

Civil Rights as Patient Experience: How Healthcare Organizations Handle Complaints

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Abstract

The non-discrimination clause of the Affordable Care Act, known as Section 1557, formally expanded patients' civil rights in nearly every healthcare setting in the U.S. in 2010. Regulations required healthcare organizations to name a person to handle grievances and set up an internal grievance process for resolving them. Drawing on interviews with 58 healthcare grievance handlers, this study examines how healthcare organizations respond to patients' discrimination complaints. We find that organizations incorporated the new right into preexisting complaint and grievance procedures, treating possible patient civil rights violations as patient experience problems. Grievance handlers smoothed over problems using customer service strategies. These procedures diminish the efforts of policymakers to expand civil rights

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protections in healthcare. For civil rights to provoke real organizational change, they would need to be handled by professionals attuned to rights consciousness.

Introduction

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 non-discrimination 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.

Though she had not heard of it, Section 1557 of the ACA was supposed to change Jennifer’s job. The text of the law provides that “[A]n individual shall not, on the ground prohibited under title VI of the Civil Rights Act of 1964 (42 U.S.C. 2000d et seq.), title IX of the Education Amendments of 1972 (20 U.S.C. 1681 et seq.), the Age Discrimination Act of 1975 (42 U.S.C. 6101 et seq.), or section 794 of title 29, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under, any health program or activity, any part of which is receiving Federal financial assistance.” Its unusual text, not listing protected categories but simply referencing other laws, was designed to show that these healthcare rights are grounded in pre-existing laws. Non-discrimination provisions already reached healthcare settings under race, age, and disability non-discrimination laws, but sex discrimination was

newly covered with the reference to Title IX. The Office of Civil Rights (OCR) at the Department of Health and Human Services (HHS) began taking complaints to enforce it when the ACA passed in 2010.

Our focus is the implementation of the Obama administration's 2016 regulations for Section 1557, which brought additional changes. These administrative rules required all covered healthcare entities to post non-discrimination notices, set up an internal grievance process for civil rights claims, and name a Section 1557 coordinator, among other things (Department of Health and Human Services 2016). There were therefore several new and potentially significant features of this new healthcare rights law (the provision itself combined with the implementing regulations): (1) it added sex to the list of protected categories in healthcare; (2) it required that at least part of someone's job be focused on civil rights in nearly all healthcare settings in the US; (3) it required a grievance process on site about civil rights claims; (4) it gave patients a private right action to file a lawsuit without waiting to go through that internal grievance process; (5) it embraced gender identity and sex stereotyping as part of sex discrimination, thereby explicitly elevating transgender healthcare rights and health equity; and (6) it expanded the scope of legal remedies to include disparate impact claims (Watson 2011).¹

Health law scholars have explicitly called for using law, including civil rights laws, to fight health disparities and promote population health (Burris and Anderson 2013; McGowan et al. 2016). It initially seemed that Section 1557 could have major impacts throughout the healthcare system, and in some ways it did. One of the biggest impacts of Section 1557 has been

¹ On June 12, 2020, the HHS Office of Civil Rights issued a new final rule for Section 1557, undoing the trans-inclusive definition of sex discrimination in favor of one rooted in fixed biological sex categories and removing the nondiscrimination notice requirements and the requirements to have a grievance handler and a process for claims, among other things (Department of Health and Human Services 2020; Keith 2020). As of this writing, the replacement rule is blocked in litigation.

the large scale removal of transgender care exclusions from ACA-governed health insurance plans, for example (Out2Enroll 2020). Both the ACA generally and these specific rights promised expanded access to health insurance and health care, and advocates hoped that the well documented patterns of discrimination, stigma, and abuse of transgender and gender variant people in health care settings would become recognized and possibly eased along with health disparities based on other categories such as race (National Center for Transgender Equality 2015; Wang, Kelman, and Cahill 2016). Business-side lawyers appeared to agree that there could be a lot more litigation pressure on insurers and healthcare providers for discrimination claims of many kinds. One healthcare attorney called Section 1557 “the future of healthcare discrimination litigation” and the “legal side of health equity,” warning clients that the private right of action and access to disparate impact claims made Section 1557 “a powerful tool in the hands of a private plaintiff” (Stevens 2015).

For most organizations, it turned out that Section 1557 implementation did not require major changes. Critically, the 2016 implementing regulation explained that “nothing in the rule bars a covered entity from combining the grievance procedure required under Section 1557 with procedures it uses to address other grievances, including those unrelated to individuals’ civil rights” (Department of Health and Human Services 2016, 31394). Civil rights offices across the federal government have long relied on internal grievance procedures as the first step of rights enforcement, and the federal statutes referenced in Section 1557 require them (Department of Education Office for Civil Rights 2018). The Centers for Medicaid and Medicare Services (CMS) regulations already provided guidance about patient grievances and complaints, pre-dating the Section 1557 requirement (2008). Most organizations simply handed the new 1557 duties to their pre-existing patient grievance handler (our general term for this role). Jennifer’s

experience is typical of the people in these roles: she is trained as a nurse and has moved into an administrative role, she is not familiar with Section 1557, but is highly attuned to patient problems filtered through personal interactions and survey data. Her primary focus is patient experience, not rights.

