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The paradox of patient consent: A feminist perspective of illness and healthcare

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**The paradox of patient consent:
A feminist account of illness and healthcare**

Through autoethnographic analysis, I present my personal illness story as a case study in patient consent. In doing so, I explore the complexities that emerge at the intersection of gender and health, including issues of autonomy and choice. Specifically, I reflect on the ideological and systemic factors that contribute to a paradox of consent versus non-compliance in US healthcare contexts. Within this paradoxical binary, control is both persistent and illusive, which is a condition fueled by individualism, paternalistic antagonism, and medical colonization. As an alternative, I offer two viable options for facilitating patients' agency in gendered health contexts, even under marginalizing conditions.

Keywords: consent, autonomy, choice, care, gender

Please make note of our ‘Care Plan Noncompliance Policy.’ Your doctor and [name of physician’s office redacted] are dedicated to providing the highest quality care to all of our patients. Due to the high frequency of patients failing to follow through with our recommendations for medical care, it has become necessary to notify patients of the following: 1) Lack of follow through with our care recommendations constitutes ‘care plan noncompliance.’ 2) We reserve the right to dismiss patients from our practice in situations of care plan noncompliance.¹

-February 20, 2017

After five years, three surgeries, office visits with more than a dozen different medical specialists, a referral, and a plea, I finally found a primary care physician who was willing to take me on as a patient. Someone willing to help me pull the complex threads of my medical history together and begin fashioning them into a recognizable pattern. Then, I received an envelope in the mail with my new patient paperwork and the notice above tucked inside, nonchalantly bringing me back to earth. To some, it may seem routine, a reminder of overwhelming patient caseloads in an inefficient healthcare system. To me, the placement of the word *care* in such close proximity to the word *noncompliance* is jarring, the threat of dismissal is triggering, and the declaration of *policy* is sobering. This is my breaking point. I have spent half a decade thinking about, recording, and sharing my illness story with a relatively small circle of friends, family, and colleagues but the above eighty-seven words compel me to broaden my audience.

Over the past 5 years, I have acquired an impressive record of medical diagnoses and endured progressively complicated medical procedures. It started with an acute onset of gallstones, for which I underwent a cholecystectomy (surgical removal of the gallbladder). Then, less than one-year later came my chronic illness diagnosis, Crohn’s disease, an autoimmune disease that causes inflammation of the intestines and brings with it a lifetime of unpredictable symptoms and complications. This diagnosis led to an ileocecal resection (surgical removal of

¹ Names of physicians, family members, and prescription medications have been removed for privacy and legal protections.

the terminal ileum portion of my small bowel) and requires ongoing bi-monthly intravenous medication. One year after my Crohn's diagnosis, I was alerted to a stealthy "liminal illness" (Forss, Tishelman, Widmark, & Sachs, 2004), cervical adenocarcinoma in situ, which is an early stage of cervical cancer that required close on-going monitoring for two years and eventually resulted in a hysterectomy. To an outsider, these appear as three different, unrelated diagnoses, but their relationship is actually quite complicated and confounded by gender-based erasure and marginalization in the US healthcare system. In an effort to untangle the intricacies of acute, chronic, and liminal illness as they intersect with gender, I offer my illness story as a case study.

Since acquiring these diagnoses, I have encountered many social situations that evoke my illness story. The way I tell this story changes depending on context and audience but one thing always remains consistent; I qualify my story by first acknowledging its implausibility. I presume that people will feel or react this way for many reasons. First, because we are socialized to doubt experiences of illness (Ware, 1992), especially those felt by women (Werner, Isaksen, & Malterud, 2004; Werner & Malterud, 2003). Second, because even I am still in disbelief at how quickly my life seems to have spiraled out of my control and landed deep inside the labyrinth of the biomedical industrial complex.

Similar to many other illness stories, control has been a central theme in my health journey. I mourn a loss of agency while justifying every decision I make as I search for promises of autonomy. Each time I think I have gained control, I watch it slip through my fingers again at every doctor's appointment and with every new symptom. As a patient, a feminist, and an academic, this journey has left me questioning: How do we make sense of the ever-changing locus of control in healthcare? How can we understand agency and autonomy in the face of complicated, ongoing illness as it intersects with gender? What do manifestations of control,

agency, and autonomy potentially teach us about contemporary ideologies of gender and health? In order to offer potential yet precarious answers to these questions, I construct here a layered, analytic autoethnographic account (Chang, 2016; Ellis, 2004; Ronai, 1995) of my experiences navigating the complexities of US healthcare. Specifically, I use personal-narrative data to generate a thematic analysis, which illuminates conceptual and theoretical considerations for health communication, particularly with regards to patient-centered care.

Through my personal narrative account, I explore the intricacies of consent, autonomy, and choice by reflecting on the ideological and systemic factors that contribute to my positionality in the margins of biomedicine. This positionality is paradoxical in that I find myself tirelessly caught between the binary forces of consent and non-compliance. If I comply then I consent and this choice makes me an advocate for my own healthcare. If I do not consent then I am non-compliant and this choice makes me responsible for my own lack of healthcare. Within this paradox, autonomy is both persistent and intermittent and choice is both real and illusive. To develop a layered account of this paradox, I first provide an overview of relevant literature that frames and questions prevailing perspectives within health communication, into which my own narrative experiences convene. This overview is followed by a deeper methodological explanation and an analytic excavation of my personal narrative.

