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Demanding Patient or Demanding Encounter?: A Case Study of a Cancer Clinic

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Abstract

This paper explores the sociological relevance of demanding encounters between doctors and patients. Borrowing from Potter and McKinlay's (2005) reconceptualization of the doctor-patient relationship, we suggest an analytic shift away from 'demanding patients' toward 'demanding encounters'. Such a shift places provider-patient conflict within a broader sociocultural context, emphasizing constraints facing *both* doctor and patient as they interact in a clinical setting. Specifically, through an ethnographic study of doctor-patient interactions at the oncology clinic of a US University Hospital, we examine the respective influences of new information technologies and patient consumerism in the production of demanding encounters in oncology. Findings suggest that these interconnected socio-cultural realities, in tandem with patient tendencies to challenge physician judgment or expertise, play a role in demanding encounters. We conclude by considering the implications of demanding encounters for doctors, patients and healthcare organizations.

Keywords

USA; demanding patients; difficult patients; doctor-patient interaction; cancer care; consumerism

Main text

Demanding patients have received considerable attention in both the clinical and sociological literature. While medical providers seek to identify the characteristics of demanding patients and minimize any deleterious effects on the clinical encounter (An,

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Rabatin, Manwell, Linzer, Brown, & Schwartz, 2009; Haas, Leiser, Magil, & Osman, 2005; Kroenke, 2009; Steinmetz & Tabenkin, 2001), sociologists instead focus on the social contexts that produce the label of “demanding” (Freidson, 1973; Lorber, 1975; Stearns, 1991). In this vein, sociologists examine the interactional moments that lead to the labeling of a patient as demanding, as well as the socio-cultural factors that increase the likelihood that such a label will emerge.

In this paper, we use ethnographic methods to document the broader socio-cultural context in which demanding patients emerge, shifting attention from patient behavior to the nature and context of the encounter itself. We argue that being labeled a demanding patient is only partially related to individual patient attributes or behaviors and cannot be reduced to “bad” doctoring. Rather, the process by which a patient becomes “demanding” is dynamic, tied to conflict within the doctor-patient interaction, as well as to broader constraints and realities. Borrowing from Potter and McKinlay's (2005) reconceptualization of the doctor-patient relationship as an “encounter”, we suggest an analytic shift away from ‘demanding patients’ toward ‘demanding encounters’. Such a shift places provider-patient conflict within a broader environmental context, emphasizing constraints facing *both* doctor and patient as they interact in a clinical setting.

Drawing on over one hundred observations of an oncology clinic- which we call Cancer Clinic- we find that demanding encounters tend to happen when patients directly or indirectly challenge physician judgment, authority or jurisdiction. These findings are consistent with existing literature that links the agentic behavior of patients to discord in the clinical encounter (Maynard, 1991; Waitzkin, 1989; 1991). Although the nature and extent of this discord has been extensively documented in conversational analyses of doctor-patient communication (Maynard, 1991; Maynard & Heritage, 2005), it is less clear how these interactions are also linked to wider social realities (Potter & McKinlay, 2005).

We argue that demanding encounters are embedded within wider socio-cultural conditions, two of which appear particularly salient to the experiences of patients at the Cancer Clinic: Patient consumerism and the emergence of the internet informed patient. While demanding encounters have long been a part of doctor-patient interaction, the contexts of these encounters change over-time as cultural values, economic circumstances and technologies also shift. We document current examples of demanding encounters between patients and providers, noting instances where wider socio-cultural conditions appear at play.

Literature Review

The subject of demanding encounters is referenced both directly and indirectly in the clinical and social scientific literatures on doctor-patient interaction. We identify three scholarly conversations relevant to the subject of demanding encounters: The discussion of “difficult” patients among clinicians; the debate about doctor-patient conflict in both the social scientific and clinical literatures; and the linking of macro-structural conditions of healthcare to microinteractional realities in the field of medical sociology.

Researchers writing for a clinical audience focus attention on the traits and characteristics of demanding or “difficult” patients, with the aim of identifying and redirecting the offending

behavior (Edberg & Hallberg, 2001; Maizes, 2000; Mikasane, 2008). Anxiety and depression, dissatisfaction with care, unrealistic expectations for care, and tendency of psychosomatic illness are just a few of the traits attributed to difficult patients (An et al., 2009; Haas, 2005; Hahn, Kroenke, Spitzer, Brody, Williams, Linzer, et al., 1996; Jackson & Kroenke, 1999; Stenmetz & Tabenkin, 2001). On the provider side, younger doctors, women and sub-specialty doctors report more encounters with difficult patients (An et al., 2009; Krebs, Garrett, & Konrad, 2006; Mathers, Jones, & Hannay 1995). In addition, physicians who work longer hours, report lower job satisfaction, and are themselves depressed report higher frustration with patients (Krebs et al., 2006; Jackson & Kroenke, 1999).

Not surprisingly, Elder, Ricer and Tobias (2006) find that difficult encounters often surface when physicians feel their professional control undermined by patients. Although clear associations between difficult clinical interactions and patient outcomes have not been established, there is evidence that *doctors* who perceive themselves as having a high number of difficult patients are more likely to experience burnout and lower job satisfaction (An et al., 2009). Demanding encounters are also commonplace: One in six patient encounters are perceived as difficult by clinicians (Jackson & Kroenke, 1999).

Although the clinical literature is overwhelmingly constructive in its discussion of difficult or problem patients, the focus tends to be on individual characteristics of either doctors or patients. In contrast, social scientists and clinicians focusing on doctor-patient asymmetry and conflict place interaction at the center of analysis (Fisher, 1991; Heritage & Maynard, 2006; Waitzkin, 1989, 1991; West, 1984). Within this vast literature, some focus on the micro-interactive dynamics of the clinical encounter, such as talk and body language (Maynard, 1991; Maynard & Heritage, 2005), while others see doctor-patient conflict as a clash of differing world-views (Kleinman, 1980, 1988; Mishler, 1984). While the consensus in the literature is that conflict is a product of entrenched power imbalances between doctors and patients (Emanuel & Emanuel, 1992; Maynard, 1991; Waitzkin, 1989, 1991), there are many in this sub-field who acknowledge that both physicians and patients play a role in maintaining status differentials (Pilnick, 1998; Pilnick & Dingwall, 2007; Schegloff, 1991; Schegloff 1997). Irrespective of the position taken on physician dominance, the literature makes clear that conflict between patients and physicians is a product of dynamic interaction.

In the broader medical sociology literature, organized medicine—rather than the individuals or interactions—is often under interrogation. In this view, physician tendencies to label or discredit patients are viewed as reflections of organizational pressures or circumstances, rather than individual prejudices or dispositions of doctors (Freidson, 1973; Mizrahi, 1986; Roth, 1972; Stearns, 1991). Although not directly engaging the question of demanding patients, Potter and McKinlay (2005) provide a useful theoretical prompt to think about the link between structural conditions in medicine and the doctor-patient relationship. The authors hypothesize that broader socio-cultural changes to the organization of medicine, such as patient consumerism, new technologies and the changing role of the state vis-à-vis medicine, directly impact the way in which doctors and patients relate. Doctor-patient contact is best conceived as an encounter, rather than a relationship in the conventional sense (Potter & McKinlay, 2005).

