

LEARNERS' AND PATIENTS' EXPERIENCES
OF DISGUST IN ACADEMIC MEDICINE

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ABSTRACT

Disgust is a part of medical education. Whether in the anatomy lab, the operating room, or the hospital wards, medical school is often the first time that future doctors see human suffering manifested in bodies that elicit embarrassment, disgust and fear. Over the course of training, seeing such bodies goes from exceptional to commonplace as doctors learn to witness and empathize with suffering without becoming overwhelmed by it. In this thesis, I examine students' first encounters with abject bodies in the anatomy lab, their later encounters with such bodies in their clinical years, and the educational programming shapes students' gaze towards these bodies as they develop from laypeople into professionals. I argue that while medical humanities curricula implemented into gross anatomy help students manage challenging personal feelings elicited by the corpse, taboos and silences during the clinical years prevent students from thinking deeply about how patients experience having bodies that elicit disgust. The dearth of reflection on feelings of disgust during clinical training leaves doctors in training ill-equipped to promote and maintain patient dignity during medical care, particularly at the end of life.

TABLE OF CONTENTS

ABSTRACT.....	ii
CHAPTER 1: INTRODUCTION.....	1
Disgust and The Abject.....	3
CHAPTER 2: THE ANATOMY LAB.....	6
Dissection as a Rite of Passage.....	7
History of Cadaver Dissection in the United States	9
Modern Anatomy Education.....	12
CHAPTER 3: TRANSITION TO CLINICAL YEARS.....	15
The Hidden Curriculum.....	16
Patient Experiences of Disgust.....	18
Provider Management of Disgust.....	21
Disgust and Care Planning.....	23
CHAPTER 4: CONCLUSIONS.....	26
WORKS CITED.....	29

CHAPTER 1: INTRODUCTION

During my second year of medical school, I asked to spend time at the Hospice House to get clinical experience that might contextualize my time in the classroom. My preceptor--either unsure or very sure what to do with me--suggested that I spend the day with the nurses aides, and that I practice observing and interacting with patients while helping to bathe them. Late in the day, I was called in to “help” change a wound dressing for a young man several years younger than me who was dying from a traumatic injury; while driving under the influence, he got into a disfiguring accident but was found not to be a candidate for full surgical repair due to underlying cardiac disease. Though I had seen human bones many times in the anatomy lab, nothing prepared me to see the femoral head of a living person, wet and vascular and riddled with osteomyelitis. Nor had anything prepared me to keep my face calm for this young man covered in blood and pus and stench.

Two years later, when I went to the Hospice House to request a letter of recommendation from the attending physician, one of the nurses stopped me and told me I looked familiar. “Weren’t you that student who helped with that big dressing change? Which patient was it...oh, the young kid down the hall?” Though blood, pus and bad smells are part of the everyday practice of a hospice nurse, I was glad that day had made an impression on somebody else. More than my white coat ceremony, my day changing the dressing for that young man felt like my initiation into medicine.

Learning to deal with the human body--and to manage the feelings of disgust that can be aroused in intimate encounters--is part of the transition from preclinical to clinical

medicine. Much has been written specifically about cadaver dissection as a formative experience in medical education; less has been written about students' initial encounters with living patient bodies on the wards and the they learn to deal with their discomfort with living patients' bodies. The experience of bodily decay is one that is mediated by multiple actors, and overlaid with both the patient and student's beliefs, values and fears as they relate to the breakdown of the human body. Students' unplanned and haphazard encounters with living patients' challenging bodies are both formative experiences for medical learners and potential sites of dignity violation for patients.

In this thesis, I explore how students encounter disgust in medical education--in both the cadaver lab and the hospital wards--and how these encounters become part of students' socialization into the medical profession. I look particularly at how disgust colors encounters with severe illness, dying and death, and how these intense experiences shape how future physicians see their role in relation to their patients. I first write about the cadaver lab, and describe how instructors have historically attempted to both suppress and mold student feelings of horror in the dissection room. I explore how modern cadaver labs (and the structured medical humanities curriculum integrated into many schools' anatomy courses) both do and do not prepare students to encounter patients with abject bodies. I then move to the clinical years and look at the addition of real patients to medical education; I explore how patients experience having a body that elicits disgust in order to identify what is at stake for patients in interactions where providers experience disgust. I conclude by discussing the gaps in both medical education and the current

medical education literature regarding the experience of disgust, and how physician failure to reflect upon and manage feelings of disgust can negatively impact patient care.