Feminist Accounts of Health

Autoethnographic accounts of gender and illness offer important insights into erasures of subjectivity and credibility, hegemonic views and structures that affect care, the complexities of negotiating identity and visibility, and advocating for specific needs and desires in biomedical contexts (e.g., Edley & Battaglia, 2016; Birk, 2013; Defenbaugh, 2013; DasGupta & Hurst, 2007; Ettore, 2005). Feminist analyses of the gendered and unequal dynamics of healthcare also

offer critical insights into identity, embodiment, and oppression in contemporary biomedicine. Many feminist scholars have considered the ways that women and minorities are individually discriminated against, systematically disadvantaged, and normatively constituted through patient-provider interactions, organizational and political constraints, and societal expectations of health (e.g., Davis, 1999; Kuhlman & Annandale, 2012; Lillie-Blanton et. al, 1999; Martin, 1999; Wamala & Lynch, 2002). Bridging these various threads of scholarship together, I aim to offer here an account of individualized manifestations of ideological and systemic power in the context of negotiating biomedical compliance and non-compliance. To organize these manifestations into a coherent interpretive framework, I turn to feminist perspectives on consent, specifically with attention to the concepts of autonomy and choice in healthcare.

Consent: Autonomy & Choice

The word consent carries with it a history of debate among feminist scholars (Drakopoulou, 2007). From varied disciplines, meanings of consent in political, legal, and sociocultural contexts have been widely contested. Questions include, can women really give consent under conditions of systemic oppression? And, does a woman's agency stem from her ability to give or deny consent? In order to engage with the concept of informed consent within the context of health and medicine, I begin by operationalizing the concepts of autonomy and choice as they are conceived in health communication and feminist literature.

Autonomy

Within healthcare, the principle of respect for patient autonomy is often touted as an ethical imperative in North America and much of Europe (Ells, Hunt, & Chamber-Evans, 2011; Sherwin, 1998b). Essentially, it is a standard of care whereby practitioners are obligated to facilitate informed consent among patients—meaning, patients are provided necessary

information to make their own medical decisions. In cases where patients are unwilling to consent or do not follow through with the commitments implied by their consent, these issues of noncompliance are generally considered a reflection of patient autonomy (Groenhout, 2010).

Literature in health communication often emphasizes the importance of patient-centered care, which is grounded in the principle of respect for patient autonomy. Two of the key functions of patient-centered care are involving patients in decision-making and providing them with the resources necessary for self-management (Epstein & Street, 2007). Care providers are discouraged from paternalistic decision-making (i.e., the provider making decisions for the patient); Instead, both provider and patient are encouraged to be actively involved in the decision-making process, thus emphasizing the needs and autonomy of the patient (Dean, 2017). There are several reasons why providers and advocates generally strive for facilitating patient autonomy. Most significantly, it holds the potential to mitigate power imbalances between patients and their providers, since ill patients and systemically disadvantaged groups are usually seen as subordinate to practitioners (Donchin, 1995; Sherwin 1998b). However, many feminist bioethicists query how much control patients really have in US biomedical contexts, even those motivated by patient-centered models of care.

The competency criteria implied by patient-centered models of informed consent often exclude historically marginalized groups who lack access to health literacy, are predisposed to assimilate in patient-provider contexts, and are commonly perceived by physicians as irrational and incompetent (Donchin, 1995; Groenhout, 2010; Sherwin, 1998b). Additionally, the assumption that patients can make reasonable decisions from available healthcare options ignores the fact that women and minorities are consistently underrepresented in the research that determines their available choices (Groenhout, 2010; Rogers & Ballantyne, 2008). To be free

from coercion, choice must exist in a sphere that is not tied to oppression. In healthcare, the ill, vulnerable, and marginalized are often coerced into decisions not by overt force but by the unequal and ideological nature of the healthcare system (Sherwin, 1998b).

Choice

The US healthcare system operates through, what Mol (2008) refers to as, *the logic of choice*, which encourages patients to desire and invest in making choices and having some level of control over their health. This logic constructs patients as consumers, citizens, and bodies/body parts to be managed and commodified through scientific knowledge and technological instruments (Mackenzie, 2010; Mol, 2008). First, patients are considered consumers who guide free-market healthcare through service and product demands. As such, they are expected to make choices based on market trends and their own market research, in which their agency is limited to either *choose* or *don't choose* between competing products. Second, in a democratic state, patients are cast as citizens who govern themselves and are defined by their ability to control themselves. Providers may serve as representatives or advocates but they are legally obligated to provide patients the opportunity to make their own decisions regarding treatment through explicit consent. Third, the logic of choice formulates healthcare, as a profession, into a linear, contractual, and scientific machine. Doctors present facts using scientific instruments and patients assess this information to make decisions regarding possible courses of action. Once a decision is made regarding a plan of care, patients are bound to their provider through a (theoretically, freely chosen) contractual relationship (Donchin, 1995).

Although the logic of choice promises to liberate patients from the “patriarchal rule” of health care providers, many patients are less concerned about who is making their decisions and

more concerned about what decisions they can and should make (Mol, 2008, p. 46). Research also shows that traditional, patriarchal models of care still reverberate in clinical settings so the individualistic push toward patient-centered decision making can unintentionally isolate patients in their choices (Ells, Hunt, & Chambers-Evans, 2011, p. 82). In other words, shared decision making may yield a higher burden of control while still leaving patients searching for answers alone. Additionally, in a scientific and contractual formulation of healthcare, patients are bound to technologies that are considered non-agentic but produce unpredictable side effects and results that doctors and science cannot always know or predict. Choice, then, is a matter of weighing the known advantages and disadvantages of medical possibilities in the moment a decision is made and these decisions are always bound to tentative and professionalized knowledge.

