This patient is a hidden messenger: NF2, watchful waiting, and records of care
by Samuel DiBella

Abstract
“Watchful waiting” is a medical approach that delays radical intervention, like surgery, but depends on regular imaging and patient self-scrutiny. To explore its social effects in a single case, I conducted an autoethnography of my patient archive from my diagnosis and 17 years of watchful-waiting treatment for neurofibromatosis, type II, a genetic disorder. I show how watchful waiting encourages self-surveillance and the stress it causes. I also discuss how the personal medical archive, with its complicated structure of reports, CDs, and notes, is a tool for communication as well as a cause of moral obligation for the patient. I contrast these uses with information studies of medical records that focus on records’ collaborative use within medical institutions. I conclude that my case has been held in stasis, reinforced by diagnostic surveillance that I participate in, due to the vagueness of “watchful waiting” as a treatment protocol and the uncertainty of more invasive treatments themselves. Through this study, I recenter patients and their needs in the discussion of medical archives and contribute to the collective recognition of disability through the genre of the illness narrative and the method of archival ethnography. I consider how my results conflict with general calls for “open notes” in medical care and cultures of life-logging and -tracking.

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Introduction
“The manual labor of being in pain every day is precarious (in part) because it is not a job you are paid to do, but a job that you pay to do, with your attention.”
— Maia Dolphin-Kute, Visceral: Essays on illness not as
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metaphor (2017)

I’m in a new city when I find myself made machine. Six months ago, the outpatient intake nurse ordered a nerve-conduction electromyography. Now, a doctor is inserting a needle into my upper thigh, through atrophied muscle, and asking me to flex. He digs and his machine growls.

The fissure of pain widens as the machine reaches a distorted scream. I realize it is me — the singing of my nerves fills the room. I screw up my eyes, and the doctor makes an ambiguous joke about COVID-19 vaccines, chips, and needles. When it is over, he fills out the .doc template the nurse prepared for him and prints me a copy. My pain and their work produced this sentence: “This study shows almost complete denervation of left femoral and obturator nerves with only a few MUPs in each distribution.” (This is the only part of the report directly incorporated into my neurologist’s notes at my next visit.) As it is, I also learned something: how much a dead nerve can hurt.

The first doctors were late, so I am late and I have to wait for the second doctors to finish something else. The self with chronic illness is one that waits (Charmaz, 1991). The surgeon asks me why I’m there; he hasn’t reviewed my records. I describe my case to him and hand over my nervous report. He leafs through, tutting when I use a different medical term than expected: bilateral acoustic neuromas (strictly true), not bilateral vestibular schwannomas. I should know, he says.

When I ask about my obturator nerve, he asks where I learned that word — the report? “It would be odd if your obturator was normal. It’s your femoral nerve that’s horribly abnormal. Nothing personal.” I wonder how the inside of my body could not be personal. He quickly realizes that I’m a watchful-waiting patient. My treatment mainly consists of long-term diagnostic imaging. There is no impending surgery. Five minutes of small talk and he leaves.

Earlier, a nurse had asked what level of pain I desired by the end of the day. I feel the throbbing pains on my leg where the needles found my nerves. Those points will ache for over a week. The normal arcing, biting pain that runs along the inside my left knee enjoys the company. The pain and the ache run together. I can’t tell if they’re the same.

I think the nurse broke her promise. All I have in exchange is this .doc, which I duly file into the slim, blue folder I brought with me for that purpose. Others — folders, a binder — await its company at home. I’m wondering why I did all this and how it could help me, and I’m worrying that the answer is, why not?

To circle around this question, I first explain how I have tried to resolve the methodological difficulties of writing autoethnography by considering advice from traditional ethnography and critical disability studies and drawing inspiration from other autoethnographies of illness or personal records. I then provide a brief overview of the information studies literature on patient records and how I see it intersecting with writing on medical surveillance and “watchful waiting.” In the actual examination of my archive, I try to show both how I am perceived by medical staff, who their intended audience seems to be, and how the concept of “watchful waiting” seems to have affected the course of my care for neurofibromatosis, type II. Ultimately, I conclude that my case has been held in stasis, reinforced by diagnostic surveillance that I participate in, due to the vagueness of “watchful waiting” as a treatment protocol and the uncertainty of more invasive treatments themselves. I end with some thoughts about how I see my case as reflecting a broader trend in U.S. healthcare where patients are expected to take part in bureaucratic paperwork, including transparency in “open notes” portals.