Disgust and The Abject

Before delving into the role of disgust in medical training and care, it is important to define disgust. Disgust has been described by anthropologists as a core emotion--one that is present across cultures and is accompanied by consistent facial expressions and physiologic responses. Disgust is evoked by stimuli that evoke fears of filth, infection or contamination, and evolutionary psychologists see disgust as an innate protective response that prompts avoidance behaviors that may keep one safe from disease (1). Some anthropologists have debated, however, whether disgust is shaped entirely by evolutionary forces or whether it is shaped by culture and used to uphold social structures and dictate acceptable behavior (1). Disgust is a complex emotion that can be accompanied by feelings of fear and anger, and it is often associated with conscious or unconscious moral judgment towards the object of one's disgust (1).

Disgust is an emotion often experienced in encounters with what some refer to as "the abject" (2). The abject is something that elicits feelings of horror and must be rejected; this rejection helps the subject construct a sense of self through defining what they "are not" (2). It both disrupts boundaries (for example, between the living and dead, sick and well) and--through its rejection--reifies these boundaries (2). Though "the abject" is not explicitly defined by its relationship to illness and death, wounds, excretion

and corpses are some of the most commonly-used examples of the abject because they confront the viewer with evidence of the frailty of the human body and fundamentally and viscerally challenge one's sense of self as a bounded, autonomous being (2).

Disgust and the abject can be useful concepts for looking at how healthcare providers develop their professional identity and navigate the challenges of being deeply immersed in suffering and death while maintaining their sense of self as one who is not (yet) aging, ill or dying. While one could argue that feelings of disgust create a distancing between providers and patients that inhibits empathy development, it is also worth noting the importance of creating boundaries so providers do not become overwhelmed by patients' suffering.

Students begin learning to navigate competing desires to maintain closeness to and distance from suffering early in the educational career when they are given access to bodies in a way that they likely weren't given in other contexts. Most medical students begin their education in the cadaver lab, where they are immediately confronted with a dead and naked body, most likely marked by visible signs of aging and illness. It is expected that students begin the course with fear and discomfort, and that they complete the course with the coping skills that make cutting open a corpse's digestive tract just another routine day of school. It is assumed that they use these same skills when later encountering abject bodies on the hospital wards.

This begs several questions. How do students develop comfort with their cadaver? How do they see the cadaver when they begin their education, and what kind of gaze are they taught to develop over the course? What are the implications for patients when

future doctors use this same gaze in the wards and clinic? To answer these questions, we must look closely at the anatomy lab, the humanities programming offered at many schools to supplement dissection, and the history of how these curricula came to be.

CHAPTER 2: THE ANATOMY LAB

After donning their short white coats for the first time at the White Coat Ceremony, most medical students look forward to (or fear) their first day of anatomy lab as part of their induction into medicine. I remember feeling excitement seeing the anatomy labs during my medical school tours, which was replaced by dread when it was my turn to dissect. I was part of the team assigned for the first day of dissection, and was surprised to find our cadaver prone, with his hands and head mummy-wrapped in bandages, ostensibly to prevent more delicate structures from drying out. By the time I learned what my donor's eyes and nose looked like, I had already flayed his arms (his muscles were atrophied almost beyond recognition when compared to muscles in the Netter guide), removed his heart and lungs (which came out in damp, spongy chunks), and sliced open his GI tract (he died constipated.) While I expected to be confronted with my donor's humanity, which would slowly disappear over my 6-week dissection, I was surprised that I was instead struck with his personhood in brief flashes throughout my time with him. At times my donor seemed like a pile of damp, inanimate pile of organs and then--we would uncover his face, or my lab-mates would point out that I was absentmindedly holding his now-skinless hand--he would be clearly and horrifyingly human.

Dissection as a Rite of Passage

Unlike the White Coat Ceremony--a recent tradition--medical trainees have been dissecting cadavers since the 3rd century BC in Ancient Greece (3). For students without prior clinical experience, the cadaver may be their “first patient”; for others with little exposure to death, the cadaver lab may be their first encounter with a human corpse. Cadaver labs are an opportunity not only for students to familiarize themselves with the human body, but also to learn to approach the human body as a physician rather than as a lay person.

