

## How Health Care Civil Rights Became Patient Experience

Greg is a grievance analyst who started out in the “Consumer Resource Center,” a division of the Patient Relations Department at the large California hospital where he works. He told us about how his experience in retail management prepared him well for his current role:

The majority of time I’ve been in retail management. And then I transitioned over into healthcare, just because healthcare has transitioned over to a really customer-focused, a patient-focused organization, as we have most of our survey scores are really tied to reimbursement rates. And so having people with a customer-service background is, you know, when you have doctors that don’t necessarily know how to be nice to people. Having that customer service background is helpful, you know, in those types of situations.

Greg’s work is typical of someone working in a larger healthcare organization. “Patient Relations is the office of record for all formal grievances and complaints that are related to clinical care issues or any service-related issues . . . or the patient’s perception of something that went wrong,” he explains. He does the “initial intake” and “document[s] the information to an internal system that we have here.” After deciding what kind of problem the issue seems to be, Greg “direct[s] those complaints out, or grievances out, to the appropriate areas to find some resolution.” Then he is responsible for communicating back to the person about their problem. If a patient seems to be describing an incident of discrimination, he would “pass the buck” to their Equal Employment Opportunity Office. When we asked him specifically about the Affordable Care Act (ACA) and sex discrimination, he replied that he would send any issues like that to the woman in charge of the sexual harassment compliance and prevention office. Greg is mistaken about the law here, interpreting patient discrimination as employment related. An

essential task of his job is recognition and sorting of problems, and he does not seem to recognize health care discrimination as a civil rights issue.

Will is a nursing administrator at an ambulatory surgical center, another type of health care organization covered by the sex discrimination clause of Section 1557. For Will, there is no need for the identity politics of civil rights because the patient care ethic takes care of it:

And what is in the best interest of the patient, okay. And that's why I keep reiterating the patient. It doesn't matter what the patient is—black, white, female, male, sexual orienta—I mean, all these things that fall under 1557, we don't address those things. All we're addressing is the patient, and what is in the best interest of the patient. I mean, we're in healthcare, we're in to help people. It doesn't really matter about the rest. I mean, it's kind of like the Hippocratic Oath, it's like I don't understand where the problem lies. Why do we have to have this written down? It's what we do!

Will knows about the legal requirements but pushes them away. Ignoring the law, misunderstanding it, reframing it, or grudgingly implanting it are common ways that health care civil rights get refracted on the ground.

Understanding what health care civil rights are means studying them where they matter most. The first place that health care civil rights matter is within health care settings such as hospitals or clinics where people seeking care may encounter discriminatory treatment. They may be ignored, denied care or specific treatments, harassed, physically mistreated, or arrested or singled out by security, for example. If this treatment occurs because of a trait that the law protects in this context, then it could be illegal discrimination. But for a problem to be seen as a health care civil rights problem, a lot of things need to happen. The person seeking care needs to understand it as wrong and to complain about it. Someone in the organization needs to receive that complaint and understand it as a problem too. The problem needs to be understood as a possible rights violation or a civil rights problem, not some other kind of problem. This process is not at all smooth, and whether it happens or not and in what ways it happens depends on many features of the organizational culture and the frameworks for problem-solving that the people in that setting use to understand what is happening when someone complains. This chapter is about how complaints—also sometimes called grievances—are understood on the ground in healthcare settings.

#### SECTION 1557 COORDINATORS AS MICROLEVEL RIGHTS WORKERS

The class of professionals and the bureaucratic workflow that I found managing patient civil rights problems is part of the what Kathleen Sutcliffe and Robert Wears call the institutionalization of the patient safety movement into managerial, scientific-bureaucratic medicine.<sup>1</sup> Moral panic and publicity about medical harms plus concerns for out-of-control healthcare costs helped drive “patient safety” and

“medical errors” to prominence in the 1990s and early 2000s. Sutcliffe and Wears argue that what could have been an interdisciplinary and more innovative movement to understand patient safety and harm was diverted into simple, instrumental tools for safety and absorbed within the bureaucratic apparatus of hospital compliance staff. These workers, mostly women with training as nurses, would manage the bureaucracy of safety in lower-status ways, guarding it from incursion by outsiders but also ensuring that “any potentially radical change to improve safety would be stifled, limiting patient safety efforts to small, nondisruptive changes on the margins of clinical work.”<sup>2</sup> Computerization of medical records and reporting systems, proceeding along at the same time, was appealing as an implementation modality for this bureaucratic, regulatory approach to safety because it could prioritize the needs of managers, designing out discretion for doctors.<sup>3</sup>

All the pieces of the hospital civil rights administration, such as it exists at all, were already evolving into place before the passage of the ACA in 2010 and its new civil rights mandate. The ACA added incentives for maintaining high scores on patient satisfaction surveys to avoid losing federal funding, fully enmeshing patient satisfaction with patient safety in the healthcare bureaucracy. There was already a required grievance procedure for any entity participating in Medicare. The world into which new patient civil rights came, in other words, was already made up as a reporting and managerial bureaucracy in which mostly women, frequently trained as nurses and responsible for multiple aspects of administrative compliance, sorted, routed, and resolved patient problems using grievance reporting software systems. This is the world I found when I started to ask about patient civil rights.

To find the people tasked with implementing Section 1557 on the ground and to understand what they were doing, my research team and I called the numbers for Section 1557 coordinators between May 2017 and October 2018, asking to speak to those people. If we could not find a named Section 1557 coordinator on the organization website, we called more general numbers and asked to speak with someone who handles patient complaints and then determined if they would indeed be a person who would work on complaints including discrimination. By “handling” patient problems, I mean in the metaphorical work sense but also in the material sense: what did these grievance handlers literally *do*, as in sort, move, and work with these problems? They described a rich world of obligations, pressures, systems, norms, and professional practices from the view of their desk every day. *Grievance handler* is my term for them because it most plainly describes what they do. Sometimes they were called the Section 1557 coordinator, but more commonly they had other titles like patient advocate or patient experience coordinator.

Our team interviewed sixty-four people from the 744 healthcare settings we called.<sup>4</sup> All names and workplaces have been replaced with pseudonyms. Fifty-nine of those people worked handling patient problems, of which forty-three (seventy-three percent) were the primary grievance handler at their facility. The others were people we reached through snowball sampling, asking the first person who

else was helping with 1557 implementation and then seeking out those people. Of the fifty-nine implementors, only fourteen had been specifically designated as the Section 1557 civil rights coordinator and knew they had this role. The remaining forty-five grievance handlers were people who would be assigned the 1557 role if the organization had complied, but there was not a named person in their clinic or hospital yet. A majority (seventy-one percent) of interview subjects worked in the domains of patient relations, risk, compliance, and quality assurance. Nursing was the most highly represented educational background (thirty-seven percent), with the rest comprised of a wide range of professional and non-advance-degreed backgrounds. Notably, there were only two attorneys in our sample.

