ibid., np.

[338] Leyla Modirzadeh, "Documentary Theater in Education: Empathy Building as a Tool for Social Change," in *Culturally Relevant Arts Education for Social Justice: A Way Out of No Way*. Hanley, Mary Stone, Gilda L. Sheppard, George W. Noblit, and Thomas Barone, eds. 1 edition. (New York, NY: Routledge, 2013), 56.

the logic of letting individuals and communities go. Jaar's work explores the politics of images and manipulates representation to evoke different ways of thinking about atrocities. His work examines situations where individuals or communities have been let go, and allowed to let die. Trained as an architect and as a filmmaker, he identifies as an architect making art.[339] Jaar's work is conceptually driven and is focused on responding to a real life event. His work retells the stories that have been willfully generally ignored if they had even been previously told at all. He does not work in one specific medium, but instead chooses one based on the ideas that inform the work: "The medium I use is the one that I feel speaks the better for the ideas I'm working with."[340] His training as an architect is integral to his work as space becomes an essential part of his projects. He seeks to discover the essence of his idea and the exhibition space in order to merge the two in the final work.[341] His goal is to balance the information and ideas he wishes to communicate with poetry to create art.[342] The resulting installations are both thought-provoking and engaging, challenging viewers to consider their own complicity within the injustices that inspire his work.

His series *Untitled (Newsweek)* 1994 exemplifies this form of activist art.[343] In this work, he pairs the visual image of seventeen Newsweek magazine covers with captions describing the genocide occurring in Rwanda at the time each issue was

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[339] "Alfredo Jaar in," Art21, Accessed January 25, 2018, https://art21.org/watch/art-in-the-twenty-first-century/s4/alfredo-jaar-in-protest-segment/.

[340] vogueitalia. "Focus on: Alfredo Jaar," November 28, ,2013, Accessed January 25, 2018, https://www.youtube.com/watch?v=EjvRtNPVzgs.

[341] "Alfredo Jaar in." Art21. Accessed January 25, 2018. https://art21.org/watch/art-in-the-twenty-first-century/s4/alfredo-jaar-in-protest-segment/.

[342] vogueitalia. "Focus on: Alfredo Jaar," November 28, ,2013, Accessed January 25, 2018, https://www.youtube.com/watch?v=EjvRtNPVzgs.

[343] David Levi Strauss, Ben Okri, and Alfredo Jaar. *Let There Be Light: The Rwanda Project 1994–1998,* New York, NY: Actar, 1998.

published. The captions also track the rising death count in Rwanda during this time period. The series culminates in the first *Newsweek* issue to depict the genocide on its cover, which is also the only photographic representation of the Rwandan genocide in the piece. In this work, Jaar uses text to direct viewers to that which is invisible and ignored, seeking to evoke knowing through imaginative engagement with his work. His work constructs emotional responses that result from the narratives he constructs with his art. He does not explicitly state the narrative he seeks to convey but instead constructs art that causes his viewer to connect his images and text through their own imaginative work. The lack of visual representation of the genocide and the inclusion of written descriptions is what evokes questions of apathy and complicity. In juxtaposing them against news being reported the viewer is engaging with the descriptions of the genocide in relation to what this news publication deemed important to report. This technique not only allows for the complicity of the media to be revealed, but it also causes viewers to relate the content in the descriptions with the content of the images. Through writing descriptions of the events, Jaar constructs a dialogue between the events in Rwanda and the response of the Western media. As Jaar notes, it illuminates the "visual climate that allows not only for *Newsweek* to do this but for the genocide to happen because it's a general indifference."[344] The pairing of image and text results with the viewer being confronted with the narrative of the complicity of American media, and populace, who largely ignored the genocide in Rwanda.

Jaar is expert at constructing series and installations that shift the perspective of

[344] vogueitalia. "Focus on: Alfredo Jaar," November 28, ,2013, Accessed January 25, 2018, https://www.youtube.com/watch?v=EjvRtNPVzgs.

the viewer to enable a new way of seeing a situation. He does this again with his work *Real Pictures*[345] (1995), which requires that viewers "see" the images by using their imagination and in doing so questions the need for the visual representation of the photograph. Jaar recognizes that photographs of trauma and atrocities can function more as spectacles that isolate viewers through illusions of connection. The image of suffering captured in photograph allows the viewer to connect to individuals with whom they remain physically distant from—to see them— but, on the other hand, they also isolate the viewer from the experience of the subject depicted in the photograph. According to Jay Prosser,

> Photography is not innocent of but can be a part of atrocity and is sometimes. . . responsible for producing photography as spectacle. . . the photographing of atrocity always involves an ethical crisis of representation.[346]

Jaar responds to this threat by removing the photograph from view and replacing it with the call to imaginatively engage with the content of the images. In the installation, Jaar has stacks of photo boxes that form monument-like structures. In each black box there is an image from the genocide in Rwanda that is hidden from view. Written on each box is the description of the image that box contains. Jaar invites the audience to see in a different way:

> …I'm inviting the audience to see but to see with their imagination by reading these texts hoping that they will see them better the logic is that when we shown these images in 94 no one saw them… because no one acted. So now this is a reverse logic it is to suggest that perhaps now you will see them better."[347]

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[345] Strauss et al., *Let There Be Light*

[346] Jay Prosser, introduction to *Picturing Atrocity: Photography in Crisis,* eds. Geoffrey Batchen, Mick Gidley, Nancy K. Miller, and Jay Prosser, (London, UK: Reaktion Books, 2012), 9

[347] vogueitalia. "Focus on: Alfredo Jaar," November 28, ,2013, Accessed January 25, 2018, https://www.youtube.com/watch?v=EjvRtNPVzgs.

His works seeks again to resist objectifying the people and events he documents through presenting the content in a unique manner.

For his process, Jaar begins with an event, often an horrific one, and, using physical space and various artistic mediums, he shares ideas and perspectives about that situation with his audience. His work rejects the logic of letting go and implores his audience to see the event from an alternative perspective and, thus, to broaden the understanding of it. As Jaar asserts, "I will not act in the world before understanding the world."[348] Activist artists seek to understand the world and then to communicate through art. Activism art extends beyond the individual artist and can also be a powerful process for educating audiences regarding issues of social justice through curricular interventions.

ART ACTIVISM CURRICULA

The practice of educating through arts activism curriculum is a diverse and growing area. In arts activism educational programs, students learn to look more closely at the world around them and learn to see the connections between their own experiences and the larger social systems within which they exist. These programs utilize arts integration as part of a process of educating learners to think and see in a different way by incorporating art to teach non-art concepts or lessons. As Hanley notes, "Arts integration involves the use of the arts to teach and learn non-arts subjects; the best form of arts integration involves learning and using the elements of the arts, as well as the pedagogy of non arts subjects."[349] Arts activism theory and framings have the potential to

[348] Alfredo Jaar. "Alfredo Jaar: The Garden of Good and Evil." Accessed March 10, 2018. https://ysp.org.uk/exhibitions/alfredo-jaar.

[349] Mary Stone Hanley, introduction to *Culturally Relevant Arts Education for Social Justice: A*

move beyond awareness to action. "By bringing question to that which has been taken-for-granted… it unveils injustice or brings attention to what was previously hidden can be particularly powerful…"[350] It reveals the injustices, which is a necessary part of working towards social justice.

Arts activism curricula utilize reflection and critical engagement with social context in order to practice "the interrogation of everyday lived experiences"[351] through art practice. The resulting works disrupt what has been normalized with art becoming "an entryway into encountering and articulating alternative experiences and thus conceiving of alternative realities."[352] Such alternate realities are important because they counter the dominant narratives that pervade healthcare education and practice. Dominant narratives are unified theories of how things work that contain assumptions that can work to reinforce oppression.[353] These narratives can constrain our understanding of the world if there is just one dominant narrative that shapes meaning. Art becomes a valuable mechanism for communicating the stories that have been rendered invisible. Within healthcare education, it is vital to educate learners on the injustices hidden, and sometimes not so hidden, in the healthcare system. As previously noted, healthcare education does not attend enough to the complexities that influence healthcare and patient experience. As Kinsella notes, "more attention to the inner lives, the human dimensions,

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Way Out of No Way. eds. Mary Stone Hanley et. al., (New York, NY: Routledge, 2013), 7-8.

[350] Elizabeth Anne Kinsella, "Educating Socially-Responsible Practitioners: What Can the Literary Arts Offer Health Professional Education?" in eds. Darlene E. Clover and Joyce Stalker, Reprint edition. Leicester, UK: NIACE, 2007), 49.

[351] Stephanie M. Anderson, "Editing Lives: The Justice of Recognition through Documentary Film Production," in *Culturally Relevant Arts Education for Social Justice: A Way Out of No Way,* eds. Mary Stone Hanley, et al., (New York, NY: Routledge, 2013): 111.

[352] Ibid.

[353] Lindemann, *Damaged Identities, Narrative Repair.*

and the taken-for-granted social, political, economic, discursive, and cultural dimensions is warranted in health professional education."[354] Arts activism curricula for healthcare students has the potential to teach that there is not only one response to illness and disease, that there is not only one way to structure the distribution, access, availability and uptake of health risks and health resources—that there is not just one way to live.[355] Arts activism theory and pedagogy can assist in helping healthcare learners to make sense of the inequities around them. The need to make sense of the political and social influences on health and healthcare is never so pressing as it is today. The current administration has made it no secret that they want to gut healthcare reform and reverse the access so many have gained under the ACA. At the free clinic, students are exposed to the human dimensions of medicine and the inner lives of their patients. Students need curricular interventions to better prepare them to respond to the stories they hear because failing to attend to the social situations of their patients can result in compromised care.

In arts activism curricula, students are provided the scaffolding they need to create artworks that "question, challenge, and strive to directly influence existing conditions of inequality and other injustice by engaging various communities in social transformation."[356] This is achieved by educating learners not only about injustice on an individual level but also its connections to the systems and structures that form them.

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[354] Kinsella, "Educating socially-responsible practitioners," 50.

[355] Yael Harlap and Hector Aristizabal, "Using Theater To Promote Social Justice in Communities," in *Culturally Relevant Arts Education for Social Justice: A Way out of No Way*, eds. Mary Stone Hanley, George W. Noblit, Gilda L. Sheppard, Tom Barone, and Lee Anne Bell (New York, NY: Routledge, 2013), 30.

[356] Dewhurst, *Social Justice Art,* 2.

THE PRACTICE OF ARTS ACTIVISM CURRICULUM

Arts activism starts with an inquiry, a curiosity. Alfredo Jaar asserts that

> …artists are thinkers, they're intellectuals and art is about thinking. For me, art is about 99% thinking and 1% making. So I spend most of my time and I ask my students to spend about 99% of their time thinking. It is about a situation, it's about the analysis of a situation, and about articulating the ideas that we want to share with the audience about the situation. And it's about *how* we want to say. It's about *what* we want to say.[357]

Arts activism curriculum starts in the same way, but with additional guidance. Educators support students as they seek to make sense of the world around them through art. Educators do not lecture but instead facilitate discussion through inquiry-based questions that evoke open-ended dialog. These questions are student-driven with faculty's role focused on guiding students through the rich process of examination and critical engagement. Arts educator Marit Dewhurst provides an in-depth explanation of an social justice art education program for high school students at a contemporary art museum in New York City. The program's "classes included a series of small studio activities integrated with in-depth conversations about modern and contemporary art and all led up to a student-driven final project to be exhibited in a culminating show."[358] The course, as many arts activism programs, included reflective practice, discussions, art workshops and time for art practice, student research, and the creation of a final project.

For their final projects, student were asked to select a topic of focus to which they felt a connection. The connection to the topic is a vital part of activist art as it is the connection that nurtures the desire to create. As Dewhurst asserts:

Foundational connections are the critical first step of making activist art.

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[357] vogueitalia. "Focus on: Alfredo Jaar," November 28, ,2013, Accessed January 25, 2018, https://www.youtube.com/watch?v=EjvRtNPVzgs.

[358] Dewhurst, *Social Justice Art,* 21.

> In locating their desire to make a work of art within their own experiences, passions, and commitments, the youth artists articulated personally meaningful rationales for their work. These connections were reminiscent of the reflection described by many practitioners as key to effective activist art-making as well as social justice education.[359]

Students explored their connections to the project through reflective practice. Students kept a journal of their written reflections on the situation they focused on and the process of making art. Learners also used these journals to record any visual evidence or imagery related to their topic.[360] Students would also use the journal to document the research they conducted to gain a broader understanding of the multitude of perspectives regarding their topic. Throughout the course the students learn art-making techniques and research their topic to expand their understanding from the micro to the macro components of it. The course culminates with the creation of a final project that is not only art but is also activism.

The process of creation and idea development was not solitary; instead, the facilitators led participants in discussions to enable them to learn with and from one another. The facilitators worked to cultivate a collaborative atmosphere and worked to reject hierarchies common in classroom settings— hierarchies that position the teacher as expert and student as subordinate and an empty vessel to be filled with the knowledge of the teacher. Arts activism curricula are designed to focus on process and seek to cultivate a more humane educational process:

> If we had one word to encapsulate the learning process, it would be *humane.* Many forces, including standardization in education, press us to dehumanize ourselves and each other. Our process of learning with and from each other models an education that serves a humanizing impulse . . . when it is done well, also serves that impulse."[361]

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[359] Ibid., 39.
[360] Ibid., 24.
[361] Harlap and Aristizabal, "Using Theater," 33.

In contrast to the dehumanizing structures that pervade education, and healthcare education, "A 'humanizing pedagogy[362]' treats teachers and students not as objects incapable of their own decision-making, but instead as subjects who can act as agents of change."[363] Teachers must work to create classrooms that are spaces of creating community rather than places that work to dehumanize students. There is a spirit of collaboration rather of competition and the building of meaningful community.

COMMUNITY THROUGH ART

One major benefit of the arts curriculum is that it creates spaces for students to learn about and explore complex issues together. By their very nature, art workshops build community through the bringing together of the participants. Communal learning and engagement interventions not only bring participants together, but also provide a space in which connections can be revealed. Because indeed it is: "Finding out what connects us, reveling in our differences; this is the process that brings us closer, that gives us a world of shared values, of meaningful community."[364] While teaching the Comics and Medicine Minimester course at UTMB we saw these forming connections firsthand. We asked students to read comics about healthcare experiences and practice, while also making comics reflecting on their own experiences and concerns. These exercises informed rich discussions that emerged both during formal discussion as well as during time allotted for art-making. This bringing together enabled participants to not only learn

[362]Lilia Bartolomé. "Beyond the Methods Fetish: Towards a Humanizing Pedagogy." Harvard Educational Review 64, no. 2 (July 1994), 173-195.

[363] Keith Catone, *The Pedagogy of Teacher Activism: Portraits of Four Teachers for Justice.* (New York, NY: Peter Lang Inc., International Academic Publishers, 2016), 17.

[364] bell hooks, *Teaching Community: A Pedagogy of Hope.* 1 edition. (New York, NY: Routledge, 2003), 197.

from the materials and instructor but also from each other. The connections occurred on two levels: first, between students who shared experiences and insights building connections where competition had been more encouraged previously, and second, between the scientific study of disease and the human dimensions of illness as depicted in comics.

The shared community of communal art-making can result in new insights and understanding through the sharing of experiences. Through gaining a more nuanced understanding of injustices students can begin to make connections between the structural and systemic forces that shape individual experience. Upon gaining this deeper understanding, learners are better equipped to start engaging in what Tom Borrup and Robert McNulty termed creative community building which:

> … describes efforts to weave multiple endeavors and professions into the never-ending work of building and rebuilding the social, civic, physical, economic, and spiritual fabrics of communities. Creative community building engages the cultural and creative energies inherent in every person and every place.[365]

Students in arts activism are gaining new understandings of the world around them and, just as Jaar's and Avery's work seek to transform the way the audiences see and engage with an issue, students are being taught to see differently through conscientization in order to rebuild that world.