Gross anatomy is a time in which students are inducted into multiple ways of looking at the human body. When medical students encounter the cadaver, they confront feelings about their own decline and death, as well as deaths that they have experienced as a friend or family member, and must learn to instead approach the human body as a physician--one who is surrounded by death and suffering but does not necessarily face the imminence of their own demise (2). Students approach their cadaver with a layperson’s sense of horror, and, to varying extents learn to map over this with other ways of seeing the body that create professional distancing (2).

One such way of seeing is the lens of biomedicine or the so-called “medical gaze” through which those in the medical field learn to see the body as a series of parts. In his book, *The Birth of the Clinic*, Michel Foucault writes about how as the science of medicine advanced in the 18th Century, practitioners shifted their line of inquiry from “what is the matter with you?” to “where does it hurt?,” increasingly localizing disease as

abnormalities in discrete parts of the body (4). This perspective is a useful framework for identifying the kinds of pathology that modern medicine is most adept at resolving. However, it also represents a departure from the whole-body, whole-person layperson experience of the body and its medical problems. The medical gaze can also be a way that physicians distance themselves from experiencing distressing phenomena in the human body while being deeply engaged with understanding and resolving their patients' disease. It is less emotionally taxing to talk about a rising creatinine than a patient struggling to breathe as their body swells with fluid.

As students both literally and figuratively break down their cadavers and learn to identify its components in the context of disease, they learn to overwrite their lay perceptions of the cadaver with a biomedical understanding of the human body. As such, gross anatomy is a key time at which the gap between how patients and doctors understand the diseased body develops. But students do not simply exchange a lay person's understanding of the body with a biomedical one; rather, they learn to move between understandings of the human body in ways that ideally allow them to relate to their patients while also protecting themselves from the emotional distress of engaging with illness, death and dying. Being able to oscillate between modes of seeing the body is key to future clinicians' ability to effectively engage with their patients (2).

History of Cadaver Dissection in the United States

Cadaver labs have never been a neutral or purely scientific learning space, and anatomy instructors have long grappled with the extent to which they emphasize the affective component of anatomy lab and its role in professional identity formation. Historically, the shortage of gifted human remains made human dissection a transgressive and morally dubious practice. Body donation was not a standardized process in the United States until the late 1960s; prior to this, cadavers in American medical education were often executed criminals, specimens stolen from graveyards, and the unclaimed remains of people who died in public institutions, hospitals, asylums and prisons. As such, the bodies used in medical education tended to be those of the poor, mentally ill and people of color--in short, they were bodies deemed less human (3). In the mid 19th century, as dissection became commonplace in medical training, records show that anatomy instructors at this point in time treated gross anatomy as a time of transition and danger, during which students' characters could become calloused and hardened or during which they could achieve a reverence for the divine not accessible to lay people (5). Instructors feared their students coming to see the body as an object, and implored their students to protect their moral character throughout their dissection (5).

Both students and instructors identified the anatomy lab as a time of transition and professional identity formation. Photos by students in the 1880 (a time when photography was sparingly accessible) show medical students choosing to depict their time in school through posed portraits of them at the dissecting table. A distinct genre of photographs

appears from this era that includes photos of students posed neutrally with their cadaver, as well as darkly comedic photos that emphasize the boundary transgressions of the anatomy lab (5). One image, “A Medical Student’s Nightmare,” for example, depicted a student asleep on the dissecting table as skeletons surrounded him as if ready to dissect; another famous image showed students playing cards with their cadaver, posed with a lit cigarette in his mouth. These photos can be seen as crass disregard for human dignity or as students’ attempts to navigate their intimate exposure to and relationship with death. Regardless, they show that the anatomy lab was an important part of students’ identity as future physicians, and that students saw dissection as an activity with moral, metaphysical and scientific lessons.

Gross anatomy’s place in medical education was challenged at the turn of the 20th century when anatomy started to be overshadowed by newer experimental sciences, and this push towards constructing medicine as an empiric, scientific profession pushed anatomists to de-emphasize the affective components of gross anatomy and present it as purely a scientific pursuit (5). As training physician-scientists became a goal of medical education, anatomy transitioned from art to science, and anatomists spoke less about the importance of cultivating sympathy through dissection. By the early 1920s, the group photographs that marked students’ initiation into medicine through dissection all but disappeared (5).