The largest single group of our interview subjects (fifty percent) worked in patient experience roles. What we call patient experience includes a variety of job titles including “patient advocate,” “patient relations associate,” “patient experience representative,” or “customer relations coordinator.” Titles sometimes explicitly linked the patient and the customer, as in “patient advocate and customer relations specialist.” At larger facilities, our respondents worked exclusively on responding to patient complaints. Among smaller organizations, however, patient experience was likely one of several responsibilities assigned to an individual. For example, at smaller rural hospitals, the patient experience role might fall to the “director of social work and risk management,” the “chief quality improvement and patient safety officer,” or the “system director of clinical risk management,” all titles our interviewees held. At ambulatory surgical centers, grievances were often handled by CEOs or executive directors.

Grievance handlers were mostly middle-aged, white (seventy-eight percent) women (seventy-six percent). A large portion of the professionals working in complaint handling (twenty-one out of fifty-eight, or thirty-six percent) were trained nurses who had transitioned into a patient experience role. For example, Michelle is a nurse and patient advocate who finds that her nursing background helps her to explain medical issues to patients and head off communication problems between doctors and patients. She explains that she deals with “everything from billing to, you know, care issues, to physician issues.” “Gosh,” she continues, “I mean, it’s really been a game of lost items, lost teeth, lost dentures. Lost shoes, I get called. But in order to be able to understand, number one, what the patient is here for, diagnosis, to be able to kind of speak the language, and then help bring it down to their level, is very helpful. So, I just think it’s a nice fit to be a nurse.”

Compliance officers and risk managers also handled patient problems. Like their counterparts in patient experience, they regarded other regulatory duties as more salient than civil rights enforcement as they did their jobs. Compliance professionals are in charge of making sure the hospital or facility’s existing policies and procedures abide by all governing rules, regulations, and professional standards. Possible discrimination complaints are a small part of the myriad compliance obligations they confront. Justin, a program manager in the compliance office

of a Michigan community hospital who is also the Section 1557 officer, explains his regulatory world:

So what we look at, just about everything. We're always looking for HIPAA [Health Insurance Portability and Accountability Act]. We're watching for any sort of Medicare/Medicaid fraud. EMTALA [Emergency Medical Treatment and Active Labor Act], any of the regular regulatory, you know, federal government compliance issues. So our primary focus, oddly enough, the one that has the highest risk, is physician contracting.

He explains that "the civil rights coordinator position had already been attached to the program manager job—it's not looked at as a separate job, a separate job title. It's like our director of medical records is also our privacy officer." Risk management is, as Jackie, director of quality and risk management at a critical access hospital in rural Michigan, explains, "[A]nything surrounding patient safety that could pose a risk for the hospital." As Sheila, a risk manager at a community hospital in a Michigan town, puts it, "When you're in risk management, you're sometimes dealing with people who have really legitimate complaints or want to sue you." These professionals respond based on a differentiated legal consciousness arranged in a hierarchy of importance, with many priorities above recognizing possible civil rights violations.

Most of the grievance handlers we interviewed were not familiar with the civil rights provision of the Affordable Care Act. Widespread noncompliance is not a surprising finding in sociolegal studies, even among professionals tasked with implementation.<sup>5</sup> For example, Justin had never heard of the specific requirements of Section 1557 despite being given the civil rights coordinator title three months before. When asked when he first heard about the legal requirements for Section 1557 he laughed, saying, "When you called me." Another grievance handler, named Jamie, a nurse turned patient advocate, described "a reference binder that I created to become more familiar with all the rules that come with the actual filing grievances for patients." She pulled it out during the interview but could not find any section in the binder for 1557. Even though she had not heard of Section 1557, Jamie had a ready answer for how she would handle a claim:

If the patient is discharged and they're calling back up to complain about their hospital stay, then I talk to the patient. So if they had a concern regarding the way that they were treated, based off of their gender, sexual orientation, then I would address it like I would any other concern, which would follow the same pattern: I'd listen to the complaint, I would file it according to our Safety First tracking, I would address it with the director or manager. I would wait for their response, and then I would follow up with a resolution letter to the patient.

Here, Jamie makes it clear that she sees no meaningful distinction between discrimination complaints and other kinds of patient concerns. Their Safety First

tracking system is the default technological framework for routing patient complaints about “the way they were treated.”

Patient grievances pertaining to discrimination consumed little attention. When asked how the frequency of discrimination grievances compared to other kinds of grievances, for example, Barb, a patient safety manager in California, said, “Ten, twenty, thirty times more. I mean we get very few related to discrimination.” Twenty-four percent of the grievance handlers in this book reported that they had never received a complaint about discrimination. But when we probed specifically on that point, we found that forty-seven percent of those said they had dealt with a discrimination-related complaint at some point during their tenure in their current role. Interview subjects with legal or compliance department experience were twice as likely to mention an experience with discrimination handling compared to those without those backgrounds. Yet only two of our respondents had practiced law or had formal legal training.

Human resources (HR) also had little role in Section 1557 implementation. HR departments typically manage employment relationships and Section 1557 is focused on discrimination against patients, so lack of HR involvement makes sense. However, it also means that the bank of professional knowledge about civil rights laws in these organizations is functionally separated from this patient experience framework. I found that most organizations did not hire a new person to comply with Section 1557’s civil rights coordinator requirement but rather gave these duties to someone who was already handling patient complaints. Participating in Medicare and Medicaid already required a grievance procedure for patient complaints, enacted in 1986, so every facility already had something in place prior to Section 1557.<sup>6</sup> The 2016 implementing regulation for Section 1557 said that covered entities could reuse whatever grievance process they already had in place, even if it was unrelated to civil rights.<sup>7</sup> So while there would be expertise about civil rights elsewhere in the organization (employee civil rights under Title VII, for example, in HR or the legal department), that framework of understanding was not really applicable to Section 1557, while another one—the Centers for Medicare & Medicaid Services or CMS grievance handling process—was already there and ready to pick up.

There was significant variation in awareness about Section 1557 across the organizations we studied, and some of this variation is likely attributable to whom we interviewed and their place in the organizational hierarchy. As would be expected, higher-level administrators at larger hospital systems knew more about the law than frontline staff in smaller care settings. Larger organizations had committees devoted to the new law. As Kathy explains her organization’s approach to Section 1557, “We pulled the regulation. Then we created a gap analysis. And this is our standard process with any new regulation or change in regulation. From that gap analysis, we create a work plan. We put together a

committee to ensure implementation.” Kathy is the senior director of compliance at a large Michigan hospital system and holds an MBA. So while there may have been well-informed administrators in a hospital, our method of contacting the advertised coordinator might still route us to someone who was not very well informed about the new regulations and would turn to other well-worn paths for doing her job with complaints more generally: listening, filing, routing, and so on.

