

# Between Control and Constraint: Charting Three Rhetorics of Patient Agency



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Attempts to pin down the slippery concept of agency have generated debate in nearly every humanities discipline, and the discipline of rhetoric is no exception. Debates within the field have produced two competing visions of rhetorical agency. The first is a “traditionalist” picture. Within this view, rhetorical agency is possessed by an individual subject whose persuasive efforts are aligned with her intentions; she is “in charge” of her rhetoric, which may or may not have the desired effect of shaping the perspectives or actions of others.

The traditionalist picture of agency bears a similarity to the ways in which physicians-as-rhetors have been imagined in the context of Western biomedicine (Segal, 2005; 2007). Physicians doled out “Doctor’s Orders,” sometimes succeeding in their attempts to shape the attitudes and behaviors of patients, sometimes not. Either way, physicians were considered the engines driving the rhetorical encounter.

Recent work on the concept of rhetorical agency considers the possibility that the field has historically oversold the rhetorical agency of the “speaker” and undersold the rhetorical agency of the “audience.” After all, an audience’s prevailing desires and expectations “bend the will” of the speaker at the same time that the speaker attempts to bend the will of the audience (Leff, 2003). New technologies have also begun to blur the notion of rhetorical agency and have invited a number of nuanced engagements with the concept,<sup>1</sup> but discussions of rhetorical agency still center to some

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<sup>1</sup> Technological advances in medicine have further complicated notions of human agency and have led to nuanced analyses, such as Scott Graham’s exploration of the agentive role played by brain imaging technologies in validating the ontological status of contested disorder

extent on the fundamental questions of what constitutes rhetorical agency, who possesses it, and when, where, and for whom is it constrained. This essay shifts attention away from the concept of rhetorical agency and towards what I am calling here the “rhetoric of agency.” These appeals to individual agency have persuasive force. Simply pointing out that someone *can* do something (i.e. has agency) can be a way of subtly suggesting that one *should* do that thing. Discourses of health and medicine provide an entry point for considering the rhetoric of agency.

In the last century, the list of things that one *can* do in order to preserve or promote one’s health has grown alongside the list of things that one is socially and often morally *expected* to do. The striking scope and moralization of health discourses and practices have given rise to a phenomenon known as “healthism” (Crawford, 1980; 2006). That health is thought of as an unqualified, universally desirable state serves to obscure much of the moral work performed by contemporary health-talk (Metzl and Kirkland, 2010). (After all, who wishes to be *unhealthy*?<sup>2</sup>) The pursuit of health has become a part of everyday life that is taken up more or less reflexively. As the setting of that pursuit migrated, in many instances, from the doctor’s office to the home office,<sup>3</sup> there has been a surge of interest in, and respect for, “patient agency” in public and professional discourses of health and medicine.

“Patient agency,” it should be noted, is something of a contradiction in terms. The etymological roots of “patient” denote gestures of submitting while the roots of “agency” emphasize a state of doing. Within the biomedical paradigm, physicians have been viewed as the active, healing agents and patients as the receptive, passive audience (Stone, 1997). Physicians working within the advent of the biomedical paradigm, according to Judy Segal, “sought explicitly to deprive patients of the sense that they could

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fibromyalgia—something patient advocate groups had been trying to accomplish for decades (Graham, 2009). In a similar vein, Carolyn Miller examines automated forms of assessment for writing that have become commonplace in standardized testing and are currently being developed to assess public speaking performances. Miller points out that whether or not such technologies are embraced will depend, to some extent, on how rhetorical agency is conceptualized (Miller, 2007).

<sup>2</sup> See Jennifer Malkowski’s article, “*Beyond Prevention: Containment Rhetoric in the Case of Bug Chasing*” for an example of the public discourse surrounding the (anti)-health practice of intentionally pursuing HIV through sexual contact (Malkowski, 2014).

<sup>3</sup> A 2012 Pew survey reports that 74% of adult Internet users in the U.S. have sought health information online.

look after themselves” (Segal, 2009, 364). Now, however, physicians often seek to instill within patients a sense that the opposite is true: that they are the active agents of their own health. As medical innovation has transformed a number of acute illnesses into chronic conditions—one of the great successes of biomedicine—patients have been increasingly relied on to monitor their own conditions and administer their own treatments (Martins, 2005). As a result, the notion of the submissive patient seems outmoded at best and a relic of medical paternalism at worst. Attributions of agency concerning the maintenance and improvement of health have begun to shift to patients themselves within a web of agency-related terms like “patient empowerment” and “patient participation.”

This article examines the rhetoric of patient agency at play within public discourses of health and medicine and in medical humanities scholarship. I argue that despite increased salience, the concept of patient agency remains vague and is capable of being operationalized and moralized in ways that escape attention. To illustrate this, I chart the rhetorical dynamics of the concept in public discourses of health and medicine. In so doing, I find that patient agency tends to be rhetoricized as one of three (overlapping) patient capacities: the capacity *to know*, the capacity *to prevent*, and the capacity *to decide*.<sup>4</sup> Ultimately, I suggest that the rhetorics of patient agency can be deployed to cultivate health subjectivities that are imbued with untenable notions of individual *control*. These three rhetorics, and notions of control therein, constrain rhetorical opportunities for making sense of the (inevitable) bodily and environmental contingencies that characterize our lives.