Plotting the course

My medical archive has followed me since my diagnosis in 2005 with NF2, a genetic condition that causes
nerve sheath cells to swell. For most, this only matters where space is precious, typically the auditory canal. There, mutant Schwann cells squeeze the nerves they hold to cause hearing damage, chronic pain, and facial paralysis at uncertain times and in uncertain combinations. The internal borders of the body become porous, as schwannomas appear undifferentiated from the live nerve they enfold. I, however, am an interesting case — a dubious compliment. I was diagnosed because I am an interesting case.

I can’t say more until I explain this archival autoethnography. I’m not new to the topic of medicine, nor do I have a detached interest. My illness, and the moral obligation to self-surveil the healthcare system has put upon me has taken me years to write about. In my case, that moral obligation is one of self-care.

Most advice for ethnographic research, the study of culture, falls apart when you try to use it in these cases. While the interpretive turn in anthropology — the discipline’s recognition that writing is not a neutral vessel — is friendly to this project, I risk appearing more certain than I am about what I study. In his warning about ethnographers as the trickster-messenger-god Hermes, Vincent Crapanzano (1986) shows how writers often accidentally slip subjectivity into intended description or attributed objective qualities to the unknown interior lives of their subjects:

“The ethnographer must make use of all the persuasive devices at his disposal to convince his readers of the truth of his message, but, as though these rhetorical strategies were cunning tricks, he gives them scant recognition. His texts assume a truth that speaks for itself — a whole truth that needs no rhetorical support. His words are transparent.” [1]

If you’re a perceiving researcher and researched subject, it’s hard to understand advice telling you not to mistake the surface of a mirror for its reflection. They’re both you. Even the craft manuals I used to guide how I took notes about my archive talk about remaining true to the language and thoughts of a studied population (Emerson, et al., 2011).

Disability studies struggles with a similar problem. To address the regular omission of the experiences of patients and people with disabilities from studies of medicine (Rier, 2010), disability scholars have strived to privilege the voices of the disabled. This, however, can encourage monopoly as well as a certain kind of triumphant healing narrative (Teare, 2022). While the ill and the disabled have a unique perspective on themselves, it is not the only useful perspective into how disease is socially constructed (Mol, 2002).

As a response, Louise Hickman and David Serlin (2018) proposed that crip research should focus on how access and disability produce knowledge, while admitting that research’s necessarily incomplete perspective. In her illness autoethnography about kidney failure, Rose Richards [2] explains how patients writing about their own experience can refute doctors’ objectifying gaze. These autoethnographies can do different things for their readers and writers: they can testify to the experience of an illness and generate a cohesive narrative that allows readers to empathize with the writer, even as that narrative gives healing structure to the writer’s messy experience; they can display the environment and context of illness to give “voice to the voiceless”; and finally, they can destabilize general understanding entirely.

In this last case, Richards [3] says:

“This is a narrative where different points of view are shown, but not assimilated into the authorial voice. This type of narrative is more open-ended and demands more from the reader. It does not do all of the thinking for the reader. Instead, it shows how messy and contingent reality can be.”

I don’t know which of these categories I will fall into for you. This writing was strange. I’ve given myself an authorial voice to talk like this to you, but this research is only possible through the work and writing of
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My patient records, then, are a check and a challenge. I’m using them to stay on topic, to heed Heewon Chang’s warning: “Unless autoethnographers stay focused on their research purpose, they can be tempted to settle for elaborate narratives with underdeveloped cultural analysis and interpretation.” But maintaining a clear line of reasoning — so comfortable for academics — also feels wrong here. I want to be aware of my own limited knowledge about my body, while recognizing and disputing medical knowledge at the same time. If I meander, I ask your patience. This is the only way I can get there.

As an editor, I performed this research through “reads” — consecutive passes through the archive that focused on different qualities or themes. In doing so, I visually dissected elements of the archive to reassemble them here, for you. As I read the archive, I took notes both about possible connections I saw and my reaction to reading each new piece of information. That same notebook followed me as I began to read, research, and attend this year’s set of medical appointments.