In sum, the principle of respect for patient autonomy and the logic of choice are individualistic orientations to medicine that task patients and providers with obtaining and rigorously evaluating complex information and advocating for reasoned decisions without deeply considering the broader social, historical, cultural, and institutional constraints that bear weight on available choices. Though these constraints may seem broad and abstract, they appear in everyday interactions and communication about health and illness; Though their implications may seem complex and unidentifiable, they are felt and experienced in daily life. My own illness story provides one extended example.

Autoethnography in Health Research

Methodologically, the following is an autoethnographic analysis; specifically, a thematic analysis that uses narrative snippets to inductively illuminate conceptual and theoretical commonalities across time within a singular story (Ellis, 2004). This analysis engages Ronai's (1995) argument for layered account. I interact with, reflect upon, and (re)construct emotional

dimensions of my experience alongside traditional methods of data collection and theoretical abstraction. I interweave transcribed data, personal reflection, and academic literature to facilitate a multi-perspectival narrative description, consideration, and examination that makes “accessible to the reader as many ‘ways of knowing’ as possible” (p. 397). To accomplish this, I follow Chang’s (2016) three criteria for autoethnography in health research.

First, I use personal experience as the “primary source of data” (p. 444). Unlike social scientific methodologies, where the researcher attempts to separate personal experience from data analysis, in autoethnography the researcher is both subject and object. Oscillating between these two positions allows for an insider perspective into the contexts, perceived intentions, and meanings that might otherwise be undiscoverable. Autoethnography also calls forth subjugated voices (Chang, 2016) and forefronts a feminist epistemology that embraces the positionality of writer/researcher as vital to what is observed and known (Sherwin, 1998a). Not only are the subject and object of research intertwined, this relationship also produces knowledge that is enriched by the unique standpoint of the researcher. Throughout the following analysis, I engage with this standpoint by offering reflections and insights regarding what emerges in my story as well as what is left out, which is informed by my positionality as a patient and a feminist scholar.

Second, Chang (2016) argues that “connecting the personal with [the] social is an integral part of autoethnography” (p. 445). This means that researchers should acknowledge and discuss how their experiences are shaped by wider, contextual factors. In order to assess the broader implications of my story, I approach the following analysis through a theoretical understanding of health and illness as ideological (Radley & Billig, 1999). Essentially, I attend to the ways that my story is not only a personal account but also reflects the world and employs “ideological themes” that implicitly and explicitly naturalize dominant understandings and interpretations of

the world (Radley & Billig, 1999, p. 20). In reflecting upon my personal experiences, I am also analyzing how my beliefs and actions reflect, construct, and resist ideological forces.

Third, Chang states, “auto-ethnography is a research method that requires a systematic approach to the research process” (p. 445). What the author means by this is that researchers should be transparent about their data collection and research methods so that analytic inferences and conclusions are evident. The following analysis is largely inspired by and generated from recorded and transcribed data. In May of 2016, I was facing a hysterectomy for my aforementioned cervical adenocarcinoma in situ diagnosis. Prior to undergoing surgery, a colleague of mine at the time suggested that I document my health journey through recorded conversation. On May 10th, 2016, we met on campus where we spent an hour and 40 minutes articulating our stories to one another. The first 54 minutes of our conversation was dedicated entirely to my own story with little interruption or interjection from my colleague. Since this present study is an autoethnographic analysis, I focus only on these first 54-recorded minutes of our conversation and offer excerpts that are solely my words. These words appear in the following analysis, without alteration, as italicized and block-formatted snippets of conversation. These excerpts were selected for inclusion because they are representative of the major themes that emerge in my story and they are reflective of significant moments in the early stages of my illness journey, from December, 2013 to May, 2016. Alongside these narrative snippets, I also include present-day narrative reflections and scholarly insights regarding context and meaning, where necessary, for analytic depth.

By analytically excavating my personal illness narrative, I attempt to uncover the conditions that construct, facilitate, and limit my medical choices. Investigation into the personal reality of health, illness, and healing offers a glimpse into the ways systemic sources of

oppression operate in everyday thoughts, feelings, and interactions. Furthermore, Sharf and Vanderford (2003) suggest that, “even in the midst of unavoidable disease or disability, the very act of generating a story allows the narrator a certain degree of agency” (p. 19). Therefore, this analysis is as an exploration of agency and an intervention into the principle of autonomy and the logic of choice. It is followed by a discussion of feminist-oriented insights regarding more viable approaches to healthcare and communication.

A Feminist Account of Patient Consent

It is September of 2017. I should be begrudgingly acquiescing to the monotony of another fall semester, but instead I sit alone on my couch wearing loose clothing with ice packs and pain medications close at hand, recovering from my ileocecal resection. I wonder how to spend the day. How far should I try to walk today? Should I push myself to make it all the way to the park down the street? Or should I just do my usual walk around the block? How much food will I be able to tolerate today? Should I attempt solid foods or should I stick to my liquid diet? This is a new kind of monotony; the slow torture of post-surgery recovery coupled with the quiet isolation of medical leave. I think about how I got here and how much I wish I could forget all the unwanted knowledge I have accrued in the last several years about US healthcare. I remember a conversation that I recorded with a colleague almost two years ago, in which she asked and I answered that exact question: “how did you get here?” I wonder what I said then and what I would say now. So, for the first time, I listen, I transcribe, and I reflect.

