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## **Doctor-Patient Relationship**

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The doctor-patient relationship is one of the most fundamental components of health care delivery. The interactions that take place between patients and doctors directly impact crucial aspects of health care, including patients' health care experiences, their health outcomes, and health care costs. Since the early twentieth century, social scientists have extensively explored the patient—doctor relationship, defining the nature and dynamics of the relationship, identifying the roles and responsibilities of patients and doctors, and analyzing how this relationship has transformed over time due to various micro- and macro-level changes within broader society (Boyer and Lutfey 2010; Lupton 1997; Lupton et al. 1991; Lutfey Spencer 2018; Parsons 1951; Timmermans and Oh 2010; Williams 2005). In this chapter, I explore this scholarship, providing a broad overview of the key theoretical approaches applied to the patient-doctor relationship. I review the literature on the patient—doctor relationship within medical sociology chronologically, with emphasis placed on key conceptualizations of patients' and doctors' roles as well as on how broader societal changes influenced, and accelerated, new identities and dynamics in the doctorpatient relationship over the course of the twentieth and twenty-first centuries in the United States. I then offer an empirical analysis of the pivotal role technology has played in shaping the patient-doctor relationship. Finally, I conclude with a discussion on how the patient-doctor relationship is a dynamic – and in many ways, privileged – process that is not uniformly experienced by the larger patient population.

# MEDICAL PATERNALISM IN THE EARLY TWENTIETH CENTURY

In the early twentieth century, the doctor-patient relationship was one characterized by medical paternalism. Medical paternalism refers to a relationship where the "general practitioner genuinely wants the best for the patient, but believes that patients often need to be guided firmly through the decision making process as they do not always know what is best for them" (McKinstry 1992: 340). Paternalism was prominent during this time period because of the identities accepted by patients and doctors. According to Talcott Parsons (1951), patients assumed

the "sick role." The sick role refers to an individual who is "in a state where he is suffering or disabled or both, and possibly facing risks of worsening, which is socially defined as either 'not his fault' or something from which he cannot be expected to extricate himself by his own effort, or generally both" (Parsons 1951: 440–441).

Furthermore, he "is not, of course competent to help himself" and instead must seek "professional, technically competent help" (Parsons 1951: 441). In this context, patients were not held responsible for becoming ill, but they were responsible for seeking out medical professionals in order to recover. They were not able to make any determinations regarding their health and well-being, and instead had to place their full trust in the medical authority of physicians, granting them complete autonomy and control over all health care decisions (Reeder 1972). Even in instances where patients may question their physician or wish to seek another opinion, Parsons (1951: 438–439) stated that:

if the patient is not satisfied with the advice his physician gives him he may properly do one of two things, first he may request a consultation, even naming the physician he wishes called in, but in that case it is physician A not the patient who must call B in, the patient may not see B independently. And above all not without A's knowledge. The other proper recourse is to terminate the relation with A and become "B's patient."

Subsequently, the patient—physician relationship was one centered on trust and full authority granted to the physician, otherwise the relationship should not persist.

The physician, therefore, was a "technical expert who by special training and experience, and by an institutionally validated status, is qualified to 'help' the patient in a situation institutionally defined as legitimate in a relative sense but as needing help" (Parsons 1951: 439). Furthermore, the physician was held responsible "for the welfare of the patient in the sense of facilitating his recovery from illness to the best of the physician's ability. In meeting this responsibility, he is expected to acquire and use high technical competence in 'medical science' and the techniques based upon it" (Parsons 1951: 447).

Their technical training, combined with the profession's institutional orientation to functional specificity, affective neutrality, and universalism, ensured their ability to properly and effectively care for the ill. As such, concerns of profit motives and physician greed could be set aside because physicians were unlike businessmen due to an institutionalized collectivity orientation that focused on the welfare of patients (Parsons 1951). This orientation guaranteed that physicians would not place financial gains above patient needs by enforcing specific behaviors, including

prohibiting physicians from advertising to patients or refusing to provide care to individuals who could not afford it.

Thus, though patients were vulnerable due to an asymmetry of knowledge and power between themselves and doctors, the structuring of the medical system established numerous institutional safeguards to prevent physicians from exploiting patients (Parsons 1951). These safeguards ensured that the physician, who was given intimate access to patients' bodies and lives, would maintain a professional relationship with patients in health care delivery (Parsons 1951). The resulting patient—doctor relationship was one driven by paternalism (Beisecker and Beisecker 1993; Coulter 1997; Emanuel and Emanuel 1992), where physicians were granted full authority in care decision making with the expectation that they always acted in the best interests of patients. Such medical paternalism remained prominent following the Second World War through the mid-1960s, which has commonly been referred to as the Golden Age of Medicine in the United States. During this period, physicians had achieved what Eliot Freidson (1970) has referred to as professional dominance, the distinguishing trait of all professions. According to Freidson (1970: XV), a profession is:

an occupation which has assumed a dominant position in a division of labor, so that it gains control over the determination of the substance of its own work. Unlike most occupations, it is autonomous or self-directing. The occupation sustains this special status by its persuasive profession of the extraordinary trustworthiness of its members. The trustworthiness it professes naturally includes ethicality and also knowledgeable skill. In fact, the profession claims to be the most reliable authority on the nature of the reality it deals with. When its characteristic work lies in the attempt to deal with the problems people bring to it, the profession develops its own independent conception of those problems and tries to manage both client and problems in its own way.