Following Potter & McKinlay, we argue that demanding encounters—those exchanges where one or more individuals in the interaction convey obvious distress, confusion, or dissatisfaction—are best understood in the context of broader socio-cultural realities. We describe situations in which demanding encounters emerge in the Cancer Clinic, highlighting how patient consumerism and the internet informed patient provide contextual backdrops for these interactions.

Socio-cultural Contexts of the Demanding Encounter

Many authors propose that contemporary trends in the organization of medicine directly impact what it means to be a patient and a physician in the U.S. context (Pescosolido, Tuch, & Martin, 2001; Potter & McKinlay, 2005). Although there are other environmental factors worthy of consideration, such as the bureaucratization of care and the speed-up of physicians' work, we focus on two trends, patient-as-consumer and the internet informed patient. Our decision to limit discussion to patient-as-consumer and the internet informed patient is driven by our findings, which suggest that these socio-cultural factors are particularly salient to demanding encounters in the Cancer Clinic.

Patient-as-Consumer

One by-product of the for-profit healthcare system in the U.S. is the growth of the patient-as-consumer, a socio-cultural reality that potentially complicates the clinical encounter (Haug & Lavin, 1981; Lupton, 1997; Potter & McKinlay, 2005; Reeder, 1972; Roter & Hall, 2006). The consumerist turn in American medicine has several characteristics, including a focus on healthcare as a commodity, increased emphasis on the costs of care, and a marked shift away from patient-as-suppliant to patient-as-skeptic (Lupton, 1997; Roter & Hall, 2006). As Deborah Lupton (1997) notes, “patients *qua* consumers are urged to refuse to accept paternalism or “medical dominance” on the part of the doctor, to “shop around”, to actively evaluate doctors' services and to go elsewhere should the “commodity” be found unsatisfactory” (p.373).

Patients' roles as consumers are reinforced in several ways, including direct-to-consumer advertising by drug companies (Potter & McKinlay, 2005); by government programs that rate physicians and hospitals in an effort to foster consumer agency in the selection of healthcare providers (a service now also provided by Zagat, known for rating restaurants in the US); and by a healthcare system that maintains the illusion that market driven care provides “choice” and “quality” for patients when in fact inequality of access remains the reality for many (Mechanic, 2004). Our point is not that patients have endless choices when it comes to healthcare, but that cultural messages about patient choice pervade contemporary rhetoric about healthcare in the U.S. (Skocpol, 1997).

One potentially positive consequence of what Bury and Taylor (2008) call ‘managed consumerism’ is the trend toward shared decision making between patients and providers (Bury & Taylor, 2008; Charles, Gafni, & Whelan, 1997; Thompson, 2007). Many healthcare organizations have become proactive about catering to patient consumers, providing a broad range of services that aim to actively involve patients in treatment decisions (Charles et al., 1997; Gabe, Olumide, & Bury, 2004; Thompson 2007). While there is little consensus on

how to define or implement shared decision making, it is generally seen as a way to “decrease the informational power asymmetry between doctors and patients by increasing patients' information, sense of autonomy and/or control over treatment decisions that affect their well-being” (Charles et al., 1997). In cancer care, for example, services like “consultation planning” offer patients an opportunity to discuss concerns, questions and treatment goals with clinic staff prior to a doctor's visit, in an effort to promote shared communication throughout treatment (Sepucha, Belkora, Tripathy, & Esserman, 2000).

This paper examines how broader trends to empower the patient consumer, such as shared decision making, serve as context for the doctor-patient encounter. In the Cancer Clinic, consultation planning is an organizational directive that encourages, even obligates, the patient to share wishes and concerns, in an environment where physicians have very little time to listen. As a result, patients and physicians approach the clinical encounter with different expectations for interaction; a reality that serves as important context for demanding encounters.

The Internet Informed Patient

Patient internet use is a relatively recent phenomenon, one that presents a potential challenge to the lay-professional divide in medicine. Sixty-three percent of the 90-120 million Americans who use the internet regularly do so to obtain health information (Cline & Hayes, 2001). Existing literature on the subject suggests that the internet and other electronic sources of medical information do in fact shape patient understandings of illness (Fox, 2005; Fox, Ward, & O'Rourke 2005; Madden & Fox, 2006; Nettleton, Burrows, O'Malley, 2005). Extant research also shows that providers view the ‘internet informed patient’ in a mixed light (Ahmad, Hudak, Bercovitz, Hollenburg, & Levinson, 2006; Broom, 2005; Helft, Hlubocky, & Daugherty, 2003; Potts & Wyatt, 2002).

Patient internet use can impact the doctor-patient encounter in several ways. Some argue that as patients collect health information online about alternative treatments or experimental therapies, they simultaneously reconfigure the lay-professional divide in medicine (Ball & Lillis, 2001; Hardey, 1999b, 2001, 2002). In this line of reasoning, patients armed with information are “empowered” to take ownership of their health and of communication with doctors (Fox et al., 2005; Hardey, 1999a, 1999b; Korp, 2006; Pitts, 2004; Ziebland, 2004). Others suggest that while possible, such empowerment depends on patient social location, the general orientation of patients to the doctor patient relationship, and the ability and willingness of patients to seek out online information (Henwood, Watt, Hart, & Smith 2003). These internet “informed” patients often remain judicious in sharing information with providers, either because the provider is dismissive or because the patient censors herself (Henwood et al., 2003; Pilnick, 1998). In this paper, we do not purport to engage the debate about whether the internet informed patient challenges the lay-expert divide, but instead we offer qualitative accounts of demanding encounters between physicians and patients that appear linked to a broader social reality of patient internet use.

To summarize, we argue that contemporary doctor-patient interaction occurs within a socio-cultural context where patients are seen as (and view themselves as) consumers and where internet use among patients is increasingly common. Both factors can impact doctor-patient

interaction, contributing to demanding clinical encounters. We identify an encounter as demanding if patient, provider or both overtly expresses repeated frustration with the overall nature or one aspect of the interaction, either during the clinical visit or in follow-up conversations. In addition, we focused on those encounters that appeared emotionally charged for both providers and patients.

Although it is difficult to imagine an oncological consultation devoid of intense emotion and overt body language, emotional neutrality was in fact the norm for both providers and patients in the Cancer Clinic, even in moments when one might predict intense emotion such as at the disclosure of a terminal status. The Cancer Clinic is not unique in this regard, as other research shows that cancer patients tend not to discuss emotional issues with their oncologists and that physicians often bypass patients' emotional cues (Detmar, Aaronson, Wever, Muller, & Schornagel, 2000; Eide, Quera, Graugaard, & Finset, 2004). The average interaction at the Cancer Clinic lasted ten to fifteen minutes and was usually a staid conversation between patient and oncologist about treatment and follow-up procedure. If chemotherapy was underway, the discussion turned to whether and how the cancer was responding and how the oncologist might alter treatment. Patients were rarely diagnosed at the Cancer Clinic, since most received the news of malignancy from their GPs. Given the quotidian nature of the majority of patient-physician interactions we observed, the expression of emotion, dissatisfaction and frustration on the part of either patient or oncologist represented a clear deviation from routine doctor-patient interaction.