Another tide change occurred following the second world war, this time brought on by sociologists rather than biomedical scientists. During a post-war boom in medical sociology, researchers noted that the shift of anatomy from art to science had created an

environment where emotionality in the dissecting room was something to be overcome in the process of developing a physician's "detached concern" (5). Cultural upheaval in the 1960s and 70s sparked renewed interest in training humanistic and scientifically competent physicians, and dissecting rooms were identified as a crucial site where future providers learned to repress the affective responses to suffering (5). Like in the mid 1800s, gross anatomy had once again become a site of danger in the professional development of young doctors.

Also in the late 60s, the work of Elisabeth Kubler-Ross prompted public interest in the study of death and dying, and legitimized the idea that physicians should confront and reflect on death and dying in order to better guide patients' through life-limiting illness (5). This cultural phenomenon coincided with the 1968 passage of the Uniform Anatomical Gift Act, which streamlined the process of donating human remains and changed the social origins of medical cadavers from unfortunate chumps to intentional donors (5, 3). As cadavers' origins became less shameful, medical schools began actively acknowledging donors and cultivating respect for them through memorial services, which began in the UK in the mid-60s and in the US in the early 70s (5). Medical educators in the 80s and 90s began discussing not only how to avoid the hardening influences of dissection and the danger of "detached concern," but also how students' highly supervised early encounters with death could become a positive stage of professional development (5).

Modern Anatomy Education

As in the beginning of the 20th century, gross anatomy's place in medical education has once again become threatened by developments in other scientific domains. Modern medicine has come to increasingly focus on a cellular and molecular understanding of the body and anatomy's place in the curriculum has had to be shortened to make room for cell biology and genetics. Dissection has also been challenged by technological advancements that provide cheaper and more efficient ways of learning anatomy. But unlike the atomists of the early 1900s who doubled down on teaching anatomy as a hard science, today's educators have chosen to emphasize human dissection as a unique opportunity to teach ethical and humanistic values and reflect on death and its significance (6). Dissection proponents argue that cadavers--unlike models--force students to engage with the body in a way that highlights individuality and personhood through artifacts like scars, tattoos and nail polish (2). Their abject position on the border between personhood and objecthood forces a reckoning with death and dying and one's relationship to the suffering and decaying body in a way that a model cannot.

Students today are encouraged to form an intimate relationship with their cadavers, seeing them as a "first patient" or "great teacher," rather than as an inanimate object (7). As a personal aside, neither of these roles seemed to accurately describe my time in the cadaver lab. Sawing my "first patient's" leg off with a hacksaw did not feel like a proper introduction to the healing arts, and I remember feeling not at all like a doctor any time I cut through his delicate vasculature (or watched the our instructors un-

precisely hack through a tangle of nerves in order to show us a structure underneath). And I felt guilty complaining that my donor's massively dilated heart and damp, brittle lungs taught me nothing about the thoracic cavity--if he was a teacher, had he failed me personally by developing congestive heart failure, or simply succumbed to chronic disease?

Unlike the relationship that a student may have with a living teacher or patient, the relationship between student and donor is largely driven by the student, with the donor becoming a blank canvas onto which a student's thoughts, fears and values are drawn. Although students surveyed in 2014 overwhelmingly reported a desire to know their donor's medical and life history, most students are provided only with the limited information on their donor's death certificate, including age, profession and cause of death; only 22% of students surveyed had been told their cadavers' birth name (7). When not provided with information about the person they are dissecting, some students take matters into their own hands. Sixty-eight percent of students who reported dissecting an unnamed donor also reported that their team had chosen a name to refer to their cadaver by, and these students who named their cadaver reported having spent more time than the non-namers speculating about their donor's life (7).

But there are limits to the extent to which students prefer to be reminded of the personhood of the cadaver that they are violently dissecting. Of the students who were not told the name of their donor, only 47.7% stated that they wished to know their donor's first name, and 35.7% reported a desire to see a photo of their donor taken during their life. While 66.5% of students who invented a name for their donor used the name

regularly during dissection, only 53.9% of students who were told their donor's real name name regularly used it (7). Students, it seems, prefer the donor's make-believe personhood to the real deal.

Through their dual position as both person and object, cadavers provide students with an incomplete education in illness, death and dying. Their abject nature forces students to confront their own thoughts and fears regarding aging, death and dying. While nuances in educational programming can shape how students develop both the empathy and distance that can help them engage professionally with human suffering, as passive and mostly-anonymous objects, cadavers fail to challenge students to consider anything but their own thoughts and ideas about death and dying. A cadaver cannot express values or religious ideas that differ from those of the student dissecting them, nor can it protest if it feels its dignity has been violated by behavior that the student has decided to be reasonable.