Subsequently, professional dominance refers to a profession's ability to have full authority and autonomy over their work. Accordingly, physicians held private, fee-for-service practices, set the qualifications of health professionals, determined interactions with patients, and controlled the relations they held with third parties, such as pharmaceutical and medical technology companies, without any external interference (Starr 1982). Physicians also held a great deal of cultural authority: they were deeply respected and experienced high levels of trust amongst the general public. The late-20<sup>th</sup> century, however, would see a widespread transformation within the provision of health care and a corresponding shift in the doctor-patient relationship, transforming

the identities, responsibilities, and experiences of both patients and practitioners (Boyer and Lutfey 2010; Lupton 1997; Timmermans and Oh 2010; Williams 2005).

# A TRANSFORMING HEALTH CARE LANDSCAPE: NEW IDENTITIES FOR PATIENTS AND PROVIDERS

Medical paternalism became an inaccurate characterization of the doctor-patient relationship by the latter half of the twentieth century, as the health care landscape underwent a complete transformation. Health care delivery, and the doctor-patient relationship, took on new dimensions as various parties become integral to the exchange of health care. Patients and doctors assumed different identities, ones that largely offset the asymmetry of knowledge and power associated with medical paternalism. However, before delving into the details of this new doctor-patient relationship, the following section explores changes to the broader health care system that facilitated the emergence of these new patient and provider roles.

It was during the Golden Age of Medicine when the foundations were established for a complete transformation in the distribution of health care within the United States. One major driving force was the growing commodification of medical care, which resulted in the emergence of a new medical landscape. This landscape became associated with numerous external parties (e.g. insurance companies, the pharmaceutical industry, the federal government) and with the infusion of money into the medical transaction (e.g. financial incentives, profit motives, etc.) (Light and Levine 1988). The rise of these external parties, with distinct objectives and incentives, established a new division of labor within health care provision. No longer a direct fee-for-service transaction between patient and physician, the exchange of medical care transformed into a complex marketplace encounter involving many parties (Conrad and Leiter 2004; Fennell and Alexander 1993; Light 2000).

These external parties took on tasks that were once solely performed by the physician (Casalino 2004), or new tasks that had become necessary within this unfamiliar health care landscape. The majority of these tasks were redistributed to external parties, primarily insurance companies, or to medical personnel and administrative staff within the clinical setting (Charles-Jones et al. 2003; Fennell and Alexander 1993). For instance, managers became integral to meet the new goals of cost-effectiveness and efficiency in clinics and hospitals. Managers were involved in care provision decisions, delegating duties and responsibilities of physicians, nurses, and other medical personnel in the clinical setting. These decisions were driven by goals of cost-saving and

efficiency, but also resulted in new divisions of labor as the professional identities and responsibilities of health professionals were reconfigured (Charles-Jones et al. 2003).

This complex division of labor reflected the newfound requirement to be able to manage the conflicting needs of individuals inside and outside the organization (Kahn, Wolfe, Quinn, Snoek, and Rosenthal 1964). Consequently, the patient—physician relationship evolved from one dealing with patients and physicians, to one that had to account for numerous third parties. These third parties, also referred to as countervailing powers, were able to impose regulations and restrictions on physicians, threatening the professional dominance they had acquired over the first half of the 20<sup>th</sup> century (Haug 1988; Light 2000; Waitzkin 2000); these groups offset the power and control physicians had amassed economically, politically and culturally (Light 2000; Light and Levine 1988) complicating the relationship between patient and doctor (Conrad and Leiter 2004; Light 2000; Waitzkin 2000).