This study examines the organizational and professional field in which grievance handlers like Jennifer encounter and manage health care discrimination claims. How do they perceive and process patient problems, and what are the implications for placing new healthcare civil rights in their hands? We interviewed 58 grievance handlers in hospitals, ambulatory surgical centers, and Federally Qualified Health Centers (FQHCs) in California, Michigan, Alabama, and New York between May 2017 and February 2019. Our focus is the professionals in health care settings who receive complaints, because what they do when they encounter a problem helps to shape what Section 1557 really means on the ground. Although the transgender inclusion issue has been a prominent feature of Section 1557, we do not limit ourselves to transgender-related issues here. Our interest is on the front end of the dispute handling process, where someone must first see and take up a patient problem.

We argue that in health care provision, patient complaints about possible civil rights violations are not framed as a legal matter but rather as lapses in proper patient services. Because of the organizational and professional context, there are multiple barriers to rights recognition in healthcare that we explain through professional logics, the tools available to the people in these jobs, and the array of incentives and meaningful pressures that shape their legal consciousness. Grievance handlers use interpersonal strategies designed to de-escalate patient anger while seeking to avoid any blame that might fall to the organization. Our findings have significant implications for understandings of healthcare civil rights on the ground as well as for socio-legal

theorizations of rights mobilization in organizations. We show that even under conditions of great attentiveness to patient grievances—often entire departments devoted to them with money at stake—it is possible to diminish and explain away patients' claims, while doing little to address discrimination or systemic inequality in U.S. healthcare provision. Approaching problems as rights violations rather than patient experience problems would mean taking conflict seriously, making a way for acknowledging forces such as racism, sexism, transphobia, and homophobia as drivers of health disparities.

Logics, Toolkits, and Rights Consciousness in the Professional Field of the Healthcare Grievance Handler

Hospitals and clinics, where most patient care takes place, are complex organizations subject to myriad regulations, from infection control to patient privacy. These sites must manage competing professional subgroups, families and patients, outside regulators, and public perceptions at the same time as they reproduce their own distinct hierarchies and cultures (Heimer 1996, 1999; Heimer and Stevens 1997). There is a deep reach of law into hospitals through civil law (malpractice), criminal law (child abuse detection), regulatory law (certification of the professions and accreditation of sites, patient privacy) (Horowitz 2012), fiscal law (rules about expending money and the strings that attach to federal dollars) (Heimer 1996), and civil rights (McGowan et al. 2016). Much sociolegal research has focused on doctors and nurses and their relationships to particular groups of patients (Anspach 1997; Heimer and Staffen 1998; Zussman 1992), with new expansions to actors such as pharmacists and their role in between the legal and the medical in disputes over emergency contraception and the opioid

epidemic (Chiarello 2013, 2015). Though there is longstanding scholarly attention to organizational theory in healthcare (Flood and Fennell 1995) and activist mobilization for healthcare rights (Nelson 2013), there has been very little attention to how non-clinical healthcare professionals act as “the law in between” to implement formal civil rights provisions on the ground in their organizations (Jenness and Grattet 2005). How health care organizations respond to a new civil rights provision will also be shaped considerably by how professionals understand its urgency and interact with each other based on pre-existing power relations and organizational practices (DiBenigno and Kellogg 2014; Heimer 1996; Kellogg 2014; Reay et al. 2013).

Following previous research on the organizational enactment of civil rights, 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 are likely to be symbolic shows of compliance that protect the employer from liability rather than prevent discrimination (Edelman 2016). Internal grievance procedures have been widely popular in the private sector for decades (Dobbin 2009; Edelman, Erlanger, and Lande 1993), and the civil rights regulators who promulgated the 2016 Section 1557 rules embraced this structure, too. “In OCR’s experience,” the 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” (Department of Health and Human Services 2016, 31395). OCR’s enthusiasm for grievance procedures is not an evidence-based assessment of these procedures’ effectiveness, but rather shows how, as Edelman (2016, 26) puts it, legal regulators “assume the validity of managerialized conceptions of law.” Tellingly in the words of the regulation, it is “the *presence*

of a coordinator and grievance procedure (emphasis added),” not their actual operation, that ensures enhanced accountability (Department of Health and Human Services 2016, 31395).

Internal complaint procedures are similarly demobilizing in the context of healthcare provision outside the U.S. In their content analysis of patient complaint letters and responses in the UK’s National Health Service (NHS), Lloyd-Bostock and Mulcahy (1992;1994) found that patients and their families received unsatisfying responses to their complaints. Montgomery found that NHS staff members drew on their everyday human encounters with patients to supplement and contest official tallies of patient experiences (2020). Yet, scholars have not focused as much on grievances in the U.S. healthcare context. In recognition of this gap, we turn to the professionals tasked with handling patient complaints to understand how they make decisions about patients’ grievances. 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.

