Medical Sociology

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Course Overview

The present course, a 12-week seminar for graduate students and upper-level undergraduates, aims to introduce students to the field of medical sociology.

The course is structured around the overarching concept of medical authority: why does medicine possess a unique degree of status and power in contemporary society? What historical processes led to the creation of that power? What contemporary developments threaten it or change the way it operates on-the-ground?

**Week One** begins with classic theories that address each of the above questions. Each reading in the week highlights not only how the medical profession has attained cultural authority, but also contains implicit views about the desirability of the ends to which that authority is put to use. In particular, we see a tension between two ideal types of the medical profession—the profession as a deserving object of patients’ trust; the profession as a (somewhat) undeserving holder of a monopoly over certain goods/services—that reappear in later weeks. **Week Two** and **Week Three** turn from the concept of medical authority to a chief example of medical authority in action: medicalization. **Week Four** introduces an updated version of medicalization theory—bio-medicalization—that focuses on themes like how advances in the degree of detail with which medical risk can be monitored leads to a shift from patients occasionally occupying a binary “sick role” to patients perpetually occupying a continuous role of being a “patient-in-waiting.”

While medicalization is an example of the success of medical authority in action, **Week Five** and **Week Six** turn to a challenge to medical authority: health-related social movements. The weeks highlight the tension that social movements face in balancing critique of medical authority with collaboration with these same medical professionals to accomplish certain goals like speedier access to medical treatments.

The previous weeks focus on actions that a medical professional takes. **Week Eight** investigates the processes through which a person becomes a medical professional. These socialization processes take us back to the debates of **Week One**. In particular, are physicians socialized into professionals worthy of patient’s trust through embodying ideals like candor in the face of mistakes and limits in their knowledge/power, or are they socialized into professionals less worthy of this trust?

**Week Nine**, **Week Ten**, and **Week Eleven** each focus on the common theme of intersection between the medical field and its “institutional logics” and fields like schools, criminal justice institutions, and civil law-focused courts with distinct logics. A common theme is that the overlapping of these fields sometimes leads medical professionals to adapt their work practices in ways that align with the norms of the overlapping field but other times produces little adaptation and much tension. Concluding, **Week Twelve** returns to the concept of bio-medicalization and focuses on emerging technologies that might challenge authority by substituting for certain facets of medical work.

Each week contains between 150 and 250 pages of reading that should be read prior to class in the order listed. Note that in the pdf version of the syllabus, to illustrate interconnections between each week, clicking on the **bolded name** of a Week takes you directly to that week’s contents—e.g., clicking on **Week Five** should take you to that week’s readings.

Learning Objectives

By the end of the course, students should understand:
1. How to recognize that medicine’s *present* degree of authority is not constant over time/geographies, and understand the historical and contemporary processes that produce that authority

2. How to critically analyze the balance of power that different social actors—lay activists, expert professionals, regulating entities—have in health-related decisions and outcomes

3. How to recognize the different organizing principles that medicine has compared to other expert systems (e.g., law; criminal justice)
Week One: The Medical Profession and its Cultural Authority


- Chapter Three- “The Profession- An Overview”
- Chapter Four- “The Structural Solution to the Problem of Professional Authority”

- Book Two, Chapter 3- “The Liberal Years”

- Introduction
- Chapter 1- “Work, jurisdiction, and competition”
- Chapter 3- “The Claim of Jurisdiction”
- Chapter 4- “The System of Professions”

The readings this week, which largely adopt a historical lens to analyze the medical profession, focus on how the medical profession secured its present degree of autonomy and cultural authority, with later week’s readings illustrating this autonomy and authority in action. Each reading also contains implicit views on not only how cultural authority was attained, but on the desirability of the ends to which this cultural authority was and is put to use.

**Topic one: the medical profession as disinterested (Parsons, 1954)**

Parsons (1954), writing during what Starr describes as an American era characterized by high levels of trust in the medical profession and confidence in the power of the scientific enterprise to alleviate a wide range of social ills, frames the puzzle that later authors return to: what is distinctive about professions, and in our case, what is distinctive about physicians in terms of their role in the overall social structure and relationship with patients/clients? Writing during a time when sociologists placed more of an emphasis on factors that ensured the smooth functioning of a complex society rather than factors that produced conflict between different actors, Parsons argues that there are two features that make professionals like physicians distinctive, with each falling under the category of disinterestedness. First is professionals’ commitment to prioritizing the interests of clients/patients over their own interests, and second is professionals’ devotion
to impersonal values like the advancement of science/technical competence.

While Parsons argues one should not draw too sharp a demarcation between the societal sphere of business/commercial activity focused on acquisition and the societal sphere of professions focused on disinterested service of clients, noting that the latter is becoming “progressively commercialized,” he argues that while the motives of individuals working in both contexts are similar, each sector places these individuals in different institutional contexts that lead the professionals to adopt different orientations to their work. And Parsons argues that the institutional context in which physicians operate is characterized by two main characteristics. First is authority—patients take physicians’ frames for problems and recommendations for how to alleviate those problems seriously even though the statements lack the force of legal penalties or coercion. Second is a universalistic rather than particularistic orientation towards clients. The patient has a claim on the physician by virtue of his or her symptoms rather than by virtue of special relationships like the fact that the patient is the physician’s friend or is part of the same ethnic/socioeconomic group.

As we will see in greater detail, the three other authors we read this week–Freidson, Starr, and Abbott–each argue that Parsons’ account is incomplete in two ways, formulating different versions of similar criticisms. First, they generally argue that Parsons treats the high status of professionals as earned on the basis of technical competence and static over time rather than a time-variant product of political and social struggles for greater power/greater degrees of autonomy, and that the historical trajectory of these latter types of conflicts matters a great deal for the present-day authority of medicine and other professions.

Second, they generally argue that Parsons does not challenge the way in which professionals use the appearance of disinterestedness to gain privileges from the state/organizations that grant the professionals a monopoly over services; while this monopoly can have beneficial effects, it can also have undesirable consequences such as permanent exclusion of other professions from certain tasks–e.g., nurse practitioners from writing prescriptions.

Yet we can contextualize these shortcomings historically by realizing that Parsons was writing during a time when society was especially trusting of the benevolence of medical professionals and when sociological writing on the professions largely mirrored that optimistic societal orientation.

**Questions to think about for this topic:**

1. Parsons is careful to argue that while people tend to draw a sharp distinction between “egoistic” versus “altruistic” motives for action, and attribute the former to those working in business/commercial ventures and the latter to professionals like physicians, that his focus is on how the same human motives play out in different institutional contexts. Drawing from the description in Starr Book Two, Chapter Three of the institutional context of post-WWII American medicine—a time characterized by recent scientific breakthroughs and rapidly growing federal investment in healthcare and scientific research—how might the historical era in which Parsons was writing influence the values and norms he attributed to medical professionals?

2. Parsons claims that professionals’ authority is distinctive from bureaucratic authority in that bureaucrats have authority on account of their official position, while professionals have authority on the basis of technical competence. The fact that the professional’s authority is rooted in technical competence makes it more
diffuse because he or she carries it with him or her from organization to organization and role to role. As professionals weigh in on a variety of topics outside the formal province of medical diagnosis/treatment—for instance, professional organizations taking formal positions on healthcare policy proposals—how might the diffuse nature of professional authority affect professionals’ credibility on these matters?

**Topic two: the medical profession as monopolistic (Freidson (1970)); the historical roots of that monopoly (Starr (2008)); and defending that monopoly against competing claims by other professionals (Abbott (1988))**

Freidson (1970) addresses a similar question as Parsons: what is distinctive about professionals in contemporary society? Focusing on physicians as a useful “case to think with,” Freidson agrees with Parsons that physicians perform work under a set of normative expectations into which they are socialized during medical training. These norms include recruitment on the basis of technical competence, using universalistic rather than particularistic standards in work, restricting work to a bounded sphere of technical competence, and cultivating objectivity/emotional distance. However, Freidson argues that Parsons misses an important distinctive value that professionals seek: independence and autonomy. And rather than independence and autonomy being automatically granted to professionals, professionals need to actively pursue it by allying themselves with powerful institutions that grant them a monopoly over certain forms of work. Or as Freidson puts it:

> The foundation on which analysis of a profession must be based is its relationship to the ultimate source of power and authority in modern society—the state. In the case of medicine, much, though by no means all, of the profession’s strength is based on legally supported monopoly over practice (p. 83)

Thus, while Parsons traces the sources of professional authority solely to that profession’s technical competence, Freidson turns our attention to how technical competence is necessary but not sufficient for securing this authority. In particular, authority is a dual function of the professional’s technical expertise and their ability to translate that expertise, with the help of powerful state institutions, into a monopoly over a certain area of practice. Freidson’s framing of authority rooted in monopoly rather than authority rooted in technical competence leads him to conclude that the medical professional’s “typical form of influence is not to persuade the client of the competence of advice on the basis of available evidence, but rather to close off alternatives to him so that he has little choice but to go to the practitioner and to rely upon the authority of incumbency in a status to which competence has been imputed” (p. 122). Thus, while Parsons and Freidson agree that the authority of medical professionals means that they usually do not need to rely on persuasion—patients take the framing of the problems seriously—they identify a different set of roots for this authority: technical competence and a commitment to a certain set of normative values (Parsons) versus technical competence, normative values, and a monopoly over the provision of certain goods and services (Freidson).
The historical roots of medicine’s monopoly (Starr, 2008)

Freidson exhibits a major departure from Parsons in seeing authority as stemming from the translation of technical competence into a monopoly over certain practices rather than solely from technical competence. However, a gap in Freidson’s account is that it treats the power of the medical profession as both the cause (independent variable) and effect (dependent variable)—for instance, in discussing how the medical professionals’ alliance with the state via licensing procedures closes off alternatives to patients, the account points to medicine’s power as both a cause of their ability to form these alliances and an effect of having formed alliances.

Starr (2008, originally 1982) argues that the power of the medical profession varies both across geographies and over time, and as a result, it is a dependent variable that needs to be explained with reference to structural and historical processes. Or as he puts it:

Much recent writing on the medical profession portrays it as a cartel, which for a while it become. But this was only a secondary part of its success. Moreover, the problem is to explain how the profession’s power was generated in the first place; it does not good to explain the cause by one of its results (p. 16).

Focusing on the cause that results in a monopoly over services as one element of the medical profession’s power, Starr describes a multi-step process whereby physicians gained greater autonomy and control over work. The first step was the growth of medicine’s cultural authority, which Starr argues is the power of medicine to shape the patient’s understanding of his or her own experience and “create the conditions under which their advice seems appropriate,” a definition that previews work on medicalization we will read in later weeks that focuses on how medical framings of problems come into being. Both changes internal to the profession—greater cohesiveness as the result of reforms to medical training—and changes external to the profession—social changes such as urbanization that resulted in less reliance on charismatic local practitioners—led to increased cultural authority.

Then, in the second step, medicine converts that cultural authority to economic power. And Starr argues that the conversion of cultural authority into political-economic power involved physicians gaining control over two arenas. First was gaining control over the market for services, which involved both drawing potential patients out of the home and community and into a more impersonal market for medical care and then seeking political limits on the number of suppliers in the market through tools like licensure laws. Second was gaining control over organizational hierarchies that govern the financing and provision of medical care—for instance, the fragmented nature of healthcare delivery in the united states meant that there was “no powerful coordinating authority” (p. 27) that could serve as a counter-weight to medicine’s power.

Understanding these two steps, we can now better interpret why medicine’s status as a monopoly is a ‘secondary’ part of its success: the profession needed cultural authority before it could successfully pressure legislatures and organizations to grant it a monopoly over the provision of certain services. This brings us to Abbott, who argues that in addition to situating the medical profession within an ecology that includes organizations like legislatures and hospitals, we should also situate the profession in an ecology composed of other professions who jostle for position in claiming monopolies over certain tasks and problems.
Defending that monopoly against competing claims by other professionals (Abbott, 1988)

Just as Starr argues that power theorists of professions neglected some nuances in how medicine as a profession has gained and defended autonomy over its work, Abbott (1988) argues that the theories neglect nuance in how the medical (and other professions’) autonomy waxes and wanes as they compete to claim jurisdiction over certain tasks and problems with other professions operating in a similar space. In particular, Abbott argues that while power theorists diverged from functionalist theorists like Parsons in their views about the desirability of the ends to which medical professionals used their position—power theorists focused on the consequences of professional power for outcomes like professional status, while functionalists focused on the consequences for alleviating patients’ illness—a shortcoming of both sets of theories was a lack of focus on inter-relations between professions. And Abbott argues that we can develop an account of these inter-relations—for instance, an account of how medical professionals in their work relate to nurse practitioners—by focusing closely on the content of professional work.

Abbott argues that the roots of a profession’s authority and power lie in its jurisdiction: the profession’s tie to certain tasks and problems, a tie whose strength waxes and wanes as professions compete over jurisdiction that often takes on an exclusive nature. Just as Starr highlights the importance of professionals not only making cultural claims to their clients that the professionals’ framing of reality ought to be authoritative, but also making political-economic claims to legislatures and organizations to formalize that authority through privileges and protections, Abbott argues that an important element of professional control over work is making claims of jurisdiction to various audiences. Though his theory is focused on professions in general rather than the medical profession in specific, the three audiences he outlines—legal/the state; public opinion; the workplace—have relevance for understanding the specific venues in which the historical processes that Starr documents, and in which the more contemporary medicalization processes that Week Two and Week Three focus on, play out.