Methods

Data presented in this paper are part of a larger study that aims to understand whether and how patients are labeled or stigmatized in various healthcare organizations. The study utilizes comparative ethnographic methods to explore doctor-patient interaction at the oncology clinic of University Hospital—which we call Cancer Clinic—a private teaching hospital that serves primarily middle class, insured patients. Oncology is a rich specialty in which to explore clinical encounters, since oncology usually involves sustained interaction with patients, but with minimal “lateral” or deep investments in client history or biography (Ford, Fallowfield, & Lewis, 1996; Potter & McKinlay, 2005). Such conditions of care, combined with high levels of patient anxiety associated with a cancer diagnosis and treatment (Payne, 1992), make oncology ideal for observing how doctors and patients manage broad constraints on care.

We employ an inductive, grounded approach to the collection and analysis of data, following a longstanding tradition of naturalistic observation in qualitative sociology (Becker, 1970; Lofland, Snow, Anderson, & Lofland, 2005; Hughes, 1971; Strauss & Corbin, 1990). As Heritage and Maynard (2006) note, such ethnographic methods are well-suited to in-depth study of the content and context of doctor-patient interaction. Ethnographic observations allow the researcher to observe interaction in real time, with sensitivity to the myriad contextual factors that influence doctor-patient communication (Heritage & Maynard, 2006).

Consistent with this ethnographic tradition, data for this study were collected through standard fieldwork methods including participant-observation and informal interviews. We observed approximately ninety hours of doctor-patient interactions in an outpatient setting, as well as provider interactions during staff meetings including tumor board (a weekly meeting where the oncologists gathered to discuss difficult presentations (and sometimes difficult patients)), administrative meetings and clinic hub rooms (spaces restricted to clinic staff where physicians review charts and exchange information with colleagues). The data from the clinic are observations of approximately 100 doctor-patient interactions, although informal interviews were conducted with clinic staff and patients before and after consultations whenever possible (roughly one third of the observations involved some informal interviewing of patients and/or doctors before or after the consultation).

Generally speaking, we shadowed doctors through the clinic, which proved the most effective way to secure access to clinical encounters and to witness physicians' "backstage" talk and behavior. Twenty oncologists work in the Cancer Clinic, but the bulk of clinical observations are of ten providers. Observations of tumor boards and hub rooms included all staff. Of the ten providers in the core group, four are men and six are women. Two are Asian-American and eight are white. The majority of patients are also white, although the clinic does serve a small population of minority patients, mostly Asian-American. A few of the providers declined to participate in direct observations of consultations, but they agreed to participate in the global observations of the clinic. All patients consented to observation, possibly because the Cancer Clinic is a teaching hospital where patients are frequently observed by medical students and interns. The patients observed ranged in age between 35-80, with the majority over fifty years. Fieldwork in Cancer Clinic took place between 2004-2005.

We recorded fieldnotes according to standard procedures, jotting notes while conducting fieldwork and expanding jottings into full notes as soon as possible. The clinic invoked the Health Insurance Portability and Accountability Act (HIPAA) and asked us not to audio tape clinical consultations, so we were unable to record conversations verbatim. We took comprehensive notes on all aspects of the interaction, paying close attention to noteworthy moments of communication. Specifically, we focused attention on body language, gestures, and emotional displays such as crying, sighing, rolling eyes, or interrupting that suggested either patient or provider found the encounter demanding. For analysis, we shared fieldnotes and interview transcripts using qualitative data analysis software. As is typical in collaborative ethnographic research, we conducted data analysis and collection simultaneously so that analytical insights could inform ongoing data collection (Buford May & Pattillo-McCoy, 2000). We secured approval for these research procedures from appropriate institutional review boards (IRB) and obtained informed consent from all subjects who participated. We have changed all proper names in this paper and some identifying details to ensure subject confidentiality.

Each author separately read and coded data, using the constant comparative method (i.e. each observation coded as demanding was compared to those previously coded as such, to identify key points of similarity and variation in the data) (Glaser, 1965). Coding focused on noting how providers and patients negotiated the clinical encounter, how providers

interacted with one another and how that information shaped the way patients were talked about or treated in the clinic. We also coded patients' subjective experiences of care whenever possible, usually by directly engaging patients before or after a consult. At regular meetings with the three authors, we discussed insights and findings from the data; clarified questions about the field sites; resolved differences in coding and interpretation; and made plans for ongoing fieldwork.

Demanding encounters in the Cancer Clinic were relatively infrequent, with a total of twenty-five encounters coded as demanding, constituting one-fourth of the total observations. We contend that while uncommon, demanding encounters are worth investigating because of the disproportionate amount of emotional and mental energy that both physicians and patients expend during such interactions (An et al., 2009). In addition, it is important to study moments of miscommunication and discord so that scholars and practitioners alike can continue to develop best practices for constructive doctor-patient interaction.

Findings: The Demanding Encounter

We present a selection of ethnographic vignettes below, chosen because they capture the key characteristics of consumerist and internet related demanding encounters found in our sample. Vignettes are “rich pockets” of representative and meaningful data that create a composite of people and events studied (Le Compte & Schensul, 1999; Miles & Huberman, 1994). Although no two demanding encounters are identical, there are consistent findings. In the demanding encounters coded as primarily “consumerist”, patients and providers clashed in some way over the course of care, with patients assertively requesting a particular service or treatment. The remaining demanding encounters tied to patient internet use involved the patient's use of online information to question a clinical diagnosis, procedure or treatment. The themes of patient consumerism and patient internet use are obviously not mutually exclusive, but we separate them here for clarity of argument. In nearly all cases of demanding encounters, it is not simply the fact that patients exhibit consumerist behavior or use the internet that provokes discord. Rather, consumerist behavior and internet use appear to be the *contexts* in which patients increasingly challenge provider judgment or expertise, the seemingly constant precursor to demanding encounters.

The Patient Consumer and Demanding Encounters

A consumer orientation among patients was observed in approximately thirteen of the twenty-five demanding encounters observed at Cancer Clinic, fueled by patients who strongly asserted specific expectations for care before and during consultation. Providers, in turn, often appeared taxed or challenged by strong patient expectation. The Cancer Clinic itself is partially responsible for creating an environment in which patients (and their choices) are placed at the center, “selling” the clinic's services to a patient population that has both the economic and cultural capital to seek cancer care elsewhere. Evidence of a patient focus can be found in the physical space of the site: A pianist playing a grand piano greets cancer patients as they enter the site; a large mosaic of patient testimonies and artwork is prominently displayed in the lobby of an adjacent building; and signs in the mahogany paneled lobby direct patients to the meditation lounge and resource center.