CONSCIENTIZATION

Arts activism creates spaces where students learn to look past their individual experiences and observations in order to see the bigger picture. Arts activism curricula

[365] Tom Borrup and Robert McNulty. *The Creative Community Builder's Handbook: How to Transform Communities Using Local Assets, Arts, and Culture.* (Saint Paul, MN: Fieldstone Alliance, 2006), xv.

focus on training learners to see the world in a different way and to critically examine the ways that systems and institutions are unjust and cause harm to individuals. The process embedded within art activism curricula illuminate the interplay between structural forces and individual experiences. In effect this curricula function as a method of consciousness-raising, or what Freire called conscientization.[366] Conscientization helps to cultivate critical thinking through educating learners to question the world within which they live and work. As Dewhurst clarifies:

> Through conscientization, learners develop the ability to ask questions of themselves and the systems surrounding them. They learn to ask why and to reflect on the many possible answers to a single question. They learn to look closely at their own realities, to see their own experiences as part of a larger social network. From this new and multifaceted view of the world, critical pedagogy suggests that young people can then begin to see how the world can be altered or re-created into a more just and equitable world. With this transformed awareness of oneself and one's society, one is no longer an object of the world, but rather, an active agent, capable of enacting change.[367]

The hope is that by illuminating these connections through art practice, students will also learn to see their relationship to the world around them and their own potential for enacting change. Without critical consciousness of the inequalities present in our society, those inequalities will never be questioned nor challenged.

Without a critical consciousness of the dominator framework in which our society functions, students are unable to question the forces causing the oppression. In her work, *Education as a Practice of Freedom,* bell hooks argues that in order to tackle inequality present in education, and our society at large, students must gain a critical consciousness

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[366] Freire, Paulo, and Donaldo Macedo. *Pedagogy of the Oppressed, 30th Anniversary Edition.* Translated by Myra Bergman Ramos. (New York, NY: Bloomsbury Academic, 2000).

[367] Dewhurst, *Social Justice Art,* 9.

about the way dominator thinking shapes what we know.[368] Dominator culture's influence on the healthcare education strengthens inequalities present in healthcare education and practice. More and more healthcare learners are trained to follow a system instead of thinking creatively. Possessing greater critical consciousness causes students to be less likely to support ideologies of domination,[369] and works to motivate opposition to these ideologies. We must work towards transforming the current education model from focusing on a regurgitation of facts to one that works to promote critical thinking.[370] This is never so evident as with the importance medical education places on standardized test scores. Students lose sight of their purpose and instead focus on the numbers alone. Throughout my time working with medical students I have heard the common phrase "I'm studying STEP."[371] When students make this assertion, they have disconnected the required board exam from the practice of medicine. It has become fragmented from the purpose of the exam—to demonstrate that one has mastered a sufficient level of knowledge in order to progress in medical school.

Outcomes-focused educational practices diminish medical students' ability to engage with topics and content that do not have direct relationship to the tests they are required to pass in order to move forward in their training. I emphasize medical students because of the ways that the numeric score has come to function as a gate in which students believe they can access their desired futures only through high exam scores. While STEP was originally intended to function as a pass/fail exam to ensure a basic

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[368] cf hooks, bell. *Teaching to Transgress: Education as the Practice of Freedom.* (New York, NY: Routledge, 1994), 2.

[369] hooks, *Teaching Community,* 8

[370] Ibid., 8.

[371] Medical students have required board exams they must complete in order to advance in their training. The first one, STEP One, is taken the summer before the third year of medical school.

competency of knowledge, it has shifted to be used to distinguish applicants for competitive specialties. When learners focus on test scores they can lose sight of the original motivation to pursue a career in medicine. Arts in healthcare curriculum that emphasizes that focuses on the artwork that is produced without attending to the process of creation can reinforce this problematic, neoliberal framework. In arts activism there is a shift away from the common focus on the final art product that renders the process invisible. Instead, activism art is "process- rather than object- or product-oriented, and it usually takes place in public sites rather than within the context of art-world venues."[372] Indeed, activism art seeks to resist a system that favors product over people. The intentional cultivation of a space where process is privileged over product, allows for students "to fully immerse themselves in the art of learning"[373] Students and teachers must focus on education as an experience rather than a task to be completed. The focus on process and the freedom from goal-oriented approaches allows for creative exploration outside the dictates of a system. "It leaves us free to imagine, question and continually strive for development and transformations towards social justice." Education is about more than just learning facts in order to get a job; it is about working towards healing, wholeness, and empowerment.[374]

ACTIVISM AND SOCIAL THEORY

One reason these programs are so effective at moving arts practice outside the individual focus and to the system influences is because art activism pedagogy is heavily informed by the work and ideas of critical social theorists. Critical social theory "…does

[372] Felshin, *But Is It Art?*, 10.
[373] cf, hooks, *Teaching Community,* 166
[374] Ibid., 42.

not promote theory for theory's sake… but encourages the production and application of theory as part of the overall search for transformative knowledge."[375] Arts activism curriculum links theory to the active practice of making art to affect social change:

> Using the arts to understand and explore resistance is a more powerful force for transformation because of the regenerative properties, the subjunctive action, the imagination, and the visioning process for creating the future. The coupling of the analytical and transformative aspects of art and art making is an important way to move through the pain while holding out hope and light.[376]

Idealistic students may start their education thinking they will help all those in need but throughout their training they learn the subtle acceptance of the injustices of the healthcare system. It would be easy to classify the providers who are complicit in this system as monsters, but to do so would render the logic that makes such actions as conceivable as invisible. The attempt to reveal this logic is important in order to better understand how such exclusion becomes normalized. When students enter into the practice of medicine they can experience the moral shock from their introduction to the logic of letting go. Jasper (1997) describes 'moral shocks' as:

> …an unexpected event or piece of information [that] raises such a sense of outrage in a person that she becomes inclined toward political action…The information or event helps a person think about her basic values and how the world diverges from them in some important way. Such individuals often search out political organizations themselves, without waiting for recruiters to contact them.[377]

There are moral shocks experienced in healthcare education when students are made aware of the brokenness of the healthcare system through witnessing the harm it causes to

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[375] Leonardo, "Critical Social Theory and Transformative Knowledge," 11.

[376] Lee Anne Bell, Dipti Desai, and Kayhan Irani, "Storytelling for Social Justice: Creating Arts-Based Counterstories to Resist Racism" in *Culturally Relevant Arts Education for Social Justice: A Way Out of No Wa*y. eds. Mary Stone Hanley et al., 1 edition. (New York, NY: Routledge, 2013), 22-23.

[377] James M. Jasper, *The Art of Moral Protest: Culture, Biography, and Creativity in Social Movements.* (Chicago, IL: University of Chicago Press), 2008, 106.

patients. I have seen this among the clinical students at UTMB who learn of the realities of the logic of letting go while volunteering at St. Vincent's and as a result become more involved. This sentiment has presented itself again and again each year as a new group of directors begins their term.

There is not one singular response to moral shocks as Jasper points out: "Most people, in most cases, resign themselves to unpleasant changes…"[378] Within healthcare settings learners may experience moral shock when discovering one's ability to help is greatly incapacitated due to system barriers. This can result in apathy, loss of compassion, and/or harmful coping mechanisms such as alcohol abuse or becoming a dehumanizer of patients. This can be further exacerbated when learners have mentors who explain away the structural harms through a narrative of personal responsibility. But for some these moral shocks will be sparks to create activist healers. Arts activism framings and pedagogy have the potential to fill the gaps of arts in healthcare education and programs.

CONCLUSION

The structure of medicine can be destructive to both clinicians and patients. Clinicians are not well-prepared for the exclusionary practices of medicine that prevent individuals from accessing needed healthcare services—structures that also prevent clinicians from providing that care. When opportunities for arts-activism informed art making are made possible for students and clinicians, a different way of knowing and healing is facilitated through this making. Art engages individuals in alternative kinds of thinking and has the potential to cultivate an experiential space of being-present with

[378] Ibid., 106.

one's own experience while also making visible the larger structures that shape and contort those experiences. It can foster new ways of seeing and experiencing patients, to process traumatic events in clinical spaces, and to cultivate sensitivity towards patients and their social contexts. Given early enough in their education, art practice can also allow for students to learn ways of making sense of the complex and sometimes contradictory lessons they learn through direct education and the hidden curriculum that pervades their education. In this education they will become regular witnesses to the broad range of suffering that results from the structural harms of medicine, but art activism allows for a way out of this suffering and assists participants in the long process of beginning:

> …to see how the world can be altered or re-created into a more just and equitable world. With this transformed awareness of oneself and one's society, one is no longer an object of the world, but rather, an active agent, capable of enacting change.[379]

Art creation helps to hold the harms to which healthcare clinicians and students must bear witness everyday. Through art creation, healthcare providers and students can gain understanding of the systems of domination that let people go from healthcare while the explore paths of resistance. It is through working towards community in education that we can collaborate towards building a better practice of medicine. The space of the student-run free clinic is an ideal starting point to develop arts-based social justice curricula for healthcare students.

[379] Ibid.

Chapter 6 Learning 'Healthcaring' in a Student-Run Free Clinic—a Model Curriculum

> I don't think there's any other reason we have art than to save us, the way our liver is there to keep us alive. I have come to regard the arts as external organs. They have always been as critical to me as my kidneys are. It's like a dialysis machine you draw yourself.
>
> -Lynda Barry

Creativity is fundamental to human experience and, as argued in the previous chapters, constitutes a powerful method for engaging providers in social justice practice. Through an art activism curriculum, healthcare learners can practice resisting the logic of letting go and injustices that persist in the US healthcare system. This final chapter presents a model for an arts-activism-informed, arts-based workshop curriculum for St. Vincent's student-run free clinic. I begin with an outline of the curriculum and then theorize and discuss the interdisciplinary elements and approaches that compose the workshop series as I present it. The curriculum I present is informed by the arts in health care literature and modeled after arts activist frameworks. It is designed to educate the student directors[380] of St. Vincent's and enhance their ability to better understand and respond to the injustices in the healthcare system and to improve the quality of care they provide for their patients. I selected St. Vincent's as the site for this project because of the social justice work that is already being done in that space, and because there is a need for learners to gain consciousness of this work. At the end of this chapter I discuss ways

[380] These include medical, nursing, physician assistant, graduate, and clinical laboratory science students who have been elected to the position of student director. These individuals help run and manage the clinic and serve as mentors to other students in the clinic.

the curriculum can be adapted for other healthcare educational settings and important qualities of the workshop facilitators. In their everyday practice of caring for patients, at least some of the time, student leaders challenge the injustices of the US healthcare system. This curriculum aims to expand that practice through educating and engaging students in intentional resistance to those harms built into the healthcare system.

CURRICULUM SYLLABUS

Holding On Through Art Curriculum (HOTAC)
St. Vincent's Leadership Workshop Series

Course Description:
The workshop series aims to collaboratively explore what it means to provide healthcare in a system filled with gaps. HOTAC guides St. Vincent's student directors in individual reflection, structural consideration, and collaboration and shared meaning-making with an ultimate emphasis on seeking change. Three workshops will be offered throughout the course of the student directorship, which lasts one year. The first workshop is incorporated as part of the director transition meeting and focuses on giving students a space to reflect on what brought them to the clinic. The second workshop focuses on examining the structural violence in healthcare and the ways it affects St. Vincent's. The final workshop focuses on imagining what justice would look like in healthcare and the everyday strategies to get there. In between workshops students will be given readings and reflective writing prompts to complete. Collaborative practice will be woven throughout the workshops.

Course Goals:
This course is designed to reconnect participants with creative expression while also providing a space for students to reflect on the complex experiences of healthcare. A major focus of this course is to expand the student's knowledge about the structural forces that constrain and shape the healthcare system, practice of medicine, and patients' health via an introduction to core concepts and contributions of the medical humanities. One main goal of the series is to cultivate awareness of structural violence through creativity, so that student leaders can respond to such injustices.

Learning Objectives:
Upon successful completion of this course, students will:

1. Expand practice and proficiency in critical thinking, writing, and reading through lectures, class discussions, and written assignments.
2. Increase understanding of the structural forces that influence healthcare access and shape clinical encounters.
3. Question and critique current medical practices and imagine how they might be

transformed and enhanced.

Required Readings:
All required readings will be provided at the transition meeting. Sharing these readings with students outside the leadership group is encouraged.

Attendance and Participation:
Attendance is an expectation as part of the role of director. Students who are unable to attend due to scheduling conflicts are still expected to participate in all other elements of the curriculum. It is expected that you will have read the assigned texts before the workshop. Additional reading groups are encouraged, as is including individuals who are not directors but are interested in participating in discussions.

Reflective Writing:
Reflective writing is an integral part of HOTAC. For three of the course meetings, students will be given a reflection question or prompt, and will be expected to write a brief one page response. Prompts will be designed to elicit students' personal interpretation and/or reactions to specific elements of the readings, not their recollection of content.

Projects and Artist Statements:
During the three workshops participants will create original works of art informed by the contents and themes studied and discussed in HOTAC. Both individual and collaborative art will be created. All art projects are created during the workshop with opportunities for students to make art outside of the three workshops. St. Vincent's leaders have the opportunity to display their art projects during the annual clinic benefit concert along with artist statements crafted from the reflective writing completed throughout the course. Interested individuals can have their art included as part of a "zine," a self-published mini-magazine,[381] that will be sold at the clinic's annual fundraising concert.

Workshop Schedule/Outline

<u>Transition Meeting Workshop (March):</u>
History and Present Free Clinic Practice: reLearning Creative Expression
1.5–2 hours

General Description
This workshop is incorporated as part of the transition meeting. The workshop begins with a presentation on the history of the free clinic movement identifying where St. Vincent's fits within that movement. Participants will reflect on what it means to be a St. Vincent's leader and why they have been chosen to be a part of the leadership. Finally the creative portion will be introduced with a re-introduction to creativity and introduction to simple art-making techniques.

[381] Todd and Watson. *Whatcha Mean, What's a Zine?*

At the conclusion of this workshop participants will be able to:

1. Articulate a general history of the free clinic movement
2. Describe the connection between the free clinic movement and the present practice at St. Vincent's
3. Practice simple printmaking techniques
4. Share their motivations and hopes (via art) for their roles as student leaders

Workshop Outline:

1. Introduction (5 min)
2. Presentation on history of the free clinic movement and the history of St. Vincent's followed by discussion (25 mins)
3. Reflection (10 mins)
4. reLearning Creativity Presentation (10 mins)
5. Activity- Blind Contour Drawing (5 mins)
6. Activity- Foam Relief Printing (20 mins)
7. Story Circle/2-3 sentence artist statement (45 mins)
8. Wrap-up (5 mins)

Assigned Readings:

Ursula Le Guin, "The Ones Who Walk Away from Omelas" in *The winds twelve quarters: short stories.* Toronto: Bantam Books, 1976, 251-259.

Workshop Materials:

1. Blank printer paper
2. Ball point pens
3. Mechanical pencils
4. Water-soluble relief printing ink
5. Print-making paper
6. Printmaking roller (brayer)
7. Styrofoam plates
8. Plastic table mat

<u>Mid-Year Workshop (July):</u>
Witnessing, Understanding, and Responding to Harms in Healthcare
2 hours

General Description
This workshop examines the structural forces that shape the experiences at St. Vincent's. Prior to the workshop students will have read all of the assigned reading and completed monthly reflective writing about their experience working as student leaders. During this workshop, students will have the opportunity to discuss the readings they completed between workshops and the ways in which those readings connect with the experiences they had in the director roles. The art-making will be focused on the creation of comics to

communicate their experiences in clinic as well as to create health education style information sheets for educating volunteers about structural harms in healthcare. Students will also have a "story circle"[382] to discuss their projects.