For instance, to preview Week Three’s readings on the interactional approach to understanding medicalization, Bosk’s work highlights how two sets of professionals—physicians and genetic counselors—negotiate jurisdiction over the provision of genetic testing results; in the Week Two readings, Eyal documents how parents made claims within the public arena for expertise and jurisdiction over certain aspects of their child’s autism diagnosis. Thus, Abbott turns our attention to both the venues in which claims made by professionals take place as well as the interaction between claims made in each venue—for instance, arguing that professionals use public opinion to “build images that pressure the legal system.” He also highlights that while monopolist theorists tend to focus on one type of settlement of jurisdictional claims—one profession is granted full control over a specific task—there are also other types of settlements such as two professions performing the same tasks but for different sets of clients (e.g., psychologists treating higher income clients and social workers treating lower income ones).

Questions to think about for this topic:

1. While each of the three latter authors—Freidson, Starr, and Abbott—highlight monopolistic aspects of physicians’ provision of medical services, Freidson makes the strongest claims about this monopoly, arguing that the physician’s influence is rooted not in persuasion but that the patient has “little choice” but to go to the practitioner. As
we see both historical and contemporary movements that involve disengagement from certain medical framings of problems and/or medical treatments—vaccine refusal; alternative and complementary medicine; different forms of out-of-hospital childbirth—how do we reconcile Freidson with these developments? Should we think of these developments as physicians losing influence or as other professionals offering attractive alternative framings of problems?

2. Starr points to two stages in medicine’s pursuit of autonomy over its work—gaining cultural authority and gaining control over a market for services/positions within organizations that provide those services. Bringing this framework in conversation with Abbott’s ecological approach, think about a profession within medicine’s ecology in some way—e.g., nurse practitioners; psychologists; midwives; religious leaders. What steps do you see these professions taking with regards to these two processes of gaining cultural authority and gaining political-economic power through markets for services and positions within organizations?
Week Two: Medical Authority in Action: Medicalization (Part I: the Conceptual Level)


- Introduction: the Pharmacopoeia of Risk Reduction
- Chapter Two: Shrinking the Symptom, Growing the Disease

In *Week One*, we saw an evolution of perspectives on medical authority. From framing authority as static and largely deserved on the basis of superior technical competence and disinterestedness ([Parsons](#)) to medical authority as also rooted in physicians’ monopoly over the provision of various goods and services ([Freidson](#)) to medical authority as resulting from the conversion of cultural power into political-economic power ([Starr](#)) to medical authority as waxing and waning as the profession makes claims for jurisdiction over certain tasks and problems that compete with claims that other professions make ([Abbott](#)).

In this week, we turn from analyzing medical authority in the abstract to analyzing one of the main uses of medical authority— or medical authority in action: *medicalization*. We can provisionally define medicalization as using medical language to define a problem and/or using medical technology to alleviate a problem. As [Abbott](#) from the previous week’s readings argues, medicalization serves as a tool for physicians to expand and defend their jurisdiction over various tasks and problems; by defining conditions like substance addiction as a medical issue rather than a moral failing, physicians secure jurisdiction over that condition, resulting in a loss of jurisdiction for professionals like clergy.

**Topic one: defining medicalization and identifying its shifting drivers ([Conrad, 1992](#); [Conrad, 2004](#))**

Though medicalization was first coined by Irving Zola as part of a critique of the institution of medicine as a form of social control, Peter Conrad’s writings on medicalization helped spark a range of empirical research on the phenomenon. In his 1992 article, [Conrad](#) distinguishes between three levels or units of analysis at which medicalization can occur, levels we will use to organize the remainder of the readings and which we will define as we introduce each block of readings.

How is medicalization related to the professional authority and status dynamics on which *Week One*’s readings focus? [Conrad](#) (1992), focusing on sources of medicalization, cites Freidson to argue that medicalization is facilitated by “professional dominance and monopolization” (p. 214). Yet he uses the case of pediatricians creating new diagnoses for childhood behavior problems to illustrate that different researchers can offer
different accounts of how the general link between professional dominance and medicalization plays out. One researcher frames pediatricians’ medicalization efforts as a way to maintain market demand for their services after declining childhood deaths following the success of vaccination/public health campaigns. Meanwhile, another researcher frames these efforts as a way for pediatricians to increase their status within the profession by creating a subspecialty with intellectually stimulating tasks. These competing accounts show that while the cultural authority to frame problems in a certain way that Starr documents, and successful claims to jurisdiction that Abbott discusses, all generally facilitate the process of medicalization, there are many variations of how this facilitation plays out.

While the medical profession’s authority is both an important driver of medicalization and is generally bolstered by the medicalization of new human problems, Conrad (2005) highlights how there are other important drivers. Previewing Week Five and Week Six where we will discuss health-related social movements, a main emphasis of the article on medicalization’s “shifting engines” is on the growing role of consumers in bringing public and industry attention to disease areas and in pressing for speedy access to new therapies to address those conditions. In contrast to Parsons’ framing of the physician-patient interactions from Week One, where the patient treated physicians’ recommendations as largely authoritative on the basis of his or her perceived technical competence, and in contrast to Freidson’s discussion of patients having “little choice” in the services they receive, Conrad argues that patients have adopted a more consumerist orientation towards medical care where they feel more free to question authority and press for alternatives. In Topic Two’s Eyal reading, we will see one consequences of the shift from a more passive patient to a more active consumer orientation: professionals not only competing with other professionals for jurisdiction, but also competing with parents in the case of autism.

**Questions to think about for this topic:**

1. Consumers engaging in medicalization has an ambiguous relationship to medical authority. On the one hand, as patients claim that they have sufficient expertise to recognize a problem that needs a medical framing and/or medical treatment to alleviate, this might signal that medical authority is growing weaker. But on the other hand, medicalization by consumers can strengthen medical authority because in seeking a medical framing of a problem, consumers implicitly acknowledge that a medical framing is the appropriate/legitimate lens. Thinking of a case where patients have questioned medical authority, how does this balance play out?

**Topic two: the conceptual level of medicalization (Eyal, 2013; Greene, 2007)**

In this second topic, we turn from defining medicalization to exploring case studies of how medicalization occurs at the first level of analysis that Conrad argues the term operates: the conceptual level. Conrad (1992) defines this conceptual level of medicalization as follows:

A medical vocabulary (or model) is used to “order” or define the problem at hand; few medical professionals need be involved, and medical treatments are not necessarily applied.
Eyal (2013) shows how a new concept of autism emerged that used medical vocabulary to define a problem—namely, a problem that existed in an ‘interstitial’ place between incurable intellectual disability on the one hand and potentially curable childhood schizophrenia. He describes how although medical professionals eventually came in to certify the legitimacy of the concept, parents of children with autism played an important role in first ‘ordering’ and ‘defining’ the problem. Framed in terms of Abbott’s concept of professional jurisdiction, we observe a shift from professions competing with other professions to claim jurisdiction, to parents claiming jurisdiction by virtue of being an ‘expert’ in their own child.

Eyal’s description of parents’ role in re-framing autism serves as a case of medicalization because while parents challenged medicine’s sole jurisdiction over the problem, they continued to use a medical vocabulary to frame their child’s behavior. For instance, Eyal documents how during the reign of Leo Kanner’s psychogenic concept of autism, which in part blamed an autism diagnosis on cold parenting or ‘refrigerator mothers,’ there was a one-way flow of information from parents to medical professionals: parents would be asked to report on the child’s symptoms and then medical professionals would take that data to make an authoritative diagnosis. Eyal argues that in order to shift to a new medical model in which the parent was not blamed, parents needed to “go around the obligatory passage point occupied by the clinician, redirect the flows of information away from it, and turn the chain of transcriptions into a two-way road” (p. 885). Framed in terms of the readings from Week One, Eyal argues that physicians were able to maintain a monopoly over the framing of autism as a particular type of medical problem by maintaining a monopoly over the flow of information about a child’s symptoms.

How did parents break this monopoly and in doing so, change the medical model of autism? Eyal documents how a checklist developed by a parent (Bernard Rimland) and included at the end of a book, Infantile Autism, broke this information flow as Rimland “began receiving completed checklists from parents containing detailed individual histories of their children, descriptions of symptoms, and the timing of their appearance...he found a way, in short, to redirect the flow of information that until now as monopolized by clinicians so that it flowed to him” (p. 885). In this sense, Eyal shows how the dynamics from Week One—medical professionals giving the authoritative framing of a problem, a framing that is part of the conceptual level of medicalization—can be disrupted by patients who redirect information flows about their own or their child’s symptoms in hopes of framing the medical problem in different terms.

The wrinkle in medicalization that Eyal focuses on is the actors doing the “medicalizing”—with parents using a redirected information flow to shift the model used to explain autism from ‘refrigerator mothers’ to a behavioral disorder best treated with concrete habilitative therapy (p. 891). Yet the new medical model for autism remained within the standard medical paradigm of a focus on observable symptoms.

In contrast, Greene’s (2007) analysis of the conceptual level of medicalization focuses on how various actors began to use a medical vocabulary to define non-observable, non-symptomatic risk markers such as hypertension and high cholesterol. Greene argues that while others frame increased medical attention to these “pre-pathologies” as a triumph of epidemiology that studies like the Framingham Heart Study enabled, “the adoption of mild hypertension as a disease was not automatic or self-evident: it hinged upon a set of promotional practices—somewhere between education and salesmanship—to give it credence in the eyes of medical practitioners and consumers alike” (p. 4). Framed in terms of Conrad’s conceptual level of medicalization, it is not self-evident that non-
symptomatic physiological changes should be an object of medical treatment.

If medicalizing non-symptomatic physiological changes was not inevitable, what actors or social processes were involved? Greene argues that pharmaceuticals to treat hypertension, diabetes, and high cholesterol—Diuril, Orinase, and Mevacor respectively—are useful analytic windows into how the transformation of non-observable risk into a medical disease did not result from “centrally planned medicalization” but occurred as a result of a more diffuse set of “researchers, clinicians, patients, regulatory bodies, manufacturers, and insurers” (p. 5) coming together around the new therapies. In Chapter Two, Greene uses the case of Diuril to treat hypertension to illustrate how new pharmaceuticals, while not being agents of medicalization in and of themselves, brought together a variety of actors, some supportive of the conceptual framing of high blood pressure as a disease in and of itself, and others maintaining that “the broad medical treatment of symptomless hypertensive patients was itself unethical” (p. 53). Diuril, the first anti-hypertensive agent with relatively mild side effects that could be administered in pill form rather than more invasively in a hospital setting, contributed to growing acceptance of the concept that mild and moderately high blood pressure was a treatable disease in and of itself. The drug’s safety profile led to the idea that “with so little to risk, clinicians could afford to be more liberal with treatment...why not treat asymptomatic hypertension” (p. 65).

The case highlights how medicalization is not the result of a unilateral drive of medical imperialism but proceeds in fits and starts, and in interaction with technologies that have the power to make certain concepts of disease seem more acceptable. A key takeaway is that medicalization is not centrally planned but often involves a de-centralized group of actors from an array of social institutions—academic researchers; practicing physicians; pharmaceutical executives; federal regulators.

Questions to think about for this topic:

1. Eyal highlights the importance of information flows for medicalization: to provide medical diagnoses, physicians need the information on which to base that diagnosis; in the case of childhood behavioral problems, this dynamic is more pronounced as medical professionals rely on parents reporting of a child’s symptoms. What are other conditions in which information flow between physicians and patients is important, and where the relative jurisdiction of professional and patients may change based on the flow of that information?

2. Greene discusses one contemporary shift in our understanding of disease—from disease as something with observable, pathological symptoms to disease as something that can be a-symptomatic but that is slowly unfolding ‘below the skin’ physiologically. As various medical technologies that enable us to ‘see’ these physiological changes develop—for instance, neuroimaging—how might this further change our understanding of medical conditions as observable versus lurking below the surface?
Week Three: Medical Authority in Action: Medicalization (Part II: the Institutional and Interactional Level)


- Chapter 2- 'The Doctor-Patient Relationship in Clinic: Routine Work’
- Chapter 3- 'Counseling as a Mop-Up Service’

The institutional level (King and Bearman, 2011; Strand, 2011)

The conceptual level of medicalization focuses on ideas and culture: how do various individuals frame problems. Mapped onto the two-stage description of medicine’s social transformation from Starr in Week One, where the first stage is medicine increasing its cultural authority by shaping the patient’s ways of understanding his or her own experience in ways that make a physician’s advice seem appropriate, the conceptual level of medicalization relates to ideas about conditions as medical in nature.

In turn, the second analytic level of medicalization—the institutional level—maps onto the second stage in medicine’s social transformation: the conversion of cultural authority into political and economic power through the profession embedding itself in various organizations. As Conrad (1992) describes, in the institutional level of medicalization:

Organizations may adopt a medical approach to treating a particular problem in which the organization specializes. Physicians may function as gatekeepers for benefits that are only legitimate in organizations that adopt a medical definition and approach to a problem, but where the everyday routine work is accomplished by nonmedical personnel

The present readings focus on the role of social organizations in creating and solidifying cultural framings of human problems as medical.
Eyal from *Week Two* largely focuses on how autism was medicalized at the *conceptual* level and in particular, how the identified prevalence of autism in American children increased as a function of social actors framing autism as a condition with more hope for amelioration than intellectual disability. King and Bearman (2011) from the present readings focus on community-level *institutions* when explaining the rise in autism’s identified prevalence. They find that the relationship between individual attributes like income, race, and education and the probability of an autism diagnosis has remained relatively constant throughout the period they study—births between 1992 and 2000—indicating that the risk associated with individual-level predictors of an autism diagnosis has not increased over time in a way that accounts for the rising prevalence. Instead, what has changed over time are the relationship between *community-level* factors—most strongly, median property levels in a zip code—and the prevalence of autism in that community. As the prevalence of autism diagnoses is increasingly rapidly, community wealth has a strong effect on increased ascertainment of autism, an effect that holds even for less wealthy members of the community (e.g., births paid for by Medicaid). Then, as the prevalence of autism in wealthier communities plateaus, we see the diagnosis start to spread (be diagnosed) in less wealthy communities.