I was not able to find many autoethnographies written about the writer’s own records but those that I did find came from a similar place: surprise at the alienation of reading your record. I think here again of the difference between reading a life log — voluntary self-description — and reading description of yourself by another. Verdery (2018) traces the version of herself (codename: “the folklorist”) created in Romanian secret police files. She describes the trauma of long-term surveillance and the life her paper self was able to lead, beyond her view.

Where official patient records reflect the practice of medical workers, autoethnographies reflect qualitative experiences of pain and chronic illness. Wilson and Golding say the “latent scrutiny” conducted by Australian care workers “left their subjects voiceless, absolutely impotent, and effectively oblivious, in the records’ creation and subsequent dissemination and utilisation, both at the time and subsequently.” Douglas and Mills (2018) each locate themselves in Australia’s medical records and colonial adoption system. They argue that archival studies should look closer at the dilemma created by institutional, yet personal, records. What’s more, these autoethnographies all point to the benefit of a researcher examining their own record — they can challenge its claims in a unique way.

For the record

In information studies, the medical record is a boundary object for understanding mysterious bodies — a center of collaboration (Berg and Bowker, 1997). These studies have marveled at the rich, but chaotic, accretion of documents from hospital departments and medical experts (Bardram and Bossen, 2005; Bansler, et al., 2016). The records are the means of insuring care continues, from shift to shift. Doctors themselves have anxiety about writing their notes for care and liability, an anxiety exacerbated by the dawn of the electronic medical record. However, even studies of records’ use over time have stuck to treatment in intensive care units or fairly short hospital stays (e.g., Reddy, et al., 2006; Isah and Byström, 2020). The working patient record is not the same as the archival patient record (Fitzpatrick, 2004). It lives with the patient.

These studies consider how records produce the bodies of patients, now legible to the medical gaze, but they often fail to mention how patients produce those records with their bodies. On the one hand, that is obvious. On the other, the cooperative labor of patients in their own care is erased. Erasure of expertise and labor from records is also not unusual in U.S. medical care: similarly, the notes of nurses don’t make their way into long-term patient records (Bowker and Star, 2000).

As Star and Strauss (1999) argue, invisible labor is not uncommon in collaborative settings. Revealing that labor’s presence is not interesting in itself. Instead, the relationship between visible and invisible labor
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should be challenged, lest patients be reduced to informative bodies. So much work is performed by patients to ensure that they can receive care: filling out forms, preparing for appointments, traveling, and securing time off from work are all part of medical care.

I’m thinking this way, because I am in a limbo created by the passing of the age of “heroic” medicine in the United States and the rise of medicine as a scientific, not artful, practice (Lawrence, 1992; Berg, 1995). Where once a doctor or surgeon’s claim to expertise came primarily from experiential knowledge and manual skill, citing scientific studies and clinical research is now seen as the correct way to inform and justify treatments. Making the labor that produces facts invisible is common practice in scientific fields (Latour and Woolgar, 1986), a domain that United States allopathic medicine now sees itself as joining. To create a more rational-seeming profession, U.S. medicine’s watch word now is “evidence-based medicine” (Lambert, 2006). Ironically, this move displaces how doctors can refer to personal experience just as it does for patients.

Compared to other high-status professionals in the United States, doctors are historically noted for the extreme importance they place on their autonomy within a workplace (Starr, 1982). That emphasis on professional autonomy has shaped the modern hospital into a nest of job hierarchies, from domestic and international medical graduates (Jenkins, 2020) to nurses, physician assistants, and support staff.

Doctors’ autonomy also affects how technology is used in medicine. Imaging fields like radiology initially threatened doctors’ ability to make uncontested claims about patients. Suddenly, technicians also possessed intimate knowledge about patient health (Starr, 1982). The current flow of documents and medical records — for the most part hidden from patients — reflects an uneasy accord between doctors and technicians. Technicians interpret results to doctors; doctors then interpret those results to patients. The careful internal circulation of medical records recalls medieval chanceries (Vismann, 2008). These files live in an ecosystem; they’re not meant to stand on their own. But patients can choose how they will carry their records and medical interpretations of those records to future appointments.