At the conclusion of this workshop participants will be able to:

1. Describe the concept of structural violence
2. Determine the ways in which structural forces shape and influence healthcare practice
3. Communicate, through comics, the ways in which structural harms shape the experiences and practices at St. Vincent's.

Workshop Outline:

1. Introduction (5 min)
2. Presentation-Structural Harm in Healthcare Practice (15 mins)
3. Comic Jam/Discussion of readings (30 mins)
4. Activity- building comics exercise (10 mins)
5. Activity- Structural Harm at St. Vincent's comic (15 mins)
6. Story Circle (40 mins)
7. Wrap up (5 mins)

Assigned Readings:

Farmer, Paul E., Bruce Nizeye, Sara Stulac, and Salmaan Keshavjee. "Structural Violence and Clinical Medicine." *PLOS Medicine* 3, no. 10 (October 24, 2006): e449. https://doi.org/10.1371/journal.pmed.0030449.

Rachel Pearson. *No Apparent Dis*tress: A Doctor's Coming-of-Age on the Front Lines of American Medicine. New York, NY: Norton, 2017. (Excerpts)

"Sketches from Outside the Margins: Stories from the Seattle/King County Clinic – PUBLIC HEALTH INSIDER." https://publichealthinsider.com/2018/01/18/sketches-from-outside-the-margins-stories-from-the-seattle-king-county-clinic/.

Comic excerpt: Nick Sousanis. *Unflattening.* Cambridge, MA: Harvard University Press, 2015. ("The Fifth Dimension," pp. 3-27, 85-98).

[382] Story circles were a integral part of CEP and proved vital in helping to build community. These consisted of participants sitting in a circle and each taking a turn discussing their projects with other participants responding to what they shared. It was in these circles that students discussed their experiences and were supported by their peers and also where ideas for improving projects were exchanged. The story circle was originally conceived by Joe Lambert, see Joe Lambert, *Digital Storytelling: Capturing Lives, Creating Community.* (New York, NY: Routledge, 2013).

Rachel Garfield, and Anthony Damico. "The Coverage Gap: Uninsured Poor Adults in States That Do Not Expand Medicaid." The Henry J. Kaiser Family Foundation (blog), November 1, 2017. https://www.kff.org/medicaid/issue-brief/the-coverage-gap-uninsured-poor-adults-in-states-that-do-not-expand-medicaid/.

Workshop Materials:

1. Drawing/printer paper, 8x10/16x20
2. Pencils
3. Black felt pens
4. Multicolored Crayons
5. Multicolored Colored pencils
6. Multicolored Markers

End of Year Workshop (February):
Imagining a Better World
2 hours

General Description

The final workshop focuses on looking to a better future. For the workshop participants will engage in brainstorming and discussions focused on imagining a better future of medicine. The students will then be guided through a series of exercises imagining what it would look like for the problems of the clinic to be solved.[383] These exercises will be subsequently repeated with increasing scopes of problems (the problem of one individual to the problems of the clinic to the problems of the hospital to the those the US healthcare system). The exercise invites students to imagine a perfect world to shift their perspective by experiencing that alternate world. Participants are asked to construct a collage image of an imaginative utopia of healthcare and a map for how to get there.

At the conclusion of this workshop participants will be able to:

1. Visualize a better healthcare landscape
2. Identify concrete actions for working towards change in at St. Vincent's
3. Imagine a more just healthcare system

Workshop Outline:

1. Introduction (5 mins)
2. Brief presentation— Seeking Utopia: Justice in Healthcare (5 mins)
3. Individual/small group project brainstorming/sketching (15 mins)
4. Story circle (40 mins)

[383] This exercise is adapted from one outlined in "Lessons from Utopia" by Stephen Duncombe and Steve Lambert. Ibid.

5. Collage making (50 mins)
6. Wrapping up (5 mins)

Questions to Think About:

How do you challenge structural harms through everyday practice?
What does justice in healthcare look like and how will you seek it in your future practice?

Workshop Materials:

1. Blank paper
2. Clippings from magazines and newspapers
3. Colored paper and other scraps
4. Scissors
5. Glue sticks and white glue
6. Paint, colored pencils, crayons
7. Masking tape

Final Art Sharing (March):
Included as part of the Benefit Concert

General Description
Every year in March, St. Vincent's holds a benefit concert showcasing the talent of UTMB and the Galveston communities. The collaborative art pieces will be displayed and students will also have the option to display their original artworks at the benefit concert[384] to share with the event's audience. Such participation is optional so students who feel comfortable sharing their work can do so. Copies of the "zines" created in the first and second workshops will be sold to help raise money for the clinic.

COURSE MATERIALS

In my work re-introducing non-art students to art-making I focus on teaching a practice that can be continued outside of the classroom or workshop. With this in mind, I

[384] No one will be forced to participate in the public display of their work. Displaying the artwork publicly is an optional activity so that only those who are comfortable sharing their art will do so. For the collaborative pieces students will be informed at the start of the project of the plan to display the work at the concert and a general agreement will be obtained that the work should be displayed. When having informal conversations with directors about the display of collaborative work I discovered that the most common response was that it would be a cool idea to have it included. While some expressed concerns about ability it seems that often that is more rooted in the unknown and that once the work has been created there is openness to it. It is vital that individuals are not forced to share their artwork without consent as that would harm their relationship with the process of art-making and therefore compromise the goals of the project.

designed the workshops to use materials that are low in cost and easy to access. The first workshop is focused on a fast and easy method of printmaking that is often utilized with elementary school children. The materials can be purchased from any general art store or online, and many of the items can be improvised from materials found at any big box store or grocery store. There is an intentional effort in the design for these workshops to ensure that participants can continue the practice after the meeting if they so choose. For workshop one, the styrofoam paper can be purchased online at amazon.com[385] with the price ranging between twelve dollars and eighteen dollars for 100 sheets. The bottom of foam paper plates can also be used in place of the foam paper and are easily accessible at most grocery or big box stores. The rubber brayer (ink roller) can be purchased from most art stores either in person or online and it is also available at amazon.com.[386] This runs around ten to fifteen dollars and can be washed and reused. While there is paper specially made for printmaking, I tend to use printer paper (both white and multicolored) for these workshops because it is easily accessible and cheaper than the formal printmaking paper. It can also be easily cut down to fit the foam plates/paper.

The second workshop is focused on making comics and, as previously discussed, comics are a very accessible art form. Part of that accessibility is the inexpensive materials. For the workshop students will be provided crayons, colored pencils, markers, pens, and paper, and will be offered guidance on visual storytelling through comics. All materials other than the larger 16x20 paper are easily found at any drug store, big box store, dollar store or grocery store. The larger paper can be found at many big box stores, art stores, or can be ordered off the internet. More art implements, such as watercolor, paper cutting or ink wash, can be added if desired by the students or if there is an additional interest of the facilitator. In my experience I have given students the

[385] See https://www.amazon.com/gp/product/B0044S89F2/ref=oh_aui_detailpage_o00_s00?ie=UTF8&psc=1

[386] https://www.amazon.com/Speedball-Deluxe-Hard-Rubber-Brayer/dp/B003IFUR9I/ref=sr_1_5?s=arts-crafts&ie=UTF8&qid=1523217595&sr=1-5&keywords=speedball+ink+roller+printmaking

opportunity to request special materials, and, while there have been some who have made requests, the majority of participants have utilized the materials that have been made available to them. Just from my own experience and practice, the students who have been making art more recently request specific art items more often, while those who are re-entering the world of creative expression tend to use the materials made available to them.

The final workshop uses another easily accessible art form of collage. For the magazines and newspapers, these can be collected over time from individuals giving them away or thrift stores. Additionally, prior course materials can be utilized as well as online sources. In past workshops I have also made available string and printed text and photocopied images for students to use. The key for this portion is providing a broad selection for students to choose from while also making participants aware that they are able to bring their own materials to contribute. The glue, tape and scissors can be purchased from the dollar store for very cheap or from any drug store, grocery store or big box store. These materials can be used for multiple years but it is important to make sure the glue is closed tightly to prevent it from drying out. It can also be kept in a sealed bag to further help prevent it from drying out. The goal of all these workshops are to offer accessible art-making exercises for participants. A major part of accessible art exercises is providing accessible materials that are not cost-prohibitive for the workshops nor for participants who want to continue their practice.

FOUNDATIONS FOR THE COURSE

Like those residents in Le Guin's story who leave the city of Omelas after imagining that there must be another way, there are also students who, during the course of healthcare education, leave the traditional training settings to seek spaces to care for patients who the system has let go. This series of workshops, called the Holding On Through Art Curriculum (HOTAC), is designed to facilitate collaborative exploration and

critical reflection on the contemporary US healthcare system to collectively seek interventions to challenge its structural harms and learn more strategies for holding onto those who the system has let go. Arts-engaged workshops offer a unique space to explore these alternative forms of care as well as the structural barriers patients and providers face. Based on spatial theory, structural violence research, and my own experiences, the workshops presented here focus on cultivating participants' creative thinking so as to meaningfully reflect on the injustices that pervade healthcare practice in the US. The workshops are designed to engage students and educate them to be more "social justice-minded," and they are also designed to improve care and services at the clinic.

As I present HOTAC, I outline the reasoning for including each component, articulating the ways it can guide participants to develop and practice the skills and understanding they will need in order to challenge the structural harms of medicine while holding on to the beneficial parts of practice. Although I present a model of arts-based curriculum for the leadership of a St. Vincent's, these workshops can be adapted for other spaces of healthcare practice and training. Throughout this chapter I will offer guidance for ways the curriculum can be adapted for other spaces and settings.

HOTAC is informed and modeled after the curriculum presented by Marit Dewhurst in *Social Justice Art: A Framework for Activist Art Pedagogy*, but caters to the specific context and space of St. Vincent's. The curriculum takes learners on a journey that begins with self-exploration and then guides students to move outside their experience to make sense of the structures that influence the individual. The ultimate goal of the curriculum is to seek change of some sort. As outlined in chapter five, the curriculum is a process of conscientization for the learners who then in turn become

agents of change. HOTAC includes three workshops spaced out over the course of a year and is designed to engage with participants' experiences at the clinic. As with any healthcare setting, there is limited time to complete the work needed to run and manage the clinic, and so the program is designed to fit within the existing structure of St. Vincent's. The target audience for these workshops is the student leadership of St. Vincent's because it is these individuals who set the tone of the clinic. These individuals serve as mentors and educators for all the students who enter this space, and as such it is vital they understand the pervasiveness of structural harms in the healthcare practice and system. These student leaders are often already engaging in social change and challenging structural violence without a clear awareness of it.

Each workshop covers content related to the individual in the clinic and incorporates art-making and discussion to deepen engagement with the structural forces that shape the landscape of healthcare in the US. HOTAC seeks to contextualize and enhance the social justice work already being done at St. Vincent's, and to explore the directors' relationships to their work at the clinic. Participants begin with self-reflection in the first workshop, before shifting to examine the influence of the system in the second workshop, and finally thinking about social justice and change in the third workshop. The HOTAC workshops are designed for fifteen to twenty people — accommodating more than this number can be difficult without making significant adjustments, but having fewer participants is not a problem. One main goal of the series is to cultivate awareness of structural violence through creativity, so that student leaders can respond to such injustices. To do so, this curriculum incorporates four main elements: individual reflection, structural consideration, collaboration/shared meaning-making, and seeking

change.

INDIVIDUAL REFLECTION

This reflective component is incorporated throughout the curriculum, where leaders maintain a digital journal about their experiences and challenges within clinic. This practice was inspired by a director who started a journal in a web-based shared drive that all other directors could access. He began the journal at the start of the 2017 year as a way to share his experiences and the lessons he learned with future directors.[387] As part of the curriculum, the journal is expanded from this original form to include prompts to which students are asked to respond. These begin with prompts asking participants to reflect on their own experiences, as well as those of their patients, to prompts that ask students to expand their consideration to the structural influences on the individual. The journals are maintained on the clinic's shared Google drive allow, which allows directors to read one another's insights while also incorporating it as part of the institutional memory of the clinic. These shared reflections have the potential to be enlightening for future clinic leadership, and serve as a reflective space with the opportunity for collective reflection due to its accessibility for all directors. Students are also given homemade journals[388] at the start of the course for any reflections they would like to keep private.

This portion of the course is greatly informed by what I learned while working on the Creative Expressions Project (CEP) at UTMB, highlighted in chapter four of this dissertation. Reflective writing was central to CEP with students completing weekly

[387] Personal conversation, 2017

[388] These consist of printer paper with a piece of card stock on the outside, folded in half and then stapled together. These are easy and inexpensive to make.

reflection on the online classroom blog. As part of this process, students were given rubrics[389] to assist them in going deeper with their reflections. These rubrics serve as guides to move students from more superficial reflection to a more critical engagement with the content. Indeed:

> …reflection is an integrated learning process with multiple, although non-linear, dimensions . . . [with] the reflection process as having three interrelated stages: return to experience, analysis, and reevaluation in terms of the emotional experiences and resulting reintegration of the outcomes that add to the learner's identity.[390]

The reflective writing component of HOTAC is designed to assist students through the process of reflection and to go deeper in their examinations of the work in which they participate. Student leaders are asked to maintain written reflections throughout their first few months as directors. Students will examine the structural components that shape the individual experiences of the clinic by focusing on a particular problem experienced by patients or providers in the clinic setting. A key component of this curriculum is to provide a space that will allow healthcare providers to process the suffering they witness as well as to develop the tools to deepen their understanding of the complexity of forces and systems that produce the preventable suffering of healthcare.

STRUCTURAL CONSIDERATIONS

When working in a free clinic, students are faced with patients' complex experience of suffering. The suffering witnessed in this space does not solely stem from the material effects of the disease, but also from the human-made harms of the healthcare system rooted in the logic of letting go. It can be emotionally difficult to bear witness to

[389] A copy of this rubric can be found in the Appendix B.

[390] James W. Peltier, Amanda Hay, and William Drago. "The Reflective Learning Continuum: Reflecting on Reflection." *Journal of Marketing Education* 27, no. 3 (December 1, 2005): 252.

the injustice that pervades healthcare practice in the US. At clinic, students meet patients who have not been able to access preventative care and thus present with diseases already in advanced states. Patients who work three jobs may not have health insurance because they work in a system that does not guarantee it, as discussed in chapter one. Healthcare providers are caught in the middle, between patients seeking care and a healthcare system that excludes many of those seeking help and restricts providers' ability to care for their patients. Learners experience harmful effects of not having the tools or resources to cope with such the stressors that result from the structural harms of healthcare, which can result in a higher rate of burnout among care providers.[391] The clinic, therefore, is a vulnerable space that can lead students to adopt the logic of letting go and believe that these individuals do not deserve help, but it is also a space where students can learn how to challenge the logic and the structural forces that support its harms.

As discussed in chapter three, St. Vincent's has a long history as a space of social justice work and thus makes an ideal site for integrating a social-justice inspired arts-based curriculum to challenge harmful logic of biomedically-oriented, neoliberally-structured healthcare. In order to better contextualize the suffering they witness, students will be given readings related to structural harm and the ways in which clinical space has been constructed to shape agency.[392] Students will be asked to forge connections between

[391] See Christina Maslach and Michael P. Leiter, "Early Predictors of Job Burnout and Engagement." *Journal of Applied Psychology* 93, no. 3 (May 2008): 498–512.; Christina Maslach and Michael P. Leiter, "It's Time to Take Action on Burnout." *Burnout Research* 2, no. 1 (March 2015): iv – v.