The authors, noting that “property values are likely acting as proxies for meaningful mechanisms,” point to institutional contributors to these patterns that they aren’t able to observe in the data. For instance, they find the strongest effects of community-level wealth for less severe cases of autism—the ones that are arguably most difficult to diagnose and detect. And differential detection/diagnosis of the same medical condition might result from different *organizations* approaches to treating a problem—for instance, if clinics operating in less wealthy communities dismiss the problem as ‘normal behavioral troubles’ while clinics operating in other communities are more apt to provide a medical label.

King and Bearman focus on institutional processes that contribute to increases in the social prevalence of an *existing* diagnosis. But before a diagnosis can spread across a population through social processes, it is often formalized into official manuals that organizations use not only in *framing* problems but for bureaucratic functions—what gets put down on the chart, what is billable to insurance. Thus, the spread of autism through different communities that King and Bearman focus on is pre-conditioned by important institutional decisions: *is* autism listed in an important diagnostic manual (the *Diagnostic and Statistical Manual of Mental Disorders*, or DSM)? Once listed, how are its symptoms described? These institutional decisions occur as the backdrop to the processes King and Bearman describe but can serve as important influences for instance in circumscribing the range of severity levels that qualify for an autism diagnosis.

Strand (2011) focuses on the main way in which psychiatric diagnoses become embedded in organizations: the DSM. His article seeks to explain the “puzzle” of 1980’s DSM-III, in which a dramatic revision of the manual moved the manual away from its earlier roots in psychodynamic theory and towards a symptoms checklist approach to diagnosis. In turn, this shift contributed to the manual’s transformation from peripheral to psychiatric practice to its present-day status as an authoritative source of diagnoses for insurance billing, pharmaceutical targets, and medical records.

Strand argues that existing research points to one of two explanations for this revolution. The first explanation, *diagnostic specificity*, argues that the main contributor to the DSM-III’s dramatic revision was insurance companies and other bureaucratic organizations who wanted more clearly-defined diagnoses for the purpose of deciding what to
reimburse and at what level. The second explanation, antibiotic specificity, argues that the main contributor was pharmaceutical companies who, looking for new therapeutic targets after the success of first-generation antipsychotics and with an expanded market following de-institutionalization’s emphasis on community-based medical treatment, wanted more specific diagnoses around which to plan drug development. In contrast to these two explanations, which point to exogeneous factors that affected how the manual served as an organizing institution for psychiatric diagnoses, Stark argues that the manual change was driven by the sort of ecological struggles that Abbott depicts: psychiatrists fighting for greater jurisdiction relative to psychoanalysts and clinical psychiatrists within the ecology of mental health professionals. In this sense, Strand shows how one sets of institutional forces that shape medicalization—how diseases are described in official diagnostic manuals—can be shaped by the type of between-profession struggles that the Week One readings focus on.

**Questions to think about for this topic:**

1. As King and Bearman note, the median property values of a zip code and its relationship with the spread of autism diagnoses—exerting a strong effect as autism increases in identified prevalence before plateauing—is likely a proxy for “meaningful mechanisms” that influence which cases of autism are identified and diagnosed. What community-level mechanisms might be behind the relationship? When thinking about mechanisms, make sure they account for the interesting pattern of zip code level wealth playing a more important role for lower SES members of that zip code (those with a Medicaid birth) than for higher SES members of that zip code?

2. As Conrad himself notes in his 2005 article, some research on medicalization can take an implicit view that medicalization has undesirable consequences for the individual receiving a medical label. In contrast, King and Bearman motivate their article in the socioeconomic gradients in health literature, which generally argues that gaining a medical label has desirable consequences for the individual as it helps that individual access healthcare resources. How can we reconcile these two lenses with which to view medical labels? How is the answer to this question complicated by medical labels that grant access to healthcare resources but also are stigmatized conditions? **Week Seven** will return to these questions in greater detail.

3. Strand shows how before the processes that King and Bearman document play out, a more fundamental institutional decision often takes place: whether to include the diagnosis in official diagnostic manuals. What social dynamics do you think shape decisions about whether to include diagnoses in official manuals?

**The interactional level (Whooley, 2010; Stivers and Timmermans, 2016; Benjamin, 2011; Bosk, 1992)**

Conrad defines the interactional level of medicalization as follows:

Medicalization occurs here as part of doctor-patient interaction, when a physician defines a problem as medical (i.e. gives a medical diagnosis) or treats a “social” problem with a medical form of treatment (e.g. prescribing tranquilizer drugs for an unhappy family life)
The readings in the week on the institutional level of medicalization often focus on whether a new medical diagnosis is formally encoded into diagnostic manuals like the DSM, insurance reimbursement schemes, and other institutions. Yet even after a problem is conceived of in medical terms and even after a label for that problem has been added to formal institutions/organizations, physicians and other medical professionals apply that medical label in interactions with patients. The readings in this topic highlight nuances in those interactions, and gaps between how the medical labels that are the product of medicalization function “on the books” versus function in practice.

**Bureaucracy and workarounds in diagnosis-related interactions (Whooley, 2010)**

Illustrating this gap between the formal/institutional level of medicalization and medicalization in practice most starkly is the contrast between Stark’s account of the rise of the DSM as a hegemonic means of framing psychiatric problems and Whooley’s (2010) argument that accounts of that rise often focus on the manual’s formal power on medicalization and neglect how the manual is used in practice. As Whooley puts it:

> The depiction of the DSM that emerges from the sociological research unwittingly portrays it as a monolithic, powerful object in and of itself; it overstates the power of formal diagnoses and obscures resistance to its through informal work practices by psychiatrists...complicated everyday diagnostic practices of psychiatrists (p. 454)

Relating to **Week One’s** readings, Whooley argues that the DSM’s success and uptake across a range of insurance, health, and other organizations puts psychiatrists in a state of structural ambivalence. On the one hand, the success of the manual solidifies the status and power of psychiatry as a profession by making its framing of medical problems ubiquitous across organizations. On the other hand, the success of the manual reduces the autonomy and discretion of individual psychiatrists who now face pressures from those same organizations to closely adhere to the manual’s standard categories. Whooley documents how psychiatrists employ various workarounds to maintain autonomy and discretion in the face of organizational pressures to stick closely to the manual’s medical labels. In doing so, he highlights that while certain medical labels might be formally institutionalized through mechanisms like inclusion in disease manuals and in insurance reimbursement schemes, there can be gaps between these formal forms of medicalization and what happens in interactions between physicians and patients about labels.

**Uncertainty, emotions, and diagnosis-related interactions (Bosk, 1992, Stivers and Timmermans, 2016)**

Whooley focuses on one type of gap between formal medicalization and what happens on the ground: psychiatrists who, reluctant to stick too closely to the DSM’s standard categories, invent workarounds to comply with the manual’s mandates while still maintaining some freedom and autonomy in how they interact with patients.

The readings in this section focus on a different sort of gap between formal medicalization and what happens in interaction: the ‘bright line’ nature of formal medical labels versus the uncertainty and emotions that occur in interactions where the physician and patient discuss a new medical diagnosis where there is no medical treatment to alleviate
the problem.

Bosk (1992), studying physicians who acted as genetic counselors in an era before the development of the large-scale genetic sequencing technology that Stivers and Timmermans (2016) focus on, investigates the challenge: when physicians provide a medical label for a condition by linking it to a possible genetic cause such as a chromosomal mutation, but have no medical treatment to offer (besides in the prenatal case, the possibility of a second-trimester abortion and in the postnatal case, an end to a patient’s “diagnostic odyssey” (Stivers and Timmermans, 2016)), how do they manage those interactions? While other studies of medicalization focus on “bright line” or deterministic diagnosis—a child is given a diagnosis of autism or not—Bosk focuses on counselors who present data about non-deterministic risk for disease. The counselors Bosk studies are tasked with “anomalous patients.” Patients whose presenting disease or phenotype has a clear diagnostic label even if that label does have genetic causes—e.g., cystic fibrosis; sickle cell anemia—are directed to the relevant subspecialty; the genetic counselors, as a ‘mop-up service,’ interact with patients who have a medical problem but for whom a clear medical label remains out of reach. Bosk notes that these interactions involve a division of labor regarding two aspects of diagnosis: the first is the technical information that underlies the presentation of risk and diagnosis, which the physicians he studies feel proficient in presenting. The second is normative judgments about how to act upon that risk information, and the emotions that accompany those normative judgments—for instance, upon learning that a future child is at elevated risk of a disease due to a genetic mutation the parents carry, whether to seek an abortion. Physicians, seeing their role as neutral purveyors of risk, emphasize that parents need to make these choices on their own or in consultation with other family members, friends, and religious leaders. Or as Bosk puts it:

Their [the genetic counselors’] relentless focus on the scientific, technical side of patient problems permits counselors to dramatize their expertise and also to avoid engaging a raft of emotional issues raised by the presence of genetic disease (p. 33)

Bosk’s account highlights two facets of medicalization. First is that as medicalization moves from the provision of a clear diagnostic label to the provision of information about risk for a future disease, physicians pursue various strategies to manage that uncertainty in interactions with patients. Second is that as Abbott from Week One notes, physicians do not always want to expand their jurisdiction; in the present case, the genetic counselors want to leave discussing the emotions and normative decisions that accompany the provision of genetic risk information out of their jurisdiction and remaining within the jurisdiction of other professionals such as the non-M.D. social worker who serves on the genetic counseling service.

Just as Bosk highlights the strategies that physicians pursue to reduce uncertainty when they provide inherently uncertain genetic risk information, Stivers and Timmermans (2016) focus on how physicians providing the results of exome sequencing—genetic sequencing focused on the coding regions (exomes) of DNA—seek to circumscribe the uncertainty associated with some genetic variants. In particular, just as the physicians

\[1\] Of course, there still may be uncertainty in the diagnosis or leading up to the diagnostic decision, but as Whooley notes, physicians may bracket this uncertainty when choosing an official diagnosis to put down in a patient’s medical record.
doing genetic counseling in Bosk are left with the anomalous cases, the physicians in Stivers and Timmermans’ genetic counseling service are brought in when a patient has a phenotype that may have a genetic basis but where the genetic basis is unclear. In turn, the results of the sequencing fall into one of five categories:

1. Benign
2. Likely benign
3. Pathogenic
4. Likely pathogenic
5. Variants of uncertain clinical significance (VUS)

Focusing on the VUS category, Stivers and Timmermans show how physicians in the interaction try to move towards greater certainty by either upgrading the causality—saying that despite the exome sequencing lab’s characterization of the variant as VUS, that the physician’s own reading of the evidence base leads him or her to view it as causal/pathogenic—or downgrading the causality, arguing that it is likely benign despite the VUS classification. What differs from their account and that of Bosk (other than the state of the genetics technology) is the role of the patient. Stivers and Timmermans argue that physicians, rather than more unilaterally upgrading or downgrading the causal status of genetic variants, are influenced by patients’ own interpretations of the basis of their child’s disease. For instance, a physician interpreting a VUS was trying to reconcile the fact that the child with the variant was symptomatic for joint pain while the father with the variant was asymptomatic; the father then noted that he actually did feel joint pain sometimes and the physician accepted that account/upgraded the perceived causal status of the variant in question. Their account reiterates the ideas from Conrad (2005) about patients’/consumers’ playing an increasingly important role in medicalization processes, and highlights that this role extends to helping physicians circumscribe undesirable uncertainty in the provision of medical information.

Race, distrust, and treatment-related interactions (Benjamin, 2011)

The medicalization readings thus far have largely focused on medical diagnosis: how do new concepts of disease emerge that give patients more hope for amelioration (Eyal, 2013) or that shift our concept of disease from something that is observable and symptomatic to non-observable and physiological (Greene, 2007)? How do non-infectious diseases like autism nevertheless diffuse unevenly throughout the population on the basis of differences in institutional resources to ascertain and provide a diagnosis (King and Bearman, 2011)? How do institutions like professional societies create the background conditions for a diagnosis by including it in diagnostic manuals (Strand, 2011) and how do physicians maintain autonomy and discretion in diagnosis-related interactions amidst a set of standardized and bureaucratized disease labels (Whooley, 2013)? How do diagnosis-related interactions change when what is being provided is not a clear medical label but the provision of more uncertain risk information (Bosk, 1992; Stivers and Timmermans, 2016)?

The present reading shifts our focus from medical diagnosis as a part of medicalization to medical treatment. Benjamin studies a group of patients who have a clear medical diagnosis that they accept: sickle cell anemia (SCD). Where the interactional negotiations
come in is in patients’ acceptance of treatment for that condition.

Benjamin focuses on the puzzle: in the wake of a much-heralded advance in medical technology for SCD—stem cell transplants—why are some African-American patients resistant to medical treatment in the form of participation in research protocols for the new intervention? Benjamin contrasts this ambivalence towards stem cell transplants among the SCD patients with the non-ambivalence of another patient population: largely Asian-American patients suffering from Thalassemia treated by a similar stem cell transplant. While one explanation focuses on individual attributes that lead patients to distrust that a new medical treatment is in their best interests, and traces distrust among African-American patients to individual awareness of historical abuses like Tuskegee, Benjamin argues that a more fruitful explanation is organized ambivalence produced by interactions between patients and physicians. In particular, patients argue that their skepticism about the value of stem cell transplants and other medical treatments for SCD is akin to the physicians’ own expressed skepticism about the patient’s own ways of managing pain and discomfort associated with the disease (e.g., techniques for managing stress that lead to flare-ups of pain; religious observance). Thus, while Eyal (2013) from Week Two focuses on patients who limit physicians’ jurisdiction by offering alternative medical framings of a problem, Benjamin focuses on how patients limit physicians’ jurisdiction by defending ways to alleviate a problem that do not involve medical treatment. Part of this defense is rooted in distrust that the physicians have their best interests at heart—after years of frustrating experience with medical treatment (e.g., racialized interactions with physicians in which they are labeled a ‘difficult patient’), the patients wonder why they are suddenly treated as attractive candidates for a new therapy being tested in research.

