# Transgender Gynecology: The Construction of Medical Knowledge and Health Social Movements as Catalysts for Change

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#### **Abstract**

This thesis examines the current state of routine transgender gynecologic care, highlighting patient discomfort and distrust of healthcare providers, particularly during the gynecological exam. I discuss how the construction of medical knowledge, including the makeup of the medical field, sources of medical information, and provider uncertainty impact the care of sexual and gender minorities. The essay also explores health social movements as catalysts for change, including their impact on challenging the dominant epidemiological paradigm and reframing stigma. A case study of the American HIV/AIDS crisis of the late 20th century demonstrates the importance of paradigm shifts for LGBTQ+ health. The essay concludes by discussing how potential solutions for change, such as shifting medical curricula, increasing representation in the medical field, and the impact of alternative healthcare providers, can improve transgender gynecologic care.

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## Glossary: Acronyms & Definitions

Transgender ("Trans")	Relating to a gender identity or gender expression that does not correspond to an individuals's sex assigned at birth
Transman	An individual who was assigned female at birth but now identifies and lives as a man
Transwoman	An individual who was assigned male at birth but now identifies and lives as a woman
Nonbinary	A gender identity that does not fit into the binary categories of male or female
TGNB	Transgender/Nonbinary
Queer	Sexual and gender identities that are not cisgender and heterosexual; a term associated with non-normativity
LGBTQ+	Lesbian, Gay, Bisexual, Transgender, Queer (or Questioning), and Others
OB/Gyn	Obstetrician/Gynecologist; a physician who specializes in gynecology and the care of pregnant people
AAMC	Association of American Medical Colleges
ACOG	American College of Obstetricians and Gynecologists
AMA	American Medical Association
AMSA	American Medical Student Association
SGM	Sexual and Gender Minority

Note: In this thesis, I periodically refer to transgender, nonbinary, and queer individuals using the singular they/them pronouns.

#### Introduction

In this thesis, I argue that health social movements enable paradigm shifts within medicine and allow for historically-gendered fields, such as gynecology, to elevate the standard of care for transgender patients and other minority populations.

Chapter one begins with a description of the routine gynecological examination for two purposes: (1) to "set the stage" for those who have not, themselves, interacted with practitioners of this field, and (2) to substantiate the claim that the field of gynecology (and obstetrics) does not currently serve transgender individuals. Following this, in my second chapter, I discuss medicine as a profession and provide a brief explanation of why the historical construction of medicine has resulted in a shortage of gender and sexual minority practitioners. In addition, I discuss how knowledge is constructed within medicine and how the path towards becoming an attending physician involves knowledge development at several phases.

In the third chapter, I introduce health social movements and provide historical examples of these movements shifting the dominant epidemiological paradigm. I focus, in particular, on the American HIV/AIDS crisis of the late 20th century in my fourth chapter and highlight ACT UP as a prime example of an embodied health movement, a type of health social movement, which reframed stigma to improve health outcomes. In addition, I note the importance of democratized health information and explain how Foucault's "medical gaze," when constructively analyzed, can resist engagement of non-normative bodies in medical settings.

Lastly, I will "connect the dots" in my last chapter and assert the claim that health social movements can improve gynecologic care of transgender patients by shifting the dominant epidemiological paradigm.

#### Chapter One: The Current State of Routine (Transgender) Gynecologic Care

"[I] recently turned 21 so I had to get my first pap smear and it was a genuine nightmare. It was so humiliating and dehumanizing. And I just want to disappear."

It's rare to know someone who looks forward to a visit with their gynecologist. After all, it can be embarrassing, shameful, and outright painful. Nevertheless, people with vaginas should expect to have their first gynecological visit between the ages of 13 and 15.2 This initial reproductive health visit allows the OB/Gyn to educate the patient and caregiver on "age-appropriate health issues." Those who become sexually active before the age of 13 are recommended to visit their provider before this time to learn about forms of birth control and methods to prevent sexually transmitted infections (STIs). Of course, whenever there are concerns related to the reproductive organs (e.g. pelvic, vaginal, or labial pain), those individuals are suggested to consult their gynecologist, as well.

#### The Waiting Room

Consistent with any medical appointment, gynecologic care visits begin in a waiting room, where one might fill out paperwork, distract themselves with material, or ponder the next hour ahead. Waiting for the gynecologist, in particular, can heighten feelings of discomfort, especially for non-female-identifying individuals. Negative interactions in the waiting area may give rise to feelings of gender dysphoria, invoke distrust of the care team, and prevent productive patient-provider interactions once the patient has entered the exam room.<sup>4</sup>

<sup>&</sup>lt;sup>1</sup> [u/ThrowAway HalowBby], 2021

<sup>&</sup>lt;sup>2</sup> American College of Obstetricians and Gynecologists, 2020

<sup>&</sup>lt;sup>3</sup> American College of Obstetricians and Gynecologists, 2018

<sup>&</sup>lt;sup>4</sup> Northwestern Medicine, 2022

The central tenet of discomfort for non-female-identifying individuals in a waiting room is the fact that they do not present as *woman*. Gynecology is a highly gendered field of medicine commonly referred to as "women's healthcare." In fact, its name comes from the ancient Greek roots *gyne*, "women," and *-logia*, "the study of." Yet there are individuals who are not women but still require routine gynecological care. To be especially clear: any individual whose reproductive anatomy is composed of a cervix, uterus, fallopian tube(s), or ovaries should routinely visit a gynecologic healthcare provider. When it comes to the waiting room at a gynecologist's office, it may seem strange to see someone who is not outwardly feminine. Perhaps they are masculine, or perhaps they are gender nonconforming—whatever the case, they deserve to be treated with respect and compassion.

The internet is a powerful tool for navigating difficulties associated with transgender livelihood. It can be utilized by transgender individuals to seek trans-friendly providers, democratize medical information, and gain experiential knowledge from other trans patients. A Reddit thread titled "I have questions about going to the gynecologist as a trans guy" is an acutely revealing display of real trans men and their experiences in this realm of healthcare. One point, in particular, that many users in this thread speak of is the discomfort associated with waiting for the physician. "It was also pretty awkward being the only dude in the waiting room," notes user Silverblatt.<sup>6</sup> A couple of users also suggested ways to partially alleviate feelings of embarrassment and awkwardness. User Souboshi writes how they brought a close female friend with them to their gynecology appointments who posed as the patient.<sup>7</sup> This might curb the weird looks and stares trans men often get at this historically-ascribed "women's" healthcare clinic."

<sup>&</sup>lt;sup>5</sup> University of Colorado OB-GYN, n.d.

<sup>&</sup>lt;sup>6</sup> [Silberblatt], 2021

<sup>&</sup>lt;sup>7</sup> [Souboshi], 2021

Though, finding a friend to fulfill this ruse is a task in itself, not to mention the associated issues of confidentiality.

More concerningly, transgender people may fall victim to the transphobia of other patients while waiting for their appointment. They may also experience distress when addressed by clinic staff who refer to the patient by their legal name ("dead name") and/or inaccurate pronouns, which forces the patient to reveal their transgender status in a largely public setting and essentially "come out." These encounters, combined or singly, may be troublesome enough to prevent the individual from returning for further care.<sup>8</sup>

#### Distrust and Discomfort: Conversation with the Provider

A vital aspect of patienthood is trust in one's medical provider, the specificities of which I will expand on in a subsequent chapter. Finding a physician who will act with compassion and vulnerability is certainly not an easy task. Even for heteronormative, cisgender persons, the act of searching for a provider can be despairing. In regard to gender queer and transgender individuals, the process is openly problematic—within the specialty of gynecology, these issues increase tenfold.

Let us now consider the experiences one might have if they are at the gynecologist for a routine wellness visit. Most clinical encounters begin when a medical assistant or nurse speaks with the patient about their medical history. Topics include surgical history, family history of disease, current medications, drinking and drug habits, sexual (health) history, and pressing medical concerns for the physician to address during the appointment, such as pelvic pain or unusual vaginal discharge. Next, they will ask: "When was the first day of your last period?" Knowledge of a patient's menstrual cycle is important for providers to know since the absence of

<sup>&</sup>lt;sup>8</sup> Deutsch & Buchholz, 2015

<sup>&</sup>lt;sup>9</sup> Mid-Atlantic Women's Care, 2019

menstruation can indicate serious medical issues and possibly pregnancy. It can also be significant in terms of medication dosage and type, specifically for medications that aim to treat heavy menstrual bleeding. <sup>10</sup> Yet, this "simple" question is truly anything but.

For gender queer individuals, especially those who identify as transgender, it can be very difficult to discuss their menstrual cycle. For transmen, menstruation may be "a reminder that [their] body will never be the way [they] want it" or that they "can't be a real man." Even if the individual does not have particularly painful or effectual periods, the event can disrupt one's reality in significant ways. For instance, a man might have to wear more "feminine" underwear to exist comfortably and to effectively utilize menstrual products (e.g. a menstrual pad). Tampon usage can also be quite triggering and generate feelings of gender dysphoria as their body sends them a monthly reminder that they should be having children. In general, menstruation is understood publicly as a women's issue. As such, transmen who are comfortable using restrooms meant for cisgender men may struggle with keeping their period contained and feeling hygienic if these bathrooms do not have sanitary bins.