[392] Students will be given excerpts to read from Nick Sousanis' *Unflattening* along with an article by Paul Farmer and his colleagues on the subject of structural harm in the clinic. Together these works illuminate the ways in which systems and spaces influence the experiences of individuals. See Paul E. Farmer, Bruce Nizeye, Sara Stulac, and Salmaan Keshavjee. "Structural Violence and Clinical Medicine." *PLOS Medicine* 3, no. 10 (October 24, 2006): e449. and Nick Sousanis, *Unflattening.* (Cambridge, MA: Harvard University Press, 2015).

the individual experience and the structural components of the issue they have selected. These connections will be sought through reflective writing, group discussion, and art-making in community.

SHARED MEANING-MAKING AND COLLABORATION

Communal creativity also serves as an important space of reflection. Providing space for creativity, and access to art-making, has the potential to allow health care providers to reflect upon their experiences in clinic and the suffering to which they bear witness. This suffering is often the result of structural forces. The HOTAC workshop series is multilayered with exercises and discussions that begin at the level of the individual paired with those meant to move the thinking beyond the individual to consider and challenge structural harms.

Story circles will be incorporated to help construct the safe space for shared meaning-making and consideration of structural harms. The story circle generates creative space where participants share the challenges they face at clinic and seek solutions together. Joe Lambert first introduced the concept of story circles as part of his digital storytelling workshops. Just as the name suggests, story circles consist of individuals in a circle taking turns sharing stories. According to Lambert, it is:

> A group process [that] invites us to see how our stories are connected. As you process out loud with others, the heart of the story may come to light, elucidating new layers of meaning. Which is why the story circle is often critical for a storyteller's writing process.[393]

For HOTAC, story circles provide space for participants to share their experiences and struggles in clinic with their fellow directors. It will also serve as a space where

[393] Lambert, *Digital Storytelling*, 55.

participants can talk through their ideas for projects while receiving feedback from the group. It is a communal space for forging connections between participants and

> … is a journey… the connections made between people in the story circle help to focus and inspire each individual throughout the process.[394]

Through story circle discussions, students share their reflections and discuss where they are and seek go with their projects. More than this, it is also a space where the community of clinic leadership is strengthened.

An emphasis on collaboration runs throughout all the workshops. Collaborative art is a process of cooperation and conversation and involves people reacting with one another.[395] These workshops incorporate collaborative art practices as well as communal art-making to maximize learning through incorporating sharing and feedback. Collaborative art-making helps students to develop the skills required for this work through conversation, negotiation, problem-solving and listening skills. The same skills nurture the relationships with patients and families in health care practice. Engaging healthcare providers in this process will enable them to exercise the skills that will improve the quality of health care interactions (both in interactions with patients and those with other providers). Incorporating collaborative elements in the workshops allows for participants to enhance their ability to connect, communicate, and collaborate with other providers. Collaboration between people is a fundamental part of a successful clinic, and it is required of the leaders as they work together to run and manage St. Vincent's. It is also necessary for seeking change for the injustices that pervade healthcare practice.

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[394] Ibid., 69.

[395] Mark Cooper and Lisa Sjostrom. *Making Art Together: How Collaborative Art-Making Can Transform Kids, Classrooms, and Communities.* 1st edition. (Boston, MA: Beacon Press, 2007), 65.

SEEKING CHANGE

The day to day participation in and running of St. Vincent's is focused on the individual in front of you at any given time. *This* patient needs medication, *this* patient needs labs, *this* patient needs food, *this* patient is ready for faculty, *this* patient needs a follow-up appointment. What is often missed is further consideration of why *these* patients and this *community* don't have access to what they need. Why, with so many options in the healthcare system, why are they so limited for some? The ultimate goal of HOTAC is for student directors to move beyond the individual level of social change, where they are already working, to have a deeper understanding of the structural forces that shape the experiences they have and witness on the individual level. Both components are important for learners but neither is sufficient by itself. With this understanding these leaders will have the tools needed to help student volunteers better understand the ways in which structural forces shape the ways the student practitioners assess patient need and vulnerability. Without an understanding of the structural forces that can result in individual behavior it is easy to attribute a lack of adherence, no shows to appointments, and/or health literacy to personal failure. Currently initiating conversations about what might attribute to that behavior has been affective for students to challenge their own assumptions. In order to ensure these kinds of conversations are possible, leadership must have an understanding of the structural forces that shape such behavior. At the start of the series students will be asked to make art about their experience in order to achieve this raised consciousness concerning the structural harms patients face, and then be supported as they expand their considerations beyond the self and to the collective. As Dewhurst notes,

> …the difference between artwork made for personal expression *about* one's experiences with inequality or other injustice and artwork made with an explicit intention to *change* the injustice. The former artwork does not necessarily require a structural analysis or strategic decisions to dismantle oppressive structures; rather, it is made to share experiences. Such socially engaged artwork may still inspire social change, but without a clear connection between critical reflection and action, the work does not fully align with social justice practices.[396]

The student leadership of St. Vincent's have already dedicated their time and energy for supporting and caring for individuals who have been let go. HOTAC is designed to complement and expand the work already being done by the incorporation of individual reflective practice and group discussion.

It is through individual reflection and the group sharing in story circles that enables a dynamo[397] to spark. Jerome Crowder identified the "dynamo" as the mechanism of the interplay between the individual reflection on the blog and group discussion in class CEP.[398] The opportunity for students to exchange ideas and learn from one another was the source of the spark. As one student noted:

> …it was the weekly group meetings that really fueled my interest as I saw my classmates' progress and listened in on the thoughtful discussions. The discussions and exchange of ideas really spark my interest into going further with my project. In the end, I found myself not only gaining more experience with digital painting, but also gaining more confidence in discussing my work. I think one of the best part of the program is the opportunity to see my classmates' projects develop and learn their stories behind their art.[399]

The sharing of stories allows for new ideas to emerge. It is a slowing down with

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[396] Dewhurst, *Social Justice Art*, 113.

[397] Jerome Crowder,"Cultivating Care through Creativity: Medical Students Self-Reflect through Artistic Expression." (presentation at the 2015 The American Society for Bioethics and Humanities 37th Annual Meeting, Houston, Texas, October 23, 2015).

[398] Ibid.

[399] Justin X, survey completed by Jerome Crowder, Creative Expressions Course responses, 2014

communal consideration that students are given the opportunity to work through struggles together.[400] This is especially helpful for the leadership of St. Vincent's because within the busy daily bustle of clinic, there is not always the time for students to engage in reflection on the work they do nor is there always time for them to consider the larger systemic problems that shape their experiences at St. Vincent's. Working with clinical students the last four years, I have witnessed their desire to learn strategies to change current systems and practices of care. Inevitably, every year, as the director term comes to an end, there are individuals who express the desire to continue this transformative work as they go into residency or practice. HOTAC seeks to forge understandings of the realities of the healthcare systems they are set to join and to also help facilitate conversations around how to continue the everyday practice of resisting injustice in healthcare.

WORKSHOP ONE: RELEARNING CREATIVE EXPRESSION

Ideally this first workshop would be incorporated as part of the official transition meeting as part of the initiation of new students into the leadership, but, as I learned this year, more restructuring needs to occur for it to be meaningfully incorporated into this transition. Each March the new set of medical, graduate, and clinical lab sciences student directors begin, and a transition meeting and training helps to prepare the new leadership for their roles in clinic.[401] This training is taught by the outgoing group of directors. The

[400] Jerome Crowder, personal communication to the author, 2014

[401] Medical students apply to the role of director and are selected by the entire board of senior directors including PA, CLS, nursing, and graduate student leaders. Most of the medical student directors served as junior directors in the clinic, though this is not a requirement. Those who have served as junior directors have experience with the policies and procedures and day-to-day operations of the clinic. Up until four years ago the only graduate student directors were those who were dual degree students also pursuing

physician assistant and nursing student directors start at earlier points in the school year due to the structure and schedule of their programs,[402] but join the March transition meeting. It would be optimal for this workshop to be added to the transition meeting because it is a space where all these groups are already together and thus an opportunity to engage all these students in more complex conversations about clinic. Rather than just focusing on the functions of clinic, students should have the chance to reflect on why they chose their roles and what they can do to contribute to the work being done at St. Vincent's. Currently, the clinic has been going through administrative shifts and this year's transition meeting was not conducive to incorporate a workshop. For this year, the series of workshops will start as the first director meeting of the year with plans to incorporate it as part of the transition meeting in future years. The work of social change is alluded to in this setting and the incorporation of an art workshop allows for it to be addressed more directly.

The first workshop begins with a presentation on the history of the free clinic movement. This presentation is informed by the history outlined in chapter two and provides students with a better understanding of the movement of which they are becoming a part. As leaders of the clinic, students are taking on more involved roles that call for commitment to the work being done in this space. General clinical volunteers see

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an MD. There has since been a shift to incorporate non-clinical graduate students in volunteer roles as well as leadership roles in the clinic. There are still limited numbers of graduate students involved in clinic so there is less turnover in this position, but there are currently efforts to recruit more.

[402] At UTMB, the PA program consists of two year, the first of primarily pre-clinical, in-class work, and the second year completing rotations all over the state of Texas. In order to accommodate this shorter time in Galveston, PA directors apply to the position their third month of school and are selected by their faculty who have access to more information on them since they are new students. Nursing students programs are only four semesters with classes starting in the Fall, Spring, and Summer. The application timing varies depending on the graduation semester of the outgoing director. These directors are selected in house by the nursing director and a smaller committee of senior directors.

patients and assist with the work of the free clinic, but leaders ensure the clinic continues to run. During my time at clinic I have observed students who join the leadership because they want to do more to help the population they have been caring for as student providers. This workshop meets students where they are and works to further contextualize their work at St. Vincent's. They first learn about the historical motivations for the emergence of the free clinic movement and then reflect on their own motivations for becoming a leader in the clinic and what they hope to contribute and accomplish while in that role. After students spend approximately ten minutes on a written reflection regarding why they chose to expand their involvement to help run the clinic, they will be re-introduced to creativity in order to transition to the art-making portion of the workshop.

The art portion of the workshop begins by directly addressing the thought likely on many participants minds: "…but I can't draw?"[403]Art-making is not accessible for many who do not identify as "artists" because of past experiences reinforcing the belief that they are not creative and should not make art. For these individuals, spaces of art-making are neither welcoming nor automatic as a coping method. This sense of art as "off-limits" is the result of a common framing of art that often comes in the form these questions: "Is it good or does it suck?"[404] At some point children are taught that art is either "good" or "bad" and for those whose art is not perceived as "good" (either by themselves or others) stop making it and loose the belief in their own creativity:

Even more suppressed than adolescents were the adults who had learned

[403] In my experience leading art workshops this was a common sentiment expressed by participants and as a result I now address it preemptively at the beginning of each workshop.

[404] Lynda Barry, a professor of Interdisciplinary Creativity at the University of Wisconsin in Madison, examines these questions in her work: Lynda Barry, *Syllabus: Notes from an Accidental Professor.* Second Printing edition. (Montreal, Quebec: Drawn and Quarterly, 2014)

> the 'I can't' song so many years ago that it has become their mantra—I can't sing, can't draw, can't dance. can't write, can't think, can't be important, can't be listened to or heard, can't be of use, can't be an actor in the world. For them the arts became a monkey-off-my-back experience when they discovered what they thought they could not do was really a matter of perception and oppressive training.[405]

The students' belief that only some have access to the realm of creativity is a fallacy and is not a space of exclusivity but instead should be a community of which we are all a part, including health care providers.

This framing posits artists as creative and others as "not creative" results in individuals self-identifying as "not creative" and thus ceasing to engage fully in arts' potentiality. In the preface for *Beginner's Guide to Community-Based* Arts, Mat Schwarzman argues that the "capacity to be creative is built into human beings at a biological level. Being creative is so natural, so basic to humanity, that very few of us even notice when we're doing it."[406] This tendency to not notice the creative thinking that fills our lives allows for the belief that one is not creative. In many of the workshops and classes that utilize art practice that I have directed [407] there were many individuals who commented that they are "not creative." Such comments confused me because these students were majoring in science, medicine, and other disciplines and fields I associated with creativity and inquiry. The students who expressed their lack of creativity were incredibly creative, as demonstrated by their engagement with the course material and their final projects. The problem they faced was instead one of identification. The belief that creativity and art is off-limits to some does not recognize the ways in which we all

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[405]Hanley, et al., *Culturally Relevant Arts Education for Social Justice.*

[406] Mat Schwarzman *Beginner's Guide to Community-Based Arts,* (Oakland, CA: New Village Press, 2005), xviii.

[407] A complete list of these can be found in Appendix B

engage in creative thinking. As Schwarzman pointed out, "Creativity—that is, the use of the imagination to come up with a new idea or a different way to solve a problem—happens everyday."[408] We all engage in creative thinking in order to navigate the challenges and experiences of our daily lives—and providers are engaged in creativity in their work of providing care to patients.

Starting with "drawing without looking," the first exercise uses the technique "blind contour drawing," which requires students to be present in their drawing rather than focusing on the outcome (what they want their drawing to become). Using a ball point pen and white paper, participants choose something or someone in the room to look at; as they draw their subject, they do not look at their paper and do not pick up their pen until they are finished. This blind contour drawing pulls participants into the present moment by removing the ability of control over the outcome. It encourages students to let go of the outcome and to focus on the present moment. So much of the process of becoming a healthcare provider is the emphasis on outcome. It also removes the pressure of producing art and instead allows for it to become silly and fun again. As Lynda Barry notes, students should learn how to follow their wandering minds through art (2008). By learning to follow the line rather than to focus on the end product, individuals learn to enter a space of healing through art. Teaching healers to enter this space has the potential to allow for a deep and nuanced reflective experience.

After making a blind contour line drawing, participants are introduced to foam plate relief printing. Using foam paper, dried out pens, and water-based ink, participants learn simple printmaking techniques. The pen is used to "carve" into the foam paper to

[408] Schwarzman, *Beginner's Guide to Community-Based* Arts, xviii.

make a reverse image and then water-soluble, printmaking ink is rolled on the foam, which is then used as a stamp on a piece of paper. The simple technique allows for quick prints so students have the opportunity to experiment and play with the materials. For their first print students will have the option to make a blind contour print or make a print while looking and will be given the freedom to choose an object to render. The supplies for this workshop are inexpensive with 100 sheets of foam paper costing around fifteen dollars,[409] water soluble relief printmaking ink, which runs around seven to ten dollars for a large tube, and printmaking paper.[410] After making their first print, students will be asked to make two prints to illustrate or represent why they decided to join the St. Vincent's leadership and what they hope to accomplish. These prints will be used as part of a collective paper quilt created by the directors. The panels of the quilt will consist of the prints of the participants which will be joined on a large piece of foam core. Students will be given time and materials to make several prints to afford them the option to experiment and play. After students have made their prints there will be a story circle during which they will each share the prints they made and about why they became a leader for the clinic as well as what they hope to accomplish. During this story circle, there will be space provided for giving feedback on the prints and ways to expand on the visual messages. Additional time after the circle will be given for students to make additional prints if desired and for each to write two to three sentence artist statements to explain their motivation for each print. The prints and artist statements will be

[409] See https://www.amazon.com/gp/product/B0044S89F2/ref=oh_aui_detailpage_o00_s00?ie=UTF8&psc=1

[410] This can be purchased via amazon.com or any art supply store. See https://www.amazon.com/Speedball-3600-Water-Soluble-Block-Printing/dp/B0017D92TO/ ref=sr_1_ fkmr0_2?ie=UTF8&qid=1523550576&sr=8-2-fkmr0&keywords= Water+Soluble+Block+ printmaking+Ink+black+tube. Drawing paper from a big box store will also work as will printer paper.

constructed into the form of a quilt with each print serving as a panel of the quilt. The quilt is presented in two forms. First, the panels will be woven together to form a quilt to be hung in clinic. Second, the artist statements will be paired with the prints, which will all be scanned for inclusion in a “zine”, which is a small self-published magazine. There will be enough printed so each director gets a copy. The point of the printed quilt is twofold. First, students will be given time and space to reflect individually on why they each have chosen to dedicate their time and energy to St. Vincent's. Second, the quilt will serve as a visual representation of the individual commitments and hopes woven together to represent the collective work they will do as a team for their year in the clinic. As there are ups and downs throughout the year, challenges and failures and frustrations, the student leaders will have a visual reminder of why they came to do what they are doing. At the conclusion of the workshop, students will be instructed on accessing the required readings and reflective writing prompts for the remainder of the year. These readings and prompts will be stored in a folder on the clinic’s shared google drive to which all directors have access.