One way to understand Section 1557 grievance handlers is as actors in a typically unresponsive internal complaint process. We know from the Title VII employment context in the United States that grievance procedures at work are likely to be symbolic shows of compliance that protect the employer from liability rather than prevent discrimination.<sup>8</sup> Internal grievance procedures have been widely popular in the private sector for decades,<sup>9</sup> and the civil rights regulators who promulgated the 2016 Section 1557 rules embraced this structure too. “In OCR’s [the Office for Civil Rights] experience,” the original 1557 rule explains, “the presence of a coordinator and grievance procedure enhances the covered entity’s accountability and helps bring concerns to prompt resolution, oftentimes prior to an individual bringing a private right of action.”<sup>10</sup> OCR’s enthusiasm for grievance procedures is not an evidence-based assessment of these procedures’ effectiveness but rather shows how legal regulators “assume the validity of managerialized conceptions of law.”<sup>11</sup>

US healthcare provision differs from the employment context in ways that transform health care civil rights in practice. Whereas the discrimination complaints are handled primarily by human resources professionals in the employment context, a wider array of professionals handles complaints in the context of healthcare provision, but the modal complaint handler had a nursing background and was situated in a patient experience department. The professionals who handle patient complaints are attuned to a different set of legal and regulatory demands specific to healthcare. Organizational decisions about *who* in the organization should respond to claims plays an important role in determining *how* complaints will be addressed. Grievances may be about many things, including but not limited to discrimination, and indeed a major question here is whether it is possible to see discrimination in the claims at all.

#### THE FRAMEWORK OF PATIENT EXPERIENCE

Jennifer is a registered nurse who has been working in the patient experience department of a large Michigan hospital for five years. It is her job to handle patient complaints about discrimination, but she has never heard of Section 1557 of the Affordable Care Act (ACA) where nondiscrimination rights were newly codified in 2010. Nonetheless, Jennifer has a well-developed

approach to detecting and handling patient problems. She explains her “concierge” approach:

Primarily, my focus is to make sure that our patients have everything they need to have the best possible experience, whether it’s through communication, whether it’s comfort items, whether it’s helping their family make arrangements from a local hotel, getting them directions, kind of like a concierge-type program. And then complaint management and resolution. Like anything to do with quality for the patient experience.

Jennifer cares about patient experience and satisfaction, and her professional orientation toward disputes is organized around these priorities. The rise of patient experience as a financial interest in healthcare required improvements in communication to patients, who come into healthcare settings hurt, confused, and adrift in the busy workplace of healthcare in which everyone is busy and knows what they are doing but them. My research uncovered a vast range of patient complaints, from lost dentures to billing problems to delays in waiting rooms to humiliating encounters with providers. The healthcare organizations’ view of the patient experience, however, is shaped by what is measured and how.

Healthcare organizations had previously measured patient satisfaction but not in any coordinated fashion. Two Notre Dame professors, Irwin Press, a medical anthropologist, and Rod Ganey, a sociologist and statistician, started a hospital patient satisfaction survey business in 1985.<sup>12</sup> Today Press Ganey is one of the major healthcare satisfaction surveying organizations. Organized national efforts to gather preferences came from the Agency for Healthcare Research and Quality in 1995, which launched the Consumer Assessment of Healthcare Providers and Systems program to study health plan enrollees experiences with their insurance.<sup>13</sup> In 2002, the Agency for Healthcare Research and Quality and the Centers for Medicare & Medicaid Services (CMS) developed the HCAHPS survey for adult hospital inpatients. CMS implemented the survey in 2006, and in 2007 hospitals received a financial incentive for using HCAHPS, enacted under the Deficit Reduction Act of 2005. Nearly ninety-five percent of eligible hospitals implemented the patient satisfaction survey that year.<sup>14</sup> Public reporting of scores began in 2008, and in the 2010 Affordable Care Act (ACA), HCAHPS scores were explicitly keyed to Medicare reimbursements under “pay for performance.”<sup>15</sup> By 2013, the CMS Hospital Value-Based Purchasing Program incorporated patient satisfaction scores in total performance scores, and hospitals would stand to earn back more, less, or an equivalent amount that CMS held back from their diagnosis-related group payments for that year. These potential losses from bad scores are what Peggy means when she warns that “they’re going to be taking back, you know, money.”

What I call the patient experience frame emerged alongside the period of increased healthcare bureaucratization over the last twenty-five years. How patients felt about their care became acutely important within healthcare bureaucracies. Institutionalization and professionalization around the patient experience

in healthcare, or “PX” as it is now branded, has proceeded along familiar lines. There are nonprofit organizations devoted to selling the development of the field of patient experience. Jason Wolf founded the Beryl Institute in 2010 as the “thought leadership arm” of the Beryl Company, a business focused on customer service in healthcare.<sup>16</sup> By 2012, the institute had shaped the Patient Experience Body of Knowledge into fifteen domains, setting a path toward further professionalization through credentialing. The *Patient Experience Journal* was founded in 2014. Jason Wolf founded the sister organization to the Beryl Institute, the Patient Experience Institute, as an independent nonprofit arm for professional certification and continuing education. One can become a “Certified Patient Experience Professional” by taking a course and exam.

Several factors in the patient experience frame are critical for shaping the landscape for civil rights. First, the concern is for patient *experience*, that is, the subjectively felt, remembered, witnessed, and reported state of mind of the person receiving health care services. Experiences are obviously important for one’s rights as a patient, but there are many moments that are important for justice that are not part of the patient’s experience in health care: anything that happens under anesthesia, the process of insurance coverage within the walls of the insurance company, and all provider thought and decision-making that occurs away from or invisible to the patient, such as charting, evaluating, recommending, forgetting, or ignoring. Second, patient experience was first framed around the hospitalized patient and centered the hospital as the regulated target and central setting for health care experience. Surveys would expand to cover outpatient doctor visits too. Vendors, professional organizations, and internal organization within hospitals built the bureaucracy of patient experience within and alongside the structures for patient safety.