Consultation planning is also part of the patient-centered orientation of the clinic. Consultation planners are medical students employed by the clinic to interview patients about their treatment concerns, questions, and goals prior to consultation with an oncologist. Roughly half of the one hundred observations involved a consultation planner; yet we did not observe a single instance where a physician extensively reviewed a consultation planning report prior to seeing a patient. A head surgical nurse corroborated that the service is only moderately successful, since most providers have little time to review the documents before seeing patients. Consultation planning at Cancer Clinic appears to be an organizational imperative designed and implemented by non-physician managers of the clinic to promote shared decision making. While consultation planners encourage patients to view the clinical visit as a place to ask questions, assert concerns and state preferences for treatment, doctors did not appear to have time to digest or incorporate this information. We argue this interactional disconnect between patient expectations and provider constraint is important context for understanding demanding encounters, particularly those that involve the consumerist behavior of patients.

Karen

Karen is a wealthy, white woman in her fifties who came to the clinic with her husband, seeking care from the clinic's director, Dr. Smith. When we observed Karen, she had been transferred to Dr. Solomon after an ongoing miscommunication with Dr. Smith about the number of cancerous nodes in her body. She reported to her consultation planner, "we were told ten were bad, then told two were bad, then one". Karen also clashed with Dr. Smith over chemotherapy, expressing reservations about its side effects. The consultation planner revealed privately that Dr. Smith is skilled at handling patients "like these", but that Karen was unsatisfied with treatment under Dr. Smith and made known her wishes to see another provider.

Karen and her husband were vocal during the consultation planning session about their need for more information about chemotherapy. Karen's husband commented to the medical student, "if they don't give us the info [about chemotherapy] I'm going to be pissed; sometimes they sugar coat it. We've heard horror stories about chemo, so we want the facts". The consultation planner reassured Karen that Dr. Solomon would review a range of options with her. After Dr. Solomon revealed during consult, however, that the standard treatment for Karen's cancer was in fact radiation and chemotherapy, both the patient and her husband were visibly unsettled. Although they understood the oncologist's recommendation, the husband explained that they "need time to do research on chemical applications, to talk to friends and to collect data from different sources". Karen explained that they have "good friends in the pharmaceutical industry", whom they wish to consult before going forward with any treatment. Dr. Solomon reiterated in a stern tone that she must accept the standard treatment or face serious health consequences. Although Dr. Solomon allowed Karen's objection to stand, saying that he would give her time to consult with others, he later told the medical resident that chemotherapy was the only treatment possible. If she refused treatment, she would have to find another doctor.

In one reading, Karen is challenging the judgment of providers in the clinic based on her personal beliefs and fears about chemotherapy. Indeed, the interview with Karen post-consultation revealed that she is a deeply religious person, skeptical of doctors and standard therapies. Even so, Karen told us that she believed a range of treatment options were available to her, a belief further validated by the young medical student serving as her consultation planner. In the context of a healthcare system that promotes consumer directed care and shared decision making, at least for those who can afford it, it is not surprising that some patients, like Karen, assume a certain degree of choice in treatment. Further, Karen's repeated sessions with consultation planners, which she identified as very useful, gave her a forum in which to raise concerns and questions about treatment; many of which went unaddressed by physicians in the clinic.

Karen could also be considered a “shopper”, a patient who frequently changes providers. On the provider side, stories about demanding encounters related to patient shoppers often emerged in the hub-room or in Tumor Board. Although providers said they were mostly annoyed and a little amused by “shoppers”, it is also evident that providers took offense at the challenge to their credentialing and experience that such behavior represented. Just as doctors use humorous quips about patients to negotiate the uncertainty and stress associated with their work (Wear, Aultman, Varley, & Zarconi, 2006), we find that patients who shop for doctors and treatments are both a source of humor, as well as stress, for doctors in the Cancer Clinic.

Patty

Many physicians had strong reactions to those patients who questioned the course of treatment or who demanded more choices or information prior to making a decision. Patty, a white woman in her forties with recently diagnosed cancer, found her way to the clinic after receiving several referrals from friends with cancer, as well as a recommendation from her ex-husband, a cardiologist. Patty has a gene that predisposes her to a very aggressive form of cancer, but one that is usually successfully treated if caught early. Patty's provider, Dr. Pearson, is an oncologist skilled at treating patients with Patty's type of cancer. Dr. Pearson directs a number of ongoing clinical trials and Patty explained to the consultation planner that she had come to the clinic to “sign-up” for one. She read about the trials online and had a friend who “recommended she sign-up right away”. Crying through the consultation planning session, Patty told the medical student that she needed “assurance of the best, effective treatment...no double-blind”, referring to the clinical trials.

Once in the exam room, Dr. Pearson went through the research protocol with Patty, drawing a diagram to explain that she would be randomly assigned to a test or control group. After a few minutes, Patty interrupted and asked Dr. Pearson to “repeat the part about random assignment”. As Dr. Pearson repeated herself, Patty interrupted, saying, “I thought I was coming to Cancer Clinic for a specific treatment” and that she did not want to be in “that group” (pointing to the control group). Dr. Pearson explained that the study only works if people are randomly assigned, which did not assuage Patty. Dr. Pearson assured the patient that she would receive a known and safe treatment in the control group, but she would not necessarily be given the experimental drug. Unhappy with this development, Patty told Dr.

Pearson that she needed to think further about the clinical trial, but that she absolutely needed treatments on Fridays, not Thursdays, as well as chemotherapy that did not make her hair fall out or cause excessive weight loss. Dr. Pearson explained that most chemotherapy creates some hair loss and wasting and that Patty's therapy would do the same. Patty began to cry, saying that she wanted the "same treatment as her friend", the kind that would preserve her hair. Clearly annoyed, Dr. Pearson told Patty that they should move forward and conduct a physical exam. Patty continued to weep intermittently as Dr. Pearson examined her.

Like Patty, patients at Cancer Clinic were often confused about clinical trials or the logic of experimental design. Recruitment and retention of trial subjects remained very low during our observations and it was common to witness patients refusing experimental treatment. Our observations indicate that patients at the Cancer Clinic perceived trials as one of the many "choices" in a range of possible services related to treatment. This is true whether they quietly rejected the option or eagerly asserted their desire to be involved. Either way, clinical trial enrollment takes place in a consumerist context where patients increasingly view doctors as "service providers" and clinical trials as a service. This definition of the situation is at odds with the physician's view of clinical trials as a research endeavor with relatively few guarantees of cure. It is important to clarify that clinical trials are not responsible for demanding encounters. We suggest instead that clinical trials are one of the many "services" *some* patients come to demand from providers in a context where patient choice and shared decision making is heralded.

The Internet Informed Patient and Demanding Encounters

Patients at the Cancer Clinic spoke openly to consultation planners about their use of internet blog sites, bulletin boards or online medical journals. Equipped with medical information, patients approached the clinical encounter with varied degrees of "informedness" and sometimes the expectation that physicians would review and validate information gathered online. The majority of doctor-patient consultations included some reference to medical information on the internet, either by the physician or the patient, although more often by patients. As with patient consumer behavior, it was only in a small number of cases (fifteen of the twenty five demanding encounters) that a patient's information seeking played a role in a demanding encounter. Demanding encounters generally resulted when patients used knowledge gleaned on the internet to push for particular treatments or therapies.