WORKSHOP TWO: WITNESSING, UNDERSTANDING, AND RESPONDING TO HARMS IN HEALTHCARE

After four months of working in the clinic, students will be brought back together for more art-making. This second meeting will occur during one of the regularly scheduled, monthly director meetings and will focus on examining the structural violence in healthcare and the ways it affects St. Vincent's. During this meeting there will be an informal presentation and discussion of structural harm, as outlined in chapter one, and the ways such harms manifest in everyday healthcare practice. Prior to the meeting, students will also be given readings related to structural harm and the ways in which

clinical space has been constructed to shape agency.[411] After this brief presentation of information, time will be allotted to discuss the readings and for students to discuss their journals together and reflect on the work they have been doing at St. Vincent's.

During the discussion of the readings and individual reflections, learners will participate in a comic jam, a collaborative exercise making comics in order to tell a collective story about the work they are doing at St. Vincent's. Susan Squier describes this exercise as:

> Starting with a piece of paper gridded into nine panels, three in a row, each student is asked to write a story captioning every panel; they then illustrate the first panel (based on the caption), and pass it to the student on the left. The next person draws the second panel, passes it to the left, and so on, until nine panels are filled… The result of a nine person collaboration is a one-page, nine-panel comic whose panels and captions collide in unexpected and wonderful ways.[412]

The comic jam begins with the caption: "A patient came to clinic needing our help…"[413] and the first participant is asked to finish the caption and to create an image with it. Participants takes turns to each create a panel to continue the story of the panel before passing the jam on to the next individual. The finished comic jam will be shared with the class before a collaborative comics building exercise. As part of the discussion of the readings and the reflection on their connections to St. Vincent's, students will be asked the following questions:

1. Identify an issue faced by the patients of St. Vincent's and the ways in which

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[411] Students will be given excerpts to read from Nick Sousanis' *Unflattening* along with an article by Paul Farmer and his colleagues on the subject of structural harm in the clinic. Together these works illuminate the ways in which systems and spaces influence the experiences of individuals. See Paul E. Farmer, Bruce Nizeye, Sara Stulac, and Salmaan Keshavjee. "Structural Violence and Clinical Medicine." *PLOS Medicine* 3, no. 10 (October 24, 2006): e449. and Nick Sousanis, *Unflattening.* Cambridge, Massachusetts: Harvard University Press, 2015.

[412] Susan Merrill Squier. "The Uses of Graphic Medicine for Engaged Scholarship." In *Graphic Medicine Manifesto,* 41–66. (University Park, PA: The Pennsylvania State University Press, 2015), 57.

[413] Ibid. This is a variation on the comic jam discussed by Dr. Squier who uses "People don't know this about me, but I used to…" A caption she credits MK Czerwiec as having suggested.

it negatively affects the health of the patient or their family
2. Why is this happening? What structures, systems, policies, and practices influence the issue you identified?

These questions are meant to provide scaffolding for students to think through the readings in relation to their own experiences. During all of my workshops I have such scaffolding questions ready if needed to help spur the conversation, but I also remain open to go where students lead the conversation. The group dynamic greatly affects how students engage in any discussion and workshop, and so facilitators must be prepared to assist when needed and also to step back when they are not.

After considering the readings, students will be led through comics-making activities to begin the process of connecting the macro and structural to the micro or individual level. The first exercise begins with students being asked to write:

1. Something they think is unfair in healthcare practice in the US
2. Something they heard in clinic
3. A challenge faced by patients at St. Vincent's

This exercise, inspired by Ivan Burnetti's text *Cartooning: Philosophy and Practice,*[414] is meant to offer students a space to explore the use of the visual to communicate. They will then be asked to illustrate the captions they have created through these prompts. They will be given the option to work together or switch to illustrate each other's' captions.

As discussed in chapter three, directors become intimately familiar with the structural harms present in the US healthcare system throughout their tenure. This next activity asks leaders to create a comic that reflects their current work in the clinic and to connect it will the larger system of medicine and the the logic of letting go. They must recognize their role in the system in order to do anything about changing it and the harms

[414] Ivan. Brunetti, *Cartooning: Philosophy and Practice,* (New Haven, CT: Yale University Press, 2011).

it causes. To discuss and brainstorm together, the students participate in a "story circle"[415] as they decide what kind of art they want to make and the kind of æffect[416] they want to have on the audience, themselves, and the clinic. During this communal sharing, the students will be asked to identify problems witnessed at clinic that we wish to address. Before the the final workshops students are expected to reflect on and distinguish between the symptoms of the problem they choose and the cause if known. They are also asked to begin brainstorming ways to alleviate the cause and ways in which they can begin to work towards a more just healthcare system.

WORKSHOP THREE: IMAGINING A BETTER WORLD

> Utopia is not a place we will ever reach; it is space that helps us think about where we want to go… it is a tool for imagining.
>
> -Duncombe & Lambert, "Lessons from Utopia"

The last workshop of HOTAC engages students in exercises to imagine what justice would look like in healthcare and the everyday strategies to work towards that utopia. The content of the third workshop meeting is focused on cultivating the ability to imagine the ways in which things could be different and better for their patients. As student directors, they are regularly exposed to what is wrong with the system as they see how it fails patients over and over again, but it is important that they not lose the ability to envision a better world. The students will then be guided through a series of exercises imagining what it would look like for the problems of the clinic to be solved.[417] This exercise will be subsequently repeated with increasing scopes of problems (the problem of one individual to the problems of the clinic to the problems of the hospital to the those

[415] Lambert, *Digital Storytelling.*

[416] Dewhurst, *Social Justice Art.*

[417] This exercise is adapted from one outlined in "Lessons from Utopia" by Stephen Duncombe and Steve Lambert. Ibid.

the US healthcare system). The exercise invites students to imagine a perfect world to shift their perspective by experiencing that alternate world:

> A step into Utopia is a step into an alternate world, and once this alternative has been experienced, our relationship with our own world is fundamentally altered. Think about what it is like traveling to other places and experiencing other cultures. Yes, we get to know the new culture, but in that process we also see our own culture in a new light. It is the same thing when visiting Utopia. Once we have been to the future we look backwards on the present with new eyes. What we once accepted as the only option is now understood as only one of many possibilities. Our perspective shifts.[418]

In the free clinic one can easily lose sight of the bigger picture in the day to day organized chaos of keeping the clinic going. There is an importance in attending to the people seeking care—to the individual needs of patients. It is akin to treating symptoms without treating the root cause of a disease, because in focusing on only on the micro the larger forces that influence those problems can be missed. Directors can, at times, take for granted the status quo; without such consciousness, they are also unable to see how they can challenge and transform it. In order for a world without the logic of letting go to be thinkable, there must be the ability to image a utopia of medicine and to spend some time in that place.

During the workshop participants are tasked with working individually or collaboratively to construct an image of imaginative utopia of healthcare and maps for how to get there. After they leave many of these students continue their commitment to care for this population seeking out opportunities to help. Some are trying to create new free clinics in their area[419] while others even assess residency choices based on which

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[418] Ibid.

[419] In the last year, two former medical student directors have reached out to me for assistance in helping to create a free clinic in the place where they are doing their residencies.

programs have clinics where residents can treat the poor.[420] This workshop is meant to give students the space to start planning this continued health caring for those populations who have been let go and to imagine the future of healthcare they want for their patients. The students will first be given time to brainstorm what they want their utopia collage to look like and asked to sketch a map to that utopia. The art maps they sketch are meant to help them remember how to keep on the journey to a place that can never exist, but which we must all work towards. After working individually or in small groups on their ideas, they will then be pulled together for a story circle. In the story circle students will be asked to share their ideas for what a utopia of healthcare would look like and the map to get there. It is in this space that they will give and receive feedback with their peers while also sharing how they hope to continue their St. Vincent's work as they transition out of the leadership role. It has been my experience if students have the space for these conversations something magical happens and students share ideas and forge plans for change.

After the story circle students will be given time to create collage utopias and/or maps to utopia. Using mixed media collage, either individually or collaboratively, students will make visual representations of their imaginative utopias of healthcare. This method was selected because of its accessibility and versatility. This is another art form that does not require specialized equipment or expensive supplies. It is likely one that most will have participated in collage-making at some point as a child, and with a variety of other materials made available, it can be individualized to each artist's vision. For any student who is unable to complete their art, they will be given the opportunity to take

[420] Every year I have worked with the directors at least three students have commented to me that they would like to go to a program where they can keep caring for the poor.

some supplies home to finish their projects or to coordinate another time for students to get together to work. Students will be asked to email in an artist's statement describing what they hope for medicine and how their artwork represents that hope. If the participants agree, these will be included as part of the art display at the annual benefit concert.

ADAPTING THE CURRICULUM

Although this curriculum was designed specifically for the space of St. Vincent's Student Clinic, it can be adapted for other clinic settings. The facilitator is a vital part of the adaptation of the curriculum. Those stakeholders of an organization who want to adapt the curriculum for their setting would benefit from a background in art or collaboration. An individual able to help with the design and teaching of art activities. Likewise, for those with backgrounds in art who wish to work with an organization, research is necessary to understand with whom they are working and to meet individuals where they are at artistically. Facilitators must be mindful of the ways in which art engagement has been discouraged for many outside of the art world, and even for those within it. Any individual engaging in this work must be collaborative and open to learning from the individuals with whom they seek to work. In the *Beginner's Guide to Community-Based Arts,* Keith Knight and Mat Schwarzman offer a conceptual map for initiating community-based art projects. This map offers guidance that is also applicable to the development of arts-based curriculum for the healthcare community. The authors Identify five main components of this map:

> Contact— Cultivate trust, mutual understanding and commitment as a foundation for your creative partnership.
> Research—Gather information about the people, places and issues you are working with.
> Action—Produce a new work of art [or art-based curriculum] that benefits

the community.
Feedback—Spark community reflection, dialogue and organizing to spread the impact of the new work.
Teaching—Pass on new community-building skills to others to sustain impact. [421]

Although Knight and Schwarzmann's work focuses on guiding individuals in community arts practices, their map is also applicable to the adaption and implementation of arts-based social justice curriculum for healthcare learners. Each of these steps is necessary for creating meaningful experiences and education through arts-based curriculum.

It is vital that individuals cultivate trust with those they wish work and it takes effort and commitment to gain a fuller understanding of the setting to which they wish to bring the art curriculum. They must work to build relationships with the leaders of the space with which they wish to work. When seeking projects with a student-run free clinic it is vital that individuals enter mindful to not bring the power structures of the academic setting. During my time with St. Vincent's I have witnessed faculty attempt to incorporate curriculum into clinic without working with leaders to plan and implement these projects in a way that makes sense for clinic. The result is a project that begins with elements not compatible with the flow and processes of the clinic. During one such project the outside faculty instructed students to arrive at a different time than the start of clinic and instructed them to stay less than the required time commitment for volunteers. A faculty entering a student-run space can easily forget that she does not hold the same position of power in the clinic as she holds in academia. It is the student leaders in these spaces who know the clinic best and are therefore assets in the planning such projects providing insights not easily available to an outsider. Additionally, failure to work within

[421] Ibid.

the existing structures of a space communicates a disrespect of the space and leaders in that space. This can result in a project set to fail before it begins.

CREATING AN EXPERIENCE OF ART: & THE CHALLENGE OF EVALUATION

"What do you want your students to remember about art 50 years from now?"[422]

With this proposed curriculum, I aim to curate an experience for the leaders of the free clinic— an experience that engages them in deeper conversations with one another about the work they already do at the clinic. I seek this through art activism because of the transformative power of creativity:

> …creativity is the human genius for transformation in a hostile natural world… creativity is our hardwired capacity to change the world into what we imagine, whether for good or for ill, and even to establish the moral compass that will determine our direction. Imagination and creativity are our ways out of the seemingly now way of human experience and as multifarious as snowflakes in a blizzard; like eating and breathing, these capacities are essential to each individual and to the survival of the species. Thus, creativity is empowering; you take risks, test the world, shape media and meaning, and thereby change the world.[423]

It is through creative thinking that learners will work to forge connections between their individual experiences and observations and the larger system influencing the setting. Art empowers learners to imagine otherwise, a necessary skill for seeking change in healthcare practice. As previously discussed in chapter five, there is an attention in the arts activism literature to the distinction between art as product and art as process. In much of art activist work, the emphasis is on the experience and process of production, which is integral to the artwork, instead of focusing on the final product itself.[424] The

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[422] Dipti Desai in Dipti Desai & Elizabeth Koch, "Educational Crisis: An Artistic Intervention" in *Art & Social Justice Education: Culture as Commons*, " 35.

[423] Hanley, "Introduction." in *Culturally Relevant Arts Education for Social Justice: A Way Out of No Way*. Hanley, et al., (New York NY: Routledge, 2013), 3.

[424] Beverly Naidus, *Arts for Change: Teaching Outside the Frame.* (Oakland, CA: New Village Press, 2009).

goal of the HOTAC workshops is to curate an experience of communal meaning-making between directors. The product is secondary and instead, just as activism art does, seeks to foster dialogue, build community, make a place to foster new connections and explorations, invite participation with the work, transform the environment or experience, reveal the reality of the situation, alter audience perception, create disruption, inspire dreaming (of another view of the world) or even create a useful tool.[425] These moments include more than just comics, printmaking, or drawing without seeing; the workshops give participants an opportunity to connect with one another and connect their work at the clinic with the larger system within which they work.

Because the focus of HOTAC is on cultivating an experience with the art produced as secondary to the purpose of the work, a challenge that will be faced is how to appropriately evaluate it. Evaluation of arts-based curriculum can be a challenge, because the outcomes that I seek, planting the seeds of social justice, do not so easily lend themselves to quantification or measurement. Additionally, attempts to evaluation arts-based curriculum can result in students censoring what they make and thus compromising the process. Such an approach can result in incredibly valuable information as is evidenced with the material that resulted from CEP. For HOTAC, I will not be taking this approach because of my desire to create an art-making space where students can explore the challenges they face working to prevent self-conscious censorship of their explorations. One way to navigate this is by shifting control to the students as much as possible. This is the main reason that students are able to opt in to display and share their work outside of the group. Participants will also have the opportunity to opt in to

[425] Stephen Duncombe, "Does it Work? The Æffect of Activist Art." *Social Research* 83, no. 1 (Spring2016 2016): 121-123.

completing evaluations of their experience. These evaluations will be used to improve the course for subsequent years but also to evaluate its value. Although there is a focus on process with HOTAC, the products created through this workshop will also serve as evidence of the effectiveness of the curriculum. Moving forward with this curriculum, more work will need to be done in order to effectively evaluate it while not compromising the space of the workshops.