Wolf’s professionalization project for patient experience has been successful. Patient experience is not always its own job category, especially at smaller hospitals where the title may be shared in one person who is also a compliance officer or risk manager, but it has certainly become a required department and job title in healthcare organizations around the country. What exactly the patient experience is remains harder to pin down, and it remains closely tied to patient satisfaction outcomes.<sup>17</sup> I heard echoes of Wolf’s core patient experience concepts throughout my interviews with grievance handlers, especially an emphasis on communication and miscommunication as the primary axis of evaluation and a somewhat nihilistic devotion to “perception is reality.” When they discussed patients’ concerns that they had been mistreated or that their rights were violated, I heard “perception is reality” while the patient’s concerns were treated as invalid or baseless. That is, it was the second part of a story in which the first part was to present doubts about what the patient said but then pivot to “perception is reality” to move on to describing the “blameless apology” one had to issue (apologizing without taking blame, as in “I’m sorry you’re so upset”). Better communication was considered

the key to managing patient perceptions, and communications failures resulted in unhappy patients for whom perception was reality.

Researchers disagree about what patient satisfaction scores really indicate and whether they are helpful for improving care. After all, there are many inevitable and unpleasant experiences in hospitals. Doctors often must deliver bad news to deliver good care. Creating the hotel-like concierge atmosphere Jennifer describes might please patients and their families but lacks any relationship to the quality of care. Expensive ambiance could drive up costs and create more work for staff but not really improve health. Physicians could be pressured to give patients what they want, such as antibiotics they do not need or other costly interventions to appease them.<sup>18</sup> There is evidence that reported patient satisfaction is related to health care outcomes, like readmission to the hospital after discharge, and to lower mortality rates.<sup>19</sup> These results suggest that patient perceptions about their inpatient care are indeed discerning about underlying quality and not simply concierge complaints about surface-level features. On the other hand, individual providers, whose ratings may dip based on one bad review in the context of overall low response rates, feel burnt out and pressured to appease patients.

In the following sections, I describe the frameworks that structure the work of grievance handlers, shaping their interpretations of patient problems. These frameworks reveal what health care civil rights can be when they are refracted through the professional grievance management structures in the American healthcare system. Within the patient experience framework, grievance handlers have certain tools to help them do their work of constructing responses to problems as they see them. People make do in their lives with the best-honed tools they have; their tools create lines of action for them to do things, and they value outcomes that they can create with those tools. Section 1557 grievance handlers work within a hierarchical medical system in which they occupy a lower status than clinical care providers but in which patient satisfaction levels have financial implications that higher-ups care about. Their professional frameworks both rationalize these hierarchies and elevate customer service practices designed for dispersing interpersonal conflict. They experience law as regulatory pressure and financial incentive on themselves, not as civil rights protection for patients. They use the tools of bureaucratic management and interpersonal conflict de-escalation to manage patient problems, demobilizing rights claims.

The primary task of patient experience professionals is to process patient feedback. These staff receive, classify, track, investigate, and resolve complaints and grievances issued by patients or patient representatives. Their work is organized around two key distinctions: (1) the complaint versus grievance distinction and (2) the clinical versus nonclinical distinction. These distinctions guide how they sort their work into categories for action. These two distinctions are closely related,

as we explain below, and hierarchically arranged. They tell handlers what kind of problem they have, what workflow to follow to dispense with it, and whose professional expertise and tool kit are appropriate.

#### COMPLAINT VERSUS GRIEVANCE: HOW REGULATIONS SHAPE PROFESSIONAL PRACTICE

The first distinction—complaint versus grievance—is a concept that comes directly out of long-standing Centers for Medicare & Medicaid Services (CMS) guidelines for how to handle patient problems. As Evan, the executive director of an ambulatory surgical center, explains, “There’s a difference between a complaint and a true grievance. CMS actually dictates a lot of that language for us.” Importantly, the legal risks that people care about here come from the regulatory bureaucracy, not from a potentially litigious person. According to CMS, complaints are problems that can be resolved more or less on the spot. Grievances are problems that are not resolved immediately and require documented action: a written response to the patient within thirty days.<sup>20</sup> I focus more on grievances and adopt the term *grievance handler* because most of the administrative bureaucracy is focused on grievances. They are more significant than complaints and have more rules and practices attached to them. The CMS regulations were by far the most common legal framework I heard about on the ground at this microlevel. When interviewees frequently told us, Oh, we’re doing all that already (meaning civil rights implementation of the new Section 1557 rule in 2016), they meant that they were responding within these existing structures.

The CMS guidelines matter because violating CMS rules could mean losing the ability to bill CMS for care. Interview subjects explained what these CMS regulations meant on the ground for them as they ranked problems and triaged their responses. “If it’s a grievance,” said Frances, a former property manager now working as a patient advocate at a medium-sized hospital, “I have to submit it in writing, and if it’s a complaint, I can verbalize that with them during the telephone conversation if I wasn’t able to close it when they originally called.” Like the financial implications of low HCAHPS scores, running afoul of CMS guidelines and losing the ability to bill Medicare is a highly salient organizational risk that arranges the priorities of any CMS-regulated healthcare setting all the way up and down (despite the fact that cutting off the use of Medicare to a hospital is a never-used and practically unusable sanction). The hospital where Frances worked had not yet posted any of the required Section 1557 language on their website nor was she aware of the law despite being the sole person to gather any patient reports of problems. Like Jamie, who had a binder about how to handle patient problems that did not include anything about Section 1557, Frances had no place in her workflow for rights or discrimination as patient problems. The preexisting CMS

process completely covers over what might be distinctive about a Section 1557 civil rights grievance.

### CLINICAL VERSUS NONCLINICAL: HOW PROFESSIONAL HIERARCHIES MAKE DISCRIMINATION DISAPPEAR

The second concept in the patient experience framework, the clinical versus non-clinical distinction, is closely related. This distinction goes beyond the CMS guidelines and reflects the workplace hierarchy between doctors and everyone else as well as the risk hierarchy that places medical mistakes at the top and interpersonal gaffes or service problems at the bottom. As grievance handlers described it, grievances usually have to do with quality of care (e.g., believing that the patient was discharged prematurely) or billing issues, while complaints usually pertain to the quality of services surrounding care, such as food, wait times, or facilities, such as, “I asked for a turkey sandwich and they brought me chicken,” or personal interactions, such as, “I think the doctor was rude because they didn’t shake my husband’s hand” (examples our interviewees described).

An exchange between the interviewer and June, the compliance manager for a system of Federally Qualified Health Centers or FQHCs, about “customer complaints” illustrates the distinctions drawn between clinical and nonclinical complaints:

*June:* We work with the Chief Medical Officer (CMO) to figure out what we do with the complaint if the complaint revolves around treatment issues. If the complaint is something like “The organization won’t let me bring my service dog,” then that complaint usually comes to me. And I try to resolve it [laughs].

*Interviewer:* How come that kind of complaint comes to you?

*June:* Because the CMO wouldn’t deal with that. So as complaints get, you know, bumped up the chain, after the site manager says to the patient, “Well, this is our policy and this is why and this is what the law says,” if the patient is still unhappy, then I’m the one who will talk to them or somebody at the compliance team.