Consistent with survey and interview data on physician attitudes about patient internet use (Broom, 2005; Potts and Wyatt, 2002), physicians at the Cancer Clinic possess rather contradictory orientations toward the internet informed patient. Dr. Skilling, a respected oncologist at Cancer Clinic, reported that the "main problem" he faces on a day-to-day basis is the uninformed patient who *thinks* he/she is informed. He estimates that eighty percent of his patients are able to sift through information on the internet and make accurate conclusions about treatment; but he also said that he spends a significant amount of consultation time convincing the remaining twenty percent of patients that their information is inaccurate. Even so, doctors actively encourage patient use of the internet as a resource for

managing disease. We observed Dr. Skilling, for example, urging patients during consultations to search for information on their cancers. When patients failed to seek out this information, Dr. Skilling was openly derisive post-consult, making comments like, “He should be on the internet”. It was not uncommon for doctors in the clinic to lament patient over-reliance on the web, but expect a certain degree of internet literacy, especially among patients perceived as well-educated. Patients, accordingly, generally have to walk the line of being informed without being over-informed or pushy about that information. These findings suggest that providers sometimes view patient internet use as beneficial to clinical consultations, especially when that use reinforces rather than undermines a biomedical view (Broom & Tovey 2008). As we discuss below, when the internet is used by patients to justify or push for alternative therapies, providers appear less enthusiastic about the internet informed patient.

Sally and her husband

Our observations indicate that demanding encounters can emerge when patients use information gleaned from the internet to challenge physician belief in biomedical cure. During one observation, we observed a white woman, Sally, in her forties with recently diagnosed cancer. Accompanied by her husband, an African-American man in his forties, Sally disclosed to the consultation planner that she had very specific goals for her interaction with her oncologist, Dr. King. First, she wanted someone to speak to her “in plain English, in layman's terms”. Second, she wanted Doctor King to talk with her about an alternative therapy she researched on the internet, black cohosh. “So far”, she told the consultation planner, “we've hit a road block with alternative medicines”. Dr. King did not review Sally's consultation planning report but was briefed by the medical student who alerted Dr. King to Sally's recent foray on the internet.

Once in the exam room, the subject of Sally's internet research came up almost immediately. Dr. King had never heard of black cohosh but sought to reassure Sally that “most anti-nausea meds [used in treatment] are complementary medicines”. Confused and seemingly annoyed, the husband interjected to say that “Sally is talking about herbs and Eastern medicine”, a comment Dr. King ignored. The husband persisted, telling the doctor, “you are probably not at liberty to say if there are [other treatments]”. Dr. King looked offended and replied, “I'm at liberty to discuss anything”, but he claimed his ultimate interest was in “effective treatment options”. Dr. King then reassured Sally and her husband that his suggestions were based on years of clinical evidence and that while there may be other options, he could not recommend herbal treatments because they have not been subjected to the scientific process and peer review. Sally's husband responded, “that kind of shuts me down. I have a problem with Western medicine”. Dr. King said he understood the criticism, but doctors are “working all the time to make it better, even if improvements are far off”. Seemingly at an impasse, Sally's husband muttered “there has to be something to Eastern medicine...it has a much longer history than Western medicine”. After changing the subject, Dr. King ordered a series of tests and chemotherapy for Sally and then abruptly left the room. Sally's husband then turned to the consultation planner to say, “He and I are going to have some challenging conversations”.

Interviewing both Sally and her husband before and after the consultation with Dr. King, it was clear that Sally expected Dr. King to be dismissive about her research of herbal remedies. She described feeling emboldened to push Dr. King on the issue after seeking information online. Sally and her husband expressed concern that the clinic “get their act together” and realize that “to us, this [the cancer] is the most important thing that is happening”. It seems that pushing Dr. King to engage the topic of alternative therapies allowed Sally and her husband a way to assert power in an environment where they felt scared, ignored and mistreated.

In a post-consultation interview, Dr. King expressed a great deal of frustration that the visit had taken twice as long as he normally allots for consultations. Beyond the issue of time, however, there are notable paradigmatic differences in the way Dr. King and Sally view treatment. These differences, which Dr. King obviously found difficult to surmount, would likely have existed independent of Sally's use of the internet. Nevertheless, the internet was an important source of support and information for Sally and therefore a contextual factor in the demanding encounter that ensued.

Like Sally, a majority of patients observed at the Cancer Clinic reported, usually to a consultation planner, that they used the internet to research and understand their illness. Simply possessing information from the internet, however, was of little consequence on its own; *how* patients used this information during a consultation was of greater importance. Some patients arrived at the clinic internet research in hand, but did not raise this new information with their doctors. For example, we observed a white woman, Anne, in her forties with recently diagnosed cancer. She came to the Cancer Clinic for a second opinion, armed with journal articles and other printouts from the internet, as well as several pages of questions written on legal notepads. Anne was determined, like Sally, to avoid what she called “conventional treatment” and had done “a lot of reading and research” about complementary and alternative therapies. Anne was able to assert her needs to the consultation planners and nurses taking her history, but when Dr. Forester arrived, Anne did not discuss her interest in a less aggressive therapy; nor did she raise the subject of herbal remedies. The example of Anne illustrates that while some patients are internet informed, only some ask providers to directly consider the information or redirect treatment on the basis of that information. In short, there are patients like Anne who perform “interactional submission” (Pilnick, 1998; ten Have, 1991), leaving physician judgment intact and reducing the likelihood of a demanding encounter.

Discussion

It is tempting to reduce demanding encounters to “bad” doctoring or patients' anti-social behavior. Certainly, idiosyncrasies of providers and patients play a role in uncomfortable, and sometimes confrontational, clinical encounters. While acknowledging the role of individual behavior in the doctor-patient dynamic, this study examines the broader, interconnected sociocultural features of the demanding encounter, specifically the roles of the internet and patient consumerism.

Taking a closer look at the socio-cultural backdrop of clinical encounters allows us to view doctor-patient conflict as interactional realities tied to larger social forces and historical contexts, such as the emergence of information culture and the consumerist turn in American medicine. Extending Potter and McKinlay's argument (2005), we contend that identifying the macro and meso level contexts of doctor-patient interaction is important because it forces an analysis beyond the confines of the consultation, or even the clinic. Stated in another way, if the problem of doctor-patient conflict is in part tied to socio-cultural conditions, then perhaps existing solutions to conflict must also take into consideration the broader context of care.

Patients who exhibit consumerist behavior, for example, are dismissed by some providers for requesting (and in some cases, demanding) certain treatments or for provider "shopping". Personality traits of individual patients notwithstanding, it is useful to look beyond the immediate micro-interactional context of interaction and consider how and why patients view themselves as entitled to make choices about care, even when those choices are unavailable or impractical (recall Patty's desire to assign herself to the experimental group). At the meso-level of the Cancer Clinic, patients are instructed from day one to see themselves as "partners in care", an idea that is reinforced through the myriad of services offered to patients, such as individual nutritionists, counselors, support-groups and consultation services. Beyond the clinic at the macro-level, public debates about healthcare frame care as a set of consumer choices. For many middle-class Americans, who spend a sizeable portion of their monthly incomes on insurance premiums and out-of pocket expenses (Agency for Healthcare Research and Quality, 2006), it is not surprising that patients would approach healthcare as they would any other service on which they have spent considerable money. Healthcare providers might find it useful to think about the ways that the cultural reality of patient-as-consumer is itself a by-product of the same system of commodified care that structures, and in some cases intensifies, their own work on a daily basis.