CONCLUSION

This workshop series is informed by my eight years of experience using arts-based curriculum with clinical and pre-clinical learners as well as the literature regarding arts in healthcare research and arts activism curricula. Teaching structural everyday violence and structuring activities for students to identify and respond to the violence in the system within which they work is a vital part of healthcare education left out of traditional learning environments. Art activism provides powerful frameworks for exploring and challenging the injustices in healthcare practice students witness. The workshops remain focused on engaging the students in the process of thinking through the injustices they witness in the free clinic and provide the scaffolding for students to dig deeper into these issues they face in a free clinic setting. The involvement and engagement of student directors in these workshops will serve as evidence of the impact of these workshops. This impact is revealed through the conversations that occur in this space, through the art that is created, and through the connections that are made between the literature participants read and their experiences at clinic. It is the space and collaboration that becomes a space for making meaning and observation of these interactions sometimes reveal deep connections made, but also they sometimes will not. The seeds of social justice are planted and as a result the lens to the experience of another

is made accessible.

Ultimately, it is not only the free clinic that functions as activism; the curriculum, and the practice of making and learning together, becomes activism as well. Like the goal of performance art, the goal of the workshops is to have an "interactive experience that is intersubjective, an experience that evokes mutual recognition, communication, and response."[426] HOTAC seeks to forge space for student directors to slow down, reflect, and collaborate through art to make sense of the complex experiences of leading at at free clinic. Ultimately, these workshops are designed to attend to "the idea that a limited number of people in a specific time/space frame can have an experience of value which leaves no visible trace."[427] The trace that is left is invisible, but meaningful nonetheless. I expect that the trace that follows the providers back to their practice and a trace that can change practice.

[426] Samira Kawash, "Interactivity and Vulnerability" *PAJ: A Journal of Performance and Art,* 21. no. 1, (1999): 51.

[427] Peggy Phelan and Jill Lane, *The Ends of Performance.* (New York: NY: University Press, 1998). 149.

Appendix A

Illustration 7: Street View, St. Vincent's House, 2017, Photograph by Amerisa Waters.

Illustration 8: The Doors of St. Vincent's House, 2017. Photograph by Amerisa Waters.

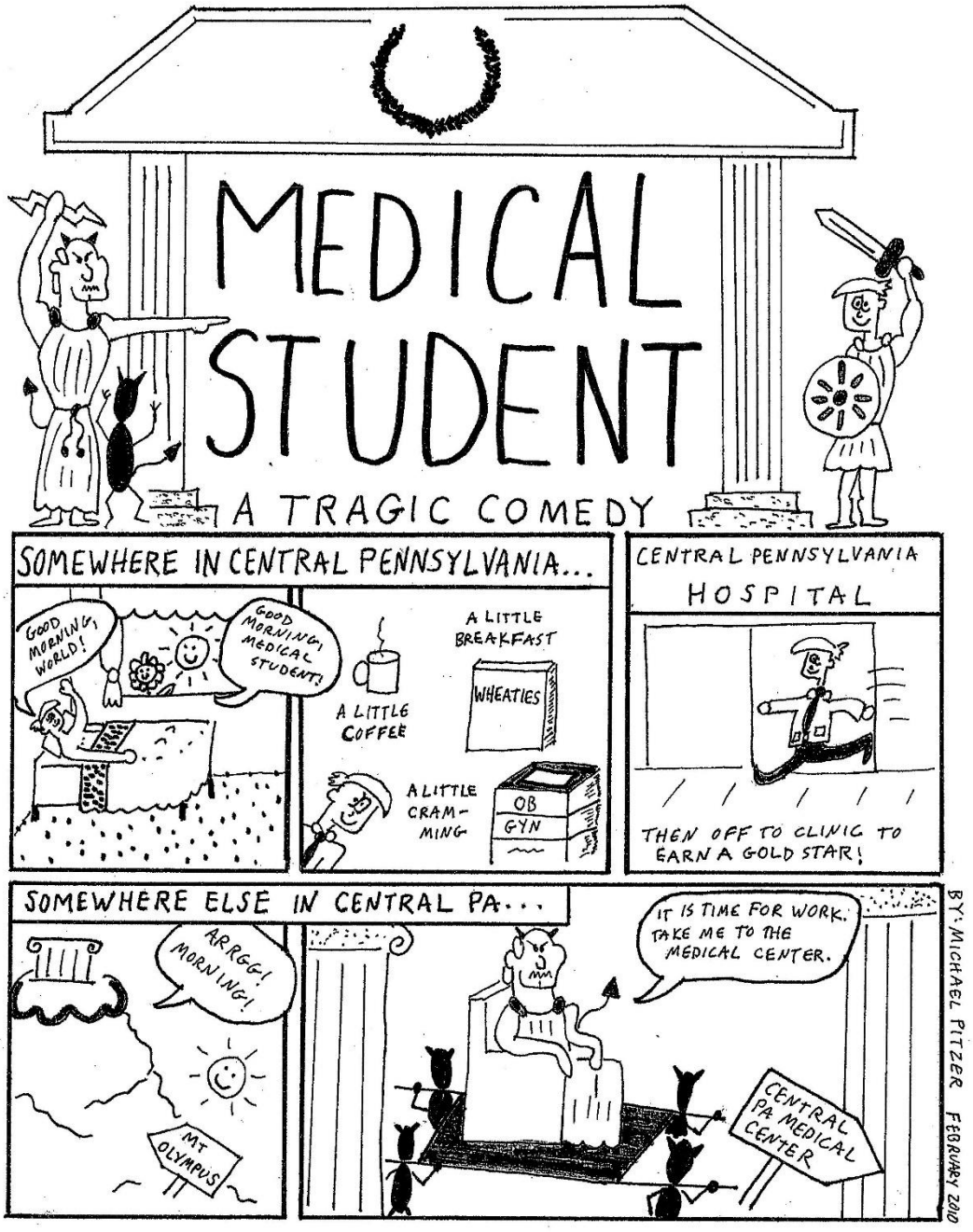
Illustration 9: Contour line drawing Demonstration, Art in Medicine Drawing Workshop, 5th Annual APRIME-Time Summer Conference, July 13, 2015. Photograph by Jerome Crowder.

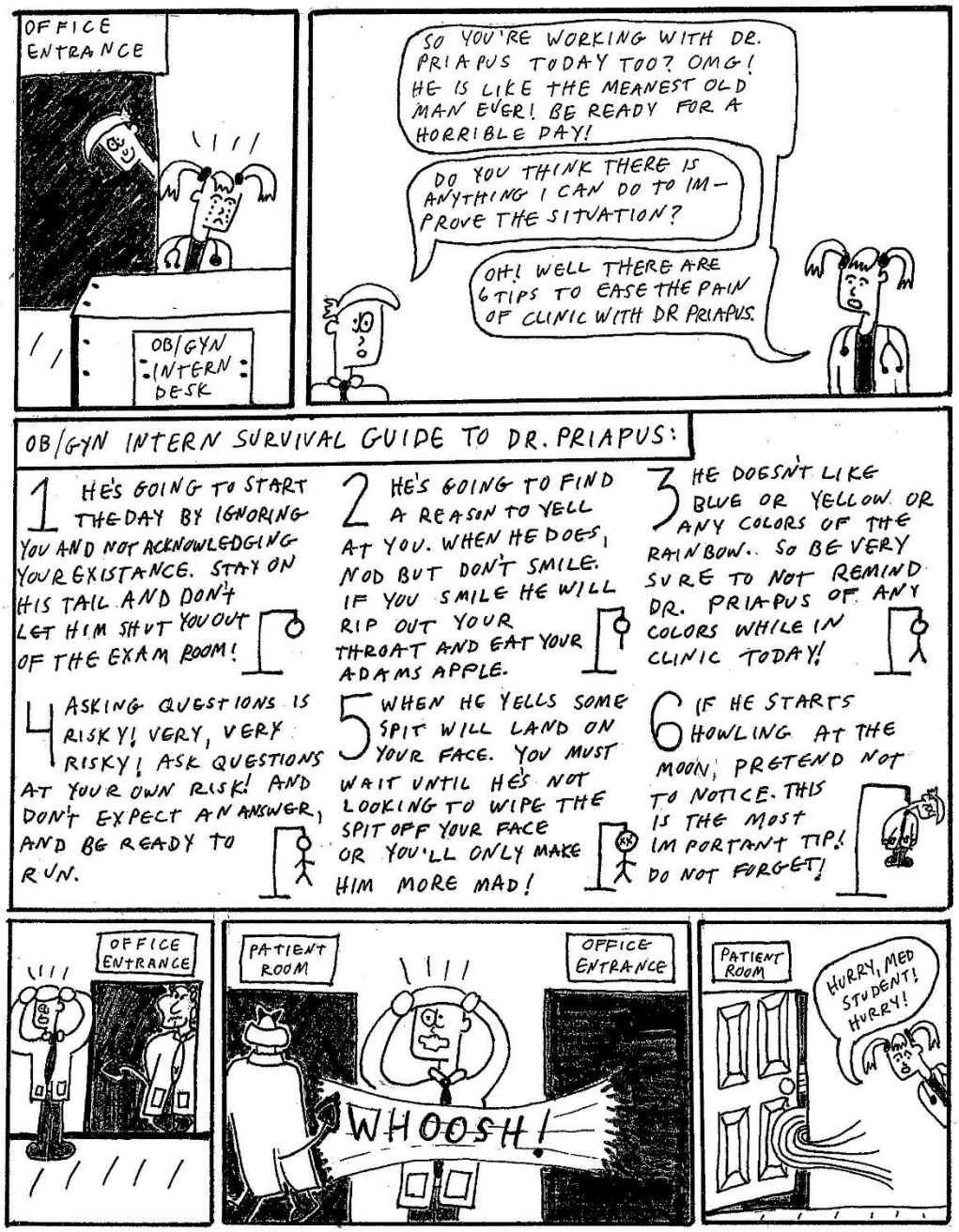
Illustration 10: Art in Medicine Drawing Workshop, 5th Annual APRIME-Time Summer Conference, July 13, 2015. Photograph by Jerome Crowder.

Illustration 11: Artwork on Display, JAMP Creative Expressions Project Final Show, June 2015. Photograph by Amerisa Waters.

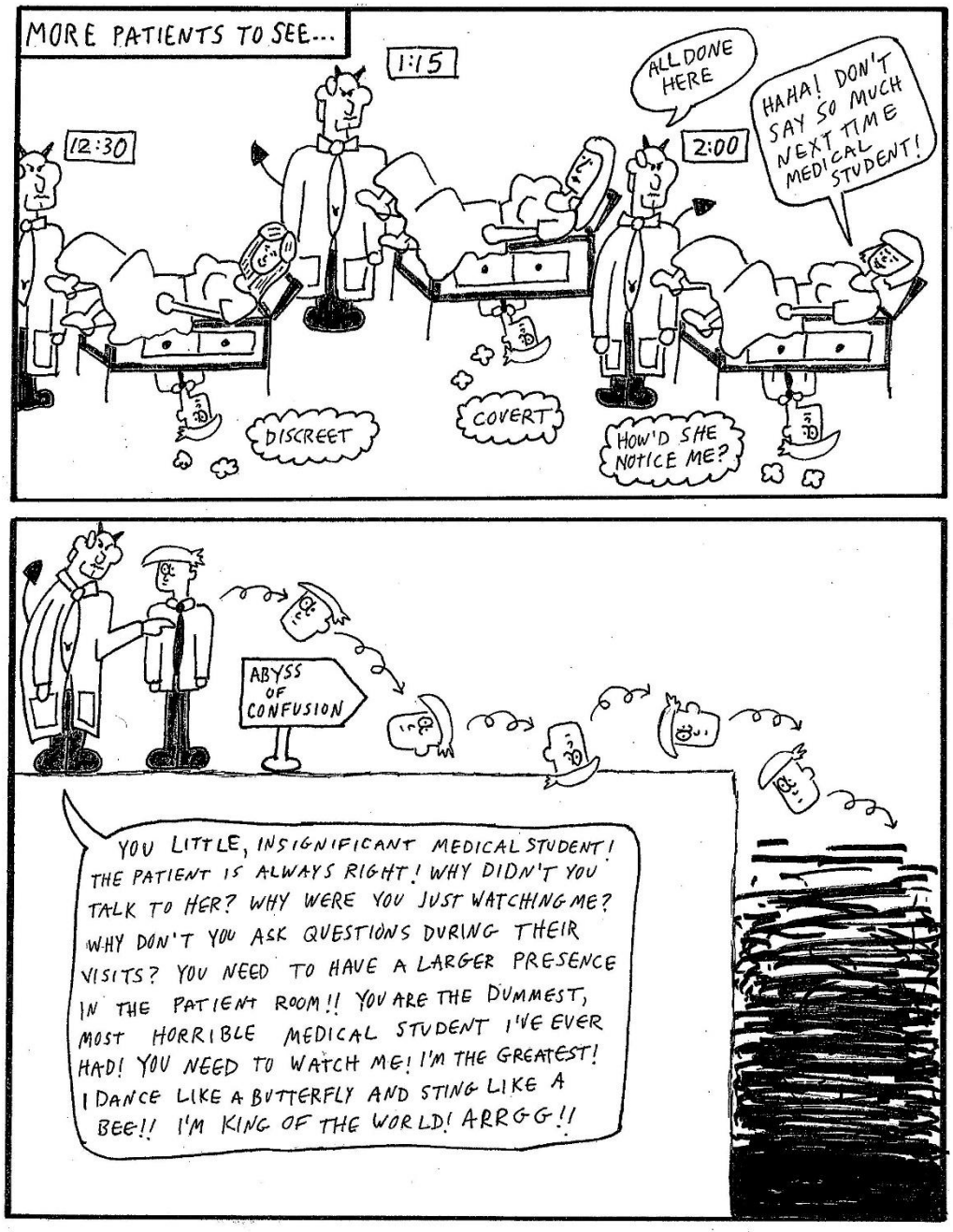
Illustration 12: Artwork on Display, JAMP Creative Expressions Project Final Show, June 2016. Photograph by Amerisa Waters.