Following these questions, the nurse or assistant will take the patient's height and weight, blood pressure, and may ask the individual to provide a urine sample. In addition, the staff member will ask them to completely undress and put on a hospital gown so the physician may complete their examination. Significant, here, is the doctor's attitude once they enter the room. A "good" doctor should exude compassion and empathy; they should not act with haste or make the patient feel uncomfortable in any way. In a similar vein, the way the physician first addresses the patient informs how the visit will play out. For transgender individuals, it significantly eases discomfort if the doctor uses the patient's preferred name and pronouns. <sup>12</sup> Before the practitioner

<sup>&</sup>lt;sup>10</sup> Mayo Clinic, 2023

<sup>&</sup>lt;sup>11</sup> Bell, 2019

<sup>&</sup>lt;sup>12</sup> Northwestern Medicine, 2022

begins their physical examination, they will ask the patient a few intimate questions in regard to their sexual history. This may include inquiring about the last time the patient had sex, if they use protection, and their knowledge of STI and vaccination status. Undoubtedly, this conversation like that before, may be concerning and discomforting. People in non-heteronormative relationships or individuals whose sexuality is not yet known by the provider may find this part of the visit particularly stressful, requiring them to "come out" once again. Before the next phase, the physical examination, consent must be obtained.

Doctors occasionally have difficulty asking for consent when examining a patient. This is partly due to varying state guidelines as well as circumstantial differences in consent procedures. Though, an argument could be made that this difficulty in asking for consent may stem from their uncertainty and anxiety in caring for this population. Although consent is important for all patients, perhaps it is even more important for transgender patients. Many transgender and nonbinary individuals experience dysphoria as a result of their anatomy and it is estimated that nearly half of them experience sexual assault at some point in their lifetime. This can greatly impact their sense of control and safety when in a vulnerable position with their genitals exposed. Feelings of discomfort and danger certainly escalate if the provider is not gentle or does not inform the patient about what they are doing and the purpose of their actions.

Language will be analyzed at several points throughout this paper, for it is a critical aspect of LGBTQ+ healthcare. For instance, "vagina" is a word used highly frequently in gynecologic exams, especially during pelvic examinations. For transgender males and nonbinary individuals, this term may be triggering and can invoke gender dysphoria. Transgender patients

<sup>&</sup>lt;sup>13</sup> Cleveland Clinic, 2022

<sup>&</sup>lt;sup>14</sup> Crissman & Stroumsa, 2020

may also utilize the term "front hole" to refer to the vagina. The provider should ask if the patient has a preference for these alternative terms prior to the gynecologic examination.

#### The Breast Exam

The gynecologic exam typically begins with a breast examination. This involves the provider examining the shape, size, and texture of the breasts as well as feeling the breast tissue and axillae for lumps and other abnormalities. <sup>15</sup> There is not sufficient research on breast cancer and transgender individuals, specifically related to the process of tumor detection and cancer diagnosis. Though, transmen and transwomen present specific needs when in a setting where the healthcare provider wishes to perform such an examination. Transgender women may be at increased risk of breast cancer due to the use of exogenous estrogen therapy. Interestingly, recent data suggests that the use of androgen hormones may lower the risk of breast cancer in transgender men. <sup>16</sup> Even after a patient has undergone a mastectomy (single or double), there is still tissue that remains and so the patient should still be examined. Regardless of gender identity, familial history of breast cancer may increase the number of screenings and physical breast examinations.

Transgender individuals may find it difficult having a provider perform a breast examination. Transgender men, in particular, may have a hard time speaking about their breasts and/or having them touched if they are at odds with their gender identity.<sup>17</sup> The provider should acknowledge this discomfort if expressed, and consider the necessity of the test so as to avoid patient discomfort and feelings of gender dysphoria.

<sup>&</sup>lt;sup>15</sup> Moreland OB-GYN, n.d.

<sup>&</sup>lt;sup>16</sup> Chen. 2023

<sup>&</sup>lt;sup>17</sup> Canadian Cancer Society, 2022

#### Patient Positioning, Stirrups, and the Speculum

While gynecologic instrumentation has evolved, the mechanics of a routine gynecological exam have remained effectively unchanged for centuries.<sup>18</sup> To begin the exam, the patient will be instructed to lie back and place their feet in stirrups to afford proper placement of the speculum and maximize the visibility of the cervix and vagina. Doing so moves the patient into the dorsal lithotomy position, wherein the patient is on their back with their hips flexed at 90 degrees.<sup>19</sup>

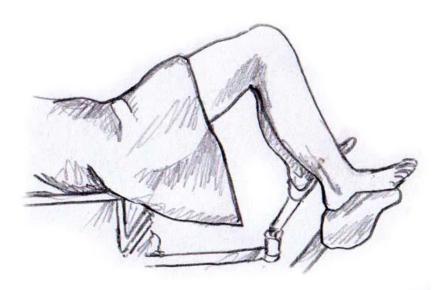


Figure 1. Dorsal lithotomy position facilitated by stirrups for the purpose of pelvic examination.<sup>20</sup>

The dorsal lithotomy position provides maximized visibility of the vagina and cervix, but can be pointedly disempowering for patients and bring about feelings of vulnerability. This body positioning in conjunction with metal stirrups (as opposed to more cushioned foot supports) can feel sterile and dehumanizing.<sup>21</sup> A randomized clinical trial conducted in 2006 by Eisenhower

<sup>&</sup>lt;sup>18</sup> Horos, 1981

<sup>&</sup>lt;sup>19</sup> Thomas, 2017

<sup>&</sup>lt;sup>20</sup> Karjane, 2021

<sup>&</sup>lt;sup>21</sup> Olson, 1981

Army Medical Center physicians found that gynecologic examinations without the use of stirrups actually decreased levels of physical discomfort from 30.4 to 17.2% and sense of vulnerability from 23.6 to 13.1%.<sup>22</sup> Although the study did not include participants who outwardly identified as transgender or genderqueer, the study's findings offer applications that, if implemented, may improve all patients' comfort. After all, the "no stirrups" method is routinely implemented by physicians outside of the United States in countries like the United Kingdom and New Zealand.<sup>23</sup> In addition to opting against stirrup usage to perform a pelvic examination, there are also alternative positions that a provider may employ, which may be less anxiety-provoking, such as the lateral position. A gynecologic provider should be open to voiced patient concerns and utilize flexibility when determining the best position for the pelvic exam to be completed.

Once the patient is in the proper position, the doctor will begin by examining the outside of the patient's genitals. They are searching for abnormalities (e.g. inflammation, swelling, or sores) of the vulva and surrounding area that may suggest infection or disease. They will also examine the Bartholin's glands and inspect the labia for growths, cysts, tumors, or polyps.<sup>24</sup> To initiate the internal examination, a bimanual exam is used to check for the size, shape, and position of the uterus; tenderness or pain; and enlarged ovaries, fallopian tubes, cysts, or tumors.<sup>25</sup> From here, the practitioner moves on to the internal exam.

#### The Internal Gynecological Examination

To begin this internal portion of the gynecological exam, the practitioner will insert a speculum into the vagina. While the speculum is the prototypical instrument in the field of gynecology, it is a device with a conflicted history, including evidence of racism and exploitation

<sup>&</sup>lt;sup>22</sup> Seehusen et al., 2006

<sup>&</sup>lt;sup>23</sup> 2006

<sup>&</sup>lt;sup>24</sup> Horos, 1981

<sup>&</sup>lt;sup>25</sup> Planned Parenthood, 2019

of Black female bodies. James Marion Sims is credited with inventing the vaginal speculum as well as surgical techniques in the field of reproductive health.<sup>26</sup> Sims' vaginal speculum was based on a bent pewter spoon, which Sims used to retract the vaginal walls and visualize the vagina and cervix.<sup>27</sup> Using this tool, Sims developed methods to treat patients with a vesicovaginal fistula (an abnormal opening between the vagina and bladder that results as a complication of childbirth). In doing so, however, he performed excruciatingly painful experiments on enslaved Black women without anesthesia, women who could not give consent nor refuse treatment.<sup>28</sup> In addition to acknowledging the speculum's flagrant history, it is important to note the impact its use has on the patient experience.



Figure 2. Graves's vaginal speculum, composed of two duckbill blades.<sup>29</sup>

Using a speculum awards the gynecologist with a proper view of the vaginal walls and cervix. The insertion of the speculum should not be acutely painful, though it can be

<sup>&</sup>lt;sup>26</sup> Holland, 2018

<sup>&</sup>lt;sup>27</sup> Tavares et al., 2012

<sup>&</sup>lt;sup>28</sup> Equal Justice Initiative, 2019

<sup>&</sup>lt;sup>29</sup> Graves Vaginal Speculum, n.d.

uncomfortable for adolescents, obese individuals, those with disabilities, and persons with a history of trauma involving the genitalia. There are certainly methods to ease discomfort during the insertion of the speculum, methods that can greatly influence the patient's impression of the gynecologic appointment overall. One such method is using a bacteriostatic, water-based lubricant to reduce the risk of pain during speculum insertion. Some providers are hesitant to do this in fear of interfering with cervical cytology results. However, a study conducted from 1998 to 1999 by the University of Washington School of Medicine notes that a small amount of water-based lubricant on the outside of the speculum does not impact cytology or microbiology results.

The size of the speculum used during the exam as well as its temperature at the time of insertion are also significant in mediating discomfort. The use of narrower speculums, such as the Pederson speculum, may reduce patient discomfort, but this benefit must be weighed against the potential for decreased provider visualization. A metal speculum that is warmed with water to an appropriate temperature can also make the patient feel more comfortable and decrease difficulties associated with insertion.