While we see echoes of Edelman’s findings in our data, it is important to consider the critical ways in which the U.S. healthcare provision differs from the employment context. Whereas the discrimination complaints are handled primarily by human resource professionals in the employment context, we find that a wider array of professionals handles complaints in the context of healthcare provision, but that the modal complaint handler had a nursing background and was situated in a patient experience department. We show here that the professionals who handle patient complaints are attuned to a different set of legal and regulatory demands specific to healthcare. Further, we argue that organizational decisions about *who* in the organization should respond to claims plays an important role in determining how complaints will be addressed. Thus, understanding the demobilization of civil rights in the context of healthcare

provision requires attention to how institutional logics, toolkits, and legal consciousness interact to produce unique forms of grievance recognition and management.

Professionals as organizational actors have considerable power to interpret, enact, or fail to implement the law as they understand it. Organizational position and professional behavior can explain variation in legal mobilization within an organization. As Chiarello (2013) has demonstrated, professional intermediaries such as pharmacists working with emergency contraception and navigating conscience exceptions can be both highly attuned to their regulatory environment but turn more to their own professional logics as they make decisions. She uses the concept of “professional logics” adapted from McAdam and Scott’s (2005) “institutional logics” to describe how healthcare professionals approach their work based on their position, status, training, and sense of themselves and others in their organizations. Heimer and Stevens’ (1997) study of social workers as frontline buffers between families and elite medical professionals shows how lower level professionals are critical for packaging the people and problems that come into the organization. Our framework foregrounds healthcare workers who are not medically trained. These actors are critical to understanding the broader organizational field of U.S. healthcare in which financial competition and incentives shape priorities.

If “professional logics” refers to the guiding principles or prevailing norms of appropriateness that originate within a professional field and shape the interpretation of problems, “toolkits” refers to the strategies available to respond to those problems as those logics reveal them. Drawn from Swidler (1986), the theory of tool kits explains how people “construct lines of action” (277). “[P]eople,” Swidler argues, “will come to value ends for which their cultural equipment is well suited” (277). We show how professionals enact the options given by these workplace logics by taking actions that seem logical given their roles and training, such as

treating patients like unhappy customers. Kellogg's (2010, 2011) study of how surgical interns mobilized or failed to mobilize for better working conditions under the shift to regulate working hours draws on concepts of the cultural and political tool kits available to them in different settings to explain when challenges to the power structure occurred and when they succeeded in producing change. Here, we are not explaining change or divergence, but rather how rights became something else. The theoretical frame of professional logics can explain *why* grievance handlers fail to see rights and see customer service problems instead, and the concept of the tool kit demonstrates *how* grievance handlers address problems as patient experience mishaps rather than as rights violations. We find that grievance handlers who deescalate conflict by constructing systemic issues as inter-personal problems perform care work (England 2005) to smooth over complaints and buffer clinical care providers.

Professional logics can help us conceptualize the process by which patients are “cooled out” (Goffman 1952; Hyman 2020), but offer less leverage over *why* some logics such as customer service prevail in this context. Silbey (2005) reminds us that the primary question in studies of law and ideology is how law maintains its hegemonic power as much as it does, and that legal consciousness is worth studying because it explains that hegemony. She also urges scholars interested in how ordinary people's legal consciousness shapes their use and mobilization of formal rights to look at mid-level institutional practices in settings like hospitals (Heimer and Staffen 1998), and we take that advice here. Scholars are naturally drawn to studying moments of high contestation, social movement activism, or dramatic conflict within organizations, but we also know that non-implementation, ignoring, diverting, and simply not-seeing are powerful reasons why laws fail to live up to their billing. In our healthcare setting for rights handling, we must explain a great deal of “not-seeing” problems as civil rights issues, with

a few exceptions, but a great deal of attention to other regulatory pressures. We adopt Ewick and Silbey’s theoretical understanding of legal consciousness as “participation in the construction of legality” (1998:46) but not simply a set of attitudes or a base of knowledge about what the law really is. As Ewick and Silbey observe, “[l]egal consciousness is produced and revealed in what people do as well as what they say” (Ibid.). Although we were attuned to variation across organizational settings, we found that a fairly unified set of governance structures structure grievance handlers’ activity.

These governance structures are the forms of law—regulations and administrative requirements—that most prominently shape a grievance handler’s job. They are based in what we call the patient experience turn in U.S. healthcare settings. The patient experience turn is the legal, regulatory, financial, and professional pivot to the patient in the U.S., understood not only as a person needing healthcare but also as a market driver of critical organizational priorities. It is part of the marketization of healthcare, in which “hospitals are under pressure to invest in what their consumers can immediately observe and economize on what they cannot” (Young and Chen 2020:22). It dates from a 2001 Institute of Medicine report on improving health care quality (Institute of Medicine 2001) and efforts by the HHS to develop what would become the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS, or “H-caps”) survey.² However, this shift also has deeper roots in movements for patient empowerment and patient-centered care more generally (Grigg and Kirkland 2018). Patient satisfaction scores have implications for revenue. Hospitals must share their HCAHPS scores publicly, and under the ACA, incentive payments under the Hospital Value-Based Purchasing program are tied to these

² Other healthcare systems, such as Great Britain’s National Health Service (NHS), have had patient grievance processes for many years, though without the same market pressures in the mixed public and private American system (Editors 1970).

ratings (Kahn and Salzberg 2019). The patient experience turn matters for healthcare civil rights because it converts civil rights into experiences, when many healthcare inequalities may result from *non-experiences*: being overlooked, forgotten, never treated, or misunderstood beyond the patient's view. When civil rights problems become just like other patient experience complaints, consumer-driven responses become a primary way that healthcare organizations de-mobilize potential patient rights claims. Theorizing professional logics, tool kits, and legal consciousness together allows us to explain how these grievance handlers understand their work, and why they do not usually adopt a rights-based approach to handling a grievance even when they are ostensibly in charge of handling civil rights grievances.