As I listen to the recording of my health narrative, I am surprised at how often I come back to articulating my culpability. I admit to taking my health for granted until something went wrong. When I searched for help from doctors, they made it sound uncomplicated—just get this test done or take this medication—so, I consented, and from then on, everything is my fault.

Every time someone offered an answer, it came with more questions. Those willing to answer my questions threatened me with pain or worse, death, if I did not comply. I felt I had no other choice so I reluctantly consented, again, until I found myself trapped in an endless cycle of consent and (non)compliance. My narrative recounting reveals how this cycle is fueled by three ideological forces: 1) individualism, 2) paternalistic antagonism, and 3) medical colonization.

As I negotiate, resist, and acquiesce to these forces I operate in the margins of healthcare. It is like staring at the center of a book where both halves come together at the spine. I can see both sides of the page—on one side, consent, the other, non-compliance—but neither is clear. I am too overwhelmed by the depth of the margin to see beyond its periphery but I am also responsible for collecting and delivering information from both sides to experts and laypersons. Diagnoses, prognoses, complex medical explanations, test results, research statistics, they all trickle down to me and I carry them away to family, friends, colleagues, insurance representatives, and new doctors—inevitably losing things along the way. Pressure to be an advocate for my own health is not a benign push toward patient autonomy and choice, it is a complicated skill required for survival.

Individualism

I actually think the story begins the summer after I finished my PhD. So, that would have been May, 2013. Um, I, a friend and I, I had gained some weight in my PhD. Um, probably like 20 lbs. than I normally carry. And, um, a friend asked if I wanted to do [weight loss program] with her. So, I did and, um, lost, fairly rapidly on [weight loss program], about 15 lbs., probably in 2 months. Um, and then, uh, kind of went off of the [weight loss program] and splurged a bit and had some gastrointestinal problems pretty immediately. Um, and, you know, later found out that it was gallstones. And, um, that, and that often happens when people lose or gain weight rapidly, they get gallstones. And, so, uh, moved, you know, to Ohio, had the gallbladder removed. Um, thought that that would take care of it but continued and actually continued to have problems.

Where I choose to start the story of my health journey in these transcribed recordings is telling of the ideologies and systems that I am entangled within. I could have started my story with the

diagnosis of gallstones, or Crohn's disease, or adenocarcinoma in situ, which I disclosed at the beginning of this article—a biomedical beginning. Or, I could have started by discussing the physical/emotional/psychological manifestations of my health and illness; like how many hours per week I spend driving to doctor's appointments or working through medical trauma. Instead, I chose to start with my decision to lose weight—a decision that is unquestionably tied to normative expectations of my gendered body. In starting this way, I immediately shift the locus of control to myself. Everything that happens next is tied to my initial choice to lose weight.

I am in pain, sitting for a long time, listening and transcribing, and I am hungry from not tolerating solid food, which makes me frustrated when I hear myself admit how much I once cared about my size. As a feminist, I envision myself telling a more nuanced story, which is not the case here. This is not surprising though, considering that individualized subjectivity, especially as it relates to control over health, dominates US American and feminist perspectives alike. Lock (1998) reveals that, "in North America a dominant ideology has become one in which the idea of being healthy, being in control of one's health, and maintaining health are internalized as part of individual subjectivity" (p. 50). She argues that locating responsibility with individuals for their health, especially with women, is a politically motivated moral discourse. This moral discourse is adopted in feminist health movements, which urge patients to resist the patriarchal impulses of health care experts and physicians; Instead, empowering patients to prevent and manage illness through their own research and vigilance (Goldstein, 1999). For many, to be a healthy feminist in a U.S. American context is to take control of your own health and resist the suspect intervention of healthcare professionals and experts.

Whether through a biomedical, feminist, holistic, or alternative medical framework, health has become increasingly entrenched in individualism (Groenhout, 2010; Wardrope, 2015;

Sherwin, 1998a). This means that regardless of what choices a patient makes, or does not make, and regardless of their outcome, they are always personally responsible. I often find myself wrestling with the complexities of this paradox throughout my health narrative, especially in the beginning, when I decided to have my gallbladder removed.

Yeah, but it was really my first major surgery as an adult. And, I really didn't think too much about it. I didn't ask a lot of questions about it. I didn't seek multiple opinions, um, because I just, you know, saw the doctor, he did a CT scan and said gallstones, they referred me to a surgeon, the surgeon said "yeah, you have to take it out" and I trusted him and went for it. And, um, I guess...looking back on that now, it's because I never had health problems. And, you always trust the doctor. You know? Why would they steer you wrong? Um, but now I'm realizing it's more complicated than that. And, in fact, um, had I known, you know, what was going on in my body, I would have been able to make different decisions. But, I can't, I try not to dwell too much on that because, I try not to keep thinking that where I am now is my fault [laughs]. Even though doing that gives me some sense of control but also, you know, lack of control at the same time. Like, I could have had control but no longer do, kind of a thing?

As much as I would like to think otherwise, I am implicitly committed to the biomedical principle of patient autonomy and the logic of choice. This excerpt, in particular, is hard to listen to because it represents my ever-present and impending struggle with the illusion of control. I remember how I felt then because I still feel it now, and I am not certain when this feeling will ever go away. The presumption is, and may always be, if I had more thorough information regarding my physiology then I might have made more informed, or at least different, choices. If I had known that having my gallbladder removed would mean *dumping bile into sick intestines* (as one of my gastroenterologists so delicately put it) then maybe I could have found a different way. Not my doctors, but me. It is difficult for me to locate agency elsewhere because my choices exist within the binary of consent and non-compliance.