In particular, one of the most significant threats to physicians' professional dominance was the emergence of managed care companies. In the 1970s, health maintenance organizations were created to produce "efficient and fair health care" (Wallack 1992: 27) and have remained the hallmark of managed care. Managed care became a solution to the exponentially growing health care expenditure in the United States. The primary objectives of managed care were to "reduce excessive and unnecessary service utilization" to ensure efficiency (Wallack 1992: 28). Therefore, in order to meet these goals, managed care companies not only controlled costs, but also determined how physicians could practice medicine. To the dismay of both patients and physicians alike, bureaucratic rules and practices quickly became deeply entrenched in health care transactions (Hafferty and Light 1995). Patients encountered a limited choice of medical practitioners and therapies while physicians' experienced restrictions on the patients they could see and the types of treatments they could provide (Mechanic 1996). Furthermore, physicians experienced constraints to their time: limits were placed on how much time physicians could spend with patients (Mechanic 1996), resulting in increasingly shorter, impersonal clinical encounters (Mechanic 2008). Consequently, patients became increasingly disenchanted with their doctors and clinical encounters, and physicians, whom had become financially reliant on these external parties, experienced diminished professional autonomy and cultural authority.

#### THE RISE OF PATIENT CONSUMERISM

This complete transformation in health care delivery gave rise to patient consumerism and a vastly different doctor-patient relationship than the one found in the early 20<sup>th</sup> century. As financial considerations became an increasingly salient issue in the exchange of medical care, physicians were now placed in an institutional position that required they balance financial considerations with the health and welfare of their patients (Rodwin 1993). This shift initiated a consumer driven model of health care (Conrad and Leiter 2004; Haug and Lavin 1983), where medical care was increasingly understood as a service that could be bought and sold, and the asymmetry of knowledge and power characteristic of patient—doctor relationships was reduced (Conrad and Leiter 2004; Haug and Lavin 1983). In this model of care provision, patients became regarded as *consumers* (Bashshur et al. 1967; Lupton 1997; Reeder 1972) and physicians as *providers* (Logan et al. 1989; Reeder 1972). Gone was the paternalistic patient—doctor relationship, and instead both parties brought "different resources to the encounter...prepared to negotiate an acceptable set of terms for the relationship," which included "agreements on both diagnosis and treatment" and resulted in "neither participant... automatically in charge" (Haug and Lavin 1981: 213).

As consumers, patients were comfortable challenging the authority of physicians, taking a proactive role in the medical decision making process at all stages of the clinical encounter—from diagnosis to payment (Charles et al. 1999; Haug and Lavin 1983; Oh 2012, 2017). Patients grew comfortable engaging in a variety of consumerist practices, which included making informed autonomous decisions, weighing financial costs when selecting both health care providers and making health care decisions, and exercising the freedom to shop, compare, purchase, and refuse providers and services (Heger Boyle and Lawler 1991; Hibbard and Weeks 1987; Lupton et al. 1991; Oh 2012, 2017). Individuals were equipped with greater bargaining and negotiation power when interacting with physicians as they were acknowledged as paying customers (Freidson 1970; Reeder 1972). While the shift towards consumerism was widespread, it is also important to note that generally individuals who tended to adopt such consumerist practices were often times "younger, more knowledgeable, more rejecting of authority in general, skeptical of physicians' service orientation, and convinced of their right to make health care decisions – who at least believe that physicians should not always be in charge" (Haug and Lavin 1981: 222).

As physicians took on the role of *providers*, and were forced to balance patient welfare with personal financial gain (Rodwin 1993), they saw the distribution of medical care as a service to be sold, in which they were in competition with other practitioners for patients (Reeder 1972). Accordingly, there was a growing fear of losing patients to competitors, which resulted in many physicians' newfound focus on patient satisfaction and patient needs (Reeder 1972). Consequently, this transformation of health care delivery resulted in a patient–doctor relationship driven much more by consumerism rather than paternalism. However, similar to the differences found across the patient populations, providers also embraced patient consumerism to varying degrees. Some physicians refused patient demands, often times citing patients' inevitable lack of competency, or they tried to persuade patients, usually successfully, to adhere to their recommendations (Haug and Lavin 1981; Timmermans et al. 2018).

This emergence of greater patient consumerism (Figert 2011) was coupled with, and accelerated by, a decline in trust of physicians over the late-twentieth century. With the increased bureaucratization of medical care, the thalidomide scandal and reports of medical experimentation, and the implementation of informed consent laws (Haug and Lavin 1983; Taylor and Merrijoy 1987), doubts were cast as to whether physicians acted in patients' best interests (Reeder 1972). This erosion of trust equipped patients with even greater agency to engage in consumer practices (Campbell 1971); patients no longer hesitated to shop for a second opinion and to switch medical practitioners (Olsen et al. 1976). Consumerism was further exacerbated due to the unabated growth of health care costs, publicized malpractice lawsuits, and reports of excessive treatments and tests performed by physicians for financial gains (Gray 1997; Reeder 1972).