Methods

This article draws on in-depth semi-structured interviews with 58 healthcare grievance handlers.³ We adopted Chiarello's (2013) nested maximum variation sample design for studying legal implementation by selecting different types of healthcare sites across states with political variation. We recruited interview subjects from non-specialty hospitals and ambulatory surgical centers in Michigan (all), Alabama (all), northern California, and the five boroughs of New York City plus select upstate areas, and all FQHCs in Michigan and New York between May 2017 and February 2019. We include one interview from a physician practice group even though we did not sample from that category generally. The types of healthcare sites were selected because a lot

³ We could not get access to patient contact information to interview them about their complaints because of privacy laws. The first author used the Freedom of Information Act (FOIA) and the appeal process to attempt to access the contact information of complainants to the Office of Civil Rights (OCR) under Section 1557, but was denied under the Privacy Act. We did not ask healthcare organizations to let us view their grievance databases since HIPAA prevents that as well.

of people use them. We chose these states to maximize political variation in transgender rights protections, the most salient aspect of the new civil rights regulations that people would have heard about, with Michigan and Alabama rated very low and California and New York rated as the most receptive by the Transgender Law Center. This sampling frame dataset of Section 1557-regulated sites, grouped by state, included the health care organization name, contact information for the designated Section 1557 coordinator if available (later anonymized), the larger corporate system of which it was a part, details such as number of beds, and our assessment of its initial Section 1557 compliance based on review of its website to see if the organization had posted the required notice of non-discrimination and a description of how to file a grievance.⁴

Between May 2017 and March 2019, a team of seven researchers including the first author and six doctoral students (including the second author), contacted all sites in our four-state dataset. The interviewers followed a detailed recruitment protocol (designed and pilot tested by the first author) starting with a phone call to the number listed as the Section 1557 coordinator on the facility website and a request to speak to that individual or the primary person on-site who handles patient complaints. Interviewers kept detailed call logs describing each outreach attempt and its outcome. A total of 744 contacts yielded 64 interviews (some not included here because they were medical staff members who did not directly handle grievances), an 8% response rate. We analyze the 58 interviews with people who worked on patient complaints in this article.

⁴ We operationalized initial Section 1557 compliance in 2017 and 2018 as a binary variable defined by the presence of required non-discrimination statement and the required listing of a Section 1557 coordinator on the website. HHS supplied boilerplate language in 2016 with the new regulations, and organizations had either taken this step or they had not. Only 290 sites or 37% percent of the 775 organizations in our dataset had posted the required elements as of 2018 (non-discrimination statement, notice about the grievance process for 1557 specifically, and some contact information for a 1557 grievance officer as a named individual or a generic title), but 63% had not. Website compliance varied from a high of 70% (AL) to 43% (MI), 37% (NYC boroughs and selected upstate areas), and 23% (N. CA).

Twenty-five percent of respondents were explicitly designated Section 1557 coordinators as indicated by websites or verbally during interviews and 45% of interviewees described the handling of complaints and grievances as their primary role. Even if a grievance handler also had other assigned duties, all interview subjects in this article worked on patient complaints or supervised those who did.

Most interviews took place over the phone (48), but where possible we traveled to conduct interviews in person (10). Questions elicited the person's approach to gathering and handling problems, with probes about discrimination and Section 1557 later on. Interviews were recorded, professionally transcribed, and coded using Dedoose software and a grounded theory approach, with the two coders achieving interrater reliability scores of .73 and .85 (high or very high agreement). If a participant did not want to be recorded (5), we took notes and coded those. All names, workplaces, and personally identifying information have been replaced with pseudonyms (IRB #HUM00120522). We asked each interviewee if we could have copies of any Section 1557-related materials produced at that site, and we were able to gather items such as internal training documents, slide decks, and in-house legal memos instructing how to comply.

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 that they would indeed be a person who would work on complaints including discrimination. Almost no one answered the phone and when someone did, they often said they would need permission to talk to us and then never responded to follow up. When we could not get through to the right person, the reason was often hard to discern (getting lost in a voicemail tree and never getting a call back, for example). Only 81 of 744 people explicitly

declined to be interviewed; all the rest of the 663 attempts that did not yield an interview were failures to connect.

Who Are Grievance Handlers?

The largest single group of our interview subjects (50%) 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. Table 1 shows the role classifications of the grievance handlers. At ambulatory surgical centers, grievances were often handled by CEOs or executive directors. Table 2 gives the breakdown of the types of healthcare organizations our interviewees worked in and where they are located.

Grievance handlers were mostly middle-aged, white (78%) women (76%). A large portion of the professionals working in complaint handling (21 out of 58 or 36%) 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 complaints. 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 had 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, “anything 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 non-compliance is not a surprising finding in sociolegal studies, even among professionals tasked with implementation (Kelly 2010). 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.