### **“IF I DON’T KNOW, I CAN FIND OUT”: PATIENT AGENCY AS THE CAPACITY *TO KNOW***

In contemporary Western societies, health-talk has become a prominent tool for the shaping of self-identity, and one of the dominant “terministic screens” through which we peer to understand, and monitor, our selves (Burke, 1964). The pursuit of health, comprised of an increasingly diverse array of health practices, has become one of Western society’s principal symbolic practices (Crawford, 2006; 2009). A central component of this

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<sup>4</sup> Here, I use the term “rhetorize” to denote the process by which a concept, term, or idea is rhetorically configured, or more simply put, *made rhetorical* and deployed in public discourses to take on a persuasive life of its own, as rhetors contextually adapt and adjust it.

journey toward health is the acquisition of health information. Robert Crawford explains that, “Individuals are *expected* to be knowledgeable. Large numbers of people eagerly seek out health information and the media oblige them in devoting extensive coverage of health matters and offering advice on a variety of health concerns” (Crawford, 2006, 402). Displaying fluency and eloquence in the languages of health and medicine functions as a form of social currency, helping to cultivate socially desirable health subjectivities.<sup>5</sup>

With the advent of Internet health and its affordances, including information-seeking, information-sharing, and health tracking tools, fresh avenues have been opened for shaping and reshaping health subjectivities. Internet-based discourses have become a primary tool for public engagements with health and medicine, as ever more users become members of online fora, add comments to web pages, and check the symptom boxes of online diagnostic quizzes (Keränen, 2014). While we tend to underestimate the extent to which health information was available prior to the Internet, one quality of Internet-based health information is unique: “apomediation,” or, the lack of mediation through “traditional” medical information gatekeepers (Segal, 2009; Eysenbach, 2008). In the past, this traditional gatekeeping task might have fallen to a publishing house or a physician. Debates about the roles played by traditional medical gatekeepers were at the heart of the women’s health movement of the 1970’s. At that time, women campaigned for health information that was more widely accessible, and relevant to wider demographic groups (Kline, 2005). Without access to relevant health information, women’s health advocates argued, opportunities for the agentive engagement of patients (especially those from marginalized groups) were severely limited.

The accessibility of the Internet for health-related purposes has come to represent not only convenience (as it means less time spent in the waiting room), but control. A recent survey of online health seekers reports that, “Our findings show that Internet users perceive themselves as more competent and in control” as a result of having sought health information online (Lemire *et al.* 2008, 136). This sense of user control is not merely a byproduct of Internet health; it is considered a desirable and necessary

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<sup>5</sup> For more on the social desirability of certain health subjectivities, see Jonathan Metzl’s and Anna Kirkland’s introduction to *Against Health* (Metzl and Kirkland, 2010).

ingredient for making “empowered consumers.” In an article cited over one hundred times, Leonie Segal states that,

[C]onsumers require more than information to contribute effectively to decisions about their own health. Consumers also require confidence and competence to act on information and a capacity to influence the services they access. This requires an understanding of their own health...and acceptance of responsibility for decisions about their own health care. Consumers need to become empowered (Segal, 1998, 31).

By this measure, the so-called “empowerment” of consumers is well underway. According to a 2012 Pew Internet Project Research Report, 72 % of U.S. Internet users say they have sought health-related information in the past year. Over 30 % of U.S. adults say that they have searched for information to identify a medical condition that they or someone else might have, and 18 % say they’ve gone online to find others who share their health concerns or conditions. In interpreting the meaning of their survey results for the public, Pew Report uses a number of bolded headings to characterize the attitudes of Internet-users, using “patient-reported” speech.<sup>6</sup> One heading, in summarizing survey results pertaining to health-seeking practices, states, “*I don’t know, but I can try to find out’ is the default setting for people with these health questions*” (Fox, 2012). Another heading used says that, “*I know, and I want to share my knowledge’ is the leading edge of health care*” (Fox, 2012). Placing the survey results under these two headings, the Pew Report draws upon the rhetorical salience of patient agency as the capacity *to know*: when people don’t have salient medical knowledge they can find out and when they know they are *able to* track and share. This presumed capacity to know constitutes both the “default setting” of Internet-health users and the “leading edge” of health care.

A common Internet-health practice that has become particularly fraught for medical humanities, health communication, and media scholars (not to mention health care professionals) is seeking and

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<sup>6</sup> In a recent article, “*Textual Standardization and the DSM 5 ‘Common Language,’*” Patty A. Kelly defines patient-reported speech as “a speech intersection between two authors or speakers, where one reports the voice of another” and says that it represents the intersection of two contexts: “the reported context (prior discourse) and the reporting context (the current iteration)” (Kelly, 2014, 176).

tracking health risks.<sup>7</sup> In a society whose layers are deeply permeated by risk discourse, it is not surprising that the Internet has become a tool for acquiring information about risks to health status (Beck, 1994). “Lifestyle risks” have become buzzwords. As Kay Richardson points out, “Consumer/citizens of the late 20<sup>th</sup> and early 21<sup>st</sup> century have been invited to apprehend life as a hazardous enterprise and to pay attention to news and information about public health issues so as to make lifestyle choices from an informed position” (Richardson, 2003, 171). When used for health-seeking purposes, the Internet affords the opportunities (not to all—the digital divide persists) to track down not only common health threats, but also *personalized* threats to health-status through the use of interactive tools. One of these is the pervasive online health quiz.