I see my archive as a counterexample for practices of self-surveillance that have become popular within the last decade, like the Quantified Self movement. Life-logging is a practice of recording and quantifying observations about yourself (Ruckenstein and Schüll, 2017). Life-logging has become popular both with hackers and patients, who can use their observations to enforce their autonomy or resist other forms of surveillance (Danesi, et al., 2018). My records have not done a similar thing for me — their collection and curation has either been enforced or a side effect of living a medicalized life. This is a reminder of the burden that bureaucracy puts on us to make ourselves legible, and therefore seen as deserving of care.

Illness and surveillance over time

In my experience of U.S. healthcare, chronic illness is an area of failed attention. When you move through hospitals, it's clear they’re meant to address moments of crisis, not prolonged difficulty. Continuity of care for chronic illness is not something they were designed to do. And little attention has been devoted to this topic in the medical literature. The complex, long-term nature of chronic illness makes it difficult for traditional experimental design to see it (van Servellen, et al., 2006).

Because my care is centered around bursts of full-day appointments, I am often a courier for the medical system. The tests they conduct take time to upload into their electronic patient portals, so I carry physical forms from appointment to appointment to fill the gap. From appointment to appointment, I use my body to deliver documents produced from my body. After each set of appointments, I dutifully request the new reports so I have them if I have to move again to a new healthcare system. I am a file transfer protocol.

I could tell you how my medical care since 2005 has been part of an ongoing trend towards
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“biomedicalization” (Clarke, et al., 2003). Biomedicalization refers to the ways medicine has become a science. That science has claimed more and more of human life as its domain, with the aid of charismatic technologies like magnetic resonance imaging (MRI) that seem to harmlessly dissect human bodies (Joyce, 2010). I don’t like terms like this, however. What actors, what institutions, could we say do the action of biomedicalizing? In my records, it’s hard to say.

Early in my research, I read about medical surveillance, built on the theories of Michel Foucault. According to Foucault, doctors’ medical gaze now extends beyond just the population of the isolated ill and onto seemingly healthy populations. That professional gaze creates a “regime of total health” where people are “expected to engage in the practice of self-surveillance” [7]. In this regime, health is maintained, not restored.

Armstrong (1995) describes that maintenance as the practice of medical surveillance. Armstrong cites the methods of medical surveillance as “pathologisation and vigilance.” He explains that doctors, aided by statistical public health measures, now categorize patients along a spectrum of health, not a stark division between the well and the ill: “[H]ealth no longer exists in a strict binary relationship to illness, rather health and illness belong to an ordinal scale in which the healthy can become healthier, and health can coexist with illness” [8].

Medical surveillance comprises the generation of images as well as the distant, statistical analysis of populations: medical advances have often gone hand-in-hand with advancement in optical devices and imaging technology [9]. This is a useful theory for thinking about public health and epidemiology, topics that take place at the level of populations and not individual bodies. It might even explain the moral imperative of health as something that must be strived for and explained.

But my disease, neurofibromatosis, type II, (NF2) does not play well with these ideas. It’s not localized to a specific place in me. This genetic disorder is present in (likely, nearly) every one of my cells, not just those seen as pathological by doctors. They direct their efforts at discerning the most pathological parts of my body and away from the minor deviations.

For years, I had assumed my NF2 was only genetically dispersed through my body but manifested in my ears and leg. Instead, I read in a 2010 radiology report: “Stable appearance of the T2 hyperintense, enhancing lesion in the left greater sphenoid wing. This could represent a fibro-osseous lesion.” That is, in another area of my skull, another schwannoma is growing. Why did I learn this by reading and not from a doctor’s voice? If a pathological part of the body yields no symptoms, is it medically real?

U.S. medicine prides itself on swift action (Ford, et al., 2020; Baraitser, et al., 2021), but when that’s not possible, the path falls apart. Chronic-illness patients suffer from the uncertainty (Charmaz, 1983). For me, the time to act might be never. I am a “watchful waiting” patient. Watchful waiting is a treatment approach that relies on regular diagnostic imaging, waiting for the results to say that the time is now; intervention is necessary and nigh. It was first developed as a method for treating pancreatic cancer patients, but it’s been adopted to treat NF2 because the chance of a completely successful surgery is so dismal.