In short, the cadaver is a tool through which students' professional development through dissection is shaped formally by educational curricula and informally by themselves and their peers. Notably, the people in the dissection room who are involved in these formative educational experiences tend to be more racially and socioeconomically homogenous than both the American population at large and the populations served by many academic medical centers. Patients--and their complicated lives, ideas and values--are silent in this process.

CHAPTER 3: TRANSITION TO CLINICAL YEARS

Patients are silent in the early years of medical school, but become an integral part of medical education in the clinical phase of school. For my medical school cohort, the transition to clinical education coincided with the Covid-19 pandemic, and with this came universal masking, visitor restrictions and telemedicine. While the residents and attendings bemoaned the new PPE, nearly all of my classmates confided that they were grateful for face coverings--whether because they covered our reactions to the shocking things patients did and said or because they masked patients' responses to our own faux-pas as we played at being doctors. As learners, rather than healers, we sometimes felt as if we had come to gawk at suffering bodies without offering anything in return. At least the masks hid our reactions to being in this strange place, and patients' reactions to having us there.

On my internal medicine rotation, me and my classmate got a text one evening from our attending that a certain evening admission was an “interesting patient” and we should try to examine her before rounds. Our resident sent us a follow-up text letting us know there were some photos in her chart, and when I opened the photos I was shocked to see that eight out of her ten fingers and the vast majority of her toes were shriveled, black and gangrenous. The next morning I met a stubborn middle-aged woman who said she doesn't like going to the doctor, and told me she hadn't noticed her hands rotting off because “the lighting in my apartment isn't very good.” Her pile of belongings included a

pair of oven mitts that she must have worn at home in denial of what she could see and feel happening to her hands.

I was grateful to my mask in that encounter, and also to the text from the resident quietly acknowledging that we, as new learners, would not have been ready to enter this patient's room without first looking at the photos and thinking about how to approach this patient with the sensitivity she deserved. At times, I felt that I was trying to learn how to handle patient bodies by repeated exposure to new and shocking things, and repeated failure to hide my surprise and horror. Receiving the chance to prepare for such an encounter gave me the rare chance for thoughtfulness and preparation.

The Hidden Curriculum

Students at most medical schools transition from the classroom to the clinic in their third year of medical school, and many students anticipate third year as the start of learning how to be a doctor in the practical sense. Third year marks a shift in student learning occurring predominantly from a top-down formal curriculum, to learning occurring increasingly through the informal interactions with instructors and peers often referred to as the "hidden curriculum." (8) There are a number of reasons why there is less standardization and administrative control over what students learn in their clinical years. Due to the nature of hospital work, students' education becomes dyssynchronous with that of their peers who are completing rotations in a different order, and at many schools students embark on rotations at different affiliated hospitals. Even within the

same rotations, students scrub into different surgeries and participate in the care of different patients. Administrators and curriculum planners have little control over when and how students encounter emotionally challenging situations on the wards and how these events shape students' developing professional identities.

Educational sociologists break down medical education into a number of domains, usually including the “formal” and “hidden” curricula; these distinctions are particularly important when studying how students not only learn the facts and science of medicine, but also become socialized into the culture of medicine and develop their professional identities (8). While medical schools ideally project uniform messages through all aspects of the curriculum, it is accepted that the ideals of professionalism formally taught to students can be contradicted by what students observe and mimic in the clinic (8). The hidden curricula has a lot in common with what the sociologist Erving Goffman describes as “back-stage” social interactions, and like them, the hidden curriculum is often assumed to have an element of truthfulness to it that is not present in “front-stage” formal education which has been constructed for observation and critique (8).

Like in the anatomy lab, students in the hospital and clinic routinely encounter bodies that evoke feelings of horror and disgust. But unlike a cadaver, the patients that students encounter come with their own anxieties about their illness and an ability to be harmed by how their providers interact with their bodies. Though much has been written about students' experiences with cadavers, little has been written about how medical

students learn to mediate their feelings of disgust in their encounters with patients, and how they manage the fears these encounters arouse for both students and patients.