One can hardly visit a health information site such as Webmd.org without encountering popups for self-administered diagnostic quizzes that advertise themselves by posing a question such as, “Do you know *your* risk of X disease?” Self-diagnostic questionnaires pertaining to mental health are of rhetorical interest in particular, since these tests measure symptoms that are complex and not always physically obvious. These have become commonplace; when conducting an internet search for the term ‘depression,’ the first two related search terms to appear are “depression quiz” and “depression test.” After answering a series of questions pertaining to moods and behaviors, the user is typically presented with a “risk profile.” These risk profiles are comprised of categories the range from “Low Risk” to High Risk.” Low-Risk users are encouraged to repeat the test in two weeks, paying special attention to moods and behaviors in the intervening time. There is not a “No Risk” category and so the test suggests that vigilance is warranted. A continued demonstration of agentive health behaviors, such as tracking down and continually monitoring

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<sup>7</sup> White and Horvitz have argued that the Internet can leave users with a distorted sense of health risk, since an internet search for a common symptom like “headache” does not result in a list of results ordered according to likelihood (White and Horovitz, 2009). Often, the top search results pertain to severe and rare conditions, not the commonest ones. They coin the term “cyberchondria” to refer to the ways in which Internet use can propel users toward tendencies of hypochondria.

health hazards, is the prescription for those living within risk categories. This includes, ostensibly, everyone.<sup>8</sup>

In the context of contemporary health-talk, the pursuit of health entails knowing our risks. In the age of Internet health, there is always more knowledge about health risks that can be sought. These risks come in all forms, from food to sex to cavity fillings. As the realm of things that one *can* know about the body expands, the Socratic notion that *all knowable things are worth knowing* is strengthened. The task of the agentive patient, then, grows longer and longer with every freshly publicized risk factor and every new screening test that becomes available. When rhetoricized as the capacity *to know*, a paradox of patient agency is that with every new piece of knowledge one becomes increasingly aware and fixated upon that which is not yet knowable. In this sense, increased knowledgeability about health-status (and especially, risks to it) is accompanied by a deeper understanding that not all risks are knowable. The knowledgeable patient is aware that the task of tracking down and indexing this knowledge is ongoing and even infinite. As a result, knowledgeability gives rise to a phenomenon that Crawford terms a “the spiral of anxiety and control.” He says,

Health-conscious people live with the knowledge of a gap between prescriptive advice and what one actually does or can do. They also live with the knowledge that, no matter how much one complies with the rules of health, dangers far exceed the personal capacity for protection through lifestyle changes and other preventive actions and that still more dangers remain hidden or soon to be discovered (Crawford, 2004, 507).

In this spiral of anxiety and efforts to control, attempts to quell worry through the acquisition of knowledge leads to renewed worry about threats that lie in wait, yet to be discovered, which in turn leads to additional attempts to quell the heightened anxiety through knowledge acquisition.

When patient agency is rhetoricized as the capacity *to know* it is arguably the case that the knowledgeable patient-agent reaches an epitomized form, ironically, in the much-maligned medical figure of the hypochondriac. The hypochondriac is constantly tracking symptoms, asking questions such as “What sorts of physical sensations am I experiencing and what am I to make of them?” and

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<sup>8</sup> For more on these self-diagnostic quizzes, see Kimberly Emmons’ *Black Dogs and Blue Worlds: Depression and Gender in the Age of Self Care* (Emmons, 2009).

tirelessly seeking out knowledge about risks to health-status. Not only this, the hypochondriac is highly knowledgeable about the nature(s) of medical knowledge and expertise. Catherine Belling's *A Condition of Doubt: The Meanings of Hypochondria* argues that the hypochondriac, despite lacking claim to substantiated evidence of medical threat, cannot ever be proven *wrong* once and for all (Belling, 2012). There are always possibilities, however slim, of which the hypochondriac is keenly aware, that her 'negative' test results are false negatives, that the symptoms that plague her have not yet been medically categorized as an illness, that her time-constrained physician is failing to notice a vital piece of information. Furthermore, the hypochondriac's central assertion and greatest fear—that she is dying, that she can never be entirely “in control” of her body—is an assertion about which she is ‘objectively’ correct. While the rhetoric of patient agency as the capacity *to know* suppresses consideration of *bodily contingency* in favor of discourses and practices that emphasize *bodily control*, we cannot escape the former by focusing only on the latter. Inevitably, we will all have experiences in which our bodies seem to be evading our control and defying our will.

### **“MY CHILDREN DON’T NEED TO FEAR THEY WILL LOSE ME”: PATIENT AGENCY AS THE CAPACITY TO PREVENT**

When patient agency is rhetoricized as knowledgeability, it is never too far from a second rhetoric of patient agency: the capacity *to prevent*. What is the knowledge of risk good for if not for preventing the materialization of risks? In the last several decades, the technological means for early detection and monitoring have expanded dramatically and so, too, have the scope and frequency of recommended screening tests. Even patients without symptoms or family histories suggestive of heightened risk are encouraged to undergo annual screenings for various ailments since, as the saying goes, “An ounce of prevention is better than a pound of cure.” In the context of preventive medicine, even the ‘healthiest’ individuals are rendered into what Nikolas Rose has termed “prepatients” or those “existentially healthy” individuals who have come to be understood as “asymptomatically ill” (Rose, 2007, 19-20).