The paradox of patient consent is that both options lead to my culpability. If I am compliant and my condition does not improve then I should have made better decisions. If I am non-compliant and my condition gets worse then I should have made better decisions. Even if I

choose an alternative route, to remove myself from the biomedical industrial complex only offers more of the same. As Frank (2013) indicates, “for people to move their stories outside the professional purview involves a profound assumption of personal responsibility” (p. 13). This is why I often narrate and justify my decisions to seek, or not seek, professional medical attention, even in the wake of concerning symptoms several months after my cholecystectomy.

My partner, would always say, “you have stomach aches a lot” or “you don’t feel well often” and I kind of just like brushed it off, like, “no, I’m fine,” like, you know, but, you know, this was even before the gallbladder got removed, he said “you don’t feel well very often.” And I was like, “no,” I was like, “I don’t think I don’t feel well often.” And, he’s like, “you often say ‘I don’t feel well’” and, I’m like, well, “I’m,” I just kind of brushed it off. Like, you know, well, you know, I’m just not, I don’t eat very well. I just thought I didn’t eat well. I thought, if I ate better I would probably feel better. But, I wasn’t really that concerned about it.

I spent nearly 10 years unknowingly managing symptoms of Crohn’s disease, all the while attributing the pain, fatigue, and weight fluctuations to poor eating habits. People minimize pain or avoid seeking medical attention for various reasons. I articulate my own reasons as personal but, as the following excerpt reveals, these justifications cannot be separated from systemic and material constraints. Even as severe stomach cramps have me curled in a ball on the bathroom floor and I can no longer deny that something is wrong, I still hesitate to seek care.

Yeah, I was by myself, so I was like, do I drive myself to the hospital and hope that, you know, I’m not, I don’t have to pull over during one of these waves of pain. Or, do I call an ambulance? Or, you know, and I was like, do I call someone I know? And, I, in my, in my gallbladder experience, when I had the gallstones I went to the emergency room with the pain, they said it was nothing. And then, it turned out later on that it was gallstones. So, I kind of figured that the same thing would happen. I thought that there was, um. I thought that there might be a pretty good possibility that I would go to the emergency room, pay a bunch of money and they would not give me any answers. And, so, I was really resistant to go because I didn’t want to pay a bunch of money for no answers. And, so, I, uh, actually ended up driving myself to the emergency room and I got to the parking lot, and, I was feeling better. I was, the, the pain wasn’t as intense. So, I didn’t go in...So, I did not go in. I went back home. And, I was up all night still in mild pain but not as severe.

I remember this night vividly, though the exact physical sensations escape my cerebral grasp, thankfully. In between breathtaking bouts of pain, I called my mother and then a nurse hotline. Both of them commented on my exasperation, noting that it was a clear sign to seek medical attention. In the end, I did not, at least not until weeks later. Each time I tell someone about this fateful night they are shocked and frustrated that I chose not to walk through those emergency room doors, as if it was solely my choice. They react as if a lifetime of having pain and symptoms dismissed by doctors did not cultivate an ethos of self-doubt. They also forget the material constraints of a neoliberal healthcare system in the U.S., under which my decision-making process is tied to my (limited) economic resources as a patient-consumer.

Health scholars have documented the ways women's pain is minimized and erased by health practitioners (Werner, Isaksen, & Malterud, 2004; Werner & Malterud, 2003). My experience is not unique in this respect, unfortunately, but the above excerpts do offer insight into the ways documented, systemic inequalities are often narrated through the ideological lens of individualism. I claim to resist biomedicine because I do not think anything is wrong but this personal judgement and my subsequent decisions are informed by my previous experiences of dismissal and the financial burden of being dismissed. The baggage of persistent erasure, which keeps me doubting my choices, is very much a product of paternalistic antagonism.

Paternalistic Antagonism

The patriarchy and misogyny that plague US medicine have led to the historical exclusion of women as professionals in the healthcare industry as well as the silencing of women's voices and experiences in patient-provider interactions and medical research (Dodds, 2008; Edley & Battaglia, 2016; Groenhout, 2010; Rogers & Ballantyne, 2008). Physicians who were trained prior to the movement toward the principle of respect for patient autonomy were

taught to treat patients according to their own judgement about what would be best for their patients, “with little regard for each patient’s own perspectives or preferences” (Sherwin, 1998b, p. 21). This paternalistic approach still resonates in healthcare today (Ells, Hunt, & Chambers-Evans, 2011). However, paternalism now operates implicitly through the language of autonomy and choice and, instead, manifests in what I call *paternalistic antagonism*.