A critical portion of any internal pelvic examination is the pap smear, named after its inventor George Papanicolaou. A pap smear screens for cervical cancer by checking for abnormal cells in the cervix that may be cancerous or precancerous. This screening has led to a significant reduction in cervical cancer incidence and mortality rates.<sup>32</sup> It can also detect human papillomavirus (HPV), a common sexually transmitted infection. During this portion of the exam, the healthcare provider will use a soft brush or tiny spatula to collect a small sample of

<sup>&</sup>lt;sup>30</sup> Bates et al., 2011

<sup>&</sup>lt;sup>31</sup> Amies et al., 2002

<sup>&</sup>lt;sup>32</sup> Safaeian et al., 2007

cells from the patient's cervix.<sup>33</sup> The sample is then sent off to a lab and patients are notified of the results within a few days. The United States Preventive Services Task Force recommends individuals over the age of 21 and under the age of 65 be screened for cervical cancer every 3 years (though some providers recommend this screening be conducted annually).<sup>34</sup> However, this data is based on cisgender women, so transgender and genderqueer individuals may receive alternative medical opinions in regard to pap smear frequency.

A doctor might ask a patient if they would like to be tested for sexually transmitted infections. These tests may also be automatically conducted, or at least recommended, based on patient history. The Center for Disease Control recommends sexually active individuals be tested for particular STIs such as chlamydia and gonorrhea on an annual basis. This testing is performed while the speculum is still inside of the vagina.<sup>35</sup> The internal gynecological examination in total only takes around 10 minutes to complete, yet these minutes can be highly distressing, especially for transgender individuals.

<sup>&</sup>lt;sup>33</sup> The National Cancer Institute, 2022

<sup>&</sup>lt;sup>34</sup> United States Preventative Forces Taskforce, 2018

<sup>&</sup>lt;sup>35</sup> Reilly, 2018

# Chapter Two: Sexual, Gender Minorities in Medicine and the Construction of Medical Knowledge

While researching the routine gynecologic examination, I couldn't help but struggle with one question: why has the field of gynecology been so slow to transform from its heteronormative, cisnormative state where only certain patients are properly cared for? In attempting to answer this question, it became evident I must explore the foundations of medicine, which students become doctors, and how medical knowledge is constructed.

#### Makeup of the Medical Field

Many scholars believe Hippocrates (born 460 BC) to be the father of modern medicine. Conceivably his greatest contribution to the field was the uncoupling of gods and magic from disease as well as his development of the humoral theory. From the time of his existence until the middle 19th century, medicine was almost exclusively practiced by men. In fact, the first woman to graduate from an American medical school was Elizabeth Blackwell in 1857. Yet, women still participated in medicine through ancillary healthcare roles, such as midwifery. This is all to say that medicine has attempted to facilitate dominance of cisgender men over all other individuals from the time of its inception. As will be discussed later, this male dominance was sustained by professionalism and prestige.

Medical schools and hospital systems are making a valiant effort to increase admittance to women as well as improve racial and ethnic diversity. In 2009, the Association of American Medical Colleges (AAMC) and the American Medical Association (AMA) developed diversity accreditation standards, which required allopathic medical schools to "attract and retain" students

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<sup>&</sup>lt;sup>36</sup> Garrison, 1966

from diverse backgrounds as well as develop programming aimed at broadening diversity amongst qualified applicants. Female applicants and matriculants to U.S. medical schools have increased dramatically over the past quarter century. 2017 was the first year in which the total number of female U.S. medical school matriculants surpassed the number of male matriculants.<sup>37</sup> What these diversity standards lack, however, are initiatives to welcome gender-expansive individuals into the field of medicine. Consequently, this translates into only a very small percentage of physicians who self-identify as transgender and nonbinary. In the 2022 AAMC Matriculating Student Questionnaire, it was reported that only 1.4% of medical students have a different gender identity from their sex assigned at birth. This may be compared to some 5.1% of American adults under 30 who identify as trans or nonbinary.<sup>38</sup> The disparity is due to several factors, though a significant cause is the experiences of such individuals in medical settings and throughout their education and training.

Oscar E. Dimant et al. published a study in 2019 regarding the experiences of transgender and nonbinary medical students and physicians in the United States.<sup>39</sup> One conclusion from this study was that transgender and nonbinary (TGNB) medical students and doctors face "significant barriers" during training, including having to hide their identities and encountering blatant displays of anti-TGNB stigma and discrimination. In hiding one's identity, a medical student or physician aligns with the historical and foundational perception of what it means to be a doctor, the particular demeanor and traits one might have in order to belong in the profession. Medicine assumes an incredibly high degree of professionalism and exclusivity. In the Middle Ages, when university training first came about, physicians were granted total and exclusive competence in

<sup>&</sup>lt;sup>37</sup> Association of American Medical Colleges, 2021

<sup>&</sup>lt;sup>38</sup> Brown, 2022

<sup>&</sup>lt;sup>39</sup> Dimant et al., 2019

the determination of effective methodology for treating the sick. 40 Today, uniform standards for medical education and licensing further enable the profession to seize socioeconomic and technical autonomy within the United States. It must be understood that a person who wishes to enter into the profession must uphold the values established by early medical doctors, values modernly enforced by institutions such as the AMA and the AAMC. These players act as gatekeepers of medicine. To this point, there are unspoken requisites for admission into medical school as well as acceptance among other premedical and medical students, attending physicians, patient populations, and the public at large. Those unspoken requisites include presenting as cisgender and heterosexual as well as having an overall (historically) professional appearance (i.e. lack of visible tattoos and piercings).41

In the Oscar E. Dimant et al. study, one participant had several people tell them that they would not be accepted into medical school if they were "out." In a similar manner, medical residents cited fears of "losing it all" if they came out during their time in fellowship.

Nondisclosure among this population is driven by concerns of transphobia, harassment, and discrimination at several points on the path toward becoming an attending physician. Here I will expand on how medical schools and healthcare settings have facilitated the repression of TGNB medical students for decades as well as the actions they might take or are currently taking to diversify the physician workforce.

Primarily, undergraduate colleges, medical schools, and medical institutions lack sufficient role models for TGNB premedical and medical students. This means that this population lacks support networks, which provide clarity and guidance on the path toward earning a medical degree. The absence of such role models is a result of having few faculty

<sup>40</sup> Freidson, 1995

<sup>&</sup>lt;sup>41</sup> Cohen, 2013

<sup>&</sup>lt;sup>42</sup> Dimant et al., 2019

members and medical school instructors who self-identify as belonging to this community. Educational institutions may attempt to improve the number of LGBTQ+ faculty (and, therefore, mentors) in several ways such as providing gender-neutral restrooms and using gender-inclusive language on all college and academic materials. Additionally, schools should make a more concerted effort to establish pipeline programs for TGNB high school and undergraduate students. Similar to how established pipeline programs aim to improve ethnic diversity in medicine, TGNB pipeline programs will encourage individuals of all backgrounds to more easily realize their potential and ability to enter into the field of medicine.<sup>43</sup>

#### The Medical School Path

Medical schools have always been incredibly selective institutions. The average allopathic medical school in the United States accepts 5.5% of applicants. 44 Students that are interested in entering into the field of medicine must, at a very young age, strive for excellence. It can be said that young adults who receive poor grades in middle school and early highschool do not (normally) consider medicine as a career path. Perhaps this is due to personal motivations or perhaps this relates to parental support and confidence in the child. Relatedly, children and young adults from lower socioeconomic backgrounds are more likely to receive less educational support and lack resources that may propel them into a career in STEM. Even as students progress through their academic career, there are still significant hurdles for these populations. One study suggests that under-represented minority premedical students are more likely to be pushed off of the premedical path due to negative experiences in required coursework, specifically in required chemistry courses. 45

<sup>&</sup>lt;sup>43</sup> Tanmoy Das, 2020

<sup>&</sup>lt;sup>44</sup> MedEdits, 2023

<sup>45</sup> Barr et al., 2008

From an intersectionality perspective, TGNB individuals are often members of another minority population; they are at an even greater disadvantage in trying to pursue a career in medicine. As previously discussed, TGNB medical students lack sufficient role models that guide them on their path to residency and beyond. Therefore, this pattern is cyclical: not only are TGNB individuals prevented from *applying* to medical school, once they are a student of medicine, they are also restricted from their truest potential and they are less likely to finally become a physician. Therefore, they are less likely to act as a mentor for future TGNB medical students.

#### Burnout of LGBTQ+ Providers

Once TGNB (minority) students become medical practitioners, there are still obstacles that remain. A significant issue for medical practitioners who identify as transgender, beyond facing discrimination and harassment in the workplace, is dealing with burnout. While burnout is potentially an issue for *all* medical providers, TGNB doctors are at greater risk of professional burnout. Since there are very few practicing physicians who are explicit about their willingness to care for this population, transgender patients are faced with a dilemma: seek care from a doctor who is inexperienced in treating "people like me" or wait for months to see a practitioner who is skilled in this subspecialty. Understandably, many TGNB patients choose to seek medical care from providers who have experience in caring for patients with non-heterosexual gender identities. This means that TGNB providers are overworked and overwhelmed, attempting to serve a population that, unbeknownst to many, is quite expansive and continually growing, Additionally, doctors are burnt out because they are forced to educate other providers on proper etiquette as well as clinical information in regard to TGNB patient populations.