For ‘prepatients,’ a lack of symptoms or of family histories that suggest heightened risk does not necessarily negate the need to stay on the alert. The patient who actively seeks out this knowledge, in the name of risk-mitigation and prevention, is often described as and lauded for “becoming educated” and “taking control” of her

risks and thus of her life.<sup>9</sup> “Education” and “control” are implied to be not only laudable goals, but responsibilities. This sense of responsibility for preventing risks from becoming reality is a *dual responsibility*: It is something that one “owes” to oneself and to a collective that consists of loved ones and the greater public. Given that screening and detection are tools that help systemically manage health care costs, prevention has become a collective interest. The actions taken *to prevent* are thus imbued with an ethical quality, since caring for oneself amounts to caring for others.

One area of preventive medicine where this dual responsibility becomes especially pronounced is genetic screening. These screenings are commonly used to assess risk for ailments like heart disease, various cancers, and other diseases both rare and commonplace. Direct-to-Consumer Genetics has made accessing these tests even easier, given the appropriate finances. One can simply order the test and have it delivered to one’s home, where the test is taken and sent back to a laboratory for screening. Usually, the individual needs only to swab a piece of cotton in the mouth before sending the sample to a laboratory. Some time later, the consumer will receive a report about his or her genetic predispositions and risk factors. These tests identify a range of genetic predispositions that a patient has, from breast cancer to sickle cell anemia and many other conditions rare and common. These tests are marketed directly, typically without any governmental regulation or oversight, to consumers in the form of television and radio advertisements, and most often the Internet. These tests have been thought to bolster patient agency, particularly since they circumvent the sort of institutional involvement that could lead insurance companies to increase premiums or terminate coverage (Majdik, 2009; 2011). Conversely, some argue that this lack of regulation might ultimately undermine patient agency because it might mean that test results are relayed carelessly to users, or that the test results themselves might be inaccurate (Lynch, 2011).

Enthusiasm over the potential of genetic testing was not always as pronounced as it is now. Initially, the birth of genetic testing was met with caution about problematic future uses. Would this genetic knowledge be used to engineer the ideal child, for instance? A sense of unease about genetic power has dimmed, but not dissolved

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<sup>9</sup> For instance, see the framing of the following Mayo Clinic article on diabetes prevention: <http://www.mayoclinic.org/diseases-conditions/type-2-diabetes/in-depth/diabetes-prevention/art-20047639>.

entirely. Early fears about how genetic power might eventually “control” us and our endless human appetites for enhancement have not gone away entirely. It seems, however, that the pendulum has swung in the opposite direction (Coors, 2003). Now, we more often think of genetic power in terms of how we can use it to put ourselves in control via risk detection and mitigation rather than the other way around.

Within the discourses of genetic testing, especially Direct-to-Consumer Genetic testing, the concepts of control and personal responsibility come to the forefront. In their exploration of the metaphorical language used to describe genes and genetics in public discourse, Celeste Condit and Deirdre Condit argue that the desirability of the “recipe” metaphor for genetic testing (as opposed to the “blueprint” metaphor) comes from its “implicit appeal to an active human agent in control of the process” (Condit and Condit, 2001, 34). The recipe metaphor implies that we rather than our genes are the ultimate determiners of our destinies. Despite the uniqueness of our genetic codes, our genetic destinies are linked. The knowledge we acquire about our genetic predispositions will be translated into courses of action that have an impact on others. As Carlos Novas and Nikolas Rose explain,

When an illness or a pathology is thought of as genetic, it is no longer an individual matter. It has become familial, a matter both of family histories and potential family futures. In this way genetic thought induces “genetic responsibility”—it reshapes prudence and obligation, in relation to getting married, having children, pursuing a career and organizing one’s financial affairs (Novas and Rose, 2000, 486).

The sense of dual responsibility implied by the rhetoric of patient agency as the capacity *to prevent* recently became a topic of public discussion when actress Angelina Jolie published a letter in the *New York Times*. The letter, entitled “My Medical Choice,” explained her decision to undergo prophylactic double mastectomy after learning that she had a genetic predisposition for breast and uterine cancer. In the letter, she defends her decision by, in essence, gesturing toward the dual responsibility that prevention has come to entail, stating, “I can tell my children that they don’t need to fear they will lose me to breast cancer... I want to encourage every woman, especially if you have a family history of breast or ovarian cancer, to seek out the information and medical experts who can help you through this aspect of your life, and to make your own informed choices” (Jolie, 2013).

The public response to this letter was overwhelmingly positive. Letters to the editors of the *New York Times* tended to emphasize Jolie's bravery, empowerment, and generosity, both in the decision itself to undergo the double mastectomy and the decision to publicly share her experience and knowledge with others. One of the few exceptions to the public embrace of Jolie's statement came from musician and breast cancer survivor Melissa Etheridge, who expressed her opinion to *Washington Blade* (DiGuglielmo, 2013). According to her, Jolie's choice was rooted in fear, not bravery. The evolution of genetic screening methods and preventive treatments will inevitably make the distinction between "fear-based" and "bravery-based" choices hotly contested rhetorical ground, and will force consideration of what exactly one becomes an *agent of* when making these choices: an agent of empowerment or an agent of anxiety?