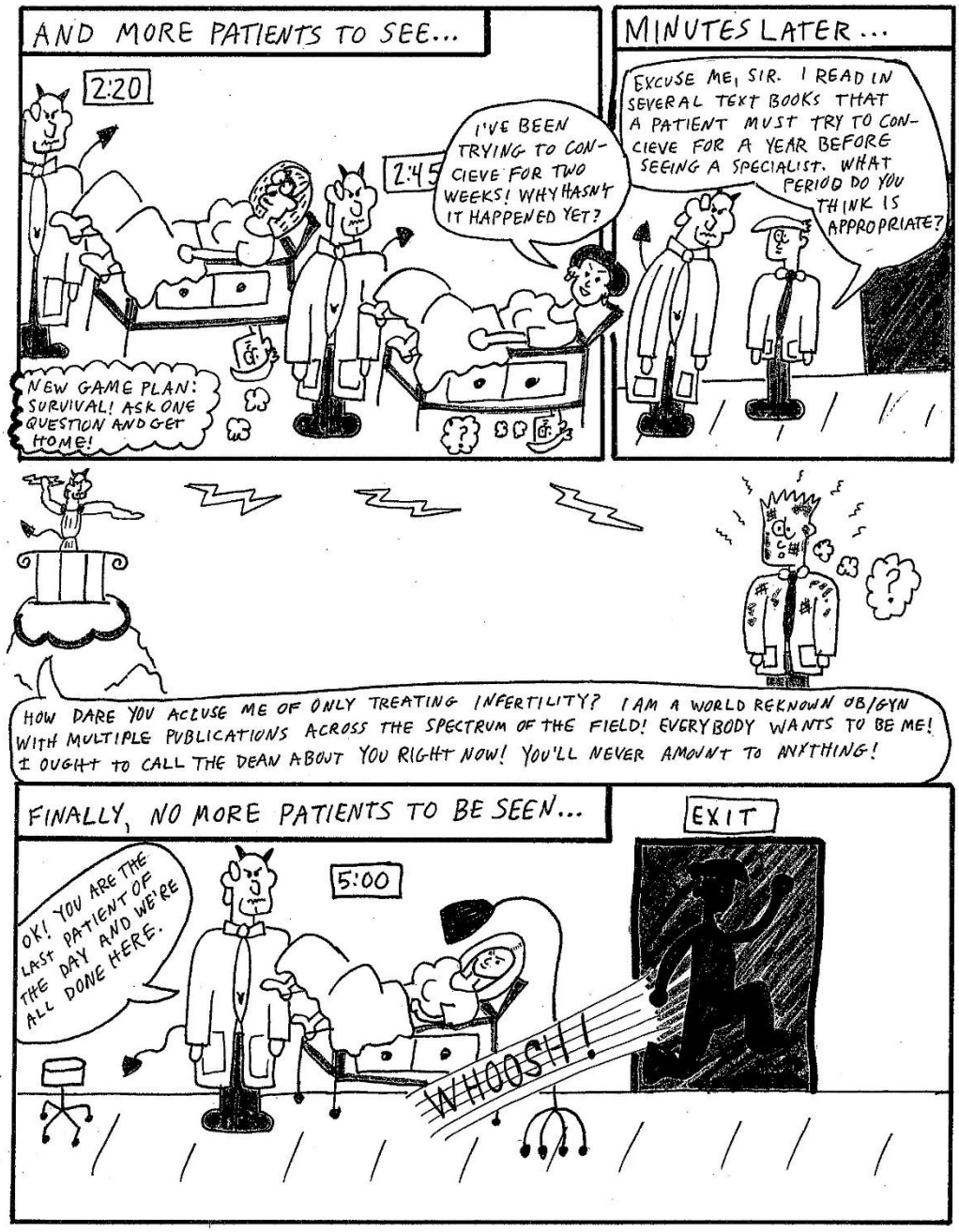
Illustration 13: Medical Student: A Tragic Comedy, Michael Pitzer, 2015. Reproduced with permission.

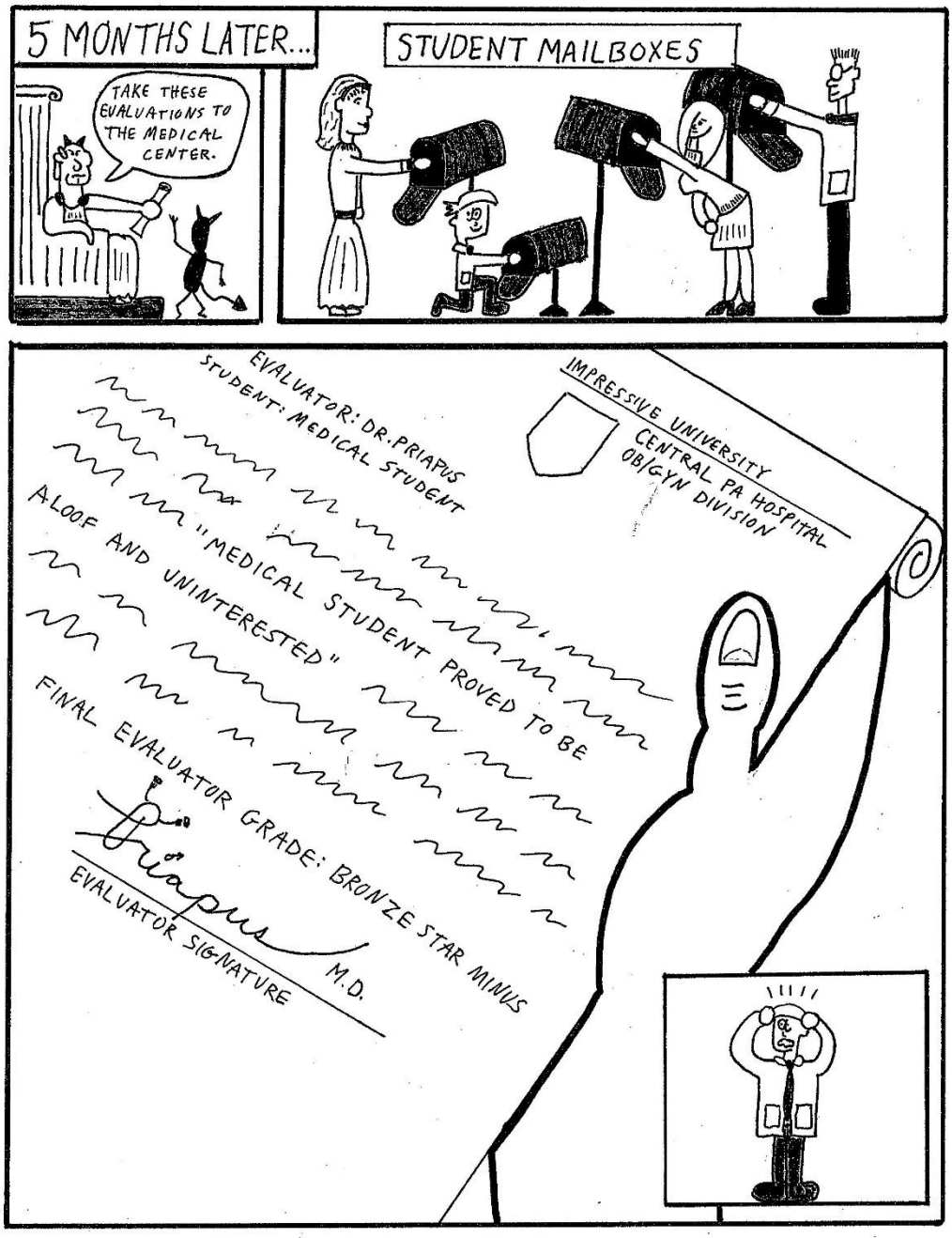



OFFICE ENTRANCE
OB/GYN INTERN DESK
SO YOU'RE WORKING WITH DR. PRIAPUS TODAY TOO? OMG! HE IS LIKE THE MEANEST OLD MAN EVER! BE READY FOR A HORRIBLE DAY!
DO YOU THINK THERE IS ANYTHING I CAN DO TO IMPROVE THE SITUATION?
OH! WELL THERE ARE 6 TIPS TO EASE THE PAIN OF CLINIC WITH DR PRIAPUS.
OB/GYN INTERN SURVIVAL GUIDE TO DR. PRIAPUS:
1 HE'S GOING TO START THE DAY BY IGNORING YOU AND NOT ACKNOWLEDGING YOUR EXISTANCE. STAY ON HIS TAIL AND DON'T LET HIM SHUT YOU OUT OF THE EXAM ROOM!
2 HE'S GOING TO FIND A REASON TO YELL AT YOU. WHEN HE DOES, NOD BUT DON'T SMILE. IF YOU SMILE HE WILL RIP OUT YOUR THROAT AND EAT YOUR ADAMS APPLE.
3 HE DOESN'T LIKE BLUE OR YELLOW OR ANY COLORS OF THE RAINBOW. SO BE VERY SURE TO NOT REMIND DR. PRIAPUS OF ANY COLORS WHILE IN CLINIC TODAY!
4 ASKING QUESTIONS IS RISKY! VERY, VERY RISKY! ASK QUESTIONS AT YOUR OWN RISK! AND DON'T EXPECT AN ANSWER, AND BE READY TO RUN.
5 WHEN HE YELLS SOME SPIT WILL LAND ON YOUR FACE. YOU MUST WAIT UNTIL HE'S NOT LOOKING TO WIPE THE SPIT OFF YOUR FACE OR YOU'LL ONLY MAKE HIM MORE MAD!
6 IF HE STARTS HOWLING AT THE MOON, PRETEND NOT TO NOTICE. THIS IS THE MOST IMPORTANT TIP! DO NOT FORGET!
OFFICE ENTRANCE
PATIENT ROOM
OFFICE ENTRANCE
WHOOSH!
PATIENT ROOM
HURRY, MED STUDENT! HURRY!


INSIDE THE PATIENT ROOM
9:45
HELLO?
10:30
HELLO?
11:05
PLEASE ACKNOWLEDGE ME!!!
A FEW MOMENTS LATER IN THE HALL..
OKAY! NOT SO BAD! AT LEAST HE HASN'T YELLED AT ME YET!
OFFICE ENTRANCE
PATI ROOM
MEDICAL STUDENT!
WHAT THE HECK IS THE MATTER WITH YOU?
UH OH...
WHY DIDN'T YOU INTRODUCE YOURSELF TO ME APPROPRIATELY? YOUR PATHETIC PRESENCE DOESN'T EXCUSE SUCH BEHAVIOR!! I'M TOO IMPORTANT TO BE BOTHERED WITH YOU! YOU DON'T MATTER! TODAY, YOU JUST WATCH, DON'T TALK, AND DON'T ASK QUESTIONS! GOT IT?
NEXT PATIENT IS HERE!


MORE PATIENTS TO SEE...
12:30
1:15
2:00
ALL DONE HERE
HAHA! DON'T SAY SO MUCH NEXT TIME MEDICAL STUDENT!
DISCREET
COVERT
HOW'D SHE NOTICE ME?
ABYSS OF CONFUSION
YOU LITTLE, INSIGNIFICANT MEDICAL STUDENT! THE PATIENT IS ALWAYS RIGHT! WHY DIDN'T YOU TALK TO HER? WHY WERE YOU JUST WATCHING ME? WHY DON'T YOU ASK QUESTIONS DURING THEIR VISITS? YOU NEED TO HAVE A LARGER PRESENCE IN THE PATIENT ROOM!! YOU ARE THE DUMMEST, MOST HORRIBLE MEDICAL STUDENT I'VE EVER HAD! YOU NEED TO WATCH ME! I'M THE GREATEST! I DANCE LIKE A BUTTERFLY AND STING LIKE A BEE!! I'M KING OF THE WORLD! ARRGG!!


AND MORE PATIENTS TO SEE...
2:20
2:45
I'VE BEEN TRYING TO CONCIEVE FOR TWO WEEKS! WHY HASN'T IT HAPPENED YET?
NEW GAME PLAN: SURVIVAL! ASK ONE QUESTION AND GET HOME!
MINUTES LATER...
EXCUSE ME, SIR. I READ IN SEVERAL TEXT BOOKS THAT A PATIENT MUST TRY TO CONCIEVE FOR A YEAR BEFORE SEEING A SPECIALIST. WHAT PERIOD DO YOU THINK IS APPROPRIATE?
HOW DARE YOU ACCUSE ME OF ONLY TREATING INFERTILITY? I AM A WORLD REKNOWN OB/GYN WITH MULTIPLE PUBLICATIONS ACROSS THE SPECTRUM OF THE FIELD! EVERYBODY WANTS TO BE ME! I OUGHT TO CALL THE DEAN ABOUT YOU RIGHT NOW! YOU'LL NEVER AMOUNT TO ANYTHING!
FINALLY, NO MORE PATIENTS TO BE SEEN...
EXIT
5:00
OK! YOU ARE THE LAST PATIENT OF THE DAY AND WE'RE ALL DONE HERE.
WHOOSH!!


5 MONTHS LATER...
TAKE THESE EVALUATIONS TO THE MEDICAL CENTER.
STUDENT MAILBOXES
EVALUATOR: DR. PRIAPUS
STUDENT: MEDICAL STUDENT
IMPRESSIVE UNIVERSITY
CENTRAL PA HOSPITAL
OB/GYN DIVISION
"MEDICAL STUDENT PROVED TO BE ALOOF AND UNINTERESTED"
FINAL EVALUATOR GRADE: BRONZE STAR MINUS
Priapus
M.D.
EVALUATOR SIGNATURE


BAD EVAL EXPRESS... BUT STUDENTS HAVE A WAY OF PULLING TOGETHER IN ROUGH TIMES!
EXPRESS
BAD EVAL
EXPRESS
BAD EVAL
COORS
BVD
HE SAID I WAS AN EMBARRASSMENT TO THIS SCHOOL AND MY FAMILY!
HE SAID I WAS THE MOST INEPT STUDENT HE'D EVER MET!
HE SAID I WAS THE REASON SOME FAMILIES SHOULD BE FORCIBLY STERILIZED!
OVERTIME SPORTS BAR
HE SAID I WAS ALOOF AND UNINTERESTED!
LATER THAT NIGHT...
GOOD NIGHT WORLD!
GOOD NIGHT MEDICAL STUDENT
ARRGG! NIGHT!
MT OLYMPUS
THE END

Appendix B

VISUALIZING ILLNESS— COMICS & MEDICINE MINIMESTER SYLLABUS

Visualizing Illness through Comics
Minimester 2017

COURSE DESCRIPTION

In the past two decades many autobiographical comics have emerged that provide detailed descriptions of the lived experience of illness. Graphic narratives of illness convey the complexities of illness, trauma, loss, and suffering through the pairing of image and text. This minimester course offers the opportunity to explore the human face of illness through comics. Class activities will be a combination of exploration, creation, discussion, evaluation and reflection through a series of workshops and didactic sessions. Students will be taught the fundamentals of comics making and engage in the practice as a means of reflecting on and conveying their experiences of learning to become physicians. Additionally, students will read and discuss comics on a variety of health care and illness experiences including, but not limited to, cancer, end-of-life, caregiving, Parkinson's, transplant, mental health, trauma, grief, These works will function as visual case studies that provide the patient, caregiver, and health provider perspectives of illness. In addition to reading comics, students will also make their own comics narratives. Class time will be spent reading and discussing excerpts from autobiographical and fiction comics while also making comics. Students will be given time to explore the works and ultimately will select one work to read on their own and later present to the rest of the class. Throughout the course, class time will be spent making and discussing comics with each day focused on a particular theme.

Students will:

- Explore the patient and caregiver experience of illness through visual case studies (comics).
- Enhance the capacity for empathy through reading graphic narratives about illness and medical care.
- Discuss the inter-relational components of the clinical encounter and the ways in which encounters can break down.

- Examine comics as a form of reflective practice.
- Analyze and critically reflect on graphic narratives.
- Create an original comic based on a meaningful health care experience.
- Connect the lived experience of illness to the science of illness to cultivate an ability to better integrate the science and art of medical practice.
- Improve communication skills through the telling of their own stories through image and text.

COURSE REQUIREMENTS

Attendance & Participation

* Students will attend all sessions (unless excused with the course director)
* Students will be expected to attend all class sessions and actively participate in all in class didactics and exercises.

Clinical Shadowing and Reflection

* Each student will be required to complete a shadowing experience with Dr. Beach or Dr. McCammon. There will be a sign up of available dates/times that will be made available the first day of class.
* After completing the shadowing experience, each student will write a one to two paragraph reflection on their experience and on what they observed. The reflection will be due in class the day after your shadowing experience.

Daily Journal

* Each student will keep a daily journal. Entries will consist of in-class exercises as well as at home exercises. The journals will be checked for completion but will not be read in depth as this is meant to be a space for you to explore and develop your ideas.

Comic book presentation

* Students will read a Graphic Novel of their choosing (see bibliography for selection) and will write a one page response paper. The paper will focus on the student's response to the work and each student will give a ten minute presentation about the work they selected and their response to it.
* select a short excerpt to share with your class
* develop questions to respond to

Final Project

* During the two week course, students will be asked to develop a narrative about healthcare. This can be based on a personal experience as a patient, loved one, or provider. It can be an imagined experience based on an issue of healthcare that concerns the student whether that be the influence of power on the

patient/provider relationship, end-of-life care, your own role as a provider, etc. Each student will create a comic out of the narrative they develop and share that comic with the class during our final meeting.