Hannah Locke is a medical doctor in the field of obstetrics and gynecology and an assistant professor of OB/Gyn at Indiana University Medical School. They speak boldly on the "extra legwork" forced upon LGBTQ+ doctors, especially those in the realm of academic medicine. They write, "LGBTQ+ people in academic medicine are doing the legwork—showing up at conferences, speaking, presenting, and educating—but rarely are they paid for their time and expertise."<sup>46</sup> They recently left the private obstetrics and gynecology practice because it was exhausting being the sole LGBTQ+ doctor on staff, in other words, "the gay." Locke notes that any time a medical student wished to be mentored on the topic of gender-expansive reproductive medicine or there was a conference, etc., the burden would fall upon Locke to undertake the unpaid labor for the benefit of the whole clinic environment.

#### Sources of Medical Information

Doctors gain a proficient understanding of the human body and methods by which to treat health conditions from several different sources. Most predominantly, medical schools develop curricula and assign associated material aimed at providing students with a vast breadth of knowledge in the subject of medicine. Though, I would argue that knowledge of gender as it applies to various fields—especially that of obstetrics and gynecology—is constructed from *secondary* sources, including continuing health education programs and peer-to-peer mentorship, and is facilitated by an individual's desire to practice gender-based medicine.

In researching medical school curricula distinctively focused on LGBTQ+ health, sources by-and-large report the desperate lack of didactic and clinical training on the subject. The American Medical Student Association (AMSA) reported that LGBT health is often "totally overlooked" or at its best, not covered adequately or with sufficient detail.<sup>47</sup> The AMSA website

<sup>&</sup>lt;sup>46</sup> Lankau, 2022

<sup>&</sup>lt;sup>47</sup> American Medical Student Association, n.d.

provides several links for information on incorporating such subjects into students' medical school curricula. Though, in reference to Dr. Hannah Locke's point, why should this burden fall upon the sparse number of LGBTQ+ medical students within the United States? When healthcare governing boards and instructional medical institutions fail to adequately restructure curricula to align with shifting societal conceptions on the body, the burden is placed upon LGBTQ+ healthcare providers as well as motivated members of the public and grassroots organizations to enact structural changes within professional medical education systems.

Continuing Medical Education (CME) is used to describe post-graduate educational activities that serve to enhance knowledge, skills, and professional performance standards utilized by physicians. As Many states require that practicing physicians complete a certain number of CME courses each year in order to maintain licensure. Doctors may earn CME credits in a variety of ways. Classes, seminars, lectures, workshops, conferences, and webinars are all activities that fulfill this requirement. The Accreditation Council for Continuing Medical Education (ACCME) is the organization that oversees CMEs, and they, along with accreditor partners, grant an organization the authority to provide Continuing Medical Education. Importantly, only eligible institutions are able to become certified CME providers. These include state medical societies, accredited medical schools, national physician member organizations, and national medical specialty societies. Doctors, public health professionals, and activists work in tandem to develop CME activities and curricula.

One CME opportunity of particular relevance to the subject of this paper is hosted by the National LGBT Cancer Network and co-developed by the Society of Gynecologic Oncology titled "Creating LGBTQ+ Culturally Humble Medical Professionals." It has modules relevant to

<sup>&</sup>lt;sup>48</sup> National Institutes of Health, 2017

<sup>49</sup> Sermo 2023

<sup>&</sup>lt;sup>50</sup> Center for Health Care Strategies, Inc., n.d.

gynecological providers, though all medical professionals may benefit from the learning objectives. There are also published lectures and conference recordings that count for Continuing Medical Education credit, such as "Reproductive Care and Obstetrics for Transgender and Gender Diverse People," from the 2022 Advancing Excellence in Transgender Health Care Conference.

#### Provider Uncertainty and Clinical Empathy

For a physician to admit uncertainty, they must relinquish total control over their patient. They must resign exclusive competency over the body and, therefore, allow patients to assert ownership over their own bodies. In caring for transgender patients, it should be realized that in many cases, the patient is more knowledgeable of their own body as well as their clinical needs and desires. In this vein, providers must practice humility and empathy, accepting their uncertainty and (potential) discomfort. Doing so requires physicians to work against the central pillars that substantiate the field of medicine, chiefly elitism and professionalism as outlined earlier on in this section. In renouncing these values, physicians inadvertently exercise more compassion in patient interactions. This is appreciable for a number of reasons, and it is essential to the development of a therapeutic relationship between a care provider and their patient.

According to Dr. Don Eby, an emergency physician from Ontario, Canada, "[this] relationship is vitally important to practicing medicine effectively. Empathy is, therefore, something worth trying to understand." 51

Though empathy is tactically difficult to learn, there are a variety of tools by which patients may assess their healthcare provider and for doctors to assess themselves. One such tool is titled The Consultation and Relational Empathy (CARE) tool developed in 2004 by Dr.

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<sup>&</sup>lt;sup>51</sup> Eby, 2018

Stewart Mercer and their colleagues in the department of general practice at Glasgow University and Edinburgh University.<sup>52</sup> The findings of several studies show that doctors and their patients do not perceive (and thereby score) expressions of empathy in the same way. Researchers question the accuracy of physicians' personal perceptions of empathy, given that the subject is commonly *learned* by medical students during their studies and post-graduate clinical experiences.<sup>53</sup> Additionally, some question the ability of physicians to genuinely and cognitively empathize with every patient since doing so can be emotionally draining and difficult under modern, economically-motivated time constraints.<sup>54</sup> Despite this fact, it is my opinion that physicians can and should exercise empathy, especially in cases of caring for transgender or gender and sexual minority patients.

Earlier on in this chapter, I discussed foundational reasons behind physicians' hesitance in caring for the transgender population. To reiterate, physicians are conditioned to exercise confidence and complete understanding of the patient and their body, stemming from historical interpretation of what it means to be a physician. Despite this, caring for transgender patients is a specific scenario in which empathy is more highly valued than clinical comprehension. As such, a significant portion of learning to care for this population must involve the development of a provider's willingness to exercise empathy when speaking with patients. This is not to say that objectivity and intelligence are not valued skills for this patient population. A physician, when caring for members of the LGBTQ+ community, must delicately perform an "internal balancing act." Becoming too emotionally involved with the patient, say, expressing too great a degree of empathy, can encourage burnout and the provider risks loss of objectivity. Though, by refraining

<sup>&</sup>lt;sup>52</sup> Stanford Medicine, n.d.

<sup>&</sup>lt;sup>53</sup> Eby, 2018

<sup>&</sup>lt;sup>54</sup> Zinn. 1993

from connecting with the patient (failing to express compassion and empathy), the doctor may be unable to successfully care for the individual.<sup>55</sup>

At this point in my thesis, it should be understood that a significant goal of the field of medicine, certainly as it concerns ethics and public health matters, should be the promotion of care for minority populations, including transgender and nonbinary individuals. As it currently stands, LGBTQ+ people have a tumultuous relationship with "the doctor," and a significant reason why is that they believe no physician understands them. Setting aside the few practitioners who dedicate their personal and professional lives to the betterment of this community, the typical doctor (for the purposes of this paper, a gynecologist) tends to lack skills that are directly therapeutic to these patients, standing in the way of productive patient-physician interactions by sustaining patient anxiety and stress. Therefore, medical schools, in association with governing boards and licensing organizations, should do more to recognize the importance of empathy and how it may be successfully exercised by doctors. Empathy may be understood as a "reliable professional skill," thereby aligning with the historical perception of medicine, a field rooted in professionalism and utmost expertise. 56

Alongside these skills that may be fostered throughout healthcare professionals' years of medical training, there are other avenues for gynecological reform to come about. Health social movements, for example, actually involve transgender patients (laypersons) working in tangent with members of medicine to catalyze medical paradigm shifts. In doing so, medicine is able to dissociate from its gendered foundations and doctors feel empowered to care for this minority population.

<sup>&</sup>lt;sup>55</sup> Hirsch, 2019

<sup>&</sup>lt;sup>56</sup> Halpern, 2003

#### Chapter Three: Health Social Movements as Catalysts for Change

#### **Defining Health Social Movements**

Health social movements (HSMs) exist at the intersection of medicine, sociology, politics, and "other social institutions." Organized around health-related issues, these movements attempt to shift the dominant epidemiological paradigm by pressing the institution of medicine to change in significant ways. Medical sociologists have paid particular interest to these health social movements over the past decade which allows them to learn a great deal about the "institution of medicine" and how the field comes into conflict with patients and activists.

Importantly, these movements exemplify the work of health activists in demanding medicine evolve to meet shifting societal and social needs. Phil Brown et al. in "Health Social Movements: Advancing Traditional Medical Sociology Concepts" write that as sociologists are [beginning to] take HSMs more seriously, they are redefining illness experience and medical interaction. While, historically, medical conditions have been conceptualized on a more micro level, health social movements explore the ways that "illness experiences linked to collective action can shape healthcare institutions, medical research, and government policy." "57"

In a similar work by Brown et al., three types of health social movements are defined. The first category, "health access movements," involves the access and provision of healthcare services. The second category, "embodied health movements," challenges science on etiology, diagnosis, treatment, and prevention. Explicitly, these HSMs surround constituents and laypersons challenging the existing body of knowledge on a disease or health condition by inserting their own experiences. Lastly, the third category of health social movements is "constituency-based health movements." These are movements that highlight and bring attention

<sup>&</sup>lt;sup>57</sup> Brown et al., 2010

to health inequalities based on race, ethnicity, gender, class, sexuality, etc. Brown notes that this last category describes such fights as the women's health movement, gay and lesbian health movement, and environmental justice movement. We will now consider how the second category, embodied health movements, can realistically define the inclusion of transgender individuals in all fields of medicine.