Questions to think about for this topic:

1. One common theme of the reading is patients’ increasingly active role in medicalization processes— from Whooley’s account of how psychiatrists sometimes consult and negotiate with patients about how to put down a diagnosis that helps with insurance reimbursement while minimizing stigma to Stivers and Timmermans’ discussion of genetic counselors negotiating with patients about upgrading versus downgrading the perceived causality of a genetic variant. What broader changes outside the field of medicine do you think have facilitated increased involvement of patients in medical decision-making? What are some positives and drawbacks of this trend from the perspective of social inequality?

2. Benjamin’s article highlights the role of trust in physician-patient interactions related to medical treatment, which underscores that the Week One readings largely fail to delve into how the cultural authority of physicians manifests itself different for patients from different racial/ethnic groups. How might large historical events such as Tuskegee and other research scandals for African-American populations shape how medicalization plays out for this patient group? How might distrust manifest itself in different interactions between physicians and patients?
Week Four: Medical Authority in Action: Medicalization, Risk, and Patients-in-Waiting


In the previous week’s readings, Bosk and Stivers/Timmermans each focus on how physician-patient interactions unfold in a setting defined by a particular technology: genetics. Yet the stage of the technology differed between the two research sites. Bosk studied genetic counseling at a time when genetic testing was confined to broad characterizations of chromosome-level mutations through karotyping, or imaging of entire chromosomes. Stivers and Timmermans studied genetic counseling at a time when genetic testing, drawing exome sequencing technology, could characterize the precise alleles—e.g., AA versus AT—of hundreds of thousands of variants on genes found on all chromosomes.

Figure 1: *Left panel:* illustration of chromosome-level karotyping; *Right panel:* schematic of exome sequencing that highlights degree of information revealed about within-chromosome variation between individuals

Figure 1 illustrates the change in the degree of detail about between-individual variation that each technology reveals, from allowing clinicians and patients to visualize only blunt changes to the entire structure of the chromosome to allowing these same parties to visualize minute degrees of variation in an individual’s genome. What does this shift in the technical means for visualizing illness and health imply for broader processes of medicalization?
Clarke et al. (2003) argue that technological shifts like the one illustrated in Figure 1 necessitate a theoretical shift from the concept of medicalization to the concept of bio-medicalization. They point to five processes that characterize an “increasingly technoscientific biomedicine” and that necessitate a theoretical shift.

The first is a shift in the political-economic facets of medicine. They argue that while the post-WWII era of medicine was governed by a medical-industrial complex with heavy public investments in both biomedical research and healthcare delivery, this funding model has shifted to what they call the “Biomedical TechnoService Complex, Inc.” marked by increased privatization of both research and healthcare delivery. Clarke et al. argue that this privatization has taken a particular form: there remains substantial government investment in the early and foundational stages of the development of pharmaceuticals and medical technologies but the later stages are marked by increased “commodification.” They point to the fact that while patenting genetic material was once considered inconceivable, the successful (at the time) BRCA1 patents by Myriad indicate increasing social acceptance of medical products as private commodities. Relating their arguments back to the readings in Week One that focus on the alliances physicians formed to convert their cultural authority into political-economic power, Clarke et al.’s description suggests that part of physicians’ power is derived by increasingly common alliances with pharmaceutical companies important for “strapped academic medical centers” (p. 168) funding gaps.

The second process that characterizes bio-medicalization, and the main focus of the present week, is a focus on “health, risk, and surveillance.” Clarke et al. argue that a key feature of bio-medicalization is the shift from medicine focused on illness/disease—helping patients recover when an illness “strikes” (p. 172)—to a focus on helping patients meet the “individual and moral responsibility to remain healthy” (p. 172). At the root of this shift is a change from healthy as a binary concept to healthy as a matter of degree. That is, instead of treating patients who do or do not occupy a sick role at a given point in time (Parsons), the focus of medicine has shifted to the idea that individuals are at varying degrees of risk for different conditions and that this risk needs to be assessed at a high degree of frequency.

Yet Greene from Week Two also focused on a shift in medicine conceiving of illness as something observable and symptomatic to medicine treating physiological markers of risk—hypertension and high cholesterol—as diseases in and of themselves. What differs between this process during the era he studies (1950’s-1970’s), which Clarke et al. characterize as falling within the era of medicalization, and the risk surveillance practices they attribute to the bio-medicalization era?

Two differences stand out. First is that two sets of technological advances—advances in genomic sequencing (or what they call, the “molecularization and geneticization of biomedicine” (p. 175)) and advances in neuroimaging technology—render ever more minute contributions to risk more visible to physicians, researchers, and patients. Clarke and co-authors argue that this technically-enabled detail characterizes the third process in bio-medicalization: “the technoscientization of medicine.” For instance, the shift in the degree of detail of genetic technology that Figure 1 documents has been accompanied by parallel shifts in the degree of detail that neuroimaging technology can make visible, such as structural MRI that outlined a brain’s anatomical features being followed by func-
tional MRI that measures blood flow as a signal of region-specific activation in response to stimuli. This enhanced degree of detail expands the boundaries of medicalization to include more subtle bodily changes. Second, and previewing the readings in Week Five and Week Six about increased patient/“consumer” involvement in medicine, and the reading in Week Twelve on self-tracking technologies, there is an increased emphasis on “self-surveillance.” Patients are expected to actively monitor their own health risks rather than rely solely on expert professionals to engage in this monitoring.

The remaining two processes that characterize bio-medicalization are less of a focus of the remainder of this Week’s readings, but do foreshadow topics we turn to in future weeks. First is how advances in communication and information technology change the way that medical knowledge is produced and distributed. Foreshadowing the Week Five and Week Six readings, one change is the increased availability of health-related information on the internet both through more official sources and through informal message boards where “users exchange their own knowledges and experiences with others” (p. 177). Just as Eyal from Week Two showed how parents established some jurisdiction over the diagnosis of autism by changing the flow of information away from a one-way street from patients to physicians, message boards where patients congregate serve as alternative spaces for information flows in ways that might decrease the cultural authority of physicians.

The final process Clarke and co-authors focus on, and one that also foreshadows the research on health-related social movements in Week Five and Week Six, is the role of biomedical technologies in identity development through various mechanisms (e.g., technology allowing one to obtain a previously inaccessible identity like infertility treatments and the identity of biological “mother”; new categories of health-related identities such as identities centered on risk). Throughout these changes, we see two general processes that relate to the authority of medicine discussed in Week One. First is that the change in medicine’s focus from disease as a “yes” or “no” category to health as a matter of degree expands medicine’s jurisdiction with few limits, since each individual is at varying degrees of risk for some outcome. Second is that amidst this expansion of medicine’s jurisdiction, patients are both expected to supplement their interactions with physicians in the defined walls of a clinic with self-surveillance of health risk outside its walls and are aided in doing so by internet resources, message boards, and other new forums for disseminating health-related information.

Clarke et al. focus on what is new about the era of expanded risk surveillance. Rosenberg (2009) provides historical context and argues that the present focus on risk was enabled by a much earlier shift in the late 19th/early 20th century in how society views disease. In the 19th century, disease was more of a holistic concept—as Rosenberg argues, “sickness was labile and individual, an aggregate of constitution, circumstance, and behaviour” (p. 802). Individuals engaged in the self-surveillance that Clark et al. document—they worried about a loss of appetite or abnormal urine, and what that might signal. But these same individuals thought the problems signaled general issues with one’s constitution and health, rather than risks for specific clinical outcomes.

The major shift that paved the way for medicine’s focus on risk was to viewing ailments as belonging to “distinct entities, construed as existing in archetypical form outside their manifestation in any particular man or woman” (p. 802). Once disease became contained in sharply circumscribed categories that exist outside any individual patient, for each category, there can be an “increasingly dense substance of thresholds, algorithms, screening practices, treatment protocols” to assess how close an individual is to belong-
ing in that category. Hence screening for “precancerous” legions that enlists a “previous healthy woman...into the world of sickness”; the pre-diabetes, hypertension, and high cholesterol that Greene in [Week Two] documents, and the genetics and neuroscience-enabled forms of screening that Clarke et al. focus on. Rosenberg’s contribution is in highlighting that although new technologies change the intensity of risk management, the development of disease-specific risk screening protocols and algorithms was contingent upon an earlier shift in social understandings of disease from holistic and idiosyncratic to sharply defined and unfolding across all individuals via common mechanisms.

**Topic two: examples of the role of risk in medicalization (Timmermans and Buchbinder, 2010; Beard and Neary, 2013)**

The next two readings, both drawing upon qualitative methodologies, illustrate how risk plays a role in expanding which individuals come under medical surveillance. Their focus on different patient pools—newborns/their parents (Timmermans and Buchbinder, 2003) versus aging individuals (Beard and Neary, 2013)—different technologies, and risk for different outcomes, allows us to contrast how the lived experience of risk differs along these dimensions.

**Timmermans and Buchbinder** focus on mandatory screening of newborns for a defined list of 24 rare metabolic disorders (e.g., PKU; galactosemia; with the most common being sickle cell anemia). The first phase of this screening, mandatory for all births, uses a dried blood spot to analyze whether a newborn has metabolite values outside the normal range. If so, clinicians will often proceed to a second phase of testing—genetic sequencing—to “confirm or rule-out specific diagnoses with a greater level of precision” (p. 411). The researchers enter at this second phase, observing interactions between parents and the genetics team at a California clinic when parents first learn of abnormal test results.

The findings illustrate several of the processes outlined in Clarke et al.’s theory of bio-medicalization, while also highlighting mances left out of the theory. First is the role of self-surveillance in medical care; since California does not require newborn screening, many parents were shocked in learning about the abnormal test condition. Contributing to this shock was the idea that they had engaged in appropriate surveillance of risks during pregnancy—as the authors put it, “the shock is enhanced by the fact that many couples opted for ultrasounds and other prenatal tests during pregnancy” (p. 413). This highlights how the proliferation of risk-detecting technologies—ultrasounds and other surveillance technologies during pregnancy; dried blood spot-based testing immediately following childbirth—means that patients have rarely exhausted the methods of risk detection available.

Another finding that confirms the processes that Clarke et al. outline is parents’ avaricious use of the internet after learning about an abnormal test result, where they come upon a biased set of worst-case scenario outcomes. Yet while one would predict from the [Week One] readings that physicians would then try to undermine the internet’s authority relative to their own, the authors document how physicians do so. As they describe, “the physicians and nurses in our study warned parents not to look on the Internet or at least not to believe everything they read...to back up their recommendations, the geneticists often referred to information that was still in press or recently published, or to personal conversations with leading researchers” (p. 413). Thus, physicians push back on the internet’s role in partially democratizing health-related knowledge by referencing
privileged information sources—unpublished articles not yet accessible via PubMed; information gleaned from valuable ties in their professional networks—to preserve authority in the face of competing distribution sources for medical knowledge.

In addition to illustrating these nuances, Timmermans and Buchbinder conclude by arguing that a new concept derived from their research—patients-in-waiting—is a useful framework that unites different ways that an expanding set of individuals fall under medical surveillance. These individuals include those with genetic susceptibility for future disease, those with the protodiseases like hypertension that Greene from Week Two studies, and children with developmental delays that place them on an ambiguous continuum from normal to delayed to disabled. Common features include ambiguity about whether one is “already sick, going to become sick and if so, what their sickness will entail” (p. 417), externally-imposed uncertainty about the nature of disease (e.g., they are brought into the role of patients-in-waiting through specific policies and interventions like mandatory newborn screening or recommended mammograms at a specific interval after a certain age), a lengthy trajectory of “medical gatekeeping to establish or relinquish a diagnosis,” and an altered identity (in this case, the “family’s projection of the normality of their child” (p. 419). In outlining these common characteristics of patients-in-waiting, Timmermans and Buchbinder also help place bounds on who occupies this role. They do so by emphasizing the role of institutions and medical gatekeepers in bringing patients into this role: the families who have newborn screening conducted without any abnormalities are not socialized into the role, while those asked to return to the clinic and learn about the ambiguous results are.

Beard and Neary (2013) focus on a very different patient population and outcome those patients are at risk for: patients given a diagnosis of “Mild Cognitive Impairment” (MCI), a disease characterized by some cognitive difficulties distinct from normal aging that may or may not progress into Alzheimer’s disease. Yet their interviews with these patients highlight the usefulness of the concept of patients-in-waiting for this dissimilar case. For instance, Beard and Neary reveal confusion among the individuals, perhaps used to a more binary model of diagnosis, about whether or not they had a disease—they knew they were having problems a bit worse than normal aging, but emphasized that these problems were distinct from “real diseases” like Alzheimer’s. This ambiguity among individuals about where they fall along a spectrum of normal aging to some problems to the feared specter of Alzheimer’s and related dementia is likely to be exacerbated by advanced in neuroimaging that allow researchers and clinicians to envision biomarker precursors of dementia (e.g., amyloid build-up) before the patient even exhibits the symptoms of mild cognitive impairment.
Week Five: Challenges to Medical Authority—Health-Related Social Movements (Overview of the Landscape)


Many of the previous weeks’ readings foreshadowed the rise of health-related social movements. For instance, we see the progression from Abbott in Week One framing medical authority as depending on jurisdiction, and thus waxing and waning with different jurisdictional challenges, to Eyal in Week Two showing how these jurisdictional struggles occur not only between professions but also between professions and laypeople like parents. Conrad in Week Two identified a growing role for patients/“consumers” as an engine of medicalization. Whooley in Week Three noted that psychiatrists, will not fully deferring to patients on what diagnosis to record in that patient’s chart, engage the patient in helping them settle on a diagnosis severe enough to be reimbursable by insurance but not overly stigmatizing. Finally, the readings in Week Four focus on how technological transformations create new identities for patients to organize not only around a diagnosed disease but around risk for that disease, as well as how online resources like message boards create patient-to-patient information flows that supplement physician to patient flows.