My own narrative uncovers incidents of belittlement, conversational authoritarianism, and condescension that providers employed in order assert their professional judgement as definitive. After my night of intense gastrointestinal discomfort, I made an appointment to see my general practitioner. He ordered a CT scan that showed narrowing in my small bowel so I was sent to a gastroenterologist for an endoscopy and colonoscopy. These procedures confirmed what my doctors had suspected, though they never mentioned to me as a possibility, which is the diagnosis of Crohn’s disease. As I struggle to understand the gravity of my newly diagnosed chronic illness and search for control over my health, I am met with belittlement:

So, then I went to my follow-up appointment and, um, and then he just sort of, like, started throwing medications at me. He was like, “well I want to start you on this, uh, steroid,” and I’m like, “OK.” And then he was like, “and then I want to think about longer treatment, longer term treatment plans.” And, he’s the first person who told me, uh, [prescribed medication]. And, he, you know, told me that it was an injection drug. He told me that I would, you know, um, do it at home and that I would need a nurse to teach me how to do it. And it was just like all very overwhelming. Like, what is going on? Uh, that it was an immunosuppressant, that it had all these potential side effects. And, then, I, you know, immediately, of course, said, “well, what else can I do that’s not a drug? Like, what are like holistic, or natural kinds of things?” And he, kind of laughed at me and said “I know people your age are really into that kind of stuff but you need to realize that you have a serious chronic illness that isn’t just manageable by, you know, magic pills and diets.”

I know now, after nearly five years of trial and error, that what I was angling for in this moment—a prescription for lifestyle changes precipitated by me rather than a pharmaceutical company—is yet another faulty crux of patient autonomy and the logic of choice. The holistic

turn in health has contributed to the politically motivated moral discourse of individualism because practitioners “stress the responsibility of the individual in contributing to the origins of his/her illness, and the changes needed to bring about a cure or improvement” (Goldstein, 1999, p. 39). This *healthism*, as Sherwin (1998b) refers to it, is a movement toward wellness programs that encourage individuals “to be active in the pursuit of their own health” and “take primary responsibility for the monitoring and improvement of their health” (p. 48). What I thought I was asking my doctor for was more control but, in reality, it was just the same amount of responsibility with less oversight. At the time, though, I was searching, practically begging, for this agency because my pre-diagnosis existence was predicated upon it; it was all I had known. Regardless, my attempts are thwarted, over and over again. My role as a patient is reduced to administering prescribed medication or falling victim to magic. This definitive belittlement reaffirms my place in the margin. I am stuck between consent and non-compliance and both options lead to my culpability. Out of desperation, I looked for second, third, and fourth opinions, but the paternalistic antagonism only escalates and I finally meet my fate on a cold examination table in the office of doctor number four.

This is where he basically put the fear of surgery in me. He basically said “you either do [prescribed medication] or you have to have surgery to remove these strictures.” Because the [prescribed medication] has the possibility of reducing inflammation and then making the strictures go away on their own, or with the help of the [prescribed medication]. But, otherwise, if I don’t do that then I’m gonna have to have surgery. So, it was like, you know, I was so anti-[prescribed medication], and I also asked him about alternative things. He said that that alternative things are, um, have not been proven to be useful in treating Crohn’s. They are proven to help with symptom management in addition to medicine but nothing on their own.

My resistance to immunosuppressant medication is met with a stronger paternalistic force this time: control of the conversation. I have spent months researching the potential side effects, long-term complications, and alternatives to this prescribed treatment plan and I am more

overwhelmed than ever. Family members recommend yoga and meditation, friends-of-friends swear by impossible diet regimens, and high school classmates pitch me the miracle products they are selling through direct sales. I cling to alternative medicine as a viable, and even better, option even though it still binds me to medicalization and self-monitoring. All this personal researching and strategizing, which has kept me lying awake at night for months, is promptly transformed into a black hole of time. My doctor usurps the conversation and directs me toward his predetermined outcome, which is a covert tactic of control (Donchin, 1995).

At this point, the vilification of holistic approaches to health by my doctors reveals to me the paternalistic antagonism employed by the biomedical industrial complex and I am eager to escape it, but I do not want surgery. I acquiesce to expert opinions and begin taking the prescribed medication. However, my persistent skepticism and the illusion of agency almost lead to a missed diagnosis. Even when a practitioner offers sound advice, reminding me to see my gynecologist for an annual exam, I must navigate through a heavy fog of paternalistic antagonism, this time in the form of condescension.

I saw a, um, resident. I saw a medical resident, 'cause [name of hospital] is a teaching hospital, and he was very, um, I don't know how to explain it. He was, he asked a lot of questions. He wasn't, he didn't have a very warm bedside manner. He was kind of assertive. He was very young and he kind of made inappropriate jokes. Nothing, like, crazy sexist or anything like that but, just, you know, would make jokes about bowel movements. You know, kind of, like, very sophomoric humor. And, I just remember thinking, like, this guy and I, me and this guy are the same age and this is very strange because, I don't know. Um, and, so but he actually at one point said, um, "have you had your annual pap?" And I said, "oh, no, I've been meaning to do that." And he said, "well, you REALLY need to do that." And I said, "OK." And he goes, "if you're on [prescribed medication] you REALLY need to do a pap smear, you know, as, every year." And I said, "OK." And I kind of, like, brushed it off, like, "OK, guy, thanks for telling me, you know, thanks for mansplaining my body to me." But, um, OK, fine. You're, you know, I have to get one anyway, I might as well.

The annual gynecologic exam that followed this encounter is the one that led to my liminal diagnosis of adenocarcinoma in situ, which, at the time, required immediate biopsy

surgery. Though not immediately life threatening, this diagnosis was devastating. It meant my days with my uterus were numbered. It also complicated my Crohn's treatment in ways that lead to the surgery that I find myself recovering from now. Had I chosen to be non-compliant because of my biomedical skepticism and not had the biopsy before the diagnosis became invasive, I would have been personally responsible. The doctors are rendered blameless, as they were providing the standard of care, even though I felt antagonized and patronized when I questioned their recommendations. In other words, my agency is presumably located in my ability to make my own healthcare decisions but those decisions exist within a system of covert oppression and coercion. This system is justified and bolstered by its reliance on medical colonization.