Brown et al. (2004) focus on embodied health movements and their unique ability to shift the medical paradigm. The authors find this category of health social movements distinctive in three ways:

- 1) it connects the biological body with social movements (especially in regard to the embodied experience of disease);
- 2) it works to challenge existing medical and scientific knowledge and common practices;
- 3) it commonly involves the collaboration of activists with health professionals in the pursuit of satisfactory treatment and prevention, quality research, and expanded funding for medical and drug research.

Echoing this last point, layperson activists within these embodied health movements attempt to gain a place at "the scientific table" in the hopes that their encounters with healthcare personnel and personal illness experiences may help shape research, drug development, and day-to-day clinical encounters between healthcare providers and patients.

#### Challenging the Dominant Epidemiological Paradigm

A dominant epidemiological paradigm (DEP) is a standardized model of illness, a "shared set of entrenched beliefs and practices about disease treatment and causation embedded

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<sup>&</sup>lt;sup>58</sup> Brown et al., 2004

within a network of institutions, including medicine, science, the government, and the media."<sup>59</sup> Embodied health movements work to challenge a dominant epidemiological paradigm if said paradigm is based upon false assumptions of the human body, etiology, or individuals' expression and understanding of their biology. One case, in particular, that demonstrates the power of embodied health movements (health social movements) in shifting a dominant paradigm is the case of breast cancer science, as discussed by Brown et al. in "A Lab of Our Own: Environmental Causation of Breast Cancer and Challenges to the Dominant Epidemiological Paradigm."

The dominant epidemiological paradigm for breast cancer has, historically, centered on individual behavioral and hereditary factors rather than environmental or sociological factors in disease causation and the promotion of well-being. As such, breast cancer research most commonly centers on personal lifestyle choices (diet, exercise, drug, alcohol use, etc.) as well as genetics (key genome mutations) as opposed to studying environmental factors that can impact the epidemiology of breast cancer. Individualist outlooks on disease causation carry a "moralistic" undercurrent that holds individuals responsible for their health status despite population data that demonstrate the importance of social structural factors in determining health and disease in populations." In addition, this historical paradigm for breast cancer has failed to acknowledge the social determinants of health, which profoundly influence health outcomes.

Social determinants of health (SDoH) are the macro-level and underlying social, economic, and physical conditions in which people grow, live, work, and age.<sup>61</sup> In essence, they are "the non-medical factors that influence health outcomes."<sup>62</sup> Examples of such determinants

<sup>&</sup>lt;sup>59</sup> Zavestoski et al., 2004

<sup>&</sup>lt;sup>60</sup> Brown et al., 2006

<sup>&</sup>lt;sup>61</sup> American Medical Association, n.d.

<sup>&</sup>lt;sup>62</sup> World Health Organization, 2022

include income level, education, food security, and access to affordable, quality healthcare. According to the World Health Organization and numerous studies, SDoH account for between 30-50% of health outcomes, meaning that personal choices (micro-level decisions one makes in regard to their health and well-being) only have partial impact. <sup>63</sup>

The authors note that controversies surrounding scientific research on breast cancer challenge the dominant epidemiological paradigm in three arenas that frame the process of knowledge production and fact-creation. Those are: doing science, interpreting science, and acting on science (the DIA model, doing-interpreting-acting). This structure of knowledge-production is cyclical, meaning that interpreting and acting upon science actually leads to further "doing of science."

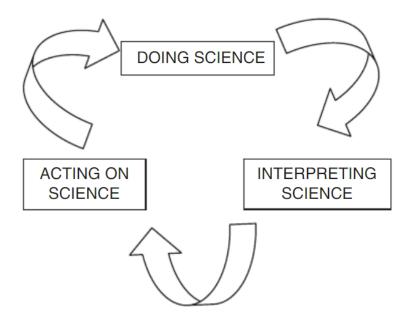


Figure 3. DIA model reflecting the process of knowledge creation and fact production within breast cancer research<sup>65</sup>

<sup>63 2022</sup> 

<sup>&</sup>lt;sup>64</sup> Brown et al., 2006

<sup>65 2006</sup> 

In addition to changing the *type* of scientific research, these authors also note the significance of scientists recognizing the extent of their knowledge gaps; more specifically, how direct layperson involvement in research may redirect inquiry and change how research is conducted. As opposed to one end of the continuum, where scientists work independently of layperson input in the development and execution of research (question formulation, methods, data analysis, or dissemination of data), direct lay-activist collaboration with researchers allows communities suffering from particular health complications to direct research efforts and, therefore, the political actions and regulations that follow. "The magnitude of lay involvement in breast cancer research signifies the broad societal importance of the disease itself and is representative of campaigns for public representation in other illnesses as well." In other words, this forced paradigm shift indicates the significance of patient and activist involvement in all areas of medicine—from disease epidemiology to drug research to provider education on inclusionary clinical practices.

A similarly significant case that resembles the power of embodied health movements is the case of the "Western disease," what Somalis in North America call autism since there is no word for the condition in the Somali language. There is evidence that indicates that Somali refugees and immigrants in North America have higher rates of autism spectrum disorder (ASD) in comparison to other communities. In Toronto, Somali parents began to question the statistically high rates of autism within their community; they forced an "epistemic community," which is united around a "coherent theory" of the development, defining features, and productive treatments of autism spectrum disorder. After forming this cohort, they began working alongside researchers and medical professionals to investigate gut bacteria and its connection to the development of the disorder. The community's central argument, the basis of their research, is

<sup>66 2006</sup> 

that the diet and medical environment in North America (the use of preservatives, GMOs, and antibiotics) explain the high rates of autism within the Somali diaspora.<sup>67</sup>

The Somali parents' embodied health movement certainly pushed against the dominant epidemiological paradigm by suggesting that forced migration, racial exclusion, and non-Western conceptions of health are important for understanding embodied illness experiences, challenging the mainstream medical understanding of autism spectrum disorder. Claire Decoteau argues that the Somali parents forged their embodied health movement based on a "politicized collective illness identity," a concept originally determined as necessary to the formation of embodied health movements by Brown et al. in 2004. This politicized illness identity comes about when an individual "links" their experiences with a certain illness (i.e. their illness identity) to a broader social understanding that disease is due to uneven distribution of power and social imbalance within society.

#### The Internet as a Tool

Up until this point, the health social movements I have mentioned have largely existed and thrived outside of the bounds of technology. Arguably the most well-recognized HSM, The Aids Coalition to Unleash Power (ACT UP), came about at a time when communication took place in person and protests happened in the streets. My question here is, how have health social movements changed and/or advanced since the large-scale integration of technology in everyday life? This question is important to grapple with, considering any modern-day HSMs will involve technology. More specifically, in defining a productive HSM to combat exclusionary medical practices against transgender individuals, technology may be utilized to maximize membership and influence members of the medical community.

<sup>&</sup>lt;sup>67</sup> Decoteau, 2017

Visual communication through art was a central messaging tool of ACT UP in its public defiance of the pharmaceutical industry and government's reaction to the AIDS crisis in the early 1990s. In my next chapter, I will be expanding on this coalition—the impact of its art and the accomplishments of such striking visual media. Though currently, I find it interesting to consider how health social movements, specifically ACT UP, would have looked different had they existed in an age where technology impacts every aspect of living. One would expect that technology has aided in the formation and development of present-day health social movements. Consider, for example, a mother who lacks information about their child's recent autism diagnosis. Instead of turning to a doctor to help grapple with the weight of this diagnosis, they might turn to the internet as a means of learning information and connecting with other mothers of autistic children. In doing so, laypersons involve themselves in the process of diagnosis and treatment, which enables them to work collaboratively with physicians in the creation of their child's particular treatment plan. In addition, websites of issue-related organizations such as Autism Speaks exist as a depository of knowledge and epicenter of resources particular to certain health conditions. Alongside a directory of autism services and support as well as an associated blog for more personal connections between friends, family members, and individuals with autism, the website provides autism diagnosis criteria (DSM-5) and knowledge "kits" for newly diagnosed families. Providing these resources, Autism Speaks enables laypersons to involve themselves within current medical practices related to autism. This is critical in the development of HSMs as well as in the formation of advocacy and activist groups that aim to challenge the dominant epidemiological paradigm surrounding this disease.

#### Health as a Private to Public Experience

Related to expanding health social movements fostered by the large-scale adoption of technology, there exists another significant transformation: illness has transformed from what was a largely private experience to (potentially) a very public one. Technology enables individuals from all over the world to become activists in health social movements. It has given a historic number of people a social and political voice. More explicitly, protests and campaigns no longer have to be in one location or have a united leadership to be impactful.