When patient agency is rhetoricized as the capacity *to prevent*, it complicates ingrained Western notions that our health subjectivities are individuated, bounded, and autonomous. Yet the rhetoric of patient agency as the capacity *to prevent* implies a range of other people who merit consideration when we make healthcare decisions for ourselves. This, in turn, might imply that our health subjectivities aren't so individuated after all—they are bonded. The rhetoric of bonded health subjectivities has democratic appeal, and could be deployed to argue that we should take better care of one another by, for instance, promoting wider access to affordable health care. But in public discussions of health care policy (e.g. "Obamacare") the social dynamics of health have more often been instrumentalized as a tool for arguing that those with "preventable illnesses" or "lifestyle illnesses" are "draining the system" with their irresponsible decisions.<sup>10</sup> After all, so the logic goes, they are ultimately "in control" of their own health destinies, and that *could have* made other choices. Within the rhetoric of patient agency, the "*could have*" lapses often and subtly into the "*should have*." While preventing health risks from materializing is framed as a matter of *social* responsibility, the failure to do so is a *personal* failing. This moralization of preventive health products and services can become especially problematic when considering the democratic accessibility of these products and services. It is possible that the rhetorics of prevention will continue to obscure questions of cost and accessibility. In this case, preventive treatments will become

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<sup>10</sup> See, for instance: <http://abcnews.go.com/Health/Diet/story?id=3683683>. This is an old *topos*, going back to the heyday of eugenics a century ago.

yet another of the many health “dividing practices” that reinforce stratification between those who are well-equipped to promote their overall health-status and those who are not.

### **“RESTORING A SENSE OF CONFIDENCE AND CONTROL THROUGH CHOICE”: PATIENT AGENCY AS THE CAPACITY TO DECIDE**

The rhetorics of patient agency as the capacity *to know* and the capacity *to prevent* overlap with a final rhetoric of patient agency: the capacity *to decide*. Charges of paternalism and power asymmetry have long plagued the medical profession, voiced notably by sociologists, rhetoricians, and feminist theorists. Sociologist Elliot Freidson argued that medicine has been the dominant profession, mostly because of its freedom from market dictates, and that other professions have attempted to model themselves after its autonomy (Freidson, 1970). In the heyday of medicine’s professional dominance, a doctor’s decisions were thought to be *orders* handed down to patients, not dialogues to be had with them. Some have begun to question whether such a period of intense professional dominance and paternalism ever truly existed outside of the scholarly literature, but it seems clear enough—especially given the body ‘compliance’ literature<sup>11</sup>—that patients have long been imagined as passive, inert bodies whose main options are either to comply with or to defy doctors’ decisions, as opposed to authoring decisions on their own terms (Coburn, 2006).

The rhetorical dynamics of medical decision-making have shifted considerably since the days of “doctor’s orders,” perhaps at least in part, for the oft-claimed purposes of ‘returning power’ back to the patients, but perhaps, too, for other reasons, such as administrative concerns over legal liability and employers’ interests in shifting a greater burden of insurance costs to their employees.<sup>12</sup> Regardless of underlying motivations, the concept of patient-driven decision-making has generated much discussion, especially as it concerns two of the most significant medical events of an individual’s life: birth and death. These have become events over which the patient is now given greater decision-making responsibility than in decades past. Patients are encouraged, and in

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<sup>11</sup> See Segal for a description of the rhetorical shift from compliance to concordance (Segal, 2007).

<sup>12</sup> See Crawford for more about how the current economic climate has, in part, helped transform “health-talk” into “responsibility-talk” (Crawford, 2006).

some cases required, to make decisions mediated by a simple sheet of paper regarding their preferences to receive or decline various technological interventions during labor and end-of-life care.

In the context of end-of-life care, patients in some hospitals are given worksheets called “Patient Preferences Forms.” After consulting with physicians, they are asked to choose, often in conjunction with or under the guardianship of family members, whether they would like to receive treatment such as antibiotics, transfusions, defibrillation, tube feedings, intubation, chest compressions, etc. Up until the 1970s it was the case that physicians were primarily responsible for selecting from these options in private bedside or hospital room conversations with patients, their families, and sometimes other colleagues. Lisa Keränen has carefully explored the rhetorical problematics of these forms and the ways in which they reflected and facilitated the shift toward patient agency. She says, “Patients, prodded by the autonomy movement, and administrators, activated by the bottom line, called physicians’ previously unassailable authority into question” (Keränen, 2007, 374).

While it seems difficult to argue against giving patients greater agency and choice in the context of a decision as intimate and irrevocable as end-of-life care, the Patient Preferences Worksheet can rhetorically delimit patients’ options for making sense of the dying process. The Patient Preference Worksheet, according to Keränen, “is deployed in the name of promoting patient autonomy and encouraging sound medical decision-making, [but] the Worksheet frames decisions as matters of technological as opposed to moral agency, and cultivates a radical restructuring of deathbed subjectivity” (Keränen, 2007, 372). This radical restructuring of deathbed subjectivity ultimately *limits the vocabularies* through which patients and their families can think and speak about dying and of what constitutes a “good” death.