The readings in the present week help formalize the ways that laypeople/patients engage with medical authority. Worth noting is that although the title for this week focuses on one form of engagement with medical authority—challenging that authority—the readings this week and the case studies that follow highlight multiple modes of engagement. These range from delving deeply into the bureaucratic details of the clinical trial process to collaborate with researchers in re-designing aspects of these trials (Epstein in Week Six) to seeking the legitimation of medical authorities for a contested diagnosis (Brown et al.’s study of Gulf War-related illnesses in Week Six). As a result, one should not overstate the extent to which health-related social movements undermine medical authority since many of these movements have a goal of gaining expert attention to or legitimation of aspects of disease put forward by the movement. Or as Epstein (2016) puts it, HSM’s “often adopt a skeptical or confrontational stance toward mainstream
medicine and public health; but that typically are also oriented toward establishing productive and collaborative relationships with their interlocutors in the hopes of advancing research and treatment” (p. 248). As we will see in the research by Tomes in Week Six, this combination—a critical stance towards some facets of medical research/treatment but general hopes to recruit allies in the medical community to provide better medical solutions to the disease sufferers’ conditions—is something that varies based on the movement and historical period.

Levitsky and Banaszak-Holl (2010) also recognize the multiple modes of engagement that health-related social movements (HSM) have with medicine. They advance a framework that focuses on another source of variation: which institutions HSM target. Building on general ideas of multi-institutional politics within the study of social movements, the authors argue that the predominant focus in existing research on these movements has focused on one target: the state. While Levitsky and Banaszak-Holl acknowledge that the state’s role in establishing “the rules that govern other health institutions” makes it a major target, they outline a variety of other targets that HSM direct activities towards. These alternative targets include professions and organizations—for instance, movements centered on Complementary/Alternative medicine having a goal of gaining greater legitimacy within allopathic medicine rather than explicitly pressing for state funding and reimbursement. Another non-state goal is that rather than targeting clear organizations, HSM’s seeking cultural acceptance and legitimacy via the framing of their condition as medical—for instance, a chapter in the volume in which Levitsky and Banaszak-Holl’s introduction appears that studies how women suffering from postpartum psychiatric illness convicted of infanticide did not seek resources from the state or other clear institutions but instead sought to shift blame from themselves as individuals to a medical system they argue missed warning signs of their conditions.

Levitsky and Banaszak-Holl, by documenting the many goals HSM’s have and institutional and non-institutional targets HSM’s pursue in pursuing those goals, pave the way for subsequent readings that highlight targets as diverse as the mass media (Armstrong et al. in the present week), the chambers of Congressional Committees making research funding decisions (Best in the present week), or the meetings of a professional society engaged in closed-door revisions to psychiatry’s diagnostic manual (Brown in Week Six).

Health-related social movements, engaging in activism towards these diverse targets, often either explicitly or implicitly focus on securing some resource from the target. The next two readings focus on a specific type of health-related social movement: disease-specific advocacy groups. Each asks: when there is a finite amount of some resource—media attention (Armstrong, Carpenter, and Hojnacki, 2006) or National Institutes of Health (NIH) research funding (Best, 2012)—what helps one disease garner a larger slice of the proverbial pie, leaving another disease with a smaller slice?

Armstrong, Carpenter, and Hojnacki (2006), after first documenting significant variation in the amount of media attention that seven different diseases receive, ask: what predicts a disease receiving higher or lower amounts of media attention? The first feature they examine is disease burden—both the degree of burden, operationalized as mortality, and who suffers that burden, operationalized as female v. male, and black v. white mortality. While results are sensitive to the inclusion of HIV/AIDS’s, which is an outlier in terms of the main outcomes and predictors, when excluding HIV/AIDS’s, an increase in a disease’s population-level mortality is associated with increased media attention. Yet who dies matters in addition to the aggregate count of deaths, with the ratio of black-white
mortality (higher = more black deaths from disease relative to whites) associated with less media coverage. Finally, and related to the themes in the present week’s readings, the authors find generally positive relationships between what they call “politically active organizational communities”—what proportion of the advocacy organizations registered to lobby with Congress?—and media attention.

The findings add empirical richness to two dynamics of the HSM framework that Levitsky and Banaszak-Holl set forth. First is that HSM, while important, are also not wholly determinative of the allocation of finite resources. The authors consistently find independent effects of disease mortality—and more particular, white mortality—on media attention that operate in conjunction with advocacy effects. Second, and related to the multi-institutional politics framework, we see how a measure of a disease community’s targeting of the state as an institution—registering to lobby with Congress—serves either as a proxy for or has spillover effects on the non-state institution of media outlets.

Media attention to a specific disease is one type of finite resource, and one we might think of as a fungible currency for other goods that disease sufferers seek such as more researchers working on disease alleviation or speedier FDA approval of therapies. Best (2012) focuses on one type of good that disease activists might use media attention as currency towards: NIH research funding. Understood in terms of Levitsky and Banaszak-Holl’s multi-institutional politics framework, the case highlights advocacy directed towards a federal agency’s appropriations rather than advocacy directed towards more traditional state targets like legislatures.

Best investigates a similar question as Armstrong et al. but applied to a different finite resource: in a finite pie of biomedical research funding, what predicts the size of a disease’s slice? Analyzing 53 diseases from 1989-2007, and focusing on the main predictor of the number of advocacy groups associated with each disease in a given year, Best first finds that increased advocacy translates into a larger funding allocation, a result robust to the exclusion of HIV/AIDS’s and breast cancer as outlier diseases. And just as diseases with a higher ratio of black to white mortality received less media attention, Best finds that diseases with predominantly Black mortality receive less research funding. In addition to these direct benefits and distributive changes that disease advocacy produced, Best argues that the advocacy had what she calls systemic effects, or changing “the political meaning of medical research” (p. 789). While it may be more natural for media attention, which prioritizes identifiable victims and sufferers’ narratives, to be sensitive to advocacy by these victims and sufferers, more puzzling is why more bureaucratic research funding decisions are sensitive to this form of pressure by identifiable victims and sufferers. Best argues that in order for advocacy by these victims and sufferers to have this effect, the groups needed to shift cultural perceptions of who the beneficiaries of medical research are. Using longitudinal data on who appeared as witnesses at House appropriations hearings, Best argues that groups’ activities both resulted in and benefited from a shift of the perceived beneficiaries of research funding from scientists/researchers as beneficiaries to patients as beneficiaries. Thus, as Epstein discusses below, the consequences of HSM move beyond securing resources to broader cultural changes in the relative degree of power of different social actors.

Armstrong et al. and Best each highlight one way in which disease-specific advocacy might have undesirable consequences. As Epstein describes, this form of zero-sum advocacy is often the type of HSM activity that attracts scholarly and media attention:

\[2\text{Operationalized somewhat differently than in Armstrong et al. as an indicator variable for whether 95\% or more of a disease’s fatalities affect Black individuals}\]
At first glance, disease-based activism almost necessarily pits advocates of specific illnesses against one another as they for attention their ‘piece of the pie’... debates about illness-specific activism—especially in the United States—tend to position the various distinct patient groups as engaged in competition that is inevitably zero-sum. Furthermore, it is plausible to argue that a narrow focus and singular mission is precisely what permits such groups to mobilize effectively, establish a coherent collective identity, and frame their agendas in ways that resonate (p. 247).

Epstein argues that while this zero-sum advocacy is one important type of movement activity, two developments prompt a focus on consequences of disease-specific advocacy that transcend undesirable zero-sum dynamics. First is the transformation that the [Week Four] readings discuss from patients occupying a clear “sick role” to patients occupying the more ambiguous role of “patients-in-waiting.” While he does not cite specific empirical examples, Epstein argues that this could mean that a “strict divide between disease-response activism and health-promotion activism may prove increasingly less tenable” (p. 347). For instance, as a growing patient population learns about their degree of risk for Alzheimer’s as measured by the build-up of amyloid in one’s brain, there could be a shift in advocacy from that directed on responding to a clear and pressing clinical condition to more prevention-focused aims that cut across several conditions.

While this first transformation is more hypothetical than observed—we do not yet have clear evidence of how the emergence of the “patients-in-waiting” role has changed disease-related activism—Epstein also points to concrete evidence of three types of cross-cutting effects of current advocacy efforts.

First are diffuse spillover effects that result from the aggregation of activism—for instance, the fact that groups have “disseminated critiques that have helped to bring about a broader cultural shift in what are imagined to be the proper roles of doctors and patients” (p. 248). While these may be more difficult to pin down empirically, they have led to transformations in our model of medicine’s authority covered in [Week One] and on medicalization’s interactional dynamics covered in [Week Three].

Second are coalitions—for instance, as researchers identify genetic contributions to various diseases, organizations like the Genetic Alliance focus on goals common to these diseases such as genetic non-discrimination legislation. Finally is frame alignment that brings disease-specific advocacy groups into contact with other social movements—for instance, as Brown et al. document in [Week Six] groups that focus on environmental contributions to diseases like breast cancer experience overlap in frames with environmental advocacy organizations, alignment that does not occur for groups focused on more biological contributors.
Week Six: Challenges to Medical Authority-
Health-Related Social Movements (Case Studies)

Tomes, Nancy. “The patient as a policy factor: A historical case study of the con-

• Chapter 7 - 'The Critique of Pure Science'

Brown, Phil et al. Contested Illnesses: Citizens, Science, and Health Social Move-
• Introduction/Chapter 1- 'Environmental Justice and Contested Illnesses'
• Chapter 2- 'Embodied Health Movements'
• Chapter 6- 'A Narrowing Gulf of Difference? Disputes and Discoveries in the Study of Gulf War-Related Illnesses'

[Week Five’s] readings, focused on the landscape of health-related social movements, highlighted several important dynamics. First was that while many movements target state institutions because of the power of these institutions to create rules governing non-state actors, it is important to pay attention to a range of activist targets (Levitsky and Banaszak-Holl). Second was that in one form of HSM activity—disease-specific advocacy groups pressing for slices of finite pies—inequalities outside the realm of disease have spillover effects onto disease allocations. Armstrong et al. highlight spillover effects of racial inequalities onto media attention, while Best shows similar spillover effects for biomedical research funding. Third is that zero-sum advocacy does not exhaust the range of social movement activity. Advocacy can have diffuse social effects that span across diseases—e.g., changing the dynamics of medical authority—that are important but challenging to empirically identify.

The present week’s readings turn from theories and empirical investigations that focus on HSM as a field to in-depth analyses of specific health-related social movements/advocacy groups. These specific cases can help in an equilibrium of theory development, highlighting facets missing from the theory or sparking new hypotheses for comparative work across diseases. An important theme that emerges across the readings is the varied relationships to medical authority that different movements have. Week Five’s readings highlighted two goals of movements that often co-exist. On the one hand, the movements are premised on arguing that something is wrong with the status quo in medical research or treatment; without grievances to express, there is little organizing impetus for HSM’s. Thus, movement activity is partially focused on diagnosing problems in the current state of health-related activities and proposing remedies. Yet when movements engage in this critique, they strike a delicate balance, since many of the remedies they propose—more attention to their cause by researchers; access to more effective or less toxic medical treatments—require the collaboration of the same medical professionals
they have critiqued. The case studies highlight how movements maintain this delicate balance between critique and collaboration and show how this balance varies even within the same movement/same advocacy organization.

The first case study—Tomes’ (2006) analysis of mental health-related advocacy—shows a shift from “survivor” movements almost wholly focused on critique over collaboration to “consumer” movements that lean heavily towards collaboration. On the critique side, the “survivor” movement emerged in the 1960’s and 1970’s and drew intellectual inspiration from antipsychiatry writings by authors like R.D. Laing and Thomas Szasz. Modeled off of groups like the Black Power and women’s liberation movement, survivor movements promoted ideas of “mad pride”—they should accept their uniqueness and develop alternative, non-medical routes alleviating some of their systems. Part of their distrust of psychiatrists was rooted in the profession’s use of involuntary confinement with few legal restrictions at the time, making the groups’ desire to find alternatives outside the medical system more understandable given their historical context. As Tomes summarizes, the movement “aimed not at influencing the mental health system, but at developing a viable alternative.” While groups proposed some collaboration with sympathetic psychiatrists and psychologists—ones who were willing to meet the groups on their own terms and allow patients large degrees of autonomy to decide whether or not to take medication—the movement was largely focused on elaborating a critique of psychiatric power that left little room for collaboration.