In this new health care landscape, patients actively sought out resources to offset the asymmetry of knowledge and power characteristic of the patient—physician relationship. Drawing from various resources, patients increasingly practiced self-diagnosis and demanded specific types of care from physicians rather than seeking out their opinions. Furthermore, with this increased erosion of trust in physicians and medicine, patients were comfortable questioning medical expertise, seeking complementary and alternative approaches to care (Winnick 2006, 2005), and engaging in health social movements to elicit changes in health care provision, research and patients' rights (Brown et al. 2004; Epstein 1995). Such forms of patient engagement and autonomy, while salient, however were not uniform across the patient population. Instead, deep inequities could be found: for instance, typical users of complementary and alternative medicine

and individuals at the frontlines of patient health movements – in turn largely shaping the movements' initiatives – have been predominantly white, highly educated, and of high socioeconomic status (Epstein 1995; Klawiter 1999). Such inequities stemming from sociodemographic characteristics systematically render specific patient groups less able to make independent health care choices and less able to find alternative options in regards to their health and well-being. Consequently, more vulnerable patient populations are unable to gain power in clinical encounters and instead have little choice in deferring to medical practitioners for diagnosis and treatment options.

Nonetheless, with these shifts in care delivery towards a consumerist model, combined with the growing discontent among patients, physicians demonstrated a renewed commitment to regaining patient trust (Mechanic 2008) by making patients' needs central to care provision (Emanuel and Pearson 2012). For instance, providers developed ways to give patients the benefits associated with longer office visits and more personal care — ensuring physicians familiarized themselves with particular patients' needs (Mechanic 2008). Other initiatives included avoiding conflicts of interest (e.g. pharmaceutical companies offering physicians incentives to promote specific therapeutic options) and addressing recurrent problems of patient safety and medical error. In addition, pay-for-performance (P4P) initiatives, which define important objectives of care and provide financial incentives for physicians to meet these objectives, were developed and adopted in numerous clinical settings (Mechanic 2008). These initiatives were implemented to help improve the quality of health care received by patients, and to renew the trust of patients in both physicians and the health care system (Mechanic 2008).

#### THE SHIFT TO PATIENT-CENTERED CARE

The strategies adopted by clinicians reflected another progressive shift in health care delivery: one towards patient-centered care. Patient-centered care refers to care provision that is "respectful of and representative to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions" (Committee on Quality of Health Care in America 2001: 40). This model of care encourages patient agency, empowerment, and inclusion in medical decision making with providers. Subsequently, patient-centered care "fosters interactions in which clinicians and patients engage in two-way sharing of information; explore patients' values and

preferences; help patients and their families make clinical decisions; facilitate access to appropriate care; and enable patients to follow through with often difficult behavioral changes needed to maintain or improve health" (Epstein et al. 2010: 1490).

Patient satisfaction is a central, and critical feature, to this mode of care delivery, often utilized as a metric to assess physician and care quality. Patient satisfaction measures ensure that the "physician has provided comfort, emotional support, education, and considered the patient's perspective in the synthesis of the clinical decision making process" (Kupfer and Bond 2012: 139). Studies have revealed that patient satisfaction is positively correlated with physicians foregoing medical paternalism, promoting effective communication with patients and families, and including them in the decision making process (Bernabeo and Holmboe 2013; Mast, Hall, and Roter 2008; Street Jr. et al. 2009). In recent years, financial incentives, such as reimbursement policies and determinations of physician compensation based on patient satisfaction metrics, have been established to further solidify the emphasis of care delivery on patient satisfaction and patients' experiences (Lyu et al. 2013; Manary et al. 2013).

#### TECHNOLOGY AND THE DOCTOR-PATIENT RELATIONSHIP

Many scholars have extensively studied the driving forces that have defined and redefined the doctor-patient relationship over the course of the twentieth and twenty-first centuries. While numerous factors have played an integral role in the changing identities of doctors and patients, advancements in technology, have arguably, been the most significant. In this section, I examine how technology has directly shaped the doctor-patient relationship, starting with the internet. The internet has facilitated patients' abilities to obtain knowledge in regards to their own health and health care options (Haug 1988), vastly transforming the patient-physician relationship. The internet has given patients access to electronic health books, health forums, and other online sources that provide a wealth of information that enables patients to self-diagnose, to learn about treatment options, and to even evaluate the financial costs associated with different treatment plans (McKinlay and Marceau 2008). Studies have revealed how patients have used the internet to compare medical facilities and to learn about physicians' histories, increasing their abilities to shop around and find the best care at the cheapest price (Hibbard and Weeks 1987; Lupton et al. 1991; McKinlay and Marceau 2008). Consequently, patients were increasingly comfortable making autonomous decisions when selecting physicians, making health care choices, and selecting health insurance policies (Hibbard and Weeks 1987; Lupton et al. 1991).