*Interviewer:* So the CMO would talk about care specific issues and you will deal with everything else.

*June:* Sure. With all the other stuff that’s not related to care.

In this exchange, June uses a complaint about bringing a service animal into the organization as an example to illustrate the distinction between more serious clinical problems that get “bumped up the chain” and lower status, nonclinical complaints. June interprets the presence of the service animal as a nonclinical issue (“not related to care”), and perhaps one that is frivolous, judging by her laughter. But

what if a person cannot get treatment because they cannot bring their service dog? The provision of care appears to be contingent on the exclusion of the service animal—a disability civil rights issue—but the distinction between what is a clinical or treatment issue that only doctors can address versus what is another kind of problem better relegated to other staff obscures that connection. One implication of the complaint versus grievance distinction is that CMS guidelines erase civil rights regulations. Seeing civil rights violations was supposed to be a new part of someone's job as the Section 1557 coordinator, but it joins the low-status work of handling complaints rather than being brokered over to higher-status recognition that may have come through treating civil rights problems as real legal risks or harms to patient care.<sup>21</sup> "Dealing with" these lower-status patient problems is feminized emotional administrative labor, diminished on multiple dimensions.

As June's explanation suggests, the bifurcation between clinical and nonclinical problems has the effect of diminishing civil rights claims in a few different ways. First, if a complaint involves a physician, it is removed from the purview of grievance handlers. Uniformly, grievance handlers described a hierarchical system in which only doctors disciplined other doctors, who are unreachable by the lower-level administrators who hold these patient experience positions. The chief medical officer, the senior physician who has the power to rebuke other doctors, "wouldn't deal with" a complaint about service dog accessibility or "all the stuff that's not related to care." Not surprisingly, the patient experience framework reinscribes the status hierarchies within the hospital, elevating "care" up and away from the realm of health care rights issues, which are imagined as trying to placate unhappy people, not delivering medical care. The legal department, a separate professional sphere from the patient experience department, is where hospital attorneys focus on risks such as possible malpractice claims from physician conduct. This bifurcation means that rights and harms from clinical care are in another domain away from civil rights issues, as if a clinical care problem could not be a civil rights problem too. The status hierarchy is also highly gendered; nearly all our grievance handlers are women and chief medical officers are more likely to be men. The care labor of soothing grievances is feminized and lower status, enacted as cleaning up the less pressing interpersonal problems of the medical encounter.

Mary, a patient relations manager at a hospital in a small city in Michigan, employs the clinical, nonclinical distinction to pull clinical care almost entirely away from human interaction. She explained how grievances map onto clinical care problems and interactions with patients map onto her domain in patient complaints. "The two biggies are the grievance, nongrievance, and that is the clinical versus the human interaction," she said. "Those are the two big categories." "Human interaction," Mary continued, "would be things like diversity. Like if a patient perceives that their color or their sexual orientation or their religious orientation is being held against them or affecting their care or something, we subcategorize all of those things [in the complaint system] so that we can break

them out.” “The clinical piece,” she continued, “that’s where that’s where you get into, you know, ‘They poked me too many times,’ ‘The doctor misdiagnosed me,’ you know.” These distinctions were common among the grievance handlers we interviewed.

This picture of clinical care is odd because doctors have human interactions, misdiagnoses could be the result of discrimination by doctors, and diversity among doctors matters too. The animating idea of Section 1557 was that addressing discrimination in health care could produce better health outcomes. Yet, here we see Mary articulating a division of labor that assigns her “human interaction,” which is the domain for which she possesses a tool kit and which is open to her action, unlike the highly regulated and bounded realm of clinical care that she cannot reach or act within. If civil rights violations were perpetrated by doctors, grievance handlers could not manage them, so they respond by conceptualizing rights problems as distinct from the clinical and lump them in with every other type of complaint they hear. Medical malpractice incidents, by contrast, are routed to hospital attorneys through risk management. Even though risk management and patient experience are sometimes professionally close and some people had both of these terms in their titles, they performed a similar sorting that replicated the status hierarchies: doctors could make clinical mistakes that could cause big, important legal problems while patient complaints about their experiences would be handled by almost entirely nonlegal administrative professionals. Their tools—permitting venting, explaining that there was no bad intent, apologizing without accepting blame—work to demobilize possible rights claims.

#### THE DROP-DOWN MENUS IN GRIEVANCE TRACKING SOFTWARE

Karen describes the software her large Michigan hospital uses to track problems: “It has very specific drop-downs where any employee can go in at any time of the day and place a complaint, a compliment, into that system.” Then the system uses “auto-firing algorithms” to alert people in departments mentioned in the entry. “It’s like forwarding an email,” she explains. These socio-technical systems sort, alert, and remind grievance handlers as they do the work of moving along and resolving complaints. The software classifies patient problems in two main ways: (1) what kind of problem and (2) where in the organization it happened. These stories are about improving quality and safety by seeing problems and apportioning blame. The first and most important categorical division that tells “what kind,” reflected in everything from the software itself to the organization of the professions within healthcare, is between the patient experience side and the clinical or risk side of problem management. Debra, a nurse and patient relations manager at a Catholic hospital in Alabama, explains the bifurcation:

Well, there's two sides to [our] event reporting system. One is the safety side, which would be, like if the patient fell out of the bed, or if patient got a wrong medication dose. Or any type of event that was an unforeseen thing that could impact the patient clinically. The other side of the event reporting system is called the feedback side. And that's my side. That's where you would enter complaints, grievances, inquiries, suggestions, that kind of thing.

Potential civil rights claims fall under the personal, the experiential, and the nonmedical side, which is lower in status and maintained by a cadre of patient experience specialists who are highly responsive yet rarely able to do much of anything to remedy a rights violation. The clinical side is the risk management side, watching for possible medical mistakes that could blow up into lawsuits. The feedback side is most concerned with patient satisfaction scores, while the risk side is most concerned with the law's external and more threatening forces. Civil rights claims thus become demobilized legally, with literally no place in the drop-down menus that most grievance handlers described. A few reported adding an option called Section 1557, but overwhelmingly the categories described have no obvious relation to any civil rights category, identity, or cognizable harm, and as I show, many grievance handlers resisted and denied this use of their system.