How did the critique-focused survivor movement either morph into or become eclipsed in power/importance by a more collaboration-focused “consumer” movement? Tomes documents how activists became embroiled in disagreements about the very topic of critique versus collaboration—with some advocating for “separatism” (excluding mental health professionals and other non-survivors from the group) but others advocating for a more inclusive approach. When families of individuals with mental illness became more involved in activism, they formed a new organization—the National Alliance on Mental Illness—that took an explicitly collaborative approach of helping researchers focused on a medical model of mental illness secure more funding from the state. Thus, we see a shift in the targets of HSM activity as critique-focused “survivor” groups were eclipsed in influence by collaboration-focused “consumer” groups—the first set of groups targeted the profession of psychiatry while the second set of groups allied with this same profession to target state institutions that allocated funding. Yet heeding Epstein’s point about more difficult to trace cultural impacts of HSM’s, the early survivor groups arguably had broad cultural impacts in promoting the idea of persons with mental illness as capable of greater degrees of autonomy than they had previously been granted by mental health professionals in a way that paved the way for more symmetric collaborations.

Epstein (1996), focusing on HIV/AIDS’s activism during the crisis’ early years, also documents the delicate balance groups struck between critique and collaboration. And a key feature of how activists struck this fact was reducing the epistemic distance between themselves as laypeople with the disease and expert medical researchers and clinicians. Epstein begins by documenting a protest at Harvard Medical School organized by the Boston chapter of ACT UP (the AIDS Coalition to Unleash Power). The activists prepared a mock course outline for an “AIDS 101” class that listed discussion topics such as why AZT consumed 90% of research funding when it was toxic/non-curative and whether the pursuit of scientific elegance was leading to preventable deaths in the HIV/AIDS’s community. Epstein argues that the content of this activism reflected a different form of engagement between lay activists and expert scientists/clinicians. As he puts it:
These were no simple slogans of the 'Up with this, down with that' variety; each cryptic item hinted at arguments of some depth and complexity. In fact, the activist agenda reflected critical engagement with the nuts and bolts of clinical research into the Acquired Immunodeficiency Syndrome and a desire to take the science of AIDS as seriously as the deadly illness demanded (p. 2).

Epstein’s analysis highlights that the tension between critique and collaboration means that HSM activism results in bi-directional effects between expert professionals and the lay activists in these movements. In the first direction, HSMs’ critical stance can change the standpoints of expert professionals. Epstein cites the example of Anthony Fauci of NIAID who became convinced by some of the activists’ criticisms of clinical trials—for instance, the idea that by exclusively restricting access to a therapy to the context of a clinical trial, the researchers were more likely to face non-compliant participants who biased the results—and worked with activists in a more collaborative way to set of “parallel track” trial designs where patients who didn’t qualify for the trial could receive the therapy. In the second direction, these collaborative efforts influence the members of the HSM themselves. For instance, Epstein discusses how many activists started with a firm “no placebo’s” stance on ethical grounds. In their collaborations with bio-statisticians, however, some activists changed their stance to viewing placebo’s as ethical in some cases by allowing a speedy trial that produced cleaner evidence than historical case-control studies. Thus, there is not only grudging compromise between HSM’s and medical professionals but a shift in positions on both sides.

Brown employs a similar framework as Epstein to his analysis of environmental health-related social movements. What differs is that these activists focus on contention over the cause of a disease—for instance, in Gulf-war related illnesses, was the disease simply a manifestation of trauma/stress (a cause that veteran’s groups contested) or a manifestation of the effects of toxic exposures like pesticides used in the place of deployment (a cause they accepted)? Thus, returning to the medicalization weeks, we see contention less over access to specific resources and more over the concept of causation behind an illness.
Week Seven: What Medical Authority Can and Can’t Fix- Social Determinants of Health


- Chapter 1- 'How Patients and Doctors Deal with Social Problems’
- Chapter 6- 'Women, Work, and the Family’


The previous weeks of the course focus on defining medical authority and on showing this medical authority in action in various domains. The present week shifts focus to how health outcomes are persistently structured by forces that lie outside the purview of medical authority and that as a result, physicians acting as individual practitioners think they have little power to fix: structural inequalities in socioeconomic status, race, and gender.

Broadly, these structural inequalities constitute the *social determinants* of health. *Phelan et al.* provide a useful framework for understanding how these social determinants operate. This framework highlights how social determinants can either operate *through* medical authority—for instance, higher socioeconomic status, through various mechanisms, facilitating access to a more timely cancer diagnosis from an oncologist in ways that reduce mortality—or can operate *independently from* medical authority—for instance, differential exposure to lead in a home producing health disparities regardless of whether or not those individuals see a physician.

More specifically, the authors outline how a fundamental social cause of health inequalities has four essential properties. First, the cause must influence multiple disease and health outcomes; for instance, the relationship between educational attainment and outcomes as diverse as mental health and cancer mortality. Second, the cause affects disease outcomes through multiple risk factors; for instance, education affecting cancer mortality both by influencing smoking behavior and by influencing the degree to which a person is aware of and complies with cancer screening guidelines. Third, the cause must involve access to *flexible* resources that an individual can use to avoid risks or minimize a disease’s consequences after onset; for instance, education provides a flexible set of resources—more knowledge of health risks; greater cultural skill in navigating complex
medical organizations; networks with physicians who can provide informal advice—that
can be used to mitigate risks for and consequences of disease. Finally, there is repro-
duction of the link between the fundamental cause and health over time through the
“replacement of intervening mechanisms” (p. S29); for instance, before the advent of
chemotherapy, education might have helped people avoid cancer risk solely by helping
those patients engage in the appropriate health behaviors while after this technology was
developed, education operates through that plus other mechanisms. The theory highlights
that the extent to which medical authority mediates the link between a fundamental so-
cial cause and health depends on the intervening mechanism in play. Returning to the
cancer case, medical authority does intervene in the mechanism of higher SES patients
surviving longer because they are more savvy about access to clinical trials of promising
experimental therapies since physicians still stand as the gatekeepers to these trials. In
contrast, medical authority does less to intervene in mechanisms like the patient opting
on his own during his young adult years to not initiate smoking.

The social characteristics that most clearly satisfy these criteria are race and gender,
and the remaining readings focus on each of these characteristics. Geronimus et al.
and Case and Deaton each focus on race. Geronimus et al. first begins with the
prevailing pattern of blacks suffering from a range of negative health disparities relative to
whites by mid-life. She sets forth the weathering hypothesis as the intervening mechanism
between race as a fundamental social cause and health outcomes. Weathering for blacks
is the “cumulative impact of repeated experience with social or economic adversity and
political marginalization” (p. 826); Geronimo argues that these repeated experiences
cause worse health less through pathways that operate through medical authority like
differential access to care or health-related products and more through biological path-
ways. Blacks and other racial minorities are forced to expend “persistent, high effort”
coping with these forms of social and political marginalization, effort that leads to stress
activation with biologically harmful consequences. The authors find evidence for this
process by measuring allostatic load, a set of biomarkers that can serve as an indicator
of cumulative stress exposure. They find that blacks at all levels of SES had higher allo-
static load than whites, and that these disparities were particularly pronounced for black
women who, due to social phenomena like mass incarceration and other public policies,
“bear much of the responsibility for the social and economic survival of Black families,
kinship networks, and communities” (p. 830). Thus, Geronimus et al. highlight that a
focus on mechanisms through which one fundamental social cause—race—affects health
disparities soon leads to intersections between that social cause and others like gender.

Similarly, Case and Deaton begin with a focus on race as a social cause of dis-
parities in mid-life (45-54) mortality but have findings suggestive of the role of gender.
The authors find the U.S. has experienced a puzzling trend relative to other advanced
industrialized nations in white mortality in mid-life: while white-mortality consistently
declined in these other nations from 1990-2010, U.S. white mortality has been rising
during this period. Chief among the causes are increases in suicide, drug and alcohol
poisoning, and chronic liver disease and cirrhosis often caused by heavy alcohol use. The
nature of these causes reveal that the mechanisms linking a social cause—white race long
thought to confer health advantages relative to other racial groups—to health outcomes
do not clearly operate through medical authority in expected ways. For instance, with
opiod-related overdoses as one reason for the increase, the disparity is created through
physicians providing a harmful substance at higher rates to white patients rather than
physicians withholding a helpful substance at higher rates. And just as the mechanisms
in Geronimus suggests intersections between race and gender, the mechanisms in Case and Deaton also point to gender but masculinity rather than femininity. In particular, the authors argue that a cause behind more proximate causes of death like suicide and drug/alcohol overdoses are things like economic risk and insecurity that, while threatening both genders, pose particularly large burdens to men who have internalized traditional “male breadwinning” roles.

While gender is implicit in Geronimus et al. and Case and Deaton, Waitzkin more explicitly focuses on gender as a fundamental social cause structuring inequalities in health. He begins by outlining several physician-patient interactions in which a medical problem unfolds amidst a social context. For instance, for the social context of female gender and housework, he introduces the following scenario:

A woman visits her doctor irregularities in her heart rhythm. She complains that palpitations and shortness of breath are interfering with her ability to do housework. The doctor checks an electrocardiogram while she exercises, changes her cardiac medications, and congratulates her in her efforts to maintain a tidy household (p. 3)

Waitzkin focuses on different options physicians have in such encounters for how to proceed with an interaction where a medical/technical problem is embedded in a larger social context, none of which are mutually exclusive. The first option is to discuss the medical/technical problem, which we see in the physician’s changing of the woman’s cardiac medications to address her complaint. The second option is to both discuss the medical/technical problem and to provide “emotional reassurance” about the contextual concerns; we see this emotional reassurance in the doctor praising the woman for her household efforts. Thus, the social context is not entirely bracketed from the medical interaction but instead is addressed through emotional assurance. A third option that Waitzkin argues is rarely taken by physicians is criticizing or recommending change to the social context; physicians and patients are comfortable discussing small adjustments but not the sort of change that would more durably change the fundamental social cause that affects the health outcome. Waitzkin thus argues that the sort of fundamental social causes that Phelan et al. focus on do crop up clinical conversations, but that medical professionals circumscribe their jurisdiction in ways that brackets professional responsibility for criticizing or reforming these social causes.
Week Eight: Transmitting Medical Authority across Professional Cohorts– Socialization into the Medical Profession

Bosk, C. L. “Forgive and Remember: Managing Medical Failure. Chicago: Univ.” (1979). Focus on:
• Introduction

• Chapter 1- 'Error, Rank, and Responsibility'


The readings in Week Five and Week Six highlighted a tension that health-related social movements faced between critique of medicine and collaboration. Underlying this tension was what Starr from Week One labels the “twin supports” (p. 10) of authority: legitimacy and dependence. While the social movements challenged the legitimacy of specific decisions made by clinicians and researchers—for instance, HIV/AIDS activists challenging the legitimacy of certain design features of clinical trials such as excluding any participants who take multiple therapies for opportunistic infections—most groups, with the exception of those who wholesale rejected medical models like the anti-psychiatry movement, were ultimately dependent upon medical professionals for the clinical and therapeutic developments the groups sought.

How should we view the desirability of such dependence on medical professionals? Addressing this question takes us back to the readings from Week One. As previously discussed, most theorists agreed that the physician-patient relationship is marked by a relationship of some dependence of the latter on the former. But theorists disagreed—sometimes implicitly rather than outright—about the desirability of this dependence. Bosk (1979) in the present week aptly characterizes those disagreements as ones about different motivations theorists attribute to the “microlevel of the doctor and the patient.” On one pole is Freidson, whom Bosk argues largely attributes motivations of financial gain and the pursuit of power to these microlevel interactions; for Freidson, the “doctor-patient relationship is an economic transaction in which the physician’s primary motivation is to maintain a privileged and protected position for himself in the marketplace” (p. 17). At another pole is Parsons, whom Bosk argues largely attributes motivations of benevolence borne out of fiduciary duties; for Parsons, the relationship is one of “fiduciary trust in which the physician’s primary interest is to safeguard the health of the individual and the collectivity” (p. 17).
Bosk argues that ultimately, the answer of which motivations guide microlevel interactions between physicians and patients—an interest in safeguarding health or a well-cultivated appearance of that interest—depends on how well the profession engages in a key task: socialization of entering members of the profession into the former orientation. While theories of deviance and social control had long been influential in the medicalization literature in medical sociology that Week Two and Week Three focused on, Bosk argues that theories of deviance and social control are also useful for examining the socialization of new professionals. Older cohorts within the profession first construct notions of what is deviant, or put differently, what counts as an error. Thus, what counts as an error in professional work does not have “unequivocal ontological status,” but instead is constructed in communication and interaction. Then, there are various forms of social control meant to monitor whether new professionals commit those errors and if so, to apply various sanctions.

When discussing these forms of monitoring and sanctioning, Bosk introduces a useful $2 \times 2$ typology that we can use to structure the remainder of the readings. The first dimension is whether the social control is applied internally—in the case of the surgeons Bosk studies, applied by one surgeon (often a supervising attending or housestaff) to another surgeon (often a 2nd or 3rd year resident)—or whether the social control is applied by external actors. The second dimension is whether the social control is informal—applied in the case of workplace cues, expressions, and interactions—or whether the social control is external (e.g., a case conference; an audit). This results in four varieties of social control that physicians and other professionals face:

1. Informal-internal social controls: “everyday ways that members of a group remind each other of their responsibilities as part of work routines”

2. Formal-internal social controls: e.g., case conferences, staff meetings

3. Informal-external social controls (e.g., a principal informally drops in to observe a teacher in a classroom; Bosk notes that these are often a privilege of rank)

4. Formal-external: e.g. audits of work

While scholars like Freidson have pointed to medicine’s lack of formal-external and informal-external controls as a cause for concern because of leeway it grants in microlevel physician-patient interactions, Bosk argues that this conclusion is premature. In particular, if a robust system of informal-internal and formal-internal forms of social control exist, and if these social controls are focused on punishing deviance in ways that align with the interests of patients—e.g., social control to punish deviant behaviors that threaten patient’s lives—then as a society, we should be less worried about medicine’s lack of external social control.