The silence about these encounters implies that students likely learn how to deal with disgust through informal socialization by peers and educators. Though patients are present in the educational milieu of the hospital, their ability to advocate for the kind of care they want to receive is limited by the power dynamics of academic medicine, where students are encouraged to emulate the attitudes and behaviors of those in the rigid hierarchy above them who are grading them. Though students and educators can choose to learn from patients' voices, they are not required to do so. Patients whose bodies elicit disgust are particularly marginalized within the hospital and can struggle to make their mark on students' education.

Patient Experiences of Disgust

Learners' transition to the wards comes with a new potential to harm, as real patients bear the consequences of students' mistakes and faux-pas. Challenging situations in the clinic are impacted by both the patient and the learners' fears, beliefs and values, and have implications beyond students' personal and professional development. For patients who inhabit bodies that elicit disgust, educational encounters with students carry the risk of becoming a site of dignity violation.

Though having such an abject body is often a result of experiencing illness, it is experienced as a distinct and embodied phenomenon rife with embarrassment not

experienced by the merely ill. Having one's body break down is an unrelenting challenge to one's dignity and sense of selfhood; the unruly and unbounded body creates the constant possibility of embarrassing incidents that disrupt one's ability to participate in everyday life (9). These bodily intrusions challenge patients' sense of selfhood as dignified, independent adults (9). Among the healthy, only infants are unable to control their own bodily excretions, and having an unbounded, abject body can cause some people experiencing loss of control over their bodies to feel they have regressed from being a fully-formed adult back to an infantile "open person" or "non-person" status (9). Though severe illness is in and of itself a state of loss of control, having something grotesque happen to one's body puts this loss of control at the forefront of everyday life and social interactions and challenges the patient's sense of self in a unique way (9).

The breakdown of the body is not just a source of embarrassment. Having a body that elicits disgust creates a unique sense of danger for those who--like many ill people--require caregiving. It is well documented that patients whose bodies elicit disgust from their caregivers receive worse care, and are at higher risk of maltreatment and abuse (1, 10). For the seriously ill, concerns about how providers perceive their bodies are not trivial, and dignity violations can trigger fears that a provider may see them as subhuman or undeserving of care and safety.

Literal breakdown of the human body can lead to marginalization and isolation in a way that less "dirty" illnesses do not; such marginalization is mediated by institutions, caregivers and patients themselves (11). When long-term care facilities like nursing homes and inpatient hospices decide which patients should be admitted and which

patients deserve continued care, they are essentially deciding what kinds of care can be performed in the home by family and community members, and which kinds of care should be performed in medical settings by paid professionals. These decisions reflect both real needs for the technology and professional staffing available in such facilities, as well as our ideas about what kinds of caregiving one could reasonably expect a loved one to provide and what kinds of tasks are too unpleasant to do without financial compensation.

While odors and excrement are far from the only reasons people are placed in long-term care, the development of disgusting symptoms is often the impetus for a switch from home-based to facility-based care (11). The sequestration of sick people with incontinence, wounds and other embarrassing illness manifestations into long term care facilities is reinforced by patients' and families' own decisions about when to seek out and/or remain in inpatient care (11). While such symptoms are discussed as if they are objective indications for professional management, they also reflect a culture of individualism and collective anxieties about providing care to the unbounded bodies (11).

Anthropologists have described a marginalization of patients that is created not only by the literal removal of bodies deemed unmanageable or disgusting from the community, but also reinforced in the everyday actions of patients themselves who sometimes undergo extreme withdrawal and a sort of "social death" once their bodies break down and begin to elicit disgust. One researcher studying British hospice units described several patients with major wounds or severe incontinents who stopped interacting with loved ones and even requested euthanasia or sedation in response to

bodily disintegration (11). Through both a literal removal from the community and a loss of confidence in interacting with friends and family, patients can lose the social identity that bolsters their sense of personhood.

Provider Management of Disgust

Patients' feelings of dignity and shame about their bodies do not exist in a vacuum. As my classmates and I learned in our clinical education, an insensitive comment or shocked facial expression can color a patient's whole experience of hospitalization. Though disgust is an emotion commonly felt by physicians, there is scant literature about how physicians manage their feelings of disgust in patient encounters, and how this impacts patient care. There is some mention of disgust in the nursing literature (particularly hospice and palliative care nursing literature) regarding how nurses deal with feelings of disgust while physically interacting with the human body and administering hands-on care (1). While some of this literature is relevant to physicians and future physicians, some of who will perform physical exams and assist in physical caregiving, this literature does not give sufficient guidance for those learning to manage their reactions to patient bodies during physician-specific activities. There is limited literature, for example, on how to address disgust in advanced care planning, though anybody who has spent time in a hospital knows, for example, that the emotion of disgust plays a major role in patients' decisions to undergo or refuse disfiguring procedures such as colectomy.