Patients were now equipped with the ability to engage in self-care (Swan 2012), diagnosing themselves and actively searching for information about illnesses and treatment options prior to stepping into a physician's office (Burrows et al. 2000; Davison et al. 2000; Greene and Hibbard 2012). Patients found resources and comfort in online self-help communities (Barker 2008; Davison et al. 2000; Eng 2001; Oravec 2001), giving them a space to commiserate over shared conditions, define symptoms, discuss treatment options, evaluate experiences, provide support, and empower patients in interactions with their doctors (Barker 2008; Davison et al. 2000; Halpern 2004). Consequently, these "well-informed" and "knowledge empowered" patients began to skip the diagnostic process and instead were scheduling visits to request specific forms of treatment or medications (McKinlay and Marceau 2008).

#### Patients' Internet-Use: The Implications of Too Much Information

In response to these shifts in the patient–physician relationship, scholars have extensively examined this transformation in patients' approaches to care, with many bemoaning the clinical consequences of such "empowered" patients, such as the over-medicalization of conditions and the growing reports of unnecessary pharmaceutical use (Bergen et al. 2017; Butler et al. 1998; Kravitz et al. 2005; Rathert et al. 2013; Stivers 2002; Weissman et al. 2004). The literature has pointed to "well-informed" patients frequently pressuring physicians for specific medications that are not always clinically indicated (Bergen et al. 2017; Butler et al. 1998; Kravitz et al. 2005; Mangione-Smith et al. 1999; Moloney 2017; Stivers 2002). Of particular concern is the overprescribing of unnecessary antibiotics (Butler et al. 1998; Mangione-Smith et al. 1999; Nyquist et al. 1998) due to the public health implications of the misuse of antibiotics and the growing emergence of drug resistant illnesses (Mehta et al. 2014).

Much of the onus of responsibility to curb such overprescribing has been placed on physicians' shoulders, with less attention placed on the role of "informed" patients' expectations in shaping the likelihood of prescription (Heritage and Stivers 1999; Mangione-Smith et al. 2003). One approach has been the utilization of "online commentary," which refers to the process of physicians' clearly communicating to patients what they are finding during the examination (Heritage et al. 2010; Mangione-Smith et al. 2003). When practicing online commentary, physicians use specific communication techniques to show the patient "no problem" or "problem" commentary; this strategy informs patients during the clinical encounter itself as to when physicians are finding concerns that require drug intervention and when they are not (Heritage et al. 2010; Mangione-Smith et al. 2003).

It is important to note that patients' internet behaviors are not solely to be blamed for the growing concerns of unnecessary prescriptions. The pharmaceutical industry, specifically its use of directto-consumer advertising for marketing rather than solely advertising to providers, is a major contributing factor behind these trends (Kessler and Pines 1990). Direct-to-consumer advertising increases patients' awareness of pharmaceutical therapies, and subsequently the likelihood that they will make requests to their physicians to receive these therapies (Kravitz et al. 2005). Proponents of direct to consumer advertising highlight that these advertisements produce wellinformed, proactive patients because they provide not only information on various pharmaceutical options, but also educate individuals on a variety of health conditions that they were unaware of (Holmer 1999; Weissman et al. 2004). This translates to patients becoming cognizant of, and accessing, new therapeutic options, resulting in better management of symptoms and conditions and in turn, improved health outcomes (Batchlor and Laoui 2003; Kravitz et al. 2005; Weissman et al. 2004). For instance, in the case of major depression, patients who referred to specific pharmaceutical advertisements were more likely to receive prescriptions for much needed antidepressants. This prevented initial undertreatment of the condition, which unfortunately was common among patients who did not mention an advertisement to their providers (Kravitz et al. 2005).<sup>6</sup>

Nevertheless, improper prescribing of pharmaceuticals is one commonly documented consequence of increased patient consumerism and agency in health care delivery. Many have argued that while technologies like the internet have helped to create more knowledgeable patients, there remains an information deficit between patients and physicians, as evidenced by these reports of patients' pressuring providers for unnecessary prescriptions. Patients often times lack proficiency in distinguishing reliable information, consequently they remain misinformed or uninformed (Henwood et al. 2003). While this may be true, it is crucial to state that patients' consumerist practices are not solely responsible for such trends, but rather numerous factors, including pharmaceutical companies, time constraints in clinical encounters, and the realities of managed care, collectively incentivize providers to repeatedly turn to pharmaceutical therapies for patient care (Moloney 2017). In Moloney's (2017) study of pharmaceutical interventions for insomnia, physicians reluctantly provided prescriptions for patients complaining of sleeplessness and insomnia. Although these clinicians would have preferred to not medicalize insomnia and to avoid prescribing drug interventions for some of their patients, patients' requests and preferences combined with insurance considerations and time limitations placed on office visits, all factored into physicians' decisions to recommend a pharmaceutical intervention.