ACT UP, for example, relied on weekly meetings to disseminate information, plan protests, and establish a depository of resources for HIV/AIDS victims. There was no online forum to connect members of this patient community or platform to provide information on disease etiology and advancing drugs. It is also interesting to consider how ACT UP's protests would have been different had they not existed in the late 20th century. As noted, art and nonviolent protest was a large way in which ACT UP spread its message; they spread the ashes of AIDS victims on the White House lawn and disrupted mass at St. Patrick's Cathedral. If today's technology had existed while the AIDS epidemic was at its peak, it seems unlikely that ACT UP would have protested in the way it did back in the 1990s. I believe that hands-on protests, such as sit-ins and disruptions of public proceedings certainly spread awareness of a disease and influence government and agency action. Contrastingly, however, technology is an artifact that is inherently political, holding incomparable power in the shifting of dominant paradigms and recasting of social relations.<sup>69</sup>

In this next chapter, I will be substantiating my claim about the power of HSMs by drawing a connection between the subject of this thesis and the American HIV/AIDS crisis of the

<sup>68</sup> Cleaves, 2019

<sup>&</sup>lt;sup>69</sup> Winner, 1986

late 20th century. More clearly, I will assess the importance of reframing stigma within healthcare—how grassroots organizations and laypersons can work hand-in-hand with providers to facilitate the betterment of public health nationwide via health social movements.

# Chapter Four: Case Study - The American HIV/AIDS Crisis of the Late 20th Century

Near the start of the 1980s, tens of thousands of Americans, particularly gay men, were dying of AIDS, and the government was doing little to hastily combat the illness. 70 These individuals felt abandoned by their families, by the government, and by society, faced with a seemingly untreatable illness. What these people did have was a collective illness identity, a cognitive and emotional connection to the broader community of HIV/AIDS sufferers and their allies. As this sense of solidarity emerged in New York City, it became politicized; the desire to challenge the science and government agencies on the etiology, diagnosis and prevention of the epidemic became inexorable.<sup>71</sup> In response to this, a powerful and productive social activist group was formed. The AIDS Coalition to Unleash Power (ACT UP) was a diverse political group, grounded in anger and committed to direct action to end the AIDS crisis. Formed in 1987, the coalition fought for accelerated treatment testing by government agencies and drug companies, decreased drug costs, and inclusion of HIV/AIDS patients and activists in the research and development process. Through its steadfast resistance to medical and governmental authority, ACT UP certainly exemplified how stigma may be re-framed to combat unfavorable health outcomes of LGBTQ+ populations.

Arguably the most impactful subdivision of ACT UP was the Treatment and Data Committee (a.k.a "Science Club"). Led by a former chemist, this group reviewed medical reports and immunology and virology textbooks to become familiarized with the science behind the HIV/AIDS crisis.<sup>72</sup> As stated by one Science Club member, "In the absence of adequate

<sup>&</sup>lt;sup>70</sup> Specter, 2021

<sup>&</sup>lt;sup>71</sup> Brown et al., 2004

<sup>&</sup>lt;sup>72</sup> Specter, 2021

healthcare, we have learned to become our own clinicians, researchers, lobbyists, drug smugglers... we have our own pharmacies and laboratories."<sup>73</sup> These actions led to medical knowledge's democratization, which reformed how physicians and government agencies conceptualized the AIDS virus. Rather than stigma dictating the knowledge base and resulting actions of this epidemic, social activist work by ACT UP initiated a more productive course of action to circumvent disease spread.

ACT UP had many significant accomplishments. One such triumph was pressuring government agencies and drug companies to accelerate drug research, testing, and development—especially in times of public health emergencies. The collective was also able to push for the lowering of existing drug costs. Third, and most relevant to this discussion, ACT UP created a "new normal" in medicine by involving sufferers of HIV/AIDS in the process of drug testing and in mass governmental campaigns for public health.

Within this chapter, I will compare the American HIV/AIDS crisis of the late 20th century with the fight for the inclusion of transgender bodies in the field of gynecology. I will incorporate historical examples of how medical stigma has led to disparate health outcomes, and how laypersons and grassroots organizations have sway in reforming medicine so that minority populations, such as transgender individuals, are more properly and empathetically cared for.

# The Power of Reframing Stigma

In Nurith Aizenman's *New York Times* article titled "How to Demand a Medical Breakthrough," she notes the methods by which ACT UP members were able to redirect their anger with the medical system and government to demand action. <sup>74</sup> Important to mention, however, is why there was so much anger in the first place. Men who have sex with other

<sup>&</sup>lt;sup>73</sup> France, 2012

<sup>&</sup>lt;sup>74</sup> Aizenman. 2019

cisgender males are disproportionately impacted by HIV since the virus transmits more easily through unprotected anal sex. <sup>75</sup> Many individuals diagnosed with the virus were gay men; the disease was considered a "gay plague," resulting in widespread homophobia across the nation. Similar to how Indian communities experienced xenophobia at the height of the cholera epidemic, gay men in the United States were isolated from the nation and left to fight for themselves. <sup>76</sup> A chief example of this was in 1982 when a press secretary for President Ronald Reagen laughed when asked about the president's tracking of the spread of AIDS. The secretary's name was Larry Speakes; this man emphasized the government's disinterest and dissociation from the virus overtaking the nation. The stigma of being gay—even the stigma associated with *engaging* with this population—was of utmost concern to these agencies. So much so that they allowed the AIDS virus to overtake the nation and a shamefully large number of Americans to perish.

ACT UP unquestionably demonstrated the power of health social movements to circumvent stigma. Near the late 1980s and around the time of ACT UP's formation, HIV/AIDS was still labeled a "gay-related immune deficiency." This was troublesome because it isolated HIV/AIDS patients who were not part of the gay community. Moreover, it enabled homophobic messaging to typify the illness' dominant epidemiological paradigm and re-directed public and governmental support away from HIV/AIDS sufferers. In the 2012 documentary *How to Survive a Plague*, one man even says, "if you ask me, I think they all deserve to die because they took it up the butt." This was, by all accounts, a problematic narrative, and it forced the actual needs of the patients to be sidelined by issues of gender and sexuality. In response to this messaging, ACT

<sup>&</sup>lt;sup>75</sup> Fitzsimons, 2018

<sup>&</sup>lt;sup>76</sup> Jain, 2020

<sup>&</sup>lt;sup>77</sup> Specter, 2021

UP acknowledged the prevalence of HIV/AIDS in gay men but used the data to advocate for condom use and advanced sexual education.

ACT UP members were conscious of the stigma-rooted negligence of the government and healthcare agencies who were determined to disassociate from LGBTQ+ Americans. As previously noted, the coalition utilized non-violent protest and art to spread their message and facilitate health. The trademark of ACT UP was a pink triangle, symbolizing gays in Holocaust concentration camps, paired with the statement "Silence = Death."<sup>78</sup>



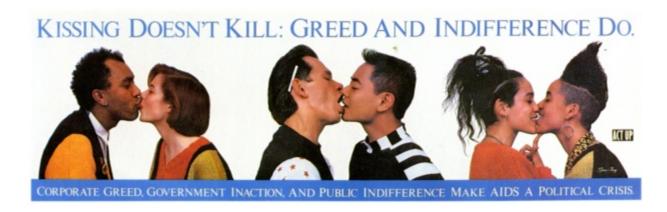
Figure 4. The AIDS Coalition to Unleash Power (ACT UP) logo.

No longer willing to be silenced by politicians and bureaucratic pharmaceutical companies, the group drew attention to the "deadly impact of homophobic public health policies." In 1988, an AIDS activist artist collective named Gran Fury was established. The group famously created the "Kissing Doesn't Kill: Greed and Indifference Do" work found on postcards and New York City buses throughout 1989, publicly drawing attention to the disease and the absence of viable protection and prevention strategies, including medication.

Figure 5. Gran Fury poster found on New York City buses (1989).

<sup>&</sup>lt;sup>78</sup> ACT UP, n.d.

<sup>&</sup>lt;sup>79</sup> Fitzsimons, 2018



All demonstrations symbolic, the work of ACT UP members showcased the group's unwavering determination to reform governmental action and public perception of the disease. For instance, the "Kissing Doesn't Kill" campaign challenged the dominant myth that kissing could transmit AIDS. Also important to note was ACT UP's inclusion of heterosexuality (alongside homosexuality) in their activist campaigns, which demonstrated the virus' ability to infect all individuals who engaged in intercourse.

## Democratization of Medical Knowledge and Foucault's Medical Gaze

As mentioned, a significant accomplishment of ACT UP, certainly of "Science Club," was the democratization of medical knowledge. In the world of public health, this implies the dissemination of medical facts and data, information that would normally be available only to medical professionals. The democratization of this knowledge enables the patient to take a more hands-on approach to their healthcare, as they are educated enough to work alongside their physicians in the determination of proper care. For LGBTQ+ health, this concept is critical; it awards power to individuals who have, historically, felt ostracized and unwelcome within medical environments.

Democratization of medical knowledge is, in fact, a highly productive means of correcting social inequities and resulting adverse health outcomes. Certainly, as technology

continues to advance and disseminate, the future of healthcare and disease education will be reformed. Related to my discussion of doctors exercising exclusive competency over the body and associated health conditions, the democratization of medical knowledge promises to push-back against historical conceptions of "the doctor." Physicians Henri Colt and Silvia Quadrelli note that it is surprising how the medical community (including medical organizations, medical journals, and nonprofit healthcare organizations) is pushing back against the liberal dissemination of medical knowledge and healthcare information.<sup>80</sup> Though, I don't find this to be surprising at all.