Fox (1957), Bosk (1979), and Menchik and Meltzer (2010), each focus on the dynamics of informal-internal social controls as a form of socialization. These empirical investigations are important for understanding if the internal forms of social control that older physicians exercise over incoming cohorts are robust, justifying Parsons’ optimism about the fiduciary relationship, or not.

Fox (1957), studying medical students at Cornell, is interested in the question of how students are socialized into greater comfort with three forms of uncertainty that

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3In the full Forgive and Remember, Bosk also turns his focus to formal-internal controls. But in the selection chosen for this week, he focuses on informal-internal control
plague medicine. The first is uncertainty based on the practitioner’s own “incomplete or imperfect mastery of available knowledge.” An example is Gross Anatomy—while science has characterized most of the anatomical features of the human body in a great degree of detail, students taking the course soon realize that they will never be able to know and remember all this available knowledge. The second is uncertainty based not on the practitioner’s own cognitive finitude but on the finitude of the scientific enterprise: the practitioner is uncertain because there are gaps in scientific knowledge about a process or condition. Fox cites pharmacology (at the time) as an example of this second form of uncertainty, where large gaps in knowledge about how drugs worked created uncertainty in clinical prescriptions. The third form of uncertainty one could call meta-uncertainty about the first two forms of uncertainty. In a given situation, a practitioner struggles with whether his or her uncertainty stems from a gap in the medical field that exempts them from accountability for not knowing or if the knowledge is available but they fail to recall it.

Describing informal-internal forms of social control that train medical students to manage these three forms of uncertainty, Fox finds an emphasis on what Bosk later characterizes as the “no surprises” norm. Being proactive and candid about the limits of one’s knowledge are each valued; hiding gaps in knowledge with over-confidence is not. As Fox describes, “if he[a medical student] acts presumptuous about his knowledge, a student will be reproached by classmates whereas an admission of ignorance on his part may evoke their approval. From their positive and negative reactions, a student learns that his classmates, like his teachers, expect him to be uncertain about what he knows and candid about his uncertainty” (p. 221).

Bosk finds a similar form of socialization of the surgical residents he studies at “Pacific Hospital.” Attendings and other more senior members of the surgical service apply informal forms of social control—making jokes; recounting stories about bad apples—to various types of errors that colleagues and resident surgeons make. Yet different types of errors are given different weight in determining the magnitude of deviance that has occurred. Supervising surgeons view what Bosk calls technical errors—errors that result from a surgical resident “performing his role conscientiously” but where “his skills fall short of what the task requires” (p. 37)—as regrettable but excusable. Framed in terms of Fox’s forms of uncertainty, even when there is available knowledge about how to perform a surgical intervention—for instance, not leaving a large bruise after a procedure—residents who make this mistake once are forgiven (but chided to remember the mistake and learn from it). In contrast, supervising surgeons view what Bosk calls normative errors as bordering on inexcusable. And relating back to Fox’s findings about candor as a prized value, these errors are characterized by a “no surprises” rule. If the resident makes a mistake that strikes the physician as a failure not of technical execution having conscientiously performed a role but a failure to conscientiously perform the role itself—for instance, through a lack of the candor Fox describes; for prioritizing non-work commitments over patient care—this transforms the error from one that can be forgotten to a more serious blemish on the trainee’s character. Veazey-Brooks and Bosk, writing three decades later, focus on the intrusion of formal-external control into these dynamics in the form of duty hour regulations that limit surgical residents to work fewer than 80 hours a week. They focus on opposition to these regulations amidst much of the “old guard” of surgery in part due to concerns about whether this will lead to lazy residents more focused on work-life balance than on avoiding normative errors.

While Fox and Bosk each focus on socialization of physicians in training—medical
students; surgical residents—Menchik and Meltzer (2010) illustrate a more horizontal form of socialization as a physician holds a particular colleague in higher or lower esteem based on how well that colleague manages Fox’s first form of uncertainty: staying abreast of medical knowledge. Their article highlights how the informal-internal control mechanisms occur horizontally as well as vertically, and affect concrete material outcomes like whether a physician is willing to refer a patient to a colleague.

Taken together on Parsons v. Freidson debate—FINISH. Mapping these on to the readings from Week One and the particular tension between Parson’s more optimistic portrait of earned fiduciary trust and Freidson’s more pessimistic portrait of how physicians might exploit that trust—argue that if it were just an economic transaction, hide uncertainty since the asymmetric nature makes it X and perhaps no incentive to be correct other than market ones.
Week Nine: Examples of Medical Authority Across the Life Course—Birth, Schooling, and Aging


Abramson, Corey M. The End Game. *Harvard University Press*, 2015. Focus on:
- Introduction - 'The End Game'
- Chapter 2 - 'The Uneven Playing Field: Disparate Contexts and Resources in Old Age'

The readings on *medicalization* earlier in the course have already highlighted several applied examples of medical authority in action. The present week, by focusing on how medical authority operates at three different points in the life course—birth; schooling; old age—highlights how the roots of medical authority differ at these three stages. In particular, a common theme across the three readings is the role of medical authority in capitalizing on a form of anxiety particular to that stage of the life course.

For Waggoner (2013), who focuses on pregnancy/childbirth, the anxiety that medical authority either does capitalize on or attempts to capitalize on is anxiety about the health of the future child. When trying to prevent threats to the future child’s health, medical and public health professionals initially focused on the mother’s behaviors during pregnancy, arguing that behaviors like *any* alcohol intake posed risks to the child’s health and that *any* degree of risk to the future child was unacceptably high from the cultural standpoint of good mothering (*Armstrong, 2003*).

Waggoner shows how anxiety about risks posed by the mother’s behavior has crept back from the conception/gestation period into a “pre-conception” period. She documents the rise of the idea that a “women’s health status and behavior before pregnancy could affect the health of her pregnancy and her fetus” (p. 346). Related to the readings from [Week Four] about *patients-in-waiting*, she documents how those in the pre-conception care movement had good intentions in casting “all reproductive-age women as potential mothers” (p. 358) such as the hope for greater political support for access to insurance for reproductive-age women. Thus, the transformation of reproductive-age women into patients-in-waiting—a transformation motivated by anxiety about the risks posed by these women’s behaviors to future child health—was not solely driven by cultural shifts but instead also driven by the political-economic context of U.S. health insurance.

While the pre-conception care movement focuses on anxiety about a child’s *future health*, King et al. focus on a different form of child-focused anxiety: anxiety about a child’s academic performance. Using data on the timing of prescriptions to children for ADD/ADHD-related stimulants over the course of the year, the authors show spikes in prescriptions during the school year when these anxieties are salient and dips in prescriptions during summers when they are not. We thus see how social anxieties about
academic performance, tied deeply to social anxieties about mobility that the other syllabus discusses, manifest themselves in medical treatment.

Finally, Abramson turns our attention to anxieties wrought by another stage in the life course: aging. The chief anxiety that aging individuals have is a loss of independence, a loss that plays out differently for different elderly individuals depending on the economic and social capital those individuals have accumulated earlier in life. Abramson highlights various ways that anxiety about a loss of independence shapes these seniors’ interactions with medical professionals. One way is the relationship between compliance with the medical professionals’ advice and the desire to remain living in the community. For lower-income individuals, medical professionals played an important role in advising social workers about whether the individual had sufficient capacity to continue living independently in the community or whether the social worker should press for placement into a Medicaid-financed nursing facility. Seniors often viewed this nursing facilities as places of last resort that they wanted to avoid at all costs. Thus, Abramson documents how some of these seniors would comply with medical advice—for instance, seeing specialists for different issues even though those visits were extremely burdensome and difficult to arrange for mobility-challenged seniors—to stay on the physician’s good side.
Week Ten: Medicine and the State—Medicine and Criminal Law


Week One show that the medical profession has a specific set of norms guiding its work, with Week Eight showing how physicians are socialized into those norms with various forms of internal/external and formal/informal social control.

The readings in the present week each highlight a similar tension: what happens when medical professionals’ work brings them into conversation with an institution—the criminal justice system—characterized by what organizational theorists call different institutional logics. The result is a combination of tension—for instance, Rothstein (2014) highlighting psychiatrists’ unwilling recruitment into the work of assessing patients for risk of violence and the logics surrounding mental illness that entails—and adaptation—for instance, Timmermans’ showing how the professional reasoning of medical examiners came to resemble that of legal practitioners when building a “case” for a death to be classified as a suicide.

Delving more deeply into this combination of tension and adaptation as medical professionals collaborate with the criminal justice system either willingly or under legal coercion, we begin with Timmermans’ (2005) ethnographic research on medical examiners who conduct investigations into causes of death. A wide array of quantitative research dating back to Durkheim argues that official suicide rates likely reflect under-reporting. But little research investigates how a death comes to be classified as a suicide and how a set of professionals’—medical examiners—norms and practices contribute to this under-reporting. The example relates to the criminal justice system because, for instance, ambiguity in the cause of death—was it a suicide or homicide—can lead to no criminal justice investigation if a death is classified as the former but an investigation if a death is classified as the latter.

Relating to the theme of tension and adaptation that characterizes medical professionals’ collaborations with criminal justice activities, Timmermans’ account highlights more adaptation than tension. Part of this might be the the result of selection into the profession of medical examiners—medical examiners are often trained as forensic pathologists, a discipline that is deliberately aimed at bringing scientific knowledge to bear on legal/forensic questions. A similar pattern holds for the local public health officials that Hoppe studies, whose orientation towards public health surveillance aligns well with legal mandates about disease status disclosure. In contrast, most of the psychiatrists that Rothstein describes neither consciously opted in neither to working on forensic issues nor on helping engage in forms of population-level surveillance.

How does adaptation occur in the context that Timmermans studies? The main way is through legal ideas about constructing a case seeping into the orientation that the
examiners have towards their work. With any death, the presumption is that it is not a suicide unless the medical examiner proves otherwise. And when proving otherwise, we see a type of lawyerly consciousness guide the examiner's work. Timmermans shows how the examiners work “not deductively—determining a suicide based on a checklist of evidence—but inductively, building a case for suicide from diverse pieces of evidence” (p. 319). For instance, the medical examiner will look at writings the decedent left behind and at toxicology reports. And Timmermans finds that some of the examiners he studies use what they call a “51 percent rule” to determine if this assembled proof constitutes a strong enough case to make a judgment of suicide. Even though the examiners do not need to present this proof in a formal court of law, some imagine an informal tribunal of the deceased individual’s close relatives who, often hoping that the death was due to natural causes rather than due to suicide, would interrogate and cross-examine that evidence. Timmermans argues that this approach is evidence of legal ideas seeping into the work of the medical professionals. As he puts it:

Following a process of differential diagnosis, clinicians usually treat the most plausible cause of illness, even when clinical uncertainty prevails (Fox 2000). Pathologists are board-certified physicians, but they are required to follow a more stringent legal standard in death determination than the guidelines orienting their clinical colleagues... the imagined confrontation [between the deceased relatives and an examiner who must defend his or her judgment of suicide] reflects the standard of certainty needed to defend one’s opinion in an adversarial cross-examination (p. 322)

Thus, while Fox from Week Eight shows how new physicians are socialized into comfort with a certain degree of uncertainty lying behind their work, Timmermans highlights how examiners’ contact with the criminal justice system changes the acceptable degree of uncertainty; examiners can no longer resort to the judgment that has the highest relative probability of being correct, but instead, must shift to the more absolute level of probability contained within the legal system’s rules of evidence. Likewise, while Bosk from Week Eight highlights how surgical residents face cross-examination from colleagues/superiors as part of informal-internal social control, the more adversarial nature of the imagined cross-examinations by relatives leads to this higher standard of certainty. These highlight that while medical professionals are socialized into the logic of the medical field, their contact with the criminal justice system shifts the substance of this training more in the direction of that alternate field. We see a similar process occur in professionals’ role in the vaccine courts that Kirkland in Week Eleven studies, where practices such as adversarial cross-examination and the fairness-focused aims of civil law concerning injury also alters medical work.

Just as Timmermans’ account of medical professionals interacting with the criminal justice field is characterized by more adaptation of the work of the former to the latter than explicit tension, Hoppe, who studies local public health officials who meet with patients newly-diagnosed with HIV as part of epidemiological surveillance efforts, finds more adaptation than tension. In Timmermans’ case, the adaptation was arguably traceable to who selects into the explicitly law-oriented field of forensic pathology. In contrast, in Hoppe’s case, the adaptation is arguably traceable to congruence between the logic of public health surveillance—which argues that some sacrifice of an individual patient’s privacy is warranted if doing so helps prevent the population-level spread of a disease—and the logic of legal surveillance, which makes similar arguments about
sacrificing individual privacy to prevent crime that threatens the collective. These two forms of surveillance intersect in state-level felony disclosure statutes that make it a crime punishable by imprisonment (in Michigan’s case, up to four years) for an HIV-positive individual to have sex without disclosing his or her sero-status to his or her sexual partner. Hoppe describes how Michigan’s law, like that in many other states, “does not require proof of malicious intent” or “evidence that the sexual practices alleged pose any risk of transmitting the virus” (p. 27).

How do the local health officials charged or empowered to detect cases of criminal non-disclosure react to being asked to conduct this form of legal surveillance? Hoppe describes how while legal action is rare, these professionals have few qualms about recommending that legal course of action to new clients who report having sexual contact with an individual that the counselor knows either from personal experience or a state database is aware of his or her HIV status. As one health official Hoppe interviewed reports, “sometimes we might say, ‘Well, we’d like you to report this to the police. We’d like you to contact the police’” (p. 36). Thus, the fact that local health officials are constrained in whether they themselves can initiate a criminal investigation, combined with their general comfort with these investigations proceeding, leads them to extend beyond their health-focused role to provide legal advice to patients they counsel.