Patient-authored birth plans function in ways that are similar to the “Patient Preferences” worksheet. Birth plans allow expectant mothers to indicate which medical treatments they prefer to receive or decline in the event of childbirth. These choices include treatments such as fetal monitoring, pain relief, epidural, episiotomy, etc. On its webpage, the American Pregnancy Association (APA) suggests that one of the primary functions of the birth plan is “to restore a sense of confidence and control.” Restoring patients’ sense of control is important because, as APA explains, “During childbirth, many women feel like they are losing control. A birth plan helps many women maintain their focus and regain a measure of control even if unexpected events occur”

(“Creating Your Birth Plan,” 2015). When authoring a birth plan, the page suggests that women draw upon, “the power of positive thinking...instead of making a list of what you don’t want, use words like ‘we hope to’ or ‘we plan to’ or ‘we anticipate.’” Women are dissuaded from using negatively framed terms such as ‘we don’t want’ or ‘we won’t use.’ Despite its purported benefits of restoring a sense of control and choice, however, the APA’s suggestions for filling out the form undercut those very benefits by stipulating the *sorts* of control and choice that are preferable. In this case, ‘we’ language suggests that control over the event is not exclusive but shared, ostensibly with a partner and/or medical personnel. Additionally, women are encouraged to minimize the degree of conviction of their choices by using qualifiers like ‘hope to’ rather than ‘do not want.’

The rhetorics of decideability embedded within the birth plan prompted Monica Crossley to conduct an autoethnography of her own childbirth experience in which she mediates upon the false notion of choice with which expectant mothers are presented. She states that,

In order for me to have made a genuine choice in this process, a number of conditions would need to have been fulfilled... First, I would need to have had genuine desires and preferences. Second, I would need to have had an understanding of the situation I was in and the options open to me. Finally, I would need to have had some means or technique of weighing up the potential outcomes and arriving at a decision (Crossley, 2007, 558).

The mere availability and utilization of birth plans as well as Patient Preferences worksheets does not guarantee that any of these three conditions will be met. What about the patient without an understanding of the situation and the possibilities open to him or her? Like the Patient Preferences Worksheet, it is possible that the birth plan constrains choice by offering *certain kinds* of choices. The technical, institutionalized framing of the birth plan, with its emphasis on technological intervention, obscures other factors of the birthing process that might be important to patients. What, too, about the patient who does not fulfill the first criterion: the patient without genuine preferences or desires? In other words, how do we account for the patient who *prefers not to choose*? In a scenario such as this, the patient who seeks expertise and guidance but is offered instead a platter of under-contextualized options could, according to Colleen Derkatch, damage the patient-physician relationship and “compromise individuals’ feelings of control and

confidence over their states of health” (Derkatch, 2010, 145). The rhetoric of patient agency as the capacity *to decide* makes it difficult to consider a patient without preferences.

These examples illustrate that while many contemporary medical practices are purportedly designed to ‘restore power’ to the patients and liberate them from the past sins of an overly domineering and paternalistic medicine, the effects are not always experienced as empowering. For example, Crossley explains that after being admitted to the hospital, despite having authored a birth plan which stated a preference for home birth, she “didn’t sleep, but just felt the sense of relief flood over me—at last, someone was taking things out of my hands and I could allow myself to ‘let things go,’ if only because that’s what the medical staff were telling me I had to do” (Crossley, 2007, 553). In this case, being relieved of the obligation to decide came closer to fulfilling her true “preferences” than did the birth plan that was designed to promote them. When a stated preference is not followed because of some unforeseen circumstance or complication, it can seem as though the author has somehow “failed” to live up to her own medical decisions. Likewise, when a chosen preference leads to an undesirable medical outcome, the weight of the decision might feel as though it is resting solely on the patient’s shoulders. Just as the dictate to choose can sometimes be disempowering, the freedom from *having to choose* can be liberating. Within the rhetoric of patient agency as the capacity *to decide*, however, the notion that freedom from choice can be liberating is incoherent. The patient who prefers not to choose loses access to the language of patient agency.

## **CONCLUSION: TOWARD BALANCING A SENSE OF CONTROL WITH A SENSE OF THE CONTINGENT**

Kenneth Burke has said that contradictions in terms, like “patient agency,” are always worthy of attention, because they reflect contradictions in our lived experiences (Burke, 1964). Each of the three rhetorics of patient agency described in this essay come packaged with notions of control that, when pushed to the limit, are paradoxical, if not contradictory. In the case of patient agency as the capacity *to know*, the patient becomes knowledgeable through the acquisition and tracking of threats to health, which can result in anxiety, which is itself a threat to health. While medical literature suggests that the active acquisition of health-information is a practice through which consumers become “empowered,” it is also a defining practice of the hypochondriac. Within the rhetoric of patient agency as the capacity *to prevent*, one’s unique,

individuated health risks, especially one's genetic risks, are translated into a matter of collective concern and responsibility. When patient agency is rhetoricized as the capacity *to decide*, the obligation to choose can actually feel disempowering; sometimes, *freedom from having to choose* feels more liberating.