Much of the existing literature regarding disgust focuses on how professionals suppress feelings of disgust while at work. Though disgust is an emotion commonly felt by those in healthcare, it can be taboo to discuss disgust in medical settings. In numerous studies, healthcare workers report finding the emotion of disgust “unprofessional,” and that they actively suppress such feelings so as to avoid making patients aware of them. One study of British palliative care professionals found that workers actively avoided using the word disgust, preferring terms like “challenging” and “difficult” experiences; many workers only recognized such feelings to be rooted in disgust when directly asked (10,11). Suppression of feelings of disgust serves two purposes; both to protect patients from experiencing the stigma and to protect healthcare workers from engaging with aspects of illness, death and dying that challenge their ability to cope with their jobs. The emotion of disgust is evolutionarily and culturally linked to fears of infection and pollution; disgust is often elicited by odors and seepages that transgress the boundaries of the bodies where they originate, and challenges the individual’s ability to separate themselves from the patient in front of them (1, 11). Disgust not only makes providers acutely aware of their body’s own fragility, but also evokes a very specific kind of suffering--a “dirty dying” that cannot be sanitized into the kind of dignified exit that providers would like to be able to promise to those they cannot cure.

Like in the cadaver lab, providers who encounter gravely ill and dying patients must find ways to manage fears about their own fragility as they attempt to engage deeply with patients whose bodies are breaking down. Interactions with living patients create special challenges for providers who, as leaders of a patient’s care team, may feel a

sense of responsibility for patients' condition and may see such bodies as a personal or professional failure. Though many who work with the seriously ill can accept that they will not be able to keep every patient alive, they may derive a sense of professional pride and identity from being able to provide a "good death" characterized by symptom control, family involvement, peace and lack of distress (12). When unruly bodies resist providers' attempts to impose the order and dignity required for a "good death," providers confront the uncomfortable limits of their professional abilities, as well as the possibility that they and their loved ones may also not be guaranteed death with dignity.

Disgust and Care Planning

While providing hands-on care to patients is a task shared between medical, nursing and other providers, big-picture treatment planning is primarily the job of physicians and advanced practitioners. Little has been written about the role that disgust--either disgust related to a patient's current body or a potential future body--plays in these conversations. Patients facing the end of their lives need to be assured that their care team will do everything they can to provide a "good death," or at least a tolerable one (13). Pain control tends to dominate these conversations as modern providers can be reasonably confident in their ability to bring pain to tolerable levels for most patients. It is more challenging for providers to know how to respond to patient concerns of unacceptable dependence, humiliation and personal disintegration (13).

But pain is far from the only concern of the seriously ill. Looking at the experiences of one extreme group of patients--those seeking medical aid in dying--can highlight the complexity of decision-making for patients experiencing severe life-limiting illness. Many people assume that intractable pain is the only kind of suffering that can be deemed so intolerable that a patient would choose to instead end their life. But no empiric study has ever shown that the desire to avoid pain plays a significant role in peoples' decisions to pursue medical aid in dying. (14, 15) In a 2009 survey of patients in Oregon requesting physician aid in dying interrogating patient's rationale for no longer wishing to be alive, patients ranked physical pain below (among other things) "wanting to control circumstances of death", "loss of independence", "perception of self as a burden" and even, "life is pointless." (16) A large 1999 Dutch survey of patients seeking aid in dying found "loss of dignity" to be the primary reason why 57% of respondents wanted to end their life, and a later 2011 qualitative study in the Netherlands also found that physical suffering was less important than existential and psycho-emotional concerns for patients requesting aid in ending their lives (15, 17). While we would like to think that suffering is quantifiable and treatable, seriously ill patients' reported major concerns are abstract and specific to the patient's experience of illness within the broader context of their life (15).