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 respondents reported

that they had never received a complaint about discrimination. But when we probed specifically on that point we found that 47% of respondents 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.

We 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, most of which involved responding to patients unhappy with their experiences in the facility. Human Resources (HR) had little role in Section 1557 implementation. HR departments 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 approach to patient rights.

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 at 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.

The Logics of Patient Experience

In these sections, we first describe the professional logics that structure the work of grievance handlers, shaping their interpretation of patient problems. Then we turn to the tool kits available to construct responses to those problems. 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 logics 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 non-clinical distinction. These distinctions

guide how they sort their work into categories for action. These two logics are closely related, as we explain below, and hierarchically arranged. These logics tell handlers what kind of problem they have, what work flow to follow to dispense with it, and whose professional expertise and tool kit is appropriate. Our focus here is on organizational culture and professional habits; the socio-technical systems for transgender rights recognition are analyzed elsewhere.

Complaint Versus Grievance: How Regulations Shape Professional Practice

The first distinction—*complaint versus grievance*—is a legal logic that comes directly out of longstanding Centers for Medicare and Medicaid Services (CMS) guidelines for how to handle patient problems. Importantly, the law that people care about here is the regulatory bureaucracy, not 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 30 days (2008, 2019b, 2019a). 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.” The CMS regulations were by far the most commonly referenced legal framework and a key resource for legal consciousness, though some subjects noted that Medicare requires a complaint department for nursing facilities and in-home services and that state law also requires a grievance process in hospitals. 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. 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 work flow for rights or discrimination as patient problems. The pre-existing CMS process completely covers over what might be distinctive about a Section 1557 civil rights grievance.

Clinical Versus Non-Clinical: How Institutional Logics Divide Responsibility

The second logic, *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 FQHCs, about “customer complaints” illustrates the distinctions drawn between clinical and non-clinical 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, non-clinical complaints. June interprets the presence of the service animal as a non-clinical issue, and perhaps one that is frivolous judging by her laughter. However, this interpretation obscures the way in which the provision of care appears to be contingent on the exclusion of the service animal. One implication of the complaint versus grievance distinction is that CMS guidelines erase civil rights regulations. Seeing civil rights

violations was “a new task created by reform,” 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 (Kellogg 2014:913).

As June’s exchange suggests, the bifurcation between clinical and non-clinical 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 professional logics of the patient grievance handler re-inscribe the status hierarchies within the hospital, elevating “care” up and away from the realm of healthcare rights issues, imagined as trying to please unhappy people. 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 highly 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, non-clinical distinction to pull clinical care almost entirely away from human interaction. She explained how grievances match onto clinical care problems and interactions with patients match onto her domain in patient complaints. “The two biggies are the grievance, non-grievance, 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 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 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 non-legal administrative professionals. Their tools—permitting venting, explaining that there was no bad intent, apologizing without accepting blame—create lines of action that demobilize possible rights claims.

Customer Service as a Professional Logic

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. Greg’s experience offers another illustration of the customer service orientation according to which patient experience is often organized. 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 past 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 is 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.

When asked how she came to be named the Section 1557 coordinator at her non-profit 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 non-discrimination, as Brenda explained when asked what training was available: "We have an extensive customer service training as far as non-discrimination." 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 the Harassment & Discrimination Assistance and Prevention Program (HDAPP) for a large university health system, told us, her hospital has “always been sensitive to this” and that is “covered in Customer Service Standards.” In summary, we have argued that the work of healthcare grievance handlers is governed by a combination of legal, institutional, and professional logics. We found that the key professional logic according to which the work of grievance handlers is organized views patient complaints as customer service problems. In the next section, we argue that grievance handlers possess a distinct toolkit from which they can construct responses.

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.

As Carla, working on diversity issues and patient experiences in Michigan, acknowledges that "we all have biases" but "it must have been a communication issue." 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 the patient discussed above, 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, corrected in their process with a combination of blameless apologies and soothing re-descriptions of intent.

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 re-interpretation tool assumes that the patient is mistaken in their belief that they have been discriminated against. Debra interpreted patient complaints based on race or body size 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."

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.” The reality is that the patient may fill out an HCAHPS survey with low scores, linking it to the financial reality of the organization. Here we see legal consciousness enacted as a combination of attentiveness with disbelief.

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.

Alternative Logics That Enabled Rights Consciousness

The vast majority of grievance handlers drew on the customer service logic, but a few more clearly articulated discrimination as a problem and handled situations with different professional logics, tool kits, and forms of legal consciousness. One of the two attorneys in our sample brought a resolutely rights-focused approach from his past experience in civil rights work. Jason had been newly hired to be the Section 1557 coordinator for a large hospital. His previous position was working as a state level civil rights investigator. In one case Jason described, he confronted a doctor in Clinical Affairs about staff canceling appointments for deaf and blind patients if proper interpreters were not available at the scheduled time, which he thought was discriminatory denial of care. The doctor deflected the issue, which seemed to Jason to be “more of a response of a doctor protecting other doctors than it was actually of a concern for the patients and for being compliant, which is interesting to me.” Jason was unique in his willingness to label patient problems as discrimination, to confront doctors, and to express frustration that doctors protected each other in what he saw as a clear example of denial of care based on disability. His tool kit, in other words, included adversarial confrontation without regard to hierarchy, and eschewed the techniques of disbelief, re-interpretation, and soothing described above. The professional logics of a former civil rights investigator did not mesh well

with the other professionals, however, and Jason found himself marginalized. The other attorney in our sample was highly attuned to the regulatory requirements of the job, but had not worked in civil rights and did not share Jason's alternative view.