The second socio-cultural factor at play in the demanding encounter is linked to the internet informed patient. Many middle-class, educated patients now rely on the internet to track down information about diagnosis and cure and to seek social support through online communities and chat rooms (Fox, 2005; Madden & Fox, 2006; Nettleton, Burrows, O'Malley & Watt, 2004). Confirming this trend, our observations suggest that patients commonly bring internet information to the clinic, some with the express intent of discussing their newfound knowledge with physicians. In this sense, the internet can be seen as a potentially equalizing or empowering force in the doctor-patient encounter, providing patients with information they might not otherwise readily access (Ferguson, 1997; Henwood et al., 2003; Pitts, 2004).

Seeking and collecting health information online does not mean patients necessarily discuss information with clinicians. Anne, like many patients, came to the clinic having researched her cancer online; but when face-to-face with her oncologist, she barely mentioned the information. So while the internet is an important part of the socio-cultural context of the doctor-patient interaction, other more predictable factors—namely, power differentials in the doctor-patient relationship—play a role in patients' willingness or ability to share internet

information with their providers. In our observations at the Cancer Clinic, patients seemed more likely to engage in “interactional submission” (Pilnick, 1998; ten Have, 1991), rather than assert an internet informed perspective or opinion. The few patients who strongly asserted an internet informed perspective—such as Sally and her husband—often found themselves in a demanding encounter with physicians. Further research is needed to understand exactly how patient use of internet technology helps or hinders the doctor-patient relationship, but our observations suggest that the internet is an increasingly important contextual factor in demanding interactions.

Demanding encounters are embedded within a myriad of socio-cultural conditions, but as we point out, these conditions offer only partial explanation of tumult between doctors and patients. Demanding encounters are most commonly linked to moments when patients directly or indirectly challenge the judgment or expertise of physicians, a finding corroborated by the literature (Elder et al., 2006). The finding also supports the longstanding view in medical sociology that physicians continue to maintain interactional dominance, even when challenged by patients (Maynard, 1991; Pilnick & Dingwall, 2007). Not all patients, however, have the social power to challenge physician judgment or expertise. Prior research shows that relative to white, high SES patients, poor and minority patients feel disempowered by the clinical encounter and feel more compelled to engage in positive self-presentation with doctors (Johnson, Saha, Arbaleaez, Beach, & Cooper, 2004; Malat, 2005). Observations involving minority patients comprised a very small part of our sample, so we are unable to make any clear assertions about the role of race and class in demanding encounters. Although existing research suggests that patient sex, age, ethnicity and marital status are not associated with provider perceptions of encounter difficulty (Jackson & Kroenke, 1999), we suggest that further research is needed to explore the link between patient social location and demanding encounters.

We offer one final point of discussion: Of what consequence are demanding encounters, for patients, providers and the U.S. healthcare system in general? We suggest that from the perspective of the individual, middle-class patient who is frustrated by a lack of quality of care, possessing a consumer orientation or using the internet to advocate for a given therapy or treatment may indeed result in expeditious care, more comprehensive information from providers, and a sense of empowerment. Looking beyond the interests of individual patients, however, there are potential long-term consequences of demanding encounters on patients and providers. Given what we know about the negative impact of difficult patients on physician burnout and well-being (An et al., 2009), further research is needed to confirm whether and how demanding encounters affect medical error, access to care and patient health outcomes.

There are several limitations to this study. Our purposive sampling of doctor-patient observations means that findings presented here offer a partial view of doctor-patient encounters, ungeneralizable beyond the Cancer Clinic. Since five of the providers on staff refused to participate in the study, it is possible that the sample suffers from a selection bias. That is, there may be something about the doctors who chose to participate (or those who did not) that make our findings unrepresentative of doctors at Cancer Clinic. Additionally, the data presented in this paper are drawn exclusively from a Cancer Clinic, as opposed to a

primary care or another specialty clinic; therefore, any assertions made about demanding encounters and their link to broader socio-cultural contexts are limited to the social world of cancer care. Finally, the fact that we relied heavily on observations and informal interviews, rather than formal, tape-recorded interviews with patients and providers, means that the observational data are insufficiently triangulated. The benefit of ethnographic observation, however, is that we were able to observe demanding encounters as they unfolded in real time, as opposed to relying exclusively on subjective accounts of discord from either patient or provider. In addition, an ethnographic approach allowed for in-depth analysis of the intersecting factors at play in the doctor-patient relationship, such as the internet and patient consumerism.

Conclusion

In this paper, we argue that demanding encounters between patients and physicians are embedded within broader socio-cultural conditions, namely the cultural shifts toward patients as consumers and the internet informed patient. These socio-cultural conditions of care work in tandem with a more predictable mechanism: The extent to which patients directly challenge physician expertise and judgment. In short, we find evidence to support the claim that there are micro, meso and macro level social processes involved in the production of demanding encounters between doctors and patients (Potter & McKinlay, 2005).

While the present study offers a detailed account of one type of medical environment, a cancer clinic, further research is needed to consider how demanding encounters vary by organizational context and by patient population. In particular, it is likely that demanding encounters exist in settings with low-income and racially diverse patient populations, but the nature of the demanding behavior, the organizational influences and the resultant interactions are likely to be different. Further study is also needed to examine whether demanding encounters are causally linked to quality of care or health outcomes, especially for underserved populations.

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References

- Ahmad F, Hudak P, Bercovitz K, Hollenburg E, Levinson W. Are Physicians Ready for Patients with Internet-Based Health Information? *Journal of Medical Internet Research*. 2006; 8:e22. [PubMed: 17032638]
- Out-of-Pocket Expenditures on Health Care and Insurance Premiums Among the Non-elderly Population. Mar. 2006 2006
- An P, Rabatin J, Manwell L, Linzer M, Brown R, Schwartz M. Burden of Difficult Encounters in Primary Care: Data From the Minimizing Error, Maximizing Outcomes Study. *Archives of Internal Medicine*. 2009; 69:410–414. [PubMed: 19237726]
- Ball M, Lillis J. E-Health: Transforming the Physician/Patient Relationship. *International Journal of Medical Information*. 2001; 61:1–10.