Medical Colonization

Once I was interpellated into the biomedical industrial complex, I found myself speaking a new language of statistics and clinical research findings. Frank (2013) uses the term *medical colonization* to describe this phenomenon, suggesting that "just as political and economic colonialism took over geographic areas, modernist medicine claimed the body of its patient as its territory, at least for the duration of the treatment" (p. 10). This colonization is driven by an undying faith in the scientific method. In many of my encounters with doctors I was reminded that questions and concerns would only be entertained when they appealed to scientific evidence and were articulated within an authoritative medical discourse, especially when weighing my options for Crohn's disease treatment.

[name removed] *also was just sort of like, you know, he was very straight forward with the science. "Well, there's this scientific evidence...there's no scientific evidence." Um, you know, I eventually saw a guy in California and he, you know, he wasn't disrespectful but he immediately was dismissive and said "you're not a candidate for no treatment, for no medical treatment. You need medicine." Um, the guy at [name of hospital], you know, similar, very similar "well, you know, why would you want to waste your time with that when we have proven medicines that work," kind of a thing. Um, so, you know, they're all about the science.*

This excerpt is not an anomaly in my health narrative. The number of times I have been asked about my day-to-day quality of life pales in comparison to the number of times I have been asked to quantify my symptoms or weigh the benefits of a treatment plan based entirely on relatively few scientific research studies that attempt to predict percentages of risk. Reliance solely on a scientific paradigm of thought is frustrating in these situations because it excludes other ways of knowing. Even more troubling though, medical colonization does not always account for complex and identity-specific health conditions (particularly if that identity is marginalized). Though biomedicine can provide lifesaving research, it is inherently exclusionary and discriminatory (Dodds, 2008; Groenhout, 2010; Rogers & Ballantyne, 2008). Even when U.S researchers are required by law to include ethnic minorities and women in their studies, they are not required to collect data or report significant differences based on these factors (Groenhout, 2010). These systemic and ideological constraints emerge in the following excerpt of my own narrative, in which I reflect on my decision to take the prescribed immunosuppressant for my Crohn's disease and its eventual impact on my cervical health.

Less than, less than one percent. In, in a female my age. The, the people who have the higher risk of cancer are teenage boys, for some reason. Uh, and that's for like blood cancers and leukemia. Um, for me, cervical cancer was never mentioned as a possibility. Uh, it was more, you know, lymphoma was a possibility. That was more the cancer that the science proved was a possibility, and it was a less than 1% chance. Um, and so, you know, of course, when he told me those odds and then told me, of course, the odds of having surgery were 70%, it made sense. Like, less than 1% versus 70%, OK, you know, I'll go for it.

Having been naive to the interworking of healthcare and medical research most of my life, my assumption up until this point was that pharmaceutical statistics were relatively generalizable across non-descript populations. Even as an educated woman, trained in the design and limits of research methodologies, it did not occur to me to inquire with my doctor about

whether or not the reported findings in these studies were inclusive of my specific anatomy. However, in this case, and many others, I am asked to make medical decisions based on pharmaceutical research that still assumes white, middle-aged, able-bodied, middle-class men as the normative model of human existence (Groenhout, 2010). I adhere to the principle of autonomy by becoming informed on statistically significant research findings, which represent potential repercussions of the prescribed course of treatment. I comply with my doctor's recommendations based on this clinical research. Only when it is too late, as I am diagnosed with adenocarcinoma in situ, do I find out that my body was always already erased from this research.

Though many of my doctors are still undecided about the role of the immunosuppressant in my adenocarcinoma case, one of my gastroenterologists referenced a study to me that was published three months after my diagnosis and suggests a strong link between certain Crohn's medications and the risk of cervical cancer. When I asked him if he would take more precautionary measures now when prescribing the medication to patients with cervixes, he said likely not, at least not until (if) more research indicates this as a standard of care. He implicitly confirms for me that my autonomy and choices in medical decisions are merely illusions.

Even when I am faced with the decision about whether or not to keep my uterus, I am asked to make this choice based on a flawed and unequal system of medical colonization.

I thought, 20-25% seems like way too high of a number to be gambling with. And, at that moment I knew that I, that it was inevitable, right? The hysterectomy, and everyone I've talked to said that. "The hysterectomy is inevitable. You will have a hysterectomy." The only question is will it be now? Will it be in 3 years? Will it be in 5 years? 'Cause no one recommended more than 5 years. Um, you know, so that was it. It was like, you know, you gotta do it so, you gonna do it now or later?

My doctor informs me that there is a 20-25% chance of recurrent cervical disease and, even if I keep my uterus now, the recommended treatment plan is to have a hysterectomy within no more than 5 years. I do not plan on having children so the exact timeline is unknown, since the

standard of care is to undergo a hysterectomy after child bearing is complete. As a woman who will not bear children, I am a statistical anomaly, left out of the purview of standard recommendations. The decision is up to me. I decide to have the hysterectomy based on the cited odds of recurrent disease but I learn later from my gynecologic oncologist that these statistics are based on fewer than a handful of studies that exist on my diagnosis, which have been conducted sparsely over the last 40 years. The night before my surgery, in a fit of anxiety-fueled insomnia, I spent hours mining the internet and medical journal databases to find answers to questions my doctors could not answer. Though the exact results are hazy, I distinctly remember finding significantly more studies on my odds of regretting infertility than on my chances of developing invasive cancer, given my liminal diagnosis. It frustrates, disheartens, and terrifies me that the majority of medical research about women focuses on reproduction (Rogers & Ballantyne, 2008). I am asked to comply with a system that does not account for me in its development and maintenance unless it benefits the procreative goals of the dominant majority. The morning of my surgery, I called my doctor and cancelled the hysterectomy. I decided to end the cycle of consent but now I was non-compliant. As always, my health was in my own hands.