Hoppe and Timmermans each describe how medical professionals willingly adapt to norms of the criminal justice system, either due to reasons of selection into a criminal law-focused sub-specialty or alignment between the logic of health surveillance in pursuit of population-level ends and that of criminal surveillance. In contrast, Rothstein highlights a case of contact that has produced more tension than adaptation among the medical professionals involved. The form of criminal justice contact is what are called state-level Tarasoff statutes. Passed in the wake of the murder by a male Berkeley graduate student who had told his clinical psychologist that he planned to kill an object of infatuation who had rejected him (Tatiana Tarasoff), the statutes charge various professionals—psychologists, psychiatrists, physicians—with a “duty to protect” or a “duty to warn.”[^4] Broadly, this duty states that when a patient discloses to a medical professional that he or she plans to harm or kill a third party, the professional is mandated to notify the police and make reasonable efforts to notify the intended victim (p. 106). If they do so, the professional is released from liability for harm—for instance, a homicide; a mass shooting—that transpires. The statutes thus task medical professionals with an explicitly criminal justice-oriented task: monitor patients not just for medical issues but also for the risk of violence the patients pose to others.

As Rothstein describes, both in the original Tarasoff case and the statutes that followed, most medical professional societies took a firm stance against placing this duty upon professionals, arguing that it constituted an unacceptable breach in trust between the physician and his or her patient. Part of this opposition is certainly traceable to medical professionals wanting to avoid added legal liability and the sorts of formal-external forms of social control on their work that Freidson notes they resent. But part of this opposition is arguably traceable to the norms Parsons in Week One describes as guiding the work of these professionals. In particular, the professionals not only aim to prioritize the interests of their clients over their own interests, but also stand in contrast to public health professionals in focusing more on benevolence towards their specific patients than on population-level concerns. Tarasoff statutes ask these professionals to breach the confidentiality and trust established with an individual patient to engage in surveillance

[^4]: Depending on the state, the statutes frame these duties differently
that is ultimately meant to benefit individual(s) other than their patient. While many argue that this tradeoff is justified, the contrast between the willingness of public health professionals who already adopt a population-level orientation in their work to engage in population-level criminal surveillance with the unwillingness of clinical professionals to adopt these population-level ends reveals how processes of adaptation or tension are shaped by existing norms and socialization into those norms.
Week Eleven: Medicine and the State– Medicine and Civil Law/Regulatory Policy

Carpenter, Daniel. Reputation and power: organizational image and pharmaceutical regulation at the FDA. *Princeton University Press*, 2014. Focus on:

- Introduction- ’The Gatekeeper’


- Introduction- ’Our Immunization Social Order’
- Chapter 3- ’Health and Rights in the Vaccine-Critical Movement’
- Chapter 4- ’Knowing Vaccine Injury through Law’


The readings in Week Ten highlight what happens when the internal logics of medicine come into contact with those of the criminal justice system, with some professionals adapting but other professional displaying tension. The present week focuses on two forms of contact that medical professionals have with a different system of justice with distinct norms: civil law. The readings center on two topics, one for each form of contact.

**Topic one: regulation of medical products (Carpenter, 2014)**

Readings by Epstein in Week Six highlight that health-related social movements not only challenge the authority of medical clinicians but also challenge the authority of biomedical researchers in setting standards of evidence for when a therapy is safe and effective enough to be released on the market. Carpenter (2014) focuses on an important third party in this equation: the Food and Drug Administration (FDA). And just as the previous week highlighted two logics of professional practice—an individual patient-focused locus that prioritizes benevolence towards one’s patient over balancing the interests of a population at large; a population-based perspective—Carpenter analyzes how similar tensions play out in the FDA in the balance between granting speedy access to therapies that might help an individual patient and generating reliable evidence that protects the population at large from drug-related adverse events.

Carpenter begins with a puzzle regarding the effectiveness of the agency at balancing these two logics: in an era where the authority of professionals and expert institutions discussed in Week One has been under near-constant attack, how is the FDA able to maintain a monopoly over the power to serve as the sole gatekeeper for the entry of new medical products into the U.S. market? Related to the readings in Week One despite the power of an individual medical professional and the profession writ large, a physician cannot prescribe products that the FDA has not approved for some indication. This constitutes an infringement on the profession’s discretion. The puzzle is that most regulatory agencies can only regulate a product or a firm “after it has set foot in the marketplace”(p. 9), while the FDA has the unique power to “restrict products from
entering a market in the first place” (p. 9). Carpenter traces this power not to the agency’s resources, which are surprisingly scant relative to its large mandate, but to its ability to cultivate a reputation that inspires praise and fear. This reputation is premised on the FDA’s public image as a “protector of patients and consumer safety”; physicians, rather than aiming to tarnish this reputation in attempts to increase their power relative to that of the bureaucracy, instead use this reputation to their advantage to advance various policy objectives. Carpenter highlights that while one relationship between physicians and bureaucracies with powers to curtail the physician’s discretion through regulation and civil litigation is antagonism, another important relationship is physicians using the cultural authority of civil bureaucracies to bolster their own cultural authority as safety-oriented.

**Topic two: regulation of injury and harm (Kirkland, 2016; Frakes, 2016)**

Kirkland focuses on an intersection of civil law and medicine that emerges even after a product is approved by the FDA: the U.S. vaccine court that adjudicates the claims of patients who argue that a state-compelled vaccine has caused them medical harm that requires monetary compensation. Kirkland argues that at first glance, these claims by patients appear to be medical and scientific questions: did vaccine X cause harm Y, and does evidence of this harm pass some threshold of scientific significance? Framed in this way, it is puzzling why these claims are adjudicated in courts of law rather than adjudicated in more medical or scientific venues.

Yet Kirkland points to two reasons why vaccine-related injuries can be suited for courts of laws with logics different from those of medical and scientific organizations. First is that the reason the individual received the vaccine in the first place is related to state goals of protecting populations, goals backed by legal compulsion to avoid free riding through herd immunity. As Kirkland describes, “if paying taxes were voluntary and not paying carried no penalty, we might expect that many people would rather keep all their money while still enjoying the roads, schools, and public services that others fund. Similarly, securing the benefits of widespread vaccine has usually meant some form of legal compulsion to avoid too much free riding in the form of exemptions” (p. 4). The public duty framing of vaccines means that injuries incurred in the course of discharging that public duty arguably take on greater political and social importance. This political and social importance moves determining causation of those injuries out of the sole jurisdiction of medical and scientific professionals.

This public duty rationale for vaccines also motivated the shift of vaccine injury-related compensation out of the standard medical torts system that Frakes and Jena (2016) describe and into a single specialized court system that funds compensation out of a trust fund built up from a 75% excise tax on each dose of vaccine sold. In particular, while vaccine injuries were initially adjudicated in the standard torts system along with other medical injuries, a few large damage awards related to the DTP vaccine in the mid-1980’s led manufacturers to retreat from the market in ways that threatened the national vaccine supply. Viewing this as a threat to population health, the government and a coalition of interest groups set up a single vaccine court that would shield manufacturers from potentially financially ruinous damage awards and instead spread the burden of paying these awards out evenly through manufacturers in the form of an excise task. Thus, the framing of vaccines as important for the public interest and threat to that
public interest posed by civil litigation and large jury awards led the government to take firmer control of how these harms are adjudicated and compensated.

Kirkland argues that the second reason why vaccine-related harm is not solely a matter of medical and scientific dispute is the moral notions that guide ideas about this harm. The focus of courts on “doing justice to an injured party” helps bring in these moral norms about what someone is owed when they experience injury in the course of discharging the public duty of vaccination. Yet Kirkland also shows how the procedures of the vaccine court need, as a result, to balance two frameworks when deciding whether a harm is traceable to a vaccine: a scientific framework that views evidence of causation as always “open for further investigation” (p. 117) and a legal framework that seeks finality about causes. In showing how courts balance these frameworks, Kirkland shows how the tension and adaptation discussed in Week Ten play out in a civil law context.
Week Twelve: Emerging Challenges to Medical Authority—Substitution for Clinical Surveillance; Substitution for Clinical Intervention

Neff, Gina, and Dawn Nafus. Self-Tracking. *MIT Press*, 2016. Focus on:
• Introduction - 'Welcome to the Quantified Self'
• 'The Quantified Self and Medicine'


The reading by Clarke et al. in Week Four introduced the notion of bio-medicalization. Changes wrought by technology are central to the concept of what is new in bio-medicalization. The present week focuses on two sets of challenges to medical authority posed by advances in technology. Each involves potential substitution by technology for some aspects of medical work. That technology threatens to substitute for certain forms of medical work is surprising from two vantage points. From a sociological standpoint, the readings in Week One focus on the success of the medical profession in securing jurisdiction over various tasks, leaving less room for technology to infringe on this jurisdiction. Furthermore, the readings in Week Eight on medical socialization—for instance, Bosk on surgical training—highlight that surgeons prize themselves not only on technical skill but also on making correct normative judgments about when to intervene surgically versus not and the appropriate course of action when something goes awry in surgery, judgments that seem difficult for technology to replace and threaten. This potential substitution would also be surprising from the standpoint of economic theories about how technologies affect work discussed in the other syllabus; for instance, David Autor and co-authors’ job polarization predicts that technology will substitute for routine labor like that found in the manufacturing sector but complements rather than substitutes for the abstract reasoning tasks that characterize professional work.

The present week focuses on two forms of potential substitution. First is substitution for what I call clinical surveillance, or the monitoring that primary care and other physicians do of things like biomarkers associated with chronic disease progression. Second is substitution for more intervention-oriented medical work like surgery.
Clarke et al. from *Week Four* argue that bio-medicalization, in addition to clinicians engaging in more surveillance of risk factors, is also marked by patients engaging in higher degrees of self-surveillance for this risk. The authors argue that the idea of “self-tracking” of health and other outcomes is hardly new: Benjamin Franklin kept a daily written record of his time use for that day (to maximize productivity) and whether he had lived up to virtues he set for himself (to maximize morality). So as they put it, “if quantification has always been with us, what is new about self-tracking?” They argue that there are two changes that make self-tracking an increasingly relevant feature of the social world. First are changes in technology—cheaper wifi-enabled phones and advances in the size and cost of sensors that allow those phones to track various outcomes have made self-tracking less cumbersome than in the pen and paper era. Second are the changes in *cultural notions* of health that Clarke et al. discuss. Neff and Nafus argue that the cultural authority of medicine and science as a frame for “why things are the way they are...makes close measure of the body both conceivable and desirable” (p. 19).

Does this self-surveillance via self-trackers for outcomes like blood pressure, sleep, glucose levels, triggers for negative health events like migraines or arterial fibrillation complement or substitute for surveillance of the same measures by medical professionals? As the authors put it, medical professionals not only compete with each other and other professions for jurisdiction over this surveillance, but also with “app stores and shopping malls for people’s attention as they seek to lose weight, sleep better, and manage symptoms of chronic disease, even though widespread beliefs in the importance of medicine is what created this situation in the first place” (p. 23).

Ultimately, this quote highlights a complicated relationship between clinical surveillance and self-surveillance through tracking technology that goes beyond the economic categories of *complements* versus *substitutes*. We see a process where medicine’s authority in framing problems as medical and in creating ideas in patients about imperatives to monitor and treat those problems contributes to the rise of self-tracking technologies that facilitate this monitoring. At the same time, those self-tracking technologies empower patients to do this monitoring in ways that occasionally bypass the involvement of medical professionals.

Nelson and Robinson (2014) focus on an example of medical professionals creating demand for a certain form of monitoring, that demand contributing to technologies that help patients engage in that monitoring, and then those same technologies occasionally bypassing medical professionals as “learned intermediaries” to interpret the resulting risk information. They highlight how Direct-to-consumer (DTC) genetic testing technology provided by companies like 23andme engaged in this bypassing by deliberately de-emphasizing medical and health-related testing to avoid coming under FDA regulation as a medical product. As they describe, some purveyors of “DTC genetics have claimed that the tests should be understood as personal, leisure pursuits that are non-medical or recreational, and therefore should not fall under the stringent regulatory schemes of agencies like the FDA” (p. 109). Thus, we see a process where the tracking of health in the form of the tracking of genetic risk information is re-framed as recreational leisure to avoid falling under the purview of stricter standards for medical goods relative to other consumer goods.
Topic two: substitution for clinical intervention? (Mukerjee, 2017; Randell et al., 2014)

The readings in the previous week show a complicated relationship between self-tracking technology and medical work, with neither a clear story of complements nor a clear story of substitutes. The readings for this topic reveal that the relationship between two forms of more intervention-oriented technology—technology to diagnose tumors and other abnormalities in X-rays (Mukerjee, 2017); robotic technology for minimally-invasive surgery (Randell, 2014)—displays a similarly complex relationship. Mukerjee highlights that radiologists facing the rise of algorithms that performed better at detecting abnormalities in X-rays than humans creatively re-defined their work in ways that retained a sense of professional identity and jurisdiction. In particular, these radiologists claimed that while the algorithms can detect that an abnormality is present, the algorithms fail to explain why. The radiologists’ role is thus shifted to the more abstract task of shifting through reasons and causes for medical issues and away from the more routine task of detecting those issues to begin with. Randell et al. note similar dynamics with respect to robotic surgery, where surgeons continue to manipulate the robot into performing various procedures but where the robot has greater stability and precision than the surgeon’s own hands. Many surgeons reported downsides of this robot-aided way of performing surgery, chief among them the absence of tactile information that guides the surgeon’s judgments about decisions like the correct amount of force to apply. Thus, surgeons retain a distinctly human attribute—tactile sensation—to position their work relative to the technology.