Most of our interviewees are mid-level compliance and patient support staff in hospitals, but we sampled ambulatory surgical centers because their business model offers a contrasting environment for the emergence of discrimination problems. These surgical centers are often doctor-owned and run by CEOs with a clear business profit model, and patient satisfaction surveying is voluntary rather than a CMS requirement as it is for the hospitals. Our sample did not capture enough organizational variation to permit strong conclusions, but it was notable how their ownership model enabled a different response to civil rights problems. Larry is the CEO of an ambulatory surgical center in New York City with a keen sense of the competitive business case against discrimination as well as the perils of customer service failures. While he cares very much about customer service, his business structure gives him a different tool kit. He fired staff whose actions upset or offended patients. In one instance, he described a grievance that resulted from a patient having to wait alone in a cold pre-operative waiting room in a gown for two and half hours because the surgeon was late. When the surgery ended, a porter escorted the patient in an elevator with garbage bags. "We literally took the patient out with the trash," he said. Larry uses the common formulation of failed communication ("[T]here was a total lack of communication"), but in contrast to the non-consequences we frequently heard about from other interviewees, he fired the porter. Larry also fired a doctor for what he understood to be explicit sex discrimination, such as asking a man with long hair to take a pregnancy test. Larry observed that, "You know, there's some validity in every single complaint. You have to realize that to some level." There is no fellow doctor as Chief Medical Officer to shield doctors from

consequences in Larry's business model. He was also highly aware that most patients complain because they do not want the same thing to happen to someone else and that a real apology can be effective. "Though we do live in a litigious society, you've just got to be very honest about exactly what occurred. 'I truly am sorry this happened to you. I've actually made [sure] that this won't happen to you again.'" Here, Larry distinguishes his approach from the "blameless apology," by expressing a belief in the importance of sincere apology, acknowledgement, and accountability.

Some grievance handlers openly wrangled with the implications of conflating customer service issues with rights violations, though this was rare. Dan, a nurse and patient safety officer in rural Michigan, identified himself as LGBT and felt that his sexual orientation gave him a different perspective on patient conflicts. Dan opined that his hospital could do more to distinguish discrimination complaints from other kinds of complaints, noting "I think there's a delineation between addressing the customer service aspect for the complaint versus 'This is a really bad violation where we violated a human being's rights.'" Yet, when asked how to distinguish discrimination from equal opportunity "rudeness," Dan, like many interviewees, said the distinction was a function of intent. When pressed about how he would know discrimination if he saw it, Dan said he would ask "[D]id we single out someone in any way, shape, or form because of color, race, disability, anything like that?" Respondents often conceptualized discrimination as an overt expression of prejudice, but did not typically contemplate implicit bias or discuss discrimination as a structural issue that might pattern patient experience in broader ways. Nor did these respondents possess the legal or discursive strategies described by Jason, for example, whose priority was to protect patients' civil rights by confronting other actors within

the organization. Dan's musing is not a fully formed alternative logic, but still shows how heightened awareness about discrimination could break through the customer service logic.

Finally, some providers wrestled with the fact that there was simply a gap in healthcare for a vulnerable person who called it discrimination. Like Dan's thoughts, we do not call this an alternative logic, but note it here because it nonetheless signals the "unbearable lightness of rights" (McCann 2014) in the absence of resources to alleviate poverty. Jan, director of an FQHC serving low income people, explained their denial of a root canal for a dental patient who was angry about it and claiming discrimination. She explained: "So we do very basic dental care and he needed a root canal, which is, you know, unfortunately a thousand dollar procedure and we don't offer that level of care. What we have available for people's basic dental care needs just barely scratches the surface of what the community needs. So I think he was just angry. It really didn't get resolved and he's probably still mad." The director saw that the patient's needs were not met because of the structural inadequacy of FQHC resources for the poor, and acknowledges that ongoing anger is a reasonable result (though her formulation of "just angry" minimizes and minimizes what could be a structural critique).

Our study limitations exemplify the challenges of "studying up," that is, gathering information from hard-to-reach professionals with jobs and information to protect (Nader 1972). It is difficult to cold call organizations and ask them to describe problems with the people they serve. Other outreach attempts that we considered such as by mail, email, or face-to-face recruiting at their professional meetings would have been either easier to ignore or were prohibited by their organizations (and even if not, skewed by who attends expensive compliance conferences). We added a financial incentive to the study design, but found that it did not increase participation, suggesting that fear of violating organizational policy by giving an

interview was stronger reason to decline an interview that could not be easily overcome. We found that people who picked up the phone were much more likely to agree to an interview, so perhaps the live connection to the requester was necessary to overcome that hurdle. As one might expect, however, most calls went to voicemail. Despite recruitment difficulties, our interviews include extensive and frank accounts of specific approaches to handling complaints as well as open admissions of ignorance and non-compliance.