A promise was made to me. There is a man (they have all been men) with a room and a knife waiting for me, should I need them. And that promise made the mandate: keep producing images of my body, and they say the harm that will be done to my body will be less for it. If I don’t make these images, I’m only hurting myself. How could I do such a thing? Every year for 17 years, I’ve spent at least two days running a gamut of MRI scans, hearing tests, and neurologist and neurosurgeon appointments.

One of the consequences of watchful-waiting treatment is a long patient record. What does that look like, and what does it mean that my record is more complete than any hospital record? I’m here because I am haunted by watchful waiting and chronic illness (Gordon, 2008). I know my family’s experiences of NF2 illness. Their experiences follow me. And I am also followed by the “I” of this record — doctors enjoin me to feed him, to help them map him, to make him more real. Every new institution I visit, I bring the catalysts and say the words that will create him anew, as asked. I’m interested in how such ethical urges are
produced from documents and data, once possessed (Igo, 2018).

But I’ve procrastinated for long enough. I too have to look.

Unboxing myself

Most of my archive fits in a FedEx box: one overstuffed binder and four folders. It’s a flood of twenty-first-century office organization. The huge folders containing the acetate MRI scans of my young body I have to carry myself, separately. The archive leans toward the time of my diagnosis. I’ve never had to recreate that initial rush of appointments before my diagnosis, and hospitals have since adopted electronic patient portals to replace physical forms. It’s hard to tell which factor did more to compress the later information. I can’t start with the binder, so I look back to the slim, blue folder.

Figure 1: My NF2 archive: the green binder, the set of folders, and the MRI acetate scans. Obligatory millenial air plant at right. Alt-text: A set of document holders spread out on a wooden kitchen table. At left, four stacked folders with black acetate sticking out of the top. At center, four folders. The orange folder has Post-It notes stuck to the front. At top is a large green binder, with plastic tab dividers. At top right, a small
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There, things have gotten messy from my lack of care. I have made no divisions or chronological order within the folder, so I randomly detach each piece of paper from their pile. The repurposed DVD mailer that now contains five MRI scans from three hospital systems is an old friend. I once took notes in thick marker strokes on the backside of a hearing test copy (this is the one the audiologist sees at my next visit). I unfold a set of drawings and instructions for physical-therapy exercises. I had tried to practice them, but constantly reminding myself of my leg’s weakness is painful (in several ways).

These items vary in age from when I was diagnosed in 2005 to last year: they are not a curation of the most helpful documents I might use in appointments. The rapid rate of change, as I receive new reports and winnow unneeded material, makes this folder a kind of “rolling archetype” (Love, 1998). If I wait long enough, it’s not clear whether any of these documents will remain, migrate to a more secure home, or find their way to the waste bin. In that way, my archive shares more with the medical record as collaborative working collection than the calcified record that waits in patient portals until your next appointment.

It’s also already in this first folder that edits to my person become clear. My files, above all, paint me as a willing subject. A neuro-opthamologist looking for the characteristic iris nodules of NF2 lists my general appearance in 2005 as “alert, oriented, calm, cooperative.” In other places, it’s noted “what a pleasure it was to participate” in my care. I imagine the patronage of referring doctors and of provider letters as cover letters for patients. How much of this compliant portrait derives from my presentation as a white masc patient with health insurance, I can’t say. Bridges (2011) shows how medical staff racialize patient populations and normalize intrusion on the privacy of Medicare patients (e.g., requiring them to visit social workers to receive neonatal care).

It’s here, in the folder I use most often, that I notice the first omission. In 2018, I referred myself to a new neurologist because the neurologist I had seen since my diagnosis ignored my reports of a new chronic pain, for years. I was worried. This new neurologist took the time and care to listen to what I said. Following a physical test of my left leg, he ordered an MRI further down my femur. It revealed a thin schwannoma extending far past the other that sits on my lumbar spine and down along my femoral nerve. My symptoms had a material cause.

In this neurologist’s provider letter, however, he addresses his writing to my general physician: “Thank you for referring Mr. Samuel DiBella to me.” She had done no such thing. Perhaps this was part of an unedited form — another section of the letter describes me as a self-referral. However, my entire description to this neurologist of why I needed a second opinion are missing. Instead, my switch is described only as a logistical preference to my now-distant previous provider.