Philosopher Michel Foucault developed in the 1960s a concept called 'the medical gaze,' which describes how in the 1700s doctors' belief of how the human body works shifted from outside forces (on the basis of religion) to an understanding of tissues and organs. This "gaze" filters out non-biomedical information related to the patient, asserting a "cognitive relativity, such that the facts of the body are dependent upon the physician's [understanding]—their perceptions, sensations, and experiences." The abstraction of the medical gaze "gives solidity to the abstruseness of the body" and allows for a bridged connection between the physician and their patient. Success of "the gaze," however, rests on its clinical performance, and so medical language (refined by the medical gaze) protects the power and wisdom of the physician.

Convoluted as this might seem, and applying a critical lens to this theory, Foucault's concept may interfere with the democratization of medical knowledge. This is because "the gaze" led to the systematic description of disease and development of esoteric medical terminology, meaning thereafter status as well as experience categorically restrained patients from engaging in the process of disease detection, prevention, and elimination.

<sup>80</sup> Colt & Quadrelli, 2006

<sup>&</sup>lt;sup>81</sup>Lange & Yu, 2014

Another way in which the medical gaze isolates patients from engaging in the process of diagnosis, particularly those of non-normative backgrounds, is through its abstraction. It organizes the (structure of the) body into an essential network, giving doctors a (supposedly) concrete physiological understanding of the human body. 82 Though Foucault's conclusion successfully stood for the separation of medicine from "fanciful cosmic explanations" of bodily ailments, the medical gaze ultimately has the effect of *othering* transgender patients. In other words, the very definition of "the gaze" stands for the conformity of bodies within medicine and creates an environment wherein transgender persons resist general (learned) principles about how the human body works.

# The Importance of Paradigm Shifts for LGBTO+ Health

A central point I would like to make in this thesis is the fact that grassroots organizing, in the form of health social movements, is an effective way of instilling change within healthcare, and ACT UP is a prototypical example of this. Layperson involvement alongside cooperation from physicians and "members" of the medical field can reframe ordinary patient care to welcome transgender bodies alongside similar non-normative patient populations. In chapter three, I described social determinants of health (SDoH), "the non-medical factors that influence health outcomes." Intrinsically related to these social determinants is the fact that transgender and nonbinary persons, in fact, most members of the LGBTQ+ community, have disproportionately poorer health outcomes in comparison to non-LGBTQ+ persons in the United States. LGBTQ+ individuals are more likely to experience substance abuse, mental health conditions, obesity and eating disorders, and heart disease. Specifically related to this thesis

<sup>82 2014</sup> 

<sup>83</sup> World Health Organization, 2022

subject, members of this community are also at higher risk for sexually transmitted infections (STIs) as well as breast and cervical cancer.<sup>84</sup>

So, why is this the case? Transgender and nonbinary individuals are very likely to experience discrimination and prejudice in many aspects of their lives. They are more likely to experience homelessness, domestic violence, weak social support networks (if any at all), and lack proximity to preferred, supportive healthcare. This known, when medical professionals and government agencies fail to establish pipelines for transgender individuals to receive proper care, they are facilitating the means by which social determinants of health result in disparate health outcomes among this patient population. Without health social movements and other effective means of improving transgender healthcare, there is no possibility of shifting the dominant epidemiological paradigm. In other words, no steadfast determination of medical schools and governing organizations to shift medical curricula and transform the teaching of future doctors. As noted, one way these movements "shift the needle" is through the democratization of medical knowledge.

The democratization of medical knowledge can likewise apply to the modern-day fight for the inclusion of trans bodies in gynecology and related fields of historically-gendered medicine. As mentioned in chapter one, Reddit forums are a space wherein trans individuals feel comfortable sharing their experiences with healthcare and connecting with community members. These online, (largely) anonymous forums also enable information sharing and create an alternative, non-biased depository for learning. In doing so, they empower transgender patients to take a more active role in healthcare encounters and ensure their own safety and well-being. This advancement of patient confidence is assuredly critical in an era where healthcare is homogenized, rooted in normative conceptualizations of the body for the purpose of maintaining

<sup>84</sup> Medina-Martínez et al., 2021

accuracy and excellence in medicine. And though the dissemination of false medical information is a real concern, a more relevant concern should be the uplifting of SGMs in health settings, which will realistically improve unfavorable health outcomes.

# Chapter Five: Connecting the Dots - Improving Transgender Gynecologic Care

In early 2018, Perry Cohen experienced an urgent health emergency. He attempted to seek care from his town's only provider who specializes in working with LGBTQ+ individuals, but the physician was unable to see him. Cohen went to another doctor, and then he tried a third. Both physicians whom he met, upon learning of Cohen's transgender status, expressed a lack of confidence in their ability and willingness to treat Perry Cohen successfully. "It wasn't about malice; it wasn't about not affirming me," he said, "but rather, they had this look of, 'Oh, no, I don't know if I'll be able to help this patient.' They didn't want to get it wrong, but they were out of their element." Cohen recalls, "I felt that their fear of messing up on a cultural or emotional level hampered their ability to do their usual rigorous critical thinking."

Perry Cohen's experience in searching for a competent provider is an all too familiar occurrence for members of the LGBTQ+ community. Particularly for transgender individuals, it is incredibly difficult to find a provider who (1) has received formal medical training in the care of this patient population, (2) has clinical experience working with transgender individuals, (3) is available to see the patient and accepts their insurance, and (4) connects with the patient and expresses empathy in clinical settings. The final requirement is difficult to fulfill for many providers. In chapter 2 of this paper, I argued that the field of medicine relies on the professionalism and confidence of providers to uphold its reputation. To this point, physicians lack sufficient didactic and procedural training in order to provide competent and compassionate care to members of sexual and gender minority (SGM) groups, certainly for transgender individuals. This education gap produces healthcare providers like the ones Perry Cohen met with and results in health disparities among transgender patients.

<sup>85</sup> Dutchen, 2018

Medical schools have just begun to shift their core curriculum so as to produce physicians equipped to care for sexual and gender minority patients. One medical school, in particular, that is making strides to amend its M.D. curriculum is Harvard Medical School. Perry Cohen and parallel voices of concern have opened Harvard's ears to the promise of improvement; the question then becomes, how does change come about?

# How Do Medical Curricula Shift Over Time?

Harvard Medical School launched the Sexual and Gender Minorities Health Equity

Initiative in the fall of 2018. This was a three-year plan to improve the medical school core
curriculum so that "all students and faculty clinicians can become exceptionally well equipped to
provide high-quality, holistic health care for sexual and gender minority patients of all ages."

The plan, alongside direct curriculum reform, notes faculty development and increased efforts to
recruit and support students and staff with interests in or experiences with sexual and gender
minority health. The initiative was made possible by a \$1.5 million dollar donation from the

Cohen and Bull-Cohen families. Money aside, this initiative exemplifies that layperson
experiences *can* and *should* be realized so that profound changes may come about within the
field of medicine. As expressed by Ed Hundert, Dean for Medical Education at Harvard Medical
School, "The most powerful vehicle to effect durable, meaningful change across current and
future generations of clinicians in all specialties caring for LGBTQ+ patients is singular:
education."

education."

At every medical school in the United States, there exists an advisory board that acts as a conduit for the implementation of key initiatives in medicine. Most often, the members of these boards are professors of the respective institution, meaning they are physicians with a

 $<sup>^{86}</sup>$  2018

<sup>87</sup> **2018** 

background in medicine and individuals who have gone through medical school themselves. Dr. John Dalrymple, Senior Associate Dean for Medical Education at Harvard Medical School, serves as the faculty chair of the HMS LGBTQ+ Advisory Committee. During his time at HMS, there was no curriculum about LGBTQ+ health. Dalrymple was "out" at this time and notes that just being "out" was a difficult circumstance.

Today, he is a principal investigator for the initiative. He, alongside physicians and administration members from collaborating health organizations in Boston, has ushered the Sexual and Gender Minorities Health Equity Initiative through multiple phases. The first component involves the team leading a committee of students and HMS faculty members in conducting a review of Harvard's four-year curriculum. Specifically, they are identifying areas for enhancement with SGM health material as well as material that contain assumptions or misinformation about sex, gender, and other LGBTQ+ issues. From there, the Advisory Committee will be creating learning objectives, adding to the six core competencies HMS students must be proficient in in order to graduate. When the plan is complete, faculty members will be supported in their integration of SGM health issues throughout pre-clerkship courses, the principal clinical experience, and the post-clerkship curriculum. In this way, *every* student earning an M.D. from HMS will undergo rigorous training in the science and clinical practice of sexual and gender minority health, "not only those with a pre-existing interest in caring for this segment of the population."

Alongside teaching the student, Harvard Medicine is committed to "teaching the teachers." This involves the creation of a faculty interest group on SGM health, which will prepare faculty educators and physician instructors to integrate LGBTQ+ health modules into their curriculum. This is significant. When clinicians and health educators express enthusiasm

<sup>88 2018</sup> 

and the critical importance of integrating gender and sexual minority health principles into the training of future medical professionals, *all* students (not just those with a connection to the LGBTQ+ community) will feel empowered to provide inclusive and affirming healthcare. In other words, the eradication of physicians' uncertainty in caring for these minority populations most easily happens when medical schools' administrative and faculty members make a concerted effort to amend their curricula.

A particular effort from HMS that I find commendable is their dedication to sharing what they have learned with other medical programs throughout the country. Dalrymple notes that he and his colleagues will share findings from the 3-year initiative with clinicians and educate faculty at national and international conferences. In a similar vein, HMS will make all of its curricular and faculty development materials available online for free, which demonstrates the school's determination to enact change not only within its medical program but in programs across the world.