This article focuses on the professional logics, tool kits, and forms of legal consciousness among grievance handlers that grow out of national legal structures such as CMS rules and HCAHPS surveys and which we found widely across interview contexts. It is likely that patient experience departments across the country operate under the same incentives and with roughly similar professional organization of the work. The sampling difficulties and homogeneous professional and organizational incentives also limited our ability to draw conclusions based on the state or the organizational type. We designed the study to capture variation on two dimensions: (1) state political orientation towards a prominent feature of Section 1557 implementation, transgender healthcare rights and (2) organization type (hospital, ambulatory surgical center, and doctor's office or FQHC). It was easier to reach someone in a hospital organization than any other type, but the skewed responses by state make it impossible to draw conclusions about the influence of geographic variation. We also could not discern meaningful variation based on Catholic or non-Catholic affiliation. We suspect that the national-level incentives around the patient experience turn are more important than geographic or religious variation for overall organizational culture, but further research with a broader, more balanced sample would be needed to confirm.

Conclusion: More Drumming Up, Less Cooling Out

Silbey (2005) noted that meso-level institutional practices can illuminate how legal consciousness results in failure to confront inequalities and mistreatments. To understand how patient civil rights work on the ground through healthcare institutions, we studied the professionals who are the first to hear about discrimination claims and who must decide how to respond. We argued that non-discrimination rights claims in health care settings are largely subsumed by the patient experience turn. This patient experience approach and the professionals who implement it are not attuned to recognizing civil rights violations in the problems and complaints they see every day. They care very much about responding to problems, but commonly delivered in ways that deflect blame (“everyone has bias” or “there are three sides to every story”) and aim for “service recovery.” The patient experience turn becomes real on the ground through everyday work practices, in other words.

We have argued that grievance handlers’ professional logics, tool kits, and legal consciousness structure their approach to handling patient problems. This conceptual framework sheds new light on the relationships between rights, medicine, and law. It reveals staff professionalization as central to shaping legal consciousness into different forms. Our respondents were guided by institutional legal concerns about the consequences of many kinds of mistakes, but these filtered down to their everyday work as imperatives about patient satisfaction. Patients can only become upset about problems they directly experience (not, for example, a surgical error while under anesthesia or a decision not to treat), and so the range of possible mistreatments becomes focused on the subset that create unhappy patients. We show how it is possible for an organization to be highly focused on implications of regulatory

compliance and to hire a professional class dedicated to responding to patient problems, but still largely fail to recognize and respond to civil rights violations.

There was little elaboration in Section 1557 or its 2016 regulations of an affirmative vision of non-discrimination on the ground in healthcare. Much of the focus was on implementing language access for non-English speakers (mandating how many local language translation options must be printed on which documents) and ensuring that transgender patients receive the same care that would be offered to a cisgender person (that is, if the hospital does hysterectomies, they cannot deny them to a transman). It is central to our critique that civil rights violations are different from other patient problems and deserve to be handled differently, but how exactly? What alternative professional logics, tool kits, and legal consciousness could help healthcare organizations respond better? We can consider what could be changed to create new possibilities for law to become real in healthcare. Two critical features of the 2016 regulation shaped the way that Section 1557 would enter healthcare: first, the focus on appointing a grievance handler and having a policy, elevating procedure as compliance, and second, allowing organizations to hand the new duties to someone already in place because of pre-existing regulatory requirements to have a grievance process. These features pre-determined the professional logics and tool kits grievance handlers would employ.

A civil rights-focused professional logic in a healthcare setting would refuse the dichotomies we identified that separate the clinical from the interpersonal, leaving discrimination to be downgraded to interpersonal unhappiness. Indeed, the 2016 regulations explicitly entertain the possibility of clinical care as a site of discrimination, such as if a doctor refused to provide surgical or medical services to someone on the basis of their gender identity (transgender status). Discrimination must be able to be captured at all levels of the patient's engagement with the

healthcare providers and staff, including contexts where there is no “patient experience” at all: in clinical decision-making, in records the patient does not see, in care provision under anesthesia or when the patient cannot experience what is happening, and in personal interactions. The professional handling the possible cases must have access tools and status in the hierarchy to probe all these contexts. A civil rights legal consciousness would focus one’s attention on identity categories and inequalities arising from racism, sexism, ableism, homophobia, and other forms of prejudice, in both their overt and more subtle forms. The fact that the 2016 regulations permitted disparate impact lawsuits should have meant that structural inequalities with an impact on vulnerable groups would be recognized (such as a hospital’s decision to stop offering gender confirmation services for transgender people). The Section 1557 rules on their own terms clearly could have supported a more robust civil rights approach, that is, but there were easier paths already carved out in the patient experience department.