- Becker, H. *Sociological Work: Methods and Substance*. Aldine; Chicago, IL: 1970.
- Broom A. Medical Specialists' Accounts of the Impact of the Internet on the Doctor/Patient Relationship. *Health*. 2005; 9:319–338. [PubMed: 15937035]
- Broom A, Tovey P. The Role of the Internet in Cancer Patients' Engagement with Complementary and Alternative Treatments. *Health*. 2008; 12:139–155. [PubMed: 18400826]
- Burford May RA, Pattillo-McCoy M. Do You See What I See? Examining a Collaborative Ethnography. *Qualitative Inquiry*. 2000; 6:65–87.
- Bury M, Taylor D. Towards a Theory of Care Transition: From Medical Dominance to Managed Consumerism. *Social Theory and Health*. 2008; 6:201–219.
- Charles C, Gafni A, Whelan T. Decision-Making in the Physician-Patient Encounter: Revisiting the Shared Treatment Decision-Making Model. *Social Science and Medicine*. 1997; 49:651–661. [PubMed: 10452420]
- Cline R, Hayes K. Consumer Health Information Seeking on the Internet: The State of the Art. *Health Education Research*. 2001; 16:671–692. [PubMed: 11780707]
- Detmar SB, Aaronson NK, Wever LD, Muller M, Shnornagel JH. How Are You Feeling? Who Wants to Know? Patients' and Oncologists' Preferences for Discussing Health-Related Quality-Of-Life Issues. *Journal of Clinical Oncology*. 2000; 18:3295–3301. [PubMed: 10986063]
- Edberg AK, Hallberg IR. Actions Seen As Demanding in Patients with Severe Dementia During One Year of Intervention: Comparison with Controls. *International Journal of Nursing Studies*. 2001; 38:271–286. [PubMed: 11245864]
- Eide H, Quera V, Graugaard P, Finset A. Physician-patient Dialogue Surrounding Patients' Expression of Concern: Applying Sequence Analysis to RIAs. *Social Science & Medicine*. 2004; 59:145–155. [PubMed: 15087150]
- Elder N, Ricer R, Tobias B. How Respected Family Physicians Manage Difficult Encounters. *Journal of the American Board of Family Medicine*. 2006; 19:533–541. [PubMed: 17090786]
- Emanuel E, Emanuel L. Four Models of the Physician-Patient Relationship. *Journal of the American Medical Association*. 1992; 267:2221–2226. [PubMed: 1556799]
- Ferguson T. Health Online and the Empowered Medical Consumer. *Journal of Quality Improvement*. 1997; 23:251–257.
- Fisher S. A Discourse of the Social: Medical Talk/Power Talk/Oppositional Talk? *Discourse and Society*. 1991; 2:157–182.
- Ford S, Fallowfield L, Lewis S. Doctor-Patient Interactions in Oncology. *Social Science and Medicine*. 1996; 42:1511–1519. [PubMed: 8771634]
- Fox S. Health Information Online. Pew Internet & American Life Project. 2005 Retrieved 1/2/08: http://www.pewinternet.org/pdfs/PIP_Healthtopics_May05.pdf
- Fox N, Ward K, O'Rourke A. The 'Expert Patient': Empowerment or Medical Dominance? The Case of Weight Loss, Pharmaceutical Drugs and the Internet. *Social Science & Medicine*. 2005; 60:1299–1309. [PubMed: 15626525]
- Freidson E. Prepaid Group Practice and the New “Demanding Patient”. *Milbank Memorial Fund Quarterly/Health and Society*. 1973; 51:473–488.
- Gabe J, Olumide G, Bury M. It Takes Three to Tango': A Framework For Understanding Patient Partnership in Pediatric Clinics. *Social Science and Medicine*. 2004; 59:1071–1079. [PubMed: 15186906]
- Glaser B. The Constant Comparative Method for Qualitative Analysis. *Social Problems*. 1965; 12:436–445.
- Haas L, Leiser P, Magil M, Osmann S. Management of the Difficult Patient. *American Family Physician*. 2005; 72:2063–2068. [PubMed: 16342837]
- Hahn S, Kroenke K, Spitzer R, Brody D, Williams J, Linzer M, deGruy V. The Difficult Patient: Prevalence, Psychopathology, and Functional Impairment. *Journal of General Internal Medicine*. 1996; 11:1–8. [PubMed: 8691281]
- Hardey M. Doctor in the House: The Internet as a Source of Health Knowledge and a Challenge to Expertise. *Health*. 1999a; 9:319–338.

- Hardey M. Doctor in the House: The Internet as Source of Lay Health Knowledge and a Challenge to Expertise. *Sociology of Health & Illness*. 1999b; 21:820–835.
- Hardey M. The Internet and the Transformation of Patients into Consumers and Producers of Health Knowledge. *Information, Communication & Society*. 2001; 4:388–405.
- Hardey M. 'The Story of my Illness': Personal Accounts of Illness on the Internet. *Health*. 2002; 6:31–46.
- Haug M, Lavin B. Practitioner or Patient- Who's in Charge? *Journal of Health and Social Behavior*. 1981; 22:212–229. [PubMed: 7288129]
- Helft P, Hlubocky F, Daugherty C. American Oncologists' Views of Internet Use by Cancer Patients: A Mail Survey of American Society of Clinical Oncology Members. *Journal of Clinical Oncology*. 2003; 21:942–947. [PubMed: 12610198]
- Henwood F, Watt S, Hart A, Smith J. Ignorance is Bliss Sometimes: Constraints on the Emergence of the 'Informed Patient' in Changing the Landscapes of Health Information. *Sociology of Health & Illness*. 2003; 25:589–607. [PubMed: 12919447]
- Heritage J, Maynard D. Problems and Prospects in the Study of Physician-Patient Interaction: 30 Years of Research. *Annual Review of Sociology*. 2006; 32:1–24.
- Hughes, E. *The Sociological Eye: Selected Papers on Work, Self and the Study of Society*. Aldine-Atherton; Chicago, IL: 1971.
- Jackson J, Kroenke K. Difficult Patient Encounters in the Ambulatory Clinic: Clinical Predictors and Outcomes. *Archives of Internal Medicine*. 1999; 159:1069–1075. [PubMed: 10335683]
- Johnson RL, Saha S, Arbaleaez JJ, Beach MC, Cooper LA. Racial and Ethnic Differences in Patient Perceptions of Bias and Cultural Competence in Health Care. *Journal of General Internal Medicine*. 2004; 19:101–110. [PubMed: 15009789]
- Kleinman, A. *Patients and Healers in the Context of Culture: An Exploration of the Borderland Between Anthropology, Medicine, and Psychiatry*. University of California Press; Berkeley, CA: 1980.
- Kleinman, A. *The Illness Narratives: Suffering, Healing, and the Human Condition*. Basic Books; New York, NY: 1988.
- Korp P. Health on the Internet: Implications for Health Promotion. *Health Education Research*. 2006; 21:78–86. [PubMed: 15994845]
- Krebs E, Garrett J, Konrad T. The Difficult Doctor? Characteristics of Physicians who Report Frustration with Patients: An Analysis of Survey Data. *BMC Health Services Research*. 2006; 6:1–8. [PubMed: 16403235]
- Kroenke K. Unburdening the Difficult Clinical Encounter. *Archives of Internal Medicine*. 2009; 169:333–334. [PubMed: 19237715]
- Le Compte, D.; Schensul, JJ. *Analyzing and Interpreting Ethnographic Data*. Sage; London: 1999.
- Lofland, J.; Snow, D.; Anderson, L.; Lofland, L. *Analyzing Social Settings: A Guide to Qualitative Observation and Analysis*. Wadsworth Publishing; Belmont, CA: 2005.
- Lorber J. Good Patients and Problem Patients: Conformity and Deviance in General Hospital. *Journal of Health and Social Behavior*. 1975; 16:213–225. [PubMed: 1159292]
- Lupton D. Consumerism, reflexivity and the medical encounter. *Social Science & Medicine*. 1997; 45:373–381. [PubMed: 9232732]
- Madden M, Fox S. Finding Answers Online in Sickness and in Health. Pew Internet & American Life Project Report. 2006 Retrieved 1/2/08: http://www.pewinternet.org/pdfs/PIP_Health_Decisions_2006.pdf
- Maizes V. Setting Limits on Demanding Patients. *American Family Physician*. 2000; 61:881. [PubMed: 10695590]
- Malat J. Race, Socioeconomic Status, and the Perceived Importance of Positive Self-Presentation in Health Care. *Social Science & Medicine*. 2005; 62:2479–2488. [PubMed: 16368178]
- Mathers N, Jones N, Hannay D. Heartsink Patients: A Study of their General Practitioners. *British Journal of General Practice*. 1995; 45:293–296. [PubMed: 7619583]
- Maynard D. Interaction and Asymmetry in Clinical Discourse. *American Journal of Sociology*. 1991; 97:448–495.