Many interviewees mentioned tracking software by RL Solutions, now RLDatix. This private vendor has over 5,000 institutional customers across nineteen countries.<sup>22</sup> It covers seventy-five percent of incident reporting in the UK health system, and in the United States its customers include the Veterans Administration (the largest US health system), the Cleveland Clinic, Mass General, Duke, Johns Hopkins, and New York-Presbyterian.<sup>23</sup> The 2020 RL Solutions brochure tells hospitals to "[u]se your data to prioritize patient advocacy and service excellence initiatives . . . [for] better patient satisfaction scores and lower readmission rates, which drives better healthcare reimbursement." The software reflects the separation of its "Feedback and Risk modules," by offering "integration . . . to minimize rework, for example, if a grievance reveals that an incident took place." An incident is a risk management event that could trigger a fine or a lawsuit, while a grievance may remain simply "Feedback." Nancy told us how she uses their RL Solutions software:

I receive on the average of maybe twelve [complaints] a month. There's predetermined categories. There is a drop-down box in this software that I was talking about that does classify, say, if somebody, you know, lost something, lost an item, then that goes under service recovery. Replace item, whatever. If they call angry and they tell us to do something, I will put that in and close it right away. And service recovery and facilitation. So those are your classifications. [What kinds of complaints are common?] Um, treatment by staff. A lot of it is not giving the medication that they want. Length of wait in the emergency room is a big one. Patients are not wanting to pay their deductible. Wait time and treatment by staff is our two largest complaints.

Federally Qualified Health Center (FQHC) managers were more aware of their patients' vulnerable statuses, such as being low income or trans. However, they were not any more likely to have ways of recognizing civil rights violations set up in their work routines. They also use similar grievance tracking software. June, who handles complaints at an FQHC, describes the categories they use for classifying complaints:

Was this about a prescription? Was it about an office visit? Is it about the site? Was it about communication? So themes kind of fall in those bigger categories. Did they have to wait too long? Were they treated rudely? So we have lots of themes. [Are there any themes that are specific to Section 1557?] No.

Jan, another FQHC grievance handler, gave very specific details about their complaint categories and also differentiated between "patient concerns, like let's say somebody slipped in the parking lot" and "clinical concerns":

[Is there any way you could tell me the categories?] Let's see . . . [reading from software interface] For just general patient concerns, it can be categories under access to appointment. Billing. Confidentiality. Clinical care. Delay in referral. Facility. Medical records. Interpreter. Lab diagnostic results. Narcotics. No return phone call. Parking lot. Prescription. Staff discourteous or disrespectful. Telephone system. And the last one is wait time. I believe it's just one general generic policy [to address all these categories].

If a patient were to complain about discrimination in the form of harassment from a care provider, for example, it would become "staff discourteous or disrespectful."

The selection of a category that the problem "is about" is content-free and seemingly neutral. If one is waiting longer, not getting return phone calls, not getting appointment spots, and so on because of one's identity, then that critical detail would be buried in the notes or fall away entirely. We never heard of an "about" category called racism, harassment, misgendering, or anything similar. As we discovered when we probed for the intersection of patient identity data and problem reporting, there is a strong norm against particularizing patient care and satisfaction problems by civil rights identity category. Jessica, a patient relations specialist at a Catholic hospital in Michigan, explains how discrimination complaints fit into the tracking software for problems of all kinds:

And then so within MIDAS [their tracking software], there are some general categories that things are sort of classified into. So if it's a staff complaint you would mark it as staff, and then you could further delineate beyond that what specifically it is. Is it, you know, a communication issue? Is it a discharge issue? Is it a wait time issue? A lot of those different categories. We do track like a discrimination complaint, or an ADA complaint, or there's also those buckets of lost belongings complaint. You know, food complaints, facility complaints, or is it a complaint made against a person, so a staff member, a clinician, or a physician.

Jessica moves so quickly from “discrimination” to “lost belongings” in her list that it is clear that discrimination is one of many problems in a jumble.

Sorting this jumble is important because it shows where in the organization the problems arise. Distinguishing types of problems (civil rights versus lost belongings, perhaps) is less important than distinguishing places. We asked Karen about how she analyzes patient satisfaction survey data. She explained that they do it “multiple, multiple ways.” They create a score card for each unit with aggregated comments for that point of entry. “Did the patient come through the ER, what was that score?” Karen filters their data by CMS patient satisfaction survey results, day of the week, time of day, work shift, diagnosis group, and provider. “There’s a number of ways that we, you know, slice and dice the data,” she says. The patients are unknowing pointers to spots of poor care, and they matter when there are enough of their complaints (lumped together) to focus in on problematic sites for healthcare administrators.

Grievance handlers care about certain markers of good care that are internally meaningful to the organization but would not be likely to correspond to a patient’s description of a civil rights violation. Jamie described breaking up scoring by patient race or sex as “irrelevant” because “as a whole, I need to move those scores.” She elaborated:

[I was just wondering if you guys ever analyze scores on the basis of sex or race or any of these identity categories.] You can run the report and base it off of race, sex, gender. I don’t believe there’s any like transgender checkbox. But as far as me running a report like that? No, because it wouldn’t be, um, statistically significant for the results in the reports I’m trying to run. It’s not what I’m looking for. I’m looking for data about how to improve our scores in different domains such as hospital responsiveness, nursing communication, and medication communication. So to break it up by gender or break it up by orientation, it would be irrelevant, because as a whole, I need to move these scores.

We also asked Erica, an African American working at a Catholic hospital in Michigan, if she tracks patient complaints by race, gender, or age. She replied that she usually does not look at them that way because she does not feel that those categories are important. “It’s overall care that we provide for the patient, the individual. To me it doesn’t matter if it’s a woman, male, child, grandmother. It’s a patient who came in for help, and it’s our job to do that for them,” she says.

We saw in the first story that there is no drop-down for problems labelled civil rights or discrimination problems in the techno-bureaucratic practices of patient complaint handling and that the focus is on places that produce a jumble of problems, not distinctions between types of problems that include civil rights violations and harassment alongside lost dentures. Here we see a second story, about how the homogenized individualization of the best care for every patient erases attention to groups who experience more healthcare discrimination. Every patient is the same in the sense that they all need the best care, and thus differentiating by identity categories (are trans patients treated worse?) does not make sense. The

Joint Commission, one of the major accreditors of hospitals, required hospitals beginning in 2023 to do what Jamie and Erica said they did not need to do at the time of our interviews: stratify their quality and safety data by patient demographic characteristics to see disparities by group.<sup>24</sup> Rather than coming in as a civil rights obligation, these ways of seeing health inequality in patient data will come through accreditation requirements.

Most people denied receiving complaints from trans people, which is not necessarily surprising given the small numbers in the population. When someone complained in a way that seemed to mirror the grievance handler's own approach in minimizing conflict, these interactions could be much more valued. Trans people who presented as authentic selves on journeys rather than assertive rights-claimers were able to put the grievance handler at ease, an example of patient impression management.<sup>25</sup> June, a compliance officer at an FQHC in Michigan, described a positive interaction with a transgender patient who "never talked about feeling discriminated against or disrespected," but instead "just said, it would be more comfortable for me if my case manager would refer to me by the name that I prefer." She explained that the patient had been "very wonderful in this situation in explaining why this was so important to them, and where they were in their journey." Describing it as "actually a really good situation," June concludes that "when people have complaints, it doesn't have to be a situation where you become adversaries."