#### Critical Players in Medical Paradigm Shifts

It may be argued that HMS students and faculty, those who facilitate the issuance of sexual and gender minority curricula, encompass a health social movement. This is because they are working as a group to draw attention to said cause, attempting to integrate sufficient resources and subject matter into medical schools. Though, it must be understood that the real core of these movements, the reason these paradigm shifts come about, is the collaboration and engagement between patients and physicians, students and teachers, laypersons and members of medicine. In referencing the example above, Perry Cohen certainly ignited the movement within Harvard Medical School to amend the school's core curriculum and correct misinformation about transgender bodies and health. He made it clear that there was a lack of competent providers who

can care for transgender individuals, and he created an initiative to change things. Luckily for him, Harvard was interested in expanding their curricula for the purpose of producing physicians equipped to care for such minority populations.

It is important to point out that Perry Cohen himself is not a physician. He is simply a self-identifying transgender man who recognized a vacancy in healthcare—both in his county and throughout the nation. Seeing how Cohen is not within the field of medicine, not a "member of the club," his story exhibits the power of laypersons in igniting health social movements. In fact, Cohen has done more for the trans community than kickstarting Harvard's SGM initiative: He and his co-parent, Brooks Bull, created the "first, independent trans healthcare clinic in the country," Transhealth. <sup>89</sup> The clinic is 100% dedicated to caring for transgender and nonbinary individuals as it is not profit-driven. Transhealth serves as a model for compassionate, sufficient trans-centered healthcare and for gender-affirming care at all levels.

#### Increasing Representation in the Medical Field

It is also significant to consider how physicians, themselves, may be classified as patients. This is why it is critical to encourage transgender and gender minority individuals to become healthcare providers. Beyond connecting with SGM patients, providers who identify as transgender grasp the importance of initiatives that aim to shift the dominant epidemiological paradigm in medicine.

Institutions like Harvard Medical School are implementing initiatives to increase gender diversity and support LGBTQ+ medical students. The Association of American Medical Colleges published, in 2022, a list of support systems for gender and sexual minority students at

<sup>89</sup> Giardina, 2021

medical colleges throughout the United States.<sup>90</sup> While some medical schools report no effort to encourage the retention of SGM students or support these students throughout their education, other institutions report several support systems. Harvard Medical School is just one example of a medical program that is dedicated to the inclusion and acceptance of SGM students. In addition to the Sexual and Gender Minorities Health Equity Initiative, which is aimed at restructuring curricula, the school is vocal about similar resources that promote the inclusion of transgender students and faculty. One such resource is LAHMS: the LGBTQ and Allies at Harvard Medical School student organization, a "collaborative place for everyone." LAHMS (in collaboration with the SGM Health Equity Initiative) offers resources such as an "OutList," restroom map, calendar of events, term list, and list of people.

It is evident in the AAMC's list of support systems for SGM students that not every medical school in the United States has enacted or will enact support systems for students who identify as a gender or sexual minority. This is not something to be concerned about. Certainly in an ideal scenario, *all* medical institutions would make it a top priority to support students and faculty members who identify as transgender, nonbinary, etc. Though, it is my belief that if even just a small number of medical colleges offer support systems for these individuals, medical paradigm shifts are still possible. Consider again ACT UP: The group was not present in all 50 states, fighting for medicinal and social solutions to the AIDS crisis. In fact, the cohort of ACT UP that fought most outwardly for their cause was primarily in New York City. Even so, nationwide change was invoked; the government publicly acknowledged that individuals were dying and the U.S. Food and Drug Administration accelerated the research and production of HIV/AIDS medication.

<sup>90</sup> Association of American Medical Colleges, 2022

From this historical example, it is clear that even one medical college making strides to improve sexual and gender minority inclusion in the field of medicine will have a great impact. Alternatively, healthcare providers who do not follow the traditional Doctor of Medicine (M.D.) route show promise of greatly improving transgender healthcare outcomes.

# Alternative Healthcare Providers and their Impact on the Field

Unquestionably, transgender gynecology is an incredibly niche field of medicine. The specialty has not been acknowledged in medical textbooks or material, certainly not in medical school curricula, until the past 15 years or so. Interestingly, the expansion and popularity of sub-fields like transgender gynecology has coincided with an increase in the popularity of "alternative pathways" in medicine.

In the 1960s, healthcare delivery was reconceptualized. The physician assistant/physician associate (P.A.) profession emerged alongside the emergence of certified nurse midwives (C.N.M.) and the nurse practitioner (N.P.) profession. These three roles were a "product of demand for greater healthcare access," particularly for low-income individuals across the United States. P.A. and N.P. professions are becoming increasingly popular among pre-health students. This is for a number of reasons. First, the "path" to become a physician assistant or nurse practitioner is much shorter than the traditional M.D. route. Additionally, the professions, at large, offer a better work-life balance. From a patient perspective, these (alternative) advanced healthcare practitioners can encourage more personable and compassionate patient-provider relationships.

Using data from a 2014 Association of American Medical Colleges study, a subsequent study was conducted that investigated patient preferences among provider types. 92 One

<sup>&</sup>lt;sup>91</sup> Cawley et al., 2012

<sup>&</sup>lt;sup>92</sup> Leach et al., 2018

significant finding was that physicians are often preferred for their qualifications and technical abilities, whereas N.P.s and P.A.s are more often preferred for their interpersonal skills. In a separate study conducted in 2010, the characteristics of patients who use physician assistants and nurse practitioners for primary care were analyzed. From the findings, participants without insurance or those with public insurance were more likely than patients with private insurance to utilize advanced healthcare providers as opposed to medical doctors. This is particularly interesting because transgender and nonbinary people are more likely to lack health insurance than cisgender individuals in the United States: 14 vs 11% as of 2020. The implementation of P.A.s, N.P.s, and certified nurse midwives in primary care facilities, therefore, presents more benefits than disadvantages. In regard to improvements in transgender healthcare, specifically within the field of gynecology, these "alternative" providers offer hope for TGNB patient populations.

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<sup>93</sup> Everett et al., 2009

<sup>94</sup> Bakko & Kattari, 2020

### **Conclusion**

Medicine is an incredibly stagnant field in regard to inclusion of, and care for, minority populations, including those of non-normative sexual and gender identities. It can take years—decades even—for real changes to be realized within medicine. Why does reform move so slowly? The field has worked, since its inception, to codify itself as the most esteemed and commendable profession in society. Some sociologists note that doctors graduate medical school with an understanding that they must exude certainty and confidence to the utmost degree. This means that physicians can assume complete and total authority over patients and their respective healthcare decisions. However, as we know, minority patient populations (including transgender individuals and those who identify as gender-nonconforming) are more often than not experts on themselves, given their unique lived experiences. When medical doctors align with these central pillars of medicine, they authorize healthcare to remain how it always has been. These salient traits that define medical doctors stand in the way of productive relationships between physicians and patients, restricting desired health outcomes and ostracizing minority patient populations.

Looking forward, concrete actions must be taken to reform medicine and produce doctors who are equipped to care for transgender patients. Certainly, in more contemporary practice specialties like transgender gynecology, change should not be expected to happen overnight. Though, this is not to say that change isn't possible. A difficult part about the substantiation of gender-expansive reproductive health (in particular) is the fact that its reworking acts against the historical comprehension of gynecology as a gendered field of medicine. Gynecology and obstetrics have been labeled as "women's health" for decades and so this battle is more onerous than implementing gender-inclusive language—truly, it is about *un-learning*. Part of this

unlearning process must involve engagement between laypersons and actors within the field of medicine. This is where health social movements come in.

Currently, there exist health advocacy groups, medical institutions, and clinicians that fight for the inclusion of transgender individuals in gynecology. Transgender patients are not alone in their fight for equitable, accessible health care. Continuing Medical Education is a way in which medicine actually requires and ensures that providers are knowledgeable about emerging subfields and topics, such as LGBTQ+ healthcare. Unsurprisingly, however, there is much more that should be done to reframe gynecology as a gender-inclusive field. Health social movements, as seen through ACT UP and similar activist groups, have a distinct and fervent power to challenge the dominant epidemiological paradigm, the codification of beliefs about disease etiology and treatment. Important to note, however, is that health social movements must realistically include laypersons and "experts" of medicine in order to categorically achieve reforms, such as gender-inclusive care.

It is interesting to note how some medical institutions *have* made a concerted effort to rework their curricula, thereby shifting how medical knowledge is constructed (or at least how students of said medical school learn to diagnose and care for patients). Universities like Harvard are implementing initiatives to increase gender diversity, support LGBTQ+ students and faculty, and more seamlessly interweave LGBTQ+ healthcare topics throughout didactic learning. This should (in theory) translate into greater provider competency in working with SGM populations. We know from history, however, that more must be done to reframe stigma in order to improve health outcomes. In theorizing a productive health social movement that aims to elevate transgender gynecologic care, I note three necessary components: (1) the movement must involve members of medicine (especially care providers that identify as members of the LGBTQ+

community) and laypersons; (2) technology must be integrated into the movement to optimize membership and awareness; and (3) reform of educational institutions and governmental healthcare organizations should be a central focus. With a determined effort and a dedication to reframing stigma, it seems plausible that gynecologic health outcomes of transgender and minority populations will categorically improve.

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