- Maynard D, Heritage J. Conversation Analysis, Doctor-Patient Interaction, and Medical Communication. *Medical Education*. 2005; 39:428–435. [PubMed: 15813766]
- Mechanic D. The Rise and Fall of Managed Care. *Journal of Health and Social Behavior*. 2004; 45:76–86. [PubMed: 15779467]
- Mikasanek T. On Caring for 'Difficult' Patients. *Health Affairs*. 2008; 27:1422–1428. [PubMed: 18780933]
- Miles, M.; Huberman, M. *Qualitative Data Analysis: An Expanded Sourcebook*. Sage; Thousand Oaks: 1994.
- Mishler, EG. *The Discourse of Medicine: Dialectics of Medical Interviews*. Ablex Publishing; Norwood, NJ: 1984.
- Mizrahi, T. *Getting Rid of Patients: Contradictions in the Socialization of Physicians*. Rutgers University Press; New Brunswick, NJ: 1986.
- Nettleton S, Burrows R, O'Malley L, Watt I. Health E-Types? An Analysis of the Everyday Use of the Internet for Health. *Information, Communication & Society*. 2004; 7:537–553.
- Nettleton S, Burrows R, O'Malley L. The Mundane Realities of the Everyday Lay Use of the Internet for Health, and their Consequences for Media Convergence. *Sociology of Health & Illness*. 2005; 27:972–992. [PubMed: 16313525]
- Payne SA. A Study Of Quality Of Life In Cancer Patients Receiving Palliative Chemotherapy. *Social Science and Medicine*. 1992; 35:1505–1509. [PubMed: 1283035]
- Pescosolido B, Tuch S, Martin J. The Profession of Medicine and the Public: Examining American's Changing Confidence in Physician Authority from the Beginning of the 'Health Care Crisis' to the Era of Health Care Reform. *Journal of Health and Social Behavior*. 2001; 42:1–16. [PubMed: 11357716]
- Pilnick A. Why Didn't You Just Say That? Dealing with Issues of Asymmetry, Knowledge and Competence in the Pharmacist/Client Encounter. *Sociology of Health & Illness*. 1998; 20:29–51.
- Pilnick, A.; Dingwall, R. *On the Remarkable Persistence of Asymmetry in Doctor/Patient Interaction*. American Sociological Association Meetings; New York, NY. 2007.
- Pitts V. Illness and Internet Empowerment: Writing and Reading Breast Cancer in Cyberspace. *Health*. 2004; 8:33–59. [PubMed: 15018717]
- Potter S, McKinlay J. From a Relationship to Encounter: An Examination of Longitudinal and Lateral Dimensions in the Doctor-Patient Relationship. *Social Science & Medicine*. 2005; 61:465–479. [PubMed: 15893060]
- Potts H, Wyatt J. Survey of Doctors' Experience of Patients Using the Internet. *Journal of Medical Internet Research*. 2002; 4:e5. [PubMed: 11956037]
- Reeder L. The Patient-Client as a Consumer: Some Observations on the Changing Professional Professional-Client Relationship. *Journal of Health and Social Behavior*. 1972; 13:406–412. [PubMed: 4648896]
- Roter, D.; Hall, J. *Doctors Talking With Patients/Patients Talking With Doctors. Improving Communication in Medical Visits, 2nd Edition*. Praeger Publishers; Westport, CT: 2006.
- Roth JA. Some Contingencies of the Moral Evaluation and Control of Clientele: The Case of the Hospital Emergency Service. *American Journal of Sociology*. 1972; 77:839–856.
- Schegloff, E. Reflections on Talk and Social Structure. In: Boden, D.; Zimmerman, DH., editors. *Talk and Social Structure: Studies in Ethnomethodology and Conversation Analysis*. Polity Press; Cambridge, MA: 1991.
- Schegloff E. Whose text? Whose context? *Discourse and Society*. 1997; 8:165–188.
- Sepucha K, Belkora J, Tripathy D, Esserman L. Building Bridges Between Physicians and Patients: Results of a Pilot Study Examining New Tools for Collaborative Decision Making in Breast Cancer. *Journal of Clinical Oncology*. 2000; 18:1230–1238. [PubMed: 10715292]
- Skocpol, T. *Boomerang: Health Care Reform and the Turn Against Government*. W.W. Norton and Company; New York: 1997.
- Stearns C. Physicians in Restraints: HMO Gatekeepers and Their Perceptions of Demanding Patients. *Qualitative Health Research*. 1991; 1:326–348.

- Steinmetz D, Tabenkin H. The 'Difficult Patient' as Perceived by Family Physicians. *Family Practice*. 2001; 18:495–500. [PubMed: 11604370]
- Strauss, A.; Corbin, J. *Basics of Qualitative Research. Grounded Theory Procedures and Techniques*. Sage Publications; New York: 1990.
- ten Have, P. *Talk and Institution: A Reconsideration of the 'Asymmetry' of Doctor-Patient Interaction*. In: In Boden, D., editor. *Talk and Social Structure: Studies in Ethnomethodology and Conversation Analysis*. Polity Press; Cambridge, MA: 1991.
- Thompson AGH. The Meaning of Patient Involvement and Participation in Health Care Consultations: A Taxonomy. *Social Science and Medicine*. 2007; 64:1297–1310. [PubMed: 17174016]
- Waitzkin H. A Critical Theory of Medical Discourse: Ideology, Social Control, and the Processing of Social Context in Medical Encounters. *Journal of Health and Social Behavior*. 1989; 30:220–239. [PubMed: 2738368]
- Waitzkin, H. *The Politics of Medical Encounters*. Yale University Press; New Haven, CT: 1991.
- Wear D, Aultman J, Varley J, Zarconi J. Making Fun of Patients: Medical Students' Perceptions and Use of Derogatory and Cynical Humor in Clinical Settings. *Academic Medicine*. 2006; 81:454–462. [PubMed: 16639201]
- West, C. *Routine Complications: Troubles with Talk Between Doctors and Patients*. Indiana University Press; Bloomington: 1984.
- Ziebland S. The Importance of Being Expert: The Quest for Cancer Information on the Internet. *Social Science & Medicine*. 2004; 59:1783–1793. [PubMed: 15312914]