Distortions in the letter about my job and my family hint at how doctors collect and filter social history information to prioritize information they see as relevant (Berg, 1996). Through this letter, through its address, I’m removed as an audience for my own medical care. In my archive, my medical instinct to pursue symptoms unto diagnosis has become invisible. Self-care has been defined as the care of another. Yet, the words the doctors use to describe me were produced in collaboration with me.

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**Blanking and bitterness**

The other folder — this one orange — is mostly my parents’. It contains artifacts of their care. I only read it in full recently but it’s all familiar. MRI appointment notifications from the first hospital have been gathered together by alligator clips (see Figure 2). Each form in its identical voice warns against arriving
This patient is a hidden messenger: NF2, watchful waiting, and records of care with magnetic objects in your body; only the dates and times differ. Each boasts a small business card from my former neurologist, also identical minus the appointment details.

Figure 2: One of the MRI appointment notices in the archive. Alt-text: A detail shot of an MRI appointment notification for March 2005. The notification commands an early arrival for the appointment, no use of sedatives or anti-anxiety medications. A note in pen at the upper right reads, “Room 2. Can play CDs. Benadryl for relaxing?”

These blank forms give form to bureaucratic knowledge (Gitelman, 2014), while also arriving serially, one after the other. It gives the impression of reading new issues of a newspaper, each with the same headline. The chronically ill patient needs to be reminded of the rules, again and again and again.
I flip over an envelope glued to the inside cover to see that it is hiding a pair of plastic patient identification cards, once necessary to get parking validation. The business cards stapled to the front of the folder draw in medical specialists, while three separate copies of my birth certificate speak to an anxiety about identification. Maps of hospitals and highways are littered throughout, new routes to the same places drawn in pen. These are the things we needed.

In other places, I find lined note paper interleaved between forms: one in my mom’s handwriting documents one of my episodes of sudden hearing distortion and the prednisone doses I was prescribed to take. Handwritten annotations pepper hospital documents either with helpful directives or jotted notes from a doctor’s oral report in an appointment.

But even official documents give way to files with other uses. Near the back, I find a secreted syllabus of Web resources, an attempt to understand neurofibromatosis. A printout from the National Institute of Neurological Disorders Web site hints at my treatment: “A strategy of watchful waiting might be more appropriate for slowly growing brain and spinal tumors, which have higher risks of surgical complications.” I look to that conditional “might” and see the balancing of risk that NF2 care involves.

One printed and copied FAQ on NF2 seems to have been meant for my teachers. My mom wrote below, “He hasn’t shared this with peers yet, but I felt you should know to help him compensate.” Not every prescription is a pill. I remember using a science project in seventh grade to study NF2 — how a particular gene can fail to produce a protein, the lack of the protein makes nerve sheath cells unable to sense their neighbors, the perceived lack of neighbors leading to a slow and inexorable growth. I stood in front of my class and told them about myself in great detail, without saying so. Someone asked me why I’d chosen this weird, very particular subject. I panicked and I said (truthfully) that my uncle had NF2. I had said as much as I could at the time. I’m trying again here.

One of the last documents in this folder is a 2005 letter in response to my parents’ Medicaid application for me. The state of Rhode Island was suspicious that my illness was not sufficiently harmful enough to merit state support — they wanted more proof, more documentation in turn. I was denied, as I have been denied support since. You’ve probably noticed that my descriptions of illness, patienthood, and disability has overlapped, perhaps more than they should. For me, they are so closely tied. It is in the hospital and through medical staff that my disability has been most produced. I often pass as able-bodied, particularly because I bear no clear marks or assistive aids (Siebers, 2004).

This year, I applied for university disability accommodations for chronic depression: throughout that process, my oral testimony about my health and history was assumed to be flawed, while documentation from a doctor would be trustworthy. To apply, I had to ask a doctor to transcribe and sign my descriptions of my symptoms. It was their signature that would make that description institutionally legible. (I was denied, as many graduate students are; see Carter, et al. [2017] on ableism in graduate education.) Each institution demands coordination from its subjects — the disabled or ill body is seen as untrustworthy on its own.

This digression, this discovery of a longer history of denial than I remembered, lead me to think about my bitterness in writing this. People with disabilities are not expected to hold bitterness in their hearts. An undesired state that can’t be changed through effort runs against the capitalist logic of the able and willing worker. All the people who recommended I take up yoga have said, whether they knew it or not, that my disability is something I have settled for. I don’t know how much work I would have to do to be able to run again, if ever.