Furthermore, while this patient-centered model of care has led to increased patient autonomy and empowerment, an asymmetry of power persists between patients and providers. Although some physicians feel compelled to provide patients with the care they desire, many physicians reject patients' findings, refuse to negotiate with them, or cultivate strategies that convince patients to accept medical expertise and adhere to provider recommended diagnosis and treatment options (Haug and Lavin 1981; Henwood et al. 2003; Timmermans et al. 2018). Accordingly, even as patients become equipped with greater knowledge, patients still commonly face an uphill battle to gain an equal voice in care provision. In addition, even with the general availability of resources such as the internet, many patients still opt to maintain a paternalistic approach to medicine and primarily seek the advice of the physician (Henwood et al. 2003; Lupton et al. 1991).

## Digitized Patients: An Expectation in the 21<sup>st</sup> Century

Internet and other information technologies have taken on new meaning in the 21<sup>st</sup> century. Rather than simply being characterized as a tool for patients to engage in consumerism or to become empowered—which have previously been attributed to negatively impacting the patient—physician relationship—use of the internet and other health technologies are now expected of patients if they wish to be deemed serious about their health and well-being. Providers often anticipate that patients will welcome serving as managers of their own health and health care by seeking out the internet (Stevenson et al. 2018), sharing information and data, and using webbased personal health repositories (Lupton 2013a). With the near universal access to the internet, along with the widespread use of mobile digital devices and other digital health technologies, patients have unprecedented opportunities to engage in self-surveillance of their health by collecting and analyzing personal biometric data (e.g. heart rate, steps, glucose, sleep, etc.), as well as being able to access health information anywhere and at any time (Goggin 2011; Swan 2012). Z

Providers have also embraced these same technologies, further reshaping health care provision (Mort et al. 2009; Oudshoorn 2011, 2012; Stevenson et al. 2018). For instance, telemedicine has emerged as a vital component of the medical system – one that fulfills the triple aim in health care (Berwick et al. 2008)<sup>8</sup> by positively impacting patients' health care experiences and improving patients' health outcomes at low financial costs (Perzynski et al. 2017). Telemedicine "involves using digital and other technologies to encourage patients to self-monitor their medical conditions at home, thus reducing visits to or from health care providers, and to communicate with health

care providers via these technologies rather than face to face" (Lupton 2013a: 259). The end result is that patients are required to engage in regular self-monitoring and self care; such "digitizing" of bodies has become the norm and patients "become 'engaged' and 'activated,' to 'take control' of their health and to produce their own data on themselves and share these data with others as well as access the data produced by medical testing and medical records" (Lupton 2013a: 260).

### **UNEQUAL ACCESS TO NEW PATIENT IDENTITIES**

Discussions of greater patient consumerism, agency, and empowerment routinely tend to disregard the privileged nature of these statuses. Scholars have extensively examined how assumptions of patient-centered care and increased patient consumerism are inaccurate characterizations of many patient populations (Andreassen and Trondsen 2010; Hibbard and Cunningham 2008; Salander and Moynihan 2010; Shim 2010). The ability to adopt consumerist or digitized practices in health care delivery relies greatly on the resources available to patients (Gage-Bouchard 2017; Hibbard and Cunningham 2008). Younger, more educated, and higher income patient groups tend to favor consumerist approaches when seeking out care (Hibbard and Cunningham 2008). These findings resonate with the patient dynamics that have emerged from the widespread acceptance of information and communication technologies in health care by both patients and providers; such heavy reliance on different modes of technology have alienated individuals and exacerbated inequities among certain patient groups. For instance, selfsurveillance and regular monitoring can be deeply overwhelming for patients (Lupton 2013a; Veitch 2010), resulting in resistance to, or complete abandonment of, such practices (Lupton 2013a). Women in particular have been found to experience increased anxiety and greater likelihood of adverse health outcomes due to such increased self-surveillance (Seçkin 2020). Furthermore, studies have revealed how the elderly, underinsured, and minority patients – especially individuals who identify as African American and Latinx – are disproportionately negatively impacted by the heavy reliance on information technologies. For instance, these populations are "less likely to live in areas with a preponderance of home broadband internet or to access the patient portal" (Perzynski et al. 2017: 929). Subsequently, individuals from these groups have limited opportunities to engage in the digital practices that have increasingly been associated with "good" or "dedicated" patients. While smartphones may alleviate some of these challenges, racial and ethnic minorities and individuals with lower socio-economic status are once again found to be at a disadvantage: these individuals are much more likely to "reach their plan's data cap" (Perzynski et al. 2017: 931) and therefore unable to utilize technologies like patient portals and data repositories when managing their own care. Such actions, or lack thereof, can result in the mislabeling of patients as "non-compliant" or "non-adherent" as providers perceive these patients as resisting or neglecting providers' recommendations and guidelines.