Though patients seeking aid in dying represent an extreme example of patients expressing distress, their survey responses demonstrate that patients have concerns beyond prognosis and pain, and that preserving patient dignity can make the difference between a tolerable and intolerable illness experience. "Dignity" is often upheld as a goal in the holistic care of patients with poor prognosis. But despite its ubiquity in the

palliative care literature, dignity is rarely defined; it is a vague term that can and often does mean different things to patients and providers (17). Dignity can include social components--like one's autonomy vs. dependency upon others and one's ability to participate in community and social life--as well as embodied components including the ability to remain clean and free from odors and excrement in accordance with social rules (17) Dignity is also a culturally-informed idea that is learned and continually reinforced through social relationships (17). Whether a patient sees themselves as the recipient of loving care or as a burden on society is dependent not only upon their situation, but also upon how those providing care communicate with them about the care they are providing.

It is impossible to promise every patient death with dignity; most life-limiting illnesses cause loss in bodily autonomy and functional status, which can lead to embarrassment and dependency. While dignity violations can feel inevitable at the end of life, patients may have preferences about how they want these experiences to be handled. For example some may prefer a family member to care for them as they become incontinent, others may prefer to receive intimate care from a paid caregiver with whom they have no prior relationship, and still others may be so distressed by incontinence that they may request liberal use of sedating medications (10, 13). It is vital that providers are comfortable and willing to discuss current and future disgusting symptoms in a way that is patient centered and not colored by their personal emotions and preferences.

CHAPTER 4: CONCLUSIONS

Late in my second year of medical school, our school created a series of pretend challenging encounters with “standardized patients,” or actors pretending to be patients. Unlike our initial standardized patient experiences, which seemed designed to teach us the nuts and bolts of the clinical interview and physical exam, these advanced encounters were scripted to give us practice reacting to patients experiencing challenges such as gender transition and transphobia, intimate partner violence, and drug and alcohol use disorder. For the final and most challenging encounter, we had to break the news to a patient that she had metastatic pancreatic cancer and likely only a few months to live.

Though the pretense of this faux encounter was laughable (what attending physician would ever let an unsupervised student to tell a patient she had cancer?) the script was well-written, and the standardized patient’s reaction was indistinguishable from real patients I had observed while shadowing--I watched as our standardized patient asked my classmate what a pancreas even was, and stared, confused and incredulous, when the pretend doctor tried to explain digestion and insulin as if this would make sense of how she had gone from a well woman with a stomach ache to a cancer patient facing imminent death.

At some point, the teaching physician took mercy on my classmate, and had a different student doctor try to counsel the same actor, supposedly two months into the future, weaker and with a scarf on her head. She had come to the office to discuss pain, fatigue, depression and her impending need to switch from cure-focused to symptom

focused care. The topic of hospice came up, along with the reality that our patient would need increased care as her illness progressed. Our patient sat quietly for a moment, looked my classmate dead in the eyes and said “Doctor, please, tell it to me straight. With the way things are going, is there going to be a time when I’m going to need somebody else to wipe my ass?” This comment--this focused on cleanliness and indignity in the face of impending death--felt realistic to me, and continues to feel realistic as I’ve gained clinical experience and seen real patients cope with difficult news.

Disgust is ever-present in the hospital and ever-feared by patients and providers alike. Although disgust is central to patient and provider experiences, taboos regarding disgust prevent open discussion of the way that feelings of disgust impact patient care. These taboos are first encountered in medical education, and continue into professional practice. The current structure of medical education makes space for initial reflections during anatomy on the human body in a state of abjection and the emotions this elicits from the learner. However, it provides little space for education and reflection once learners begin to interact with real, living patients and begin to navigate how their personal feelings of disgust impact the care of patients with diverse cultures, values and spiritualities.

Medical professionals currently don’t have the tools to fix every distressing symptom patients have, and it is hard to imagine a world where technological developments stop patients from ever experiencing incontinence or infection, particularly as they move towards the end of life. Experiencing disgust can feel shameful to medical professionals--because we can’t wholly fix the source of our disgust, because we worry

that merely feeling disgust can cause us to treat our patients worse, and because it makes us fear that should we live long enough we will one day see the breakdown of our own bodies. But patients with disgusting and distressing symptoms deserve competent and compassionate care from providers who have processed their own anxieties related to the decaying body and considered how to uphold patient dignity both implicitly in their words and body language and explicitly through the care they offer. This kind of care does not happen organically, but is rather learned and honed throughout one's career. Providing space and permission for frank discussion about feelings of disgust throughout clinical education and clinical practice could be a good first step towards figuring out how to provide patients experiencing distressing illnesses with the dignity they deserve.

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