GRADING:

Category	***Percentage***
Participation & Attendance	30%
Clinical Shadowing Response	5%
Daily Journal	15%
Comic Book Paper & Presentation	20%
Final Project	30%

SCHEDULE, READINGS AND ROOM LOCATION ***(subject to change if necessary)***

Week 1:
Session 1— Monday, August 28th, 1pm-3pm
Introduction to the Course and Introduction to Graphic Medicine

categories of comics

Before Class:
- Before Class:
    - Read Introduction to the *Graphic medicine manifesto*
    - Read selection from
        - *Taking turns* by MK Czerwiec
        - *Scars, stories, and other adventures* by MK Czerwiec
    - Visit the website www.graphicmedicine.org
        - Prior to the first class meeting visit www.graphicmedicine.org and explore the resources and materials available on the website. Find something to share with the class (this can be a comic you found that you are interested in reading, a podcast you watched or a blog post you read, something you learned about comics, etc.) In Class:
    - Introduction to the course

- Introductions & sharing of what you found on graphicmedicine.org
- Introduction to Comics & Medicine
    - With special guest MK Czerwiec, RN, MA
- Comics-making exercises
- Looking through some of the Comics library available
- Lynda Barry exercise- 2 minute diary

Review comics bibliography and rank you top 3 choices for the comic book you want to read for your individual comic presentation and email selection to rawaters@utmb.edu If selection emailed by midnight August 22nd the book will be available in class on August 23rd for check out. Each student will read a different text and text selections will be made on a first come first serve basis.
All selections must be emailed to rawaters@utmb.edu by 11:59pm, August 23rd.

Session 2— Tuesday, August 29th, 1pm-3:30pm
Introduction to Comics Theory and reIntroduction to Creativity

- Before Class:
    - Watch Scott McCloud TedTalk, "The Visual Magic of Comics"
        - (link available on Blackboard- http://www.ted.com/talks/scott_mccloud_on_comics)
    - Read selections from
        - *Everyday matters* by Danny Gregory
        - *Understanding Comics* by Scott McCloud
    - Lynda Barry Exercise- 2-minute diary

- In Class:
    - Introduction to Comics Theory
    - Re-Introduction to creativity
    - Keeping a visual journal- Journal making and Exercises to get started
    - Listen and make
    - Hand out texts for individual comic book presentation

Session 3— Wednesday, August 30th, 1pm-3pm
Visual Storytelling and Telling Illness through Comics

- Before Class:
    - Journal Exercise
    - Read "Graphic Medicine: use of comics in medical education and patient care" by Michael Green & Kimberly Myers
    - Read "Graphic medicine: comics as medical narrative" by Ian Williams
    - Read selections from
        - *Mom's cancer* by Brian Fies
        - *Cancer made me a shallower person* by Miriam Engelberg
        - *Cancer vixen: a true story* by Marisa Marchetto

        - *Our cancer year* by Harvey Pekar and Joyce Brabner
- In Class:
    - Introduction to Visual Narratives
    - Discussion of texts read
    - Comics-making and HIPAA
    - Comics-making exercises
    - Hand out texts for individual comic book presentation

Session 4— Thursday, August 31st, 2pm-4pm
Comics and Making Sense of Experience and Illness

- Before Class:
    - Journal Exercise
    - Read "Comics as a means of observation and reflection" by Rose Glenerster
    - Read selections from:
        - *Hyperbole and a half: unfortunate situations, flawed coping mechanisms, mayhem, and other things that happened* by Allie Brosh
        - *My degeneration* By Peter Dunlop-Shoal
        - Medical student comics
        - *Monsters* by Ken Dahl
        - *The bad doctor* by Ian Williams

- In Class:
    - Comics as reflection discussion
    - Stigma and understanding illness didactic
    - Discussion of works read
    - Story circle to brainstorm for final project

Session 5— Friday, September 1st, 1pm-3pm
Comics and Power (Dr. Beach)

- Before Class:
    - Journal Exercise
    - Read "Why the 15-Minute doctor appointment is dangerous" by Peter Pronovost
    - Read selections from
        - *Disrepute* by Thom Ferrier
        - "Missed it" by Michael Green
        - Medical student comics
        - Foucault comics
        - "Inhospitable" by Paula Knight
        - *Sick* by Gabby Schulz

- In Class:

- Power and medicine
- Discussion of works read
- Comics-making exercises

Week 2:
Session 6— Monday, August 29th, 1pm-3pm
Presentations of Individual reading assignment

- Before Class:
    - Journal Exercise
    - Read your selected text for comic book presentation
    - Write a 1-page paper on your reaction to the text. This is not a book report but instead should be your response to it.
    - Prepare a 10-minute presentation about the work you read and your response to it.

- In Class:
    - Turn in response paper
    - Presentations (10 minutes each)
    - Return borrowed books to Amerisa

Session 7— Tuesday, August 30th, 1pm-3pm
Comics and Understanding Difference
- Before Class
    - Journal Exercise
    - Read selections from
        - *The spiral cage* by Al Davidson
        - *A hole in the heart* by Henny Beaumont
        - *El deafo* by Cece Bell
        - *March: book three* by John Lewis, Andrew Aydin, Nate Powell
        - *Blue bottle mystery: an asperger adventure* by Kathy Hoopmand, Rachael Smith, and Mike Medaglia
- In Class:
    - Medicine and understandings of difference
    - Discussion of works read
    - in-class time to work on projects
    - Story circle- Sharing progress on final projects

Session 8— Wednesday, August 31st, 1pm-3pm
Comics and End-of-Life and Hospice (Dr. McCammon)

- Before Class:
    - Journal Exercise

    - Read selections from
        - *Things to do in a retirement home trainer park when you're 29 and unemployed* by Aneurin Wright
        - *Special exits* by Joyce Farmer
        - *Seeds* by Ross Mackintosh
        - *Can't we talk about something more pleasant?* by Roz Chast

- In Class:
    - Hospice and end-of-life care
    - Discussion of works read
    - Comics-making exercises

Session 9— Thursday, September 1st, 1pm-3pm
Comics and Caregiving and Alzeheimer's (Dr. Crowder)

- Before Class:
    - Journal Exercise
    - Read introduction to *Aliceheimer's* by Dana Walrath
    - Read excerpt of
        - *Tangles* by Sarah Leavitt
        - *Aliceheimer's* by Dana Walrath
        - *Dad's not all there anymore: a comic book about dementia* by Alex Demetris
        - *Wrinkles* by Paco Roca

- In Class:
    - The challenges of caregiving discussion
    - Discussion of works read
    - Comics-making exercises

Session 10— Friday, September 2nd, 1pm-4pm
Final Project Sharing

- Before Class:
    - Journal Exercise
    - Complete final project and prepare final presentation

- In Class:
    - Comics-sharing
    - Wrapping up the course

CREATIVE EXPRESSIONS PROJECT REFLECTIVE WRITING RUBRIC

STUDENT ID: Percentage SCORE: Artwork P/F:

CEP Reflective Evaluation Rubric

DIRECTIONS FOR FACULTY: Please indicate the rating that most accurately describes each of the four sections and provide comments in the "comments" space provided.

1. Content & Reflection (70%) Adapted with permission from Moon, JA Framework for Reflective Writing, www.tawasol.org/download/file/340/			**Basic Examples:**
☐	Critical Reflection (Excellent)	Artistry, journal and writing demonstrate fresh, original ideas. Point of view thoroughly explored, clearly expressed. Description serves process of reflection, covering issues for reflection, noting context. Clear evidence of "standing back" from events, may be indicated through internal dialogue. Account recognizes events exist in historical or social context that may influence reaction. Recognition the personal frames of reference can change according to prior experience, emotional state, acquisition of new information, review of ideas, time passing. Views and motives of others considered against those of the writer. Points for learning from experience are noted, profound questioning of one's beliefs, habits, and assumptions. Commitments to new actions noted.	*I saw a billboard and it was blue, but my friend said it was red. I'm not sure why she thought it was red. It was definitely blue. The blue reminded me of a doctor's scrubs. Why is blue the common color for scrubs? Blue is used a lot in medical settings. Blue is a calming color. I'd like to use blue in my artwork as a way of communicating its relevance in medicine.*

☐	Dialogic Reflection (Good)	Artistry, journal and writing show thoughtful reflection. Writer's point of view is apparent. Not just description but interwoven with reflective comments. External information brought in and discussed in relation to where reflection occurred. Analysis of motives or reasons for behavior. Willingness to be critical of one's own actions, some self-questioning and recognition of the impact on oneself and others. "Stepping back" from events leading to different levels of discourse. Contemplation about role of "self" in events and actions, consideration of the quality of one's own judgments and possible alternatives acknowledged, but not discussed in detail. Reflection is analytical or integrative, linking factors and perspectives.	*I saw a billboard and it was blue, but my friend said it was red. I'm not sure why she thought it was red. It was definitely blue. The blue reminded me of a doctor's scrubs.*
☐	Descriptive Reflective (Needs Improvement)	Artistry, journal and writing contain some interesting ideas, but artist does not explore them thoroughly. Description of events, reflection points implied but not reflected upon. Few references to alternative viewpoints/attitudes. Recognition that further exploration or reflection would be valuable, but no discussion or detail as to why or how. Questions beginning to be asked about the issues/actions, writer beginning to "stand back" from events but lack of responding to the questions shows little actual reflection. Some evidence of deeper consideration in relatively simple language. No real evidence of notion of alternative viewpoints in use.	*I saw a billboard and it was blue, but my friend said it was red.*
☐	Superficial Descriptive (Unsatisfactory)	Artistry, journal and writings imply restates facts rather than reflecting on his/her own experience. Description of events only, no discussion beyond description. Generally one point is made at a time. Ideas tend to be linked by sequence or storytelling rather than meaning. Emotional reactions may be made but not explored correlated to behavior. External information or ideas brought in but not questioned. No mention of how events may have impacted behaviors. Most points made with equal weight, little to no evidence of reflection.	*I saw a billboard and it was blue.*

Comments:		
2. Journal Documentation/Aesthetic Organization (20%) (Circle one descriptor)		
Excellent	Organization enhances the main ideas. Presented logically, fluency in thought and actions is exhibited	Comments and Feedback:
Good	Organization is generally good, but there may be some extraneous details or unclear to thoughts and actions.	
Needs Improvement	Includes an organizational skeleton (intro, ideas, some haptic effort) but lacks cohesion and transition in product and ideas.	
Unsatisfactory	No clear direction, main ideas are vague and connections are confusing or incomplete.	
3. Journal Documentation/Aesthetic Mechanics and Fluency (10%) (Circle one descriptor)		
Excellent	The journaling and aesthetic attempts flows and shows high level of sophistication. Strong and specific choices are used to convey meaning	Comments and Feedback:
Good	The journaling and aesthetic attempts sometimes stiff or choppy.	
Needs Improvement	The journaling and aesthetic attempts may be incomplete or rambling.	

Unsatisfactory	The journaling and aesthetic attempts are choppy, awkward, hard to follow.	
4. Art work(s) P/F You must have a grade of PASS on Artwork to get credit for course		
Pass	Created work in a reflective and thoughtful way	Comments and Feedback:
Fail	Created work that lacks completeness	

PAST ART WORKSHOPS/COURSE EXPERIENCES

With a Bachelor of Fine Arts in Photography and my background in community-based collaborative arts projects, I use the foundation of education and experience I have in art theory and practice to understand the practice of art making and to develop and teach arts-based curricula. I first began this work while doing a Masters in Interdisciplinary Studies in Bioethics and Medical Humanities at the University of Louisville as a teaching assistant on an elective, The Art of Wellness, for senior medical students. Since joining UTMB I have served as a collaborative partner for the Creative Expressions Project, a project that affords second-year medical students the opportunity to make artwork as their final project for the Humanities, Ethics, and Professionalism course. I am also the course director for a creative course offered to undergraduate students as part of the Joint Admissions Medical Program (JAMP) summer internship. In these roles I both designed and taught arts-based curricula for medical and undergraduate students. These courses included:

August 2017-September 20167
Course Designer and Co-Instructor, Visualizing Illness through Comics, Minimester Course, School of Medicine, UTMB
May 2017-June 2017
Course Director and Instructor, Creative Expressions Project, JAMP, UTMB
May 2017-June 2017
Course Director and Instructor, Medical Humanities Course, JAMP, UTMB
August 2016-September 2016
Course Designer, Visualizing Illness through Comics, Minimester Course, School of Medicine, UTMB

May 2016-June 2016
Course Director and Instructor, Creative Expressions Project, JAMP, UTMB
September 2015-December 2015
Teaching Assistant, Introduction to Graphic Health, MEHU, Graduate School of Biomedical Sciences, UTMB
May 2015-June 2015
Course Director, Co-Instructor, Creative Expressions Project, Joint Admission Medical Program (JAMP), UTMB (see photos in Appendix A).
May 2015-June 2015
Course Director, Co-Instructor, Introduction to Medical Humanities, JAMP, UTMB
May 2014-June 2014
Co-Instructor, Creative Expressions Project, JAMP, UTMB
May 2014-June 2014
Co-Instructor, Introduction to Medical Humanities, JAMP, UTMB
August-May 2013
Graduate Teaching Assistant, The Art of Wellness, School of Medicine, University of Louisville

Additionally, I have been invited to give a variety of art workshops to various groups from children to clinical and pre-clinical students to retired adults. I bring my experience in drawing, printmaking, and collaborative art to the workshops I develop both introducing various art practices to students and also coordinating with other artists to contribute expertise outside of my own. These invited workshops include:

Rediscovering Creativity, Printmaking Workshop, PEO International Chapter EF, Galveston, Texas, August 18, 2016
Expressive Comics, Comics-making Art Workshop with 9-12 year olds, Galveston Art Center Summer workshop Series, July 1, 2016
Relief Printmaking, Printmaking Art Workshop with 5-8 year olds, Galveston Art Center Summer workshop Series, July 1, 2016
History of Art and Anatomy at UTMB Printmaking Workshop, National Science Research Forum, UTMB, April 28, 2016
Waters, R. Amerisa, reLearning to Draw: Making Meaning through Art Creation-Art Workshop. 2016 Health Humanities Conference: Arts and the Health Humanities: Intersections, Inquiry, Innovations. Cleveland, Ohio, April, 4, 2016.
Art and Healing 5-part Workshop Series, University of Houston Honors College, February-March 2016
Visual Narratives of Illness, March 10, 2016
Comics and Performance, March 1, 2016
The Art of Anatomy, March 1, 2016
Art Making as Reflective Practice, February 24, 2016
Drawing Meaning: Bearing Witness through Art, February 22, 2016
Remembering Creativity: Printmaking Workshop, Arizona State University Honors College, February 1, 2016
reLearning to Draw: Making Meaning through Art Creation, Printmaking

Workshop, Gold Humanism Honor Society, UTMB Branch, August 12, 2015

Art in Medicine, Drawing Workshop co-led with Jerome Crowder, PhD, 5th Annual APRIME- Time Summer Conference, July 13, 2015 (see photos in Appendix A)

Superhero Trading Cards, Collage Art Workshop with 6-9 year olds, Galveston Art Center, Summer workshop Series, June, 12, 2015

The Art of Anatomy: Learning Anatomy through Art Creation, Lecture and Workshop, Post-Bac/Pre-Medical Student Program, University of Houston Honors College, April 24, 2015.

Introduction to the Medical Humanities through Life Drawing, Drawing Workshop, Guest Class Facilitator-Introduction to the Medical Humanities, University of Texas at Austin, April 13, 2015

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