These inequities are unsurprising when considering Janet Shim's (2010) research, which has focused on how broader social inequalities are re-created in patient—doctor interactions through cultural health capital. Cultural health capital refers to:

"a specialized form of cultural capital that can be leveraged in health care contexts to effectively engage with medical providers... CHC develops in and through the repeated enactment of health-related practices, such as consuming biomedical knowledge, exercising calculative and future-oriented approaches to decision-making and engaging in self-surveillance and risk-reduction practices".

(Shim 2010: 3)

Patients' abilities to cultivate cultural health capital are fundamentally tied to factors including race and ethnicity, socioeconomic status, gender, and educational attainment. The ability to acquire and expand one's cultural health capital is acutely important because such capital can lead to micro-advantages that grow over time, resulting in starkly different health care experiences and outcomes (Gengler 2014; Rubin et al. 2018).

For instance, Gengler (2014) explored how parents navigated care for their children, who were diagnosed with life-threatening conditions, at an elite medical institution. Drawing on the concept of cultural health capital, Gengler (2014) found that parents tended to enter into two distinct trajectories of care engagement: care-captaining and care-entrusting. Care captaining included "negotiating with health care providers, conducting sophisticated research on available doctors, hospitals, and treatments, and successfully intervening to influence the care their children received" (Gengler 2014: 346). The end result was that parents exhibited high degrees of cultural health capital as they mobilized resources, were deeply engaged in their children's care, and they were unafraid "to hold key actors accountable, and held those actors accountable when they deemed necessary" (Gengler 2014: 346). In contrast, care-entrusting individuals left the medical decision making to the physicians, resulting in immensely different care and illness experiences within the same medical institution: care-captaining parents tended to acquire advantages throughout various stages of illness management.

This is particularly concerning because patients who cultivate more cultural health capital are able to gain more respect from providers and subsequently, are given more time and resources in clinical encounters (Fenton 2019; Shim 2010), resulting in different health care trajectories (Gage-Bouchard 2017). Patients' medical knowledge and demeanor with providers dictate the likelihood that patients will be included in the medical decision making process, whether they will be offered additional resources and information (Shim 2010), and whether clinicians will defer to patients' preferences when determining treatment protocols (Fenton 2019). In contrast, patients with less cultural health capital are often labeled as passive or negligent of their care, resulting in providers failing to "supplement the toolkit they have to optimize their own care and relationships with health professionals" (Shim 2010: 8). These interactions stymie patients' abilities to generate cultural health capital and without an ability to mobilize and cultivate such capital, inequities increase.

Similar to how the advantages of cultural health capital can accrue over time, the disadvantages associated with a lack of cultural health capital can also accumulate leading to widening gaps in health. There are critical consequences for patients who routinely experience less favorable clinical encounters and fail to receive adequate treatments (Rubin et al. 2018; Sleath and Shih 2003). Rubin and colleagues (2018) found that when dealing with chronic pain management, patients with less cultural health capital had much poorer pain management compared to their more advantaged counterparts. African American women living in poverty were especially at a disadvantage in clinical encounters; they were less likely to be asked about treatment preferences or to be included in medical decisions, and were much more likely to be written off as difficult and unable to effectively manage their own pain (Rubin et al. 2018).

Similarly, Hausmann et al. (2013) found that among patients being monitored for prescribed opioid use, African American patients had an increased likelihood for being singled out for drug testing or recommended to see a substance abuse specialist, compared to White patients. Such interactions left African American patients feeling defensive and dissatisfied with care, which had implications for their health: many of these patients reported inadequate pain management. Unsurprisingly, these negative health care experiences compounded over time can foster growing distrust, apathy, and antagonism towards health care providers and the broader health care system. What are the implications of this? The critical consequence is that patients either fail to receive the care that they need or they abandon future attempts to seek out care.

Cultural health capital, and other advantages that patients possess in clinical encounters, are typically cultivated through effective interpersonal interactions and communication skills. Studies have found that racial and ethnic minorities are more likely to be misunderstood and dismissed by providers during clinical conversations (Balsa and McGuire 2001, 2003; Balsa et al. 2005; Cooper et al. 2006; McGuire et al. 2008; Rubin et al. 2018). Subsequently, as patients face an uphill battle to be sufficiently heard and understood by clinicians, they may start to forego care, especially when treatment protocols fail to effectively manage the patient's primary concerns. However, it is also important to note that cultural health capital, patient agency and empowerment, and inclusion in decision making may not always translate to better care, as providers may inappropriately defer to patients, resulting in treatment protocols that contradict standards of care (Fenton 2019; Gengler 2014; Rand et al. 2007). For instance, in clinical encounters with parents regarding HPV vaccinations for their children, providers were more likely to defer to parents' requests to delay vaccination, especially to those utilizing greater cultural health capital. Unfortunately, this decision to delay the HPV vaccine was at odds with the Advisory Committee on Immunizations Practices' recommendation to provide the HPV vaccination to children when they turn 11 or 12 years of age (Fenton 2019). Nonetheless, generally, inclusion of patients in medical care decision making and acknowledgement of patients' agency and empowerment, result in improved health care experiences and greater patient satisfaction (Yeh, Wu, and Tung 2018).