Our analysis suggests that it matters very much whether the person implementing Section 1557 is an attorney. Jason, the one civil rights attorney in our sample, treated the patient as legal client rather than as a dissatisfied customer. He ignored hospital hierarchy and challenged the top medical officer about a possible disability rights violation. He was also clearly very frustrated and felt shut out and unable to do his job because his approach conflicted with the expectations of other professionals (particularly patient experience administrators, the people who were the Section 1557 handlers nearly everywhere else). In our interpretation, Jason had appointed himself the attorney for patients who had barely even begun to articulate a legal claim, essentially “drumming up” rather than “cooling out” as his counterparts elsewhere did. As Jason found out, there is not much place in the contemporary healthcare professional landscape for someone with his approach to the Section 1557 role. Recall that there is an immediate right of

private action in 1557, so any of these patients could have litigated on their own. As sociolegal scholars know, people are unlikely to file a lawsuit on their own, so they would need to connect with someone like Jason who could help them describe their experience as discrimination.

One alternate approach, therefore, is to heighten legalization by requiring that Section 1557 complaints be handled by an attorney, perhaps one who does not work for the organization directly, or to require transparency to legal professionals, such as opening complaints for review by outside attorneys. There would be considerable barriers to these reforms, however, because of patient privacy laws, bans on direct solicitation of clients, and the likely strong resistance to increased legality in healthcare. Another angle on this approach would be to incentivize lawsuits based on the private right of action provision by increasing its visibility as an option to patients and making it more attractive to plaintiff-side employment and personal injury attorneys. HHS's investigatory powers could be significantly expanded through both funding for more investigations but also more tools for scrutiny of complaint records and dispositions. There are significant challenges here as well, starting with the Trump administration's regulations that remove the private right of action entirely from Section 1557, followed by the broader embrace of internal procedures that head off lawsuits in government policy regardless of the political party of the president. De-fanged, poorly funded administrative structures for civil rights protections are a longstanding problem more generally (Chen 2009), and considerable research shows that working with an attorney to seek justice on a civil rights claim is an uncertain, arduous adversarial process that does not guarantee real change (Berrey, Nelson, and Nielsen 2017).

Perhaps a listening session or apology is an acceptable response to a rights violation for some patients; after all, many people do not want to pursue their rights in court and would simply

like to be treated well and receive a sincere apology (Engel 2016; Lloyd-Bostock and Mulcahy 1994; Robbennolt 2009). Rabinovich-Einy (2007) argues that hospitals need a transformation in their communication culture that can provide accountability when patients complain. Would it be better to eschew the adversarial confrontation of a more legalistic approach in favor of more accountability in alternative dispute resolution (no more “blameless apologies”)? Patients and their families may be hurt, in pain, sedated, or grieving, and more likely to value a faster, more soothing resolution. We find that these resolutions may be prompt and attentive, but the organizational context and priorities of patient experience departments are not well designed to handle all healthcare civil rights enforcement. Seeing civil rights violations as more than customer service problems requires shifting the whole frame of professional logics, tool kits, and legal consciousness, likely by assigning civil rights to another professional group not wholly captured by the patient experience turn and its priorities. Regulations should elevate the organizational status of those who detect civil rights violations and re-shaping their priorities around seeing forces such as racism, sexism, transphobia, ableism and confronting them.

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Table 1. Respondents' Roles*

*Number is higher than total respondents because many held multiple roles.

Role	Count	Percent
Patient Experience	24	41%
<i>Patient relations</i>	11	19%
<i>Patient advocate</i>	7	12%
<i>Patient experience</i>	4	7%
<i>Patient representative</i>	2	3%
<i>Customer relations</i>	2	3%
Quality and patient safety	12	21%
Risk management	9	16%
Compliance and accreditation	7	12%
Health services administration	6	10%
Civil rights coordinator	4	7%
Privacy officer / HIPAA	4	7%
Recipient rights officer	4	7%
CEO/Executive Director	3	5%
Diversity, equity, and inclusion	2	3%
Nursing or nurse supervision	2	3%
Data and information management	2	3%
Interpreter services	1	2%
Social work	1	2%
Grievance analyst	1	2%
Office manager	1	2%
Ethics	1	2%
Total	86	

Table 2. Organization Type by State

Organization type	State				Total	Percent
	MI	CA	NY	AL		
Hospital, general	21	7	2	1	31	53%
Critical access hospital	7	1	--	--	8	14%
Catholic hospital	3	4	--	--	7	12%
Federally Qualified Health Center (FQHC)	6	--	--	--	6	10%
Ambulatory surgical center	3	--	2	--	5	9%
Doctor's office	1	--	--	--	1	2%
Total	41	12	4	1	58	
Percent	71%	21%	7%	2%		

Civil Rights as Patient Experience: How Healthcare Organizations Handle Complaints

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Abstract

The non-discrimination clause of the Affordable Care Act, known as Section 1557, formally expanded patients' civil rights in nearly every healthcare setting in the U.S. in 2010. Regulations required healthcare organizations to name a person to handle grievances and set up an internal grievance process for resolving them. Drawing on interviews with 58 healthcare grievance handlers, this study examines how healthcare organizations respond to patients' discrimination complaints. We find that organizations incorporated the new right into preexisting complaint and grievance procedures, treating possible patient civil rights violations as patient experience problems. Grievance handlers smoothed over problems using customer service strategies. These procedures diminish the efforts of policymakers to expand civil rights in healthcare. For civil rights to provoke real organizational change, they would need to be handled by professionals attuned to rights consciousness.