The rhetorics of patient agency identified here are all, at root, concerned with the promotion of *control*: control through knowledge, control through prevention, and control through choice. One antonym of "control" is "chance," and it is undeniably the case that much of what happens to our bodies results *by chance*, through contingencies over which we are not always able to exercise control. Many of our health practices and much of our health discourse is structured around the continued denial of contingencies. After a mastectomy, for instance, women will usually be offered the option of a prosthetic breast. Unlike a limb, this prosthetic will serve no "practical" function like walking or grasping, but it will serve a function nearly as important: to restore an impression of the body's controllability in a society in which control is an important ingredient in the cultivation of desirable health subjectivities.

Arthur Frank describes the rare virus that caused his near-fatal heart attack as highly contingent. This virus, he points out, *could have acted otherwise*. And this sort of contingency characterizes nearly all of the most-feared conditions with which we might someday find ourselves afflicted (Frank, 1995). Malignant tumors start off as 'normal' cells that do not die when they are supposed to and start to produce new cells when the body does not need them. These cells *could have acted otherwise*. Strokes result from the disturbed behavior of blood that *could have acted otherwise*. While the rhetorics of patient agency persuade us that we have ultimate control and responsibility over our bodies and health, at some point in our lives the ultimate uncontrollability of our bodies will be made apparent to us.

The rhetorics of patient agency merit continued scrutiny on the part of rhetoricians and other scholars of communication. We should continue to ask ourselves how and in what circumstances these rhetorics allow for the increased moralization of health discourses and practices. Furthermore, we should question to whom these forms of patient agency (and the time and cost they entail) are likely to be inaccessible. In other words, we should continue asking: who is well-equipped to become "an agent" of her/his own health given current conceptualizations of patient agency, and what does this mean for those who are ill-equipped? As we remain mindful of these questions and continue to scrutinize the

rhetorical dynamics of patient agency, we might begin to imagine new rhetorics of patient agency, especially those that allow for the acknowledgment of *contingency*. Feminist scholars, among others, have already begun rethinking agency as relational, as a property that arises from and is embedded and exercised within a web of social relationships (Mackenzie and Stoljar, 2000). Thinking of patient agency in this way might help to mollify some of the more problematic aspects of patient agency as described throughout this essay, including the tendency to obscure consideration of who is well-equipped to become an agent and who is not, as well as the underlying implication that we have ultimate control as individuals over our health when we know that factors outside of our control can affect our health in important ways. As the shifting medical landscape promises to continue complicating notions of patient agency, rhetorical scholarship promises to regard these complications as important opportunities for rhetorical invention.

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## Reference List

- Belling, C. *A Condition of Doubt: The Meanings of Hypochondria*. Oxford: Oxford University Press, 2012.
- Beck, U. *Risk Society: Towards a New Modernity*. London: Sage Publications, 1992.
- Burke, K. *A Grammar of Motives*. Berkeley: University of California Press, 1964.
- Coburn, D. "Medical Dominance Then and Now: Critical Reflections." *Health Sociology Review: The Journal of the Health Section of the Australian Sociological Association* 15 (2006): 432–443.  
<http://dx.doi.org/10.5172/hesr.2006.15.5.432>
- Condit, C. and D. Condit. "Blueprints and Recipes: Gendered Metaphors for Genetic Medicine." *Journal of Medical Humanities* 22 (2001): 29–39.
- Coors, M. "A Foucauldian Foray into the New Genetics." *Journal of Medical Humanities* 24 (2003): 279–289.
- Crawford, R. "Healthism and the Medicalization of Everyday Life." *International Journal of Health Services* 10 (1980): 365–388. <http://dx.doi.org/10.2190/3h2h-3xjn-3kay-g9ny>

- “Health as a Meaningful Social Practice.” *Health (London)* 10 (2006): 401–420.  
<http://dx.doi.org/10.1177/1363459306067310>
- “Risk Ritual and the Management of Control and Anxiety in Medical Culture.” *Health (London)* 8 (2004): 505–528.  
<http://dx.doi.org/10.1177/1363459304045701>
- “Creating your Birth Plan.” *American Pregnancy Association* (2014): <http://americanpregnancy.org/labor-and-birth/birth-plan>, accessed 4/21/14.
- Crossley, M. “Childbirth, Complications and the Illusion of ‘Choice’: A Case Study.” *Feminism & Psychology* 17 (2007): 543–63. Print. <http://dx.doi.org/10.1177/0959353507083103>
- Derkatch, C. “Does Biomedicine Control for Rhetoric? Configuring Practitioner-Patient Interaction.” In Leach, J. and D. Dysart-Gale (Eds.) *Rhetorical Questions of Health and Medicine*. (Pp. 129–153). Lanham: Lexington Books, 2011.
- DiGuglielmo, J. “Rippin’ & Tearin’ & Strippin’.” *Washington Blade*. (2013):  
<http://www.washingtonblade.com/2013/06/13/rippin-tearin-strippin/>, accessed 3/13/14.
- Eysenbach, G. “Medicine 2.0: Social Networking, Collaboration, Participation, Apomediation, and Openness.” *Journal of Medical Internet Research* 10 (2008):  
<http://dx.doi.org/10.2196/jmir.1030>.
- Fox, S. “2012 Health Survey Data.” *Pew Research Centers Internet American Life Project RSS* (2013):  
<http://www.pewinternet.org/2013/02/11/2012-health-survey-data>, accessed 6/14/14.
- Frank, A. *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: University of Chicago Press, 1995.
- Freidson, E. *Professional Dominance: The Social Structure of Medical Care*. New York: Atherton Press, 1970.
- Graham, S. “Agency and the Rhetoric of Medicine: Biomedical Brain Scans and the Ontology of Fibromyalgia.” *Technical Communication Quarterly* 18 (2009): 376–404.  
<http://dx.doi.org/10.1080/10572250903149555>
- Jolie, A. “My Medical Choice.” *The New York Times*. (2013):  
<http://www.nytimes.com/2013/05/14/opinion/my-medical-choice.html>, accessed 9/24/2014.