Subsequently, it is deeply problematic that the widespread transformations in the patient—physician relationship and new patient identities that have emerged over the course of the twentieth and twenty-first centuries are unevenly distributed across the population. Many groups remain marginalized and are unable, or simply do not wish, to challenge medical authority and take on more responsibilities in care provision (Andreassen and Trondsen 2010; Salander and Moynihan 2010). Yet as the current health care landscape continues to embrace patient-centered care and has come to expect savvy, engaged, digitized, and proactive patients, many health inequities will continue to persist, if not, widen. The patient—doctor relationship has deep implications for patients' health care experiences and outcomes. Providers' perceptions of patients are crucial in shaping patients' trajectories. Consequently, when patients are perceived as disengaged, negligent, and lazy due to their lack of medical knowledge, inadequate self—monitoring, and ineffective use of technologies like the internet, with little consideration of the structural factors that shape these actions and interactions between patients and providers, there are consequences for patients' health outcomes. Therefore, it is critical for scholars to continue to

examine and re-examine the patient—doctor relationship, as it is one that is not uniform but rather, a dynamic process deeply influenced by a wide array of individual and structural factors.

### **Notes**

- 1. The increased role of external parties in the medical exchange could partly be attributed to changes in the actual medical field: there was a shift towards increased specialization (Light 2000; Starr 1982). The division of labor that ensued from the emergence of various subspecialties ironically made health professionals more vulnerable to external control, diminishing the dominance they had achieved during the Golden Age of Medicine (Light 2010).
- 2. Some examples of these countervailing powers include managed care companies, medical supply companies, medical personnel and administrative staff, pharmaceutical companies, and the federal government.
- 3. It is important to note that the patient–physician relationship however could never mimic a true market transaction. Donald Light (2010) discusses this distinction stating that in markets consumers should have "complete and free information" rather than "asymmetrical" information, which is common within the exchange of health care; there will always be an inherent asymmetry of knowledge between patients and physicians. This asymmetry of knowledge manifests itself regardless of patients' abilities to gain greater agency and knowledge from various sources, ranging from the internet to direct-to-consumer advertising.
- 4. Complementary and alternative medicines are defined as the "diagnosis, treatment and/or prevention which complements mainstream medicine by contributing to a common whole, by satisfying a demand not met by orthodoxy or by diversifying the conceptual frameworks of medicine" (Ernst et al. 1995: 506). Some of the most popular alternative treatments have been varieties of Chinese medicine (typically acupuncture), chiropractic and folk healing, and homeopathic remedies (Hartley 2002). The rise in CAM can in part be attributed to achievements of biomedicine: people live longer, however in turn they also develop difficult to treat chronic conditions (Lee-Treweek 2001). The uncertainty of biomedical knowledge is another factor, as limits in biomedical treatment options leave patients looking for alternative, less orthodox therapies (Epstein 1995). A third contributing factor has been the cost-effectiveness of such services; insurance companies have capitalized on the financial benefits of complementary and alternative medicine and have even extended some of their policies to

cover particular complementary and alternative treatments for patients (Winnick Terri 2005). In response to the growing popularity of CAM, physicians supported patients' preferences for alternative therapies. Many physicians began accepting and recommending complementary and alternative medicines as a treatment course for some patients, even incorporating CAM into their own practice (Winnick 2006).

- <u>5.</u> The difference in CAM use may be a reflection not only of a lack of resources or information that facilitates use of complementary and alternative therapies, but also that CAM services may not be physically available in particular neighborhoods (e.g. low income areas).
- 6. There exist critical inequities in access to prescriptions, particularly in the arena of mental health; age, insurance coverage, and patient—physician relationships all shape the likelihood of an individual receiving a prescription, resulting in some patients being undertreated and unable to access the therapies that they need (Sleath and Shih 2003).
- 7. Even workplaces have taken advantage of the availability of these various health technologies, encouraging workers to track various health metrics (e.g. sleep, diet, and exercise) and rewarding them (usually financially) for good health behaviors (Lupton 2013b).
- 8. The triple aim in health care refers to the commitment to improve patients' health care experiences, to improve the health of populations, and to reduce health care costs (health care per capita spending) (Berwick et al. 2008).

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