## GRIEVANCE HANDLING AS CUSTOMER SERVICE

Grievance handlers are hired, trained, and train others in a customer service model of patient interaction. Seventeen of our interviewees explicitly used the language of customer service, and even those that did not use the term described working with similar aims, tools, training, and organizational structures. (As the language of customer service emerged clearly in the interviews, we asked more follow-up questions about it and elicited more detail over the course of the research.) As Sheila explained, "Handling patient complaints is the ultimate customer service job." She adds that her side job in the hospitality industry, where she has to deal with "crazy things," helps her in her hospital job. When asked how she came to be named the Section 1557 coordinator at her nonprofit Michigan hospital, Erica replied, "Because of the position that I hold as a patient advocate, they felt that patient relations—so kind of customer service personnel—that I should be the one to be the holder of it, because, again, if anybody has any complaints, concerns, or compliments I'm the one they bring 'em to and I address 'em and try to remediate what we can do to satisfy the customers."

As we noted, specific financial and legal incentives drive this patient-as-customer focus in contemporary healthcare delivery. Grievance handlers cared

very much about their institutions' HCAHPS survey scores and using their data systems to pinpoint problem areas. These satisfaction tracking tool kits enable them to gather valuable information and alert others to problems that this system can reveal. "We're always trying to improve our patient satisfaction scores," Sheila told us. "And somebody might come to me and say, like, 'Hey, we're trying to do things better on med-surg. So tell me all the complaints from last year about med-surg,' so I can sort it like that and just give them the report for their department." HCAHPS surveys and CMS grievance procedures were overwhelmingly the most salient contributors to grievance handlers' legal consciousness because of their possible financial penalties.

Grievance handlers directly associated customer service and nondiscrimination, as Brenda explained when asked what training was available: "We have an extensive customer service training as far as nondiscrimination." Casey, whose job title is patient relations coordinator at a large hospital in California, also replied that "we did trainings for employees on customer service, patient experience type of trainings." June elaborated how Section 1557 is about both rights and customer service when directly asked. "[So do you see Section 1557 being about rights or about customer service or both or . . . ?] About both. It's about people's rights to get treatment, and it's about the organization's responsibility to provide their customers that service in a way that's meaningful to them. [You mean both to the patients.] To the patients." We asked if there were other model policies that influenced Section 1557 implementation, and it was common to hear that nothing new had to be done. As Alondra, a program manager in a harassment and discrimination response office for a large health system, told us, her hospital has "always been sensitive to this" and that is "covered in Customer Service Standards."

### THE COOLING-OUT TOOLKIT

Constructing patient experience problems as customer service issues leads staff to emphasize interpersonal issues and to construct patient problems as communication failures. Many respondents chalked up patient complaints to miscommunication. Glenda, trained as a medical secretary and working as staff safety and customer relations coordinator at a small hospital in rural Michigan, exemplified this tendency when she described communication as the most common complaint she encounters.

It's most difficult to be able to hear and understand what the individual is saying [because of] human nature. You are always thinking about your one step ahead of the other individual and not slowing down that interaction and truly listening. Because sometimes you're not able to, especially in an emergent situation, you know, you're needing to act swiftly with a patient's life. So a lot of it is miscommunication, misunderstanding, you know.

Carla, working on diversity issues and patient experiences in Michigan, acknowledges that “we all have those biases” but, reflecting on a 1557 issue that she handled around “identity,” thought that “it may have been a communication issue, a misunderstanding.” Meanwhile, Catherine, a risk management worker at a rural hospital in Michigan, made a similar comment, explaining,

I believe that many of the complaints come down to communication. The complaint may start out being, you know, the doctor didn’t listen to my problem or I didn’t get what I wanted. Or it could even be, like, am I being billed for this? Or, you know, I’m being discriminated against because I’m a senior citizen. And no matter what that verbiage that the patient comes with, I find that it’s communication skills that have caused the complaint to happen.

Here, Catherine explicitly includes discrimination complaints among those often typically resulting from communication failures.

Grievance handlers typically recognized that their job required a certain performance of concern and trust in the patient’s account. Our respondents articulated varying degrees of skepticism towards patient complaints and invoked multiple strategies for how to react to a complaining patient. For instance, Debra described her reliance on what she termed the “blameless apology” to ease patient complaints and accomplish “service recovery,” an industry term for resolving patient problems. As she put it, she “lets them spew” and then apologizes but without accepting blame for the hospital. Meanwhile, Sheila exhibited even greater skepticism towards patients. She laughed when describing a patient who had asked for a discount based on a delayed surgery. “So like I had a guy who came [laughing] to me this week and wanted a discount on his bill because his surgery was delayed for three hours and he thinks that no one told he and his wife that there was going to be a delay, when I know that the doctor told them, the nurse told them. I think they were just like so anxious.” She described how she performs acceptance of the patient’s narrative, while privately questioning or rejecting its validity.

You have to just treat it as real. Like you, you have to just treat everything like that. I have to treat all kinds of things like those people who insist that nobody told them their surgery was delayed. I mean, I have to sit and listen to ‘em. But at the time, when I’m listening to them, I don’t know the whole story. Because I still have to go talk to the nurse that was caring for ‘em. I have to talk to the doctor. And so I have to listen and then I have to still write an I’m-sorry letter, as if they’re right. Because I can’t say you’re wrong. Like I can’t.

Catherine, Debra, and Sheila describe patient perceptions as malleable and inaccurate, something to be corrected in their process with a combination of blameless apologies and soothing redescriptions of intent. Sheila reflected on the emotional work of being a grievance handler in a smaller hospital. Perhaps one of the reasons she was willing to talk extensively about her experiences and feelings about

patients even when they were not flattering was because she lacks a professional community to share her own complaints. “In bigger hospitals they have whole teams who deal with those things and you have people to vent to about it,” she said.

The previous examples illustrated the way in which grievance handlers diminished patient frustration by letting patients vent and by validating or appearing to validate their concerns. In addition to these tool kit items, grievance handlers also described discursive strategies they would use to help a patient see their experience differently when handling a discrimination complaint. Catherine describes her reframing process in the following way:

[Y]ou know, that adage, you know, there are three sides to every story. So [laughs], I, you know, in resolving these issues, I really do try to work interpretively, so that one party understands what the motivation of the other party was, and kind of see the conversation through the lens of the other person. So there's a better understanding of what the intent was, rather than how they felt about it. And that goes back to the whole idea of communication, you know. Like being the root of all complaints, how you say something can really change the outcome. And asking the one single question of, you know, is there anything else that I can help you with? Is there anything else you need to know? And giving the patient the opportunity to reflect on that. Their perception of the entire encounter will be different.