- Keränen, L. "Cause Someday We All Die: Rhetoric, Agency, and the Case of the 'Patient' Preferences Worksheet." *Quarterly Journal of Speech* 93 (2007): 179–210.  
<http://dx.doi.org/10.1080/00335630701425100>
- "Public Engagements with Health and Medicine." *Journal of Medical Humanities* 35 (2014): 103–09.
- Kelly, P. A. "Textual Standardization and the DSM-5 'Common Language.'" *Journal of Medical Humanities* 35 (2014): 171–189. <http://dx.doi.org/10.1007/s10912-014-9281-9>
- Kline, W. "Please Include This in Your Book': Readers Respond to Our Bodies, Ourselves." *Bulletin on the History of Medicine* 79 (2005): 81–110.  
<http://dx.doi.org/10.1353/bhm.2005.0030>
- Leff, M. C. "Tradition and Agency in Humanistic Rhetoric." *Philosophy & Rhetoric* 45 (2012): 213–226.  
<http://dx.doi.org/10.5325/philtrhet.45.2.0213>
- Lemire, M, *et al.* "Internet Use and the Logics of Personal Empowerment." *Health Policy* 88 (2008): 130–140.  
<http://dx.doi.org/10.1016/j.healthpol.2008.03.006>
- Lynch, J. "Information at the Intersection of the Public and Technical Spheres: A Reply to Majdik." *Rhetoric & Public Affairs* 14 (2011): 369–378.  
<http://dx.doi.org/10.1353/rap.2010.0220>
- Mackenzie, C. and Stoljar, N. *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*. New York: Oxford University Press, 2000.
- Majdik, Z. P. "Judging Direct-to-Consumer Genetics: Negotiating Expertise and Agency in Public Biotechnological Practice." *Rhetoric & Public Affairs* 12 (2009): 571–605.  
<http://dx.doi.org/10.1353/rap.0.0123>
- "On Delimiting Rhetorical Invention in Biopolitics: A Rejoinder to Lynch." *Rhetoric & Public Affairs* 14 (2011): 379–89. <http://dx.doi.org/10.1353/rap.2010.0221>
- Malkowski, J. "Beyond Prevention: Containment Rhetoric in the Case of Bug Chasing." *Journal of Medical Humanities* 35 (2014): 211–228. <http://dx.doi.org/10.1007/s10912-014-9280-x>
- Martins, D. "Compliance Rhetoric and the Impoverishment of Context." *Communication Theory* 15 (2005): 59–77.

- Miller, C. "What Can Automation Tell Us About Agency?" *Rhetoric Society Quarterly* 37 (2007): 137–157.  
<http://dx.doi.org/10.1080/02773940601021197>
- Metzl, J., and A. Kirkland. *Against Health: How Health Became the New Morality*. New York: New York University Press, 2010.
- Novas, C. and N. Rose. "Genetic Risk and the Birth of the Somatic Individual." *Economy and Society* 29 (2000): 483–513.  
<http://dx.doi.org/10.1080/03085140050174750>
- Richardson, K. "Health Risks on the Internet: Establishing Credibility Online." *Health, Risk & Society* 5 (2003): 171–184.  
<http://dx.doi.org/10.1080/1369857031000123948>
- Rose, N. "The Politics of Life Itself." *Theory, Culture & Society* 18 (2001): 1–30.
- *Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century*. Princeton: Princeton University Press, 2007.
- Segal, J. "'Compliance' to 'Concordance': A Critical View." *The Journal of Medical Humanities* 28 (2007): 81–96.  
<http://dx.doi.org/10.1007/s10912-007-9030-4>
- *Health and the Rhetoric of Medicine*. Carbondale: Southern Illinois University Press, 2005.
- "Internet Health and the 21st-Century Patient: A Rhetorical View." *Written Communication* 26 (2009): 351–369.  
<http://dx.doi.org/10.1177/0741088309342362>
- Segal, L. "The Importance of Patient Empowerment in Health System Reform." *Health Policy* 44 (1998): 31–44.  
[http://dx.doi.org/10.1016/s0168-8510\(98\)00007-4](http://dx.doi.org/10.1016/s0168-8510(98)00007-4)
- Stone, M. S. "In Search of Patient Agency in the Rhetoric of Diabetes Care." *Technical Communication Quarterly* 6 (1997): 201–217.  
[http://dx.doi.org/10.1207/s15427625tcq0602\\_5](http://dx.doi.org/10.1207/s15427625tcq0602_5)
- White, R. W. and E. Horvitz. "Cyberchondria: Studies of the Escalation of Medical Concerns in Web Search." *Microsoft Research* (2008):  
<http://research.microsoft.com/apps/pubs/default.aspx?id=76529>, accessed 4/4/2014.