Though my doctors were divided on the relationship between immunosuppressant Crohn's medications and cervical cancer, none of them were comfortable prescribing me similar treatments until I had the hysterectomy. In my non-compliant, interim state, my intestinal inflammation worsened and my bowel strictures narrowed to less than 1mm, where I found myself unable to tolerate solid food and quickly losing body mass. After two weeks of an unsustainable liquid diet, I was scheduled for urgent bowel resection surgery and a last-minute leave of absence from work, which brings me to where I am now, on the couch with an icepack soothing my abdominal sutures and a laptop at my fingertips.

Epilogue

One year after I wrote the above illness story, after I cancelled my hysterectomy and underwent a bowel resection, I found out that I had recurrent cervical disease, which meant a hysterectomy was not only inevitable but also immanent. It also alerted doctors to the possibility of invasive disease, meaning an unknown presence of cancer beyond my cervix. Between the time of receiving this information and finally undergoing a hysterectomy with a gynecologic oncologist, I spent more time than I would like to admit thinking of all the choices I made and what I might have done differently. This is only more evidence of the persistent psychological torture of the principle of autonomy and the logic of choice.

In my follow-up appointment, the surgeon told me that all of my cervical/uterine biopsies were negative, which should have been cause for celebration but instead I cried; I cried at the realization that the tests, technologies, and data that urged my doctor to operate were inevitably misguided. But, who am I to argue with these objects of certainty? Now here I am, no gallbladder, no terminal ileum, no uterus, and all I have to show for it is a chronic illness and a series of “choices” to replay in my mind indefinitely.

Creating Viable Options for Autonomy and Care

Feelings of confusion, uncertainty, and loss of control while navigating complex healthcare decisions is, unfortunately, common. As patients, we are “able to do nothing, to do something” (Ettorre, 2005, p. 544). Since we are unlikely to escape the endless cycle of consent/non-compliance in the current US healthcare system, uncovering the conditions of this cycle and monitoring its power are more viable and necessary options for autonomy and control. Though we surrender and bear the weight of our consent, our stories of this burden are an unending source of social and political accountability (Frank, 2013). Inviting, listening to, and

producing health and illness stories is vital to our efforts as researchers and our development as health communicators and professionals (Geist-Martin, Ray, & Sharf, 2017).

Though the story I have recounted here reflects a time in my life that was particularly vulnerable, there have been many moments in my ongoing health journey that have revealed the potential for more equitable and empowering approaches to healthcare and communication, which are feminist in orientation. The first of these possibilities is relational autonomy, which considers a patient as inseparable from the people, contexts, and systems that constitute their choices and actions (Ells, Hunt, & Chambers-Evans, 2011; Keller, 1997; Mackenzie, 2010; Mackenzie & Stoljar, 2000; Sherwin, 1998b; Wardrope, 2015). The second of these is a logic of care, which emphasizes ongoing interaction, highlights scientific and technologic unpredictability, and embraces the role of values in medicine and health (Mol, 2008). Both of these approaches hold the potential recast healthcare as a matrix of relations and an unending conversation motivated by transparency and humility.

With regards to relational autonomy, I have found solace in narrative encounters where friends, family, or practitioners have acknowledged and validated the complex networks of relationships and systems that I operate within. For example, when my infusion nurse responded to my stories of medical error by recounting horrific though statistically rare cases from her time working in an emergency room, she explicitly and implicitly reminded me that my fears of these improbabilities are warranted. When my gynecologist complained about how there is a procedure for administering lidocaine during catheter placement in penile urethras but not vaginal urethras, she reminded me that gendered, systemic oppression in healthcare and medicine is real, not a product of my imagination. They know these truths terrify me but they also know that I am not living on an island that is separate and immune from these realities. Dominant

models of patient-centered healthcare might find these conversations tactless but for me, their candor is refreshing. I yearn for more honest interactions that remind me I am living in a flawed system rather than those that misdirect my attention away from the man behind the curtain.

With regards to the logic of care, I have found agency in being allowed to let go of rigorous self-monitoring and control. When my gastroenterologist admitted to me that medical research is imperfect but all we can do is operate from an imperfect reality until new information is available, I felt the tight grip around my decision-making brain loosen for the first time. When my primary care physician listened to me and agreed to my request that we not treat symptoms and illnesses unless they are debilitating, chronic, or life-threatening, I felt the watchful eyes of the biomedical industrial complex retreat for the first time. These moments were liberating, even if fleeting. The logic of care makes no promises and embraces the unpredictability of disease. The art of care is “to act without seeking control” and “to persist while letting go” (Mol, 2008, p. 32). Admitting to the unknown is not incompetence but vulnerability; acknowledging that scientific studies are subjective is not unethical but an act of accountability; and acquiescing to the unpredictability of technology is not neglect but a realistic relational orientation. Had I received care from the beginning rather than choice, maybe my story would be different. There is no way to know and searching for this answer is as unproductive as the logic of choice. The more important take away is that, through relational autonomy and a logic of care, my journey is still unfolding; where it goes next is not entirely up to me, and it never was.

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