Here, Catherine describes a performance of deference that gives the patient the impression that they are in control of the situation. The main goal seems to be to convince the patient that the other person's intentions were benign after all.

This reinterpretation tool assumes that the patient is mistaken in their belief that they have been discriminated against. Debra interpreted patient complaints based on race, poverty, or fatness as misinterpretations, even as she conceded that there was plenty of racial prejudice in Alabama.

I've heard them say, “Well, you know, it's because I'm so big,” or whatever. But those are very rare. More often, you're going to get the “I think it's because I'm Black,” or “I think it's because I'm not insured.” You know. Or “I think it's because I have Medicaid.” But in reality, it's not. You know, we live in the Deep South, and, you know, there's people, there's going to be prejudice, there's going to be people who feel like they're discriminated against. But in reality, I have not seen anything like that. I mean, I know it exists. It's got to exist.

When Debra describes a patient's family member who “felt like the staff was making fun of [the patient]” about his weight (as he was being helped into a car by multiple staff people), she refuses to accept the veracity of the complaint because of her belief that her staff were only trying to help. “One of the directors, he's a very, very kind director, he said something that was misinterpreted and I can't even remember what the comment was. But one of the family members felt like there was some comment that was degrading. But in the end it turned out that that wasn't the case. What it was is they mis—they misinterpreted something

somebody said.” Debra attributes the claim to misinterpretation by “people that are not particularly educated” when really “it’s not as bad as one would think, you know.” She concludes that “there’s a lot of people that immediately want to scream racial discrimination when there is none.”

Because many situations may occur with only the patient and a caregiver in the room, we asked how grievance handlers resolve opposing accounts as they conduct their internal investigation. Karen’s approach assumes that conflicting accounts of reality could be true:

I think it involves really having conversations with all parties who were a witness to that conversation. And trying to understand where each person was coming from. I kind of liken it to, if you’ve ever seen those pictures, and if you look at it one way it’s a witch, and if you look at it another way, it’s [something else], right? So I see it one way, you see it another way. It’s the same picture though, isn’t it? It’s depending on how we each view that. And so I think we have to acknowledge and respect that each of us comes to the table with a different understanding of whatever that occasion or that conversation or that encounter was, and try to discern from that what is the truth.

Nearly every person acknowledged, however, that when it was a patient’s word against a staff person’s with no other witnesses, there would be very little they could do. Evidence that the same care provider has been the subject of multiple complaints could lead to action against that employee, and employees lower on the hierarchy than doctors were more likely to be described as receiving discipline or remedial action. Doctors only receive rebukes from the doctor at the top of the hierarchy, the chief medical officer, and are not subject to discipline from lower-level staff in patient relations.

One cannot let on to the patients that their stories are not credible. Casey from patient relations in an urban California hospital shows how grievance handlers privately disbelieve complaints while outwardly assigning validity to the patient’s perception, which still presents a problem for a hospital. “Oftentimes a patient will say they feel like something is based on their race, sometimes on their gender identification. And when we dig down into it and investigate it and talk to people involved, that wasn’t, didn’t really, come into play. It’s of course kind of hard sometimes to prove or disprove. I always take the opportunity as a reminder and a learning experience for everyone involved at how things could be perceived. And whatever the patient’s perception is their reality, and so that’s how we address it.” Jordan, a former McDonald’s manager turned patient relations manager at a Michigan hospital, viewed patient perceptions as a reality to be dealt with. “If a person calls me and they said, hey, this happened, and I felt this person was rude and whatever, I let the manager know and they address it with that person. Because the patient’s perception is a reality.” Casey and Jordan’s phrasing, repeated throughout our conversations with grievance handlers, draws directly from Jason Wolf’s patient experience professional training materials. “Experience remains beholden to one test,” Wolf argues. “It is only as true as the *perceptions* of those

having the experience.”<sup>26</sup> The patient’s perception is reality. The phrase means that the patient’s perception is the grievance handler’s reality for their rights-work job, not that the discrimination the patient described is reality.

The people in healthcare organizations whose job it is to recognize and address civil rights violations against patients—the Section 1557 grievance handlers—are poorly equipped to do it well. They are passive recorders of what could be transgender discrimination cloaked in other terms like “rude staff” or “miscommunication.” Overall, across contexts, grievance handlers use very similar work tools in similar ways. These tools are not designed to obfuscate civil rights claims; they are designed to flag and push along ordinary problems while alerting administrators to legal risk. But they create stories of nonproblems through lack of a place in the drop-down menu, through cooling-out practices, through relativizing and dismissing patient experience, and through the homogenizing story of the best care for every patient regardless of identity. This refusal to consider identity traits as meaningful is an enactment of so-called color blindness, in which doing justice to someone is supposedly accomplished by ignoring their salient identity traits. Under this view, every patient is equally special and none of them are more deserving of specific recognition than any other. Concern for health disparities in subgroups by race or sex completely disappears under this homogenizing logic.

Additionally, the division between clinical incidents that comprise real risks and feedback that endangers patient survey scores forces an awkward division between poor treatment or harassment and the real health damage that can occur, perhaps later on or because the person does not return to care. It is focused on what regulations make important to hospitals, but it does not reflect a coherent view of how discrimination might harm people’s health. The hope was that Section 1557 would address health disparities under the assumption that certain groups were receiving worse care or being mistreated and that a rights-based remedy could help undo that. This chapter showed how some commonplace forms of rights denialism that have been well documented in other contexts have unique appearances in healthcare. Rights denialism combines with the dynamics of color-blind racism,<sup>27</sup> encoded and reproduced through the socio-technical systems of problem management in hospitals.

Health care civil rights are refracted through the everyday professional practices of the people who receive patient complaints. The first step toward mobilizing a right is raising the denial of it as a problem. Section 1557 specified particular people to receive reports of those problems and thus to be the first person on the ground to reframe and respond to problems. Healthcare settings are complex sites that already have structures and incentives in place to interpret patient problems, and civil rights violations are not the most important problems there. We already knew that unconscious bias and outright stigmatization were significant problems in healthcare settings, but I have shown that there are other structural barriers to robust understandings of civil rights. These are the outcomes of other policies,

such as trying to incentivize quality patient care by centering the patient experience, and they are not self-consciously opposed to trans health rights or civil rights in general. But the patient experience framework becomes demobilizing for rights through its professional norms, priorities, language, software programs, workflows, and status within the organization. The next level is the mesolevel of health insurance plans. This level moves to a more professionalized and remote context for disputes over health care civil rights as trans and non-binary people wrangle with the insurance bureaucracies both on paper and through intermediaries such as doctors and therapists.