By writing this, by not praising by default the doctors and medical staff who have participated in my care, I risk falling into the trope of the “bitter cripple” (Barnes, 2015). The bitter cripple is a villain by and through their visible disability. As my limp and pain increase, I will only better fit this false image.

Discussing this article with my advisor, I said something they heard as “curriculum of bitterness.” As I sat with that phrase, it seemed more and more appropriate for describing the process of reading through my
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files. By this I mean that it is hard to read and remember so much of your own and your family’s stress and unhappiness. But also, these files are the artifacts of my education in my disability and the U.S. healthcare system.

How you get your education, however, affects how you can argue for what you know. As I mentioned before, U.S. doctors, as a rule, secured professional autonomy through systems of certification and have worked particularly hard to protect their autonomy (Starr, 1982). Their expertise, their social and cultural right to be an authority, is defined through that process and the laws that support it. But their expertise comes at a cost for others. During the AIDS crisis, for example, ACT UP activists had to squeeze patients’ knowledge into clinical forms before it could be used to help anyone (Epstein, 1995).

When I started this project, I thought I would find proof for contests of expertise — that these records would be a tool for grounding and certifying personal knowledge in matters of diagnosis and treatment. I didn’t find such proof. Conflict was written out of my provider letters, and the handwritten notes never address themselves to a medical audience.

I have, however, more agency than an institutionalized, acute-care patient. I’ve had access to health insurance in a country that refuses to recognize healthcare as a human right. When my reports of chronic pain were ignored, I found a doctor that would listen. I’ve looked into physical therapy and sign language, prescriptions that I’ve never received from a doctor but that ultimately have more chance to improve my life than any surgery. For NF2, all they can do is arrest harm; they cannot heal. And even though I can’t use these sources in conflicts over my care (there is no diploma for an invisible college), they can still explain how I became a “watchful waiting” patient.

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**Binding description**

This three-ring binder is thick, and it is the hardest and most confused collection to get through. My parents saved paper by printing on the backs of other things — there are pictures of my mom’s paintings, unrelated e-mails, and airline tickets. It’s in these files that my case history and interesting-ness are established.
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Figure 3: One of the early MRI reports in the three-ring binder. I’ve redacted some personal information and the identifying information of specific medical workers. Alt-text: A three-ring binder opened up with a manila divider at left and an MRI report at right. Newspaper articles and other MRI reports stick out at the edges. The report describes a November 2007 test that calculated the volume of my two vestibular schwannomas.

Shortly past another array of MRI appointment notices, I flip to an e-mail between my mom and my first neurologist. There are photographs that I’d forgotten. I can’t show you these photographs. It would mortify my younger self, and I would like to do him this kindness. Shortly after I was diagnosed with NF2, the left side of my face was paralyzed in an episode of Bell’s palsy. “Idiopathic,” they called it. That means they had no idea what caused it.

There are three photos of my young face, half frozen and looking scared. In one, I am trying to close my eyes but the whites are still visible above my unmoving mouth. I had to wear an eyepatch for months, and it’s still possible to see the crook in my smile if you look for it. In the next set of images, months have passed and I have an almost-joyous manic look as I try to flex my face for the photo. My mom writes in her e-mail:

“Because of the Palsy, his left side isn’t a good surgical candidate, and they wouldn’t want to possibly affect the right side with surgery, so we need to let the Bell’s Palsy cure itself, if it will.

They also agreed at this time that radiation is not a good option for so young a boy.”

A hint then of an interruption in operation — if my face hadn’t frozen, surgery might have been an option. I
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think here of my relatives who have undergone surgery for NF2, only for their facial nerves to be severed or damaged. And my age, just before puberty, made me a dangerous candidate for radiation treatment.

Even though they come early, these photos are the end result of a whirlwind of diagnostic activity. My mom noticed that, as a boy, I started to run “funny.” This marked action lead to consultations with pediatrics and oncolgists until they could find the cause of the one inch disparity in the lengths of my legs — a schwannoma wrapped around my lumbar spine. This binder also contains a bulk of NF2 research in printed Web sites and a packet of research article abstracts. These were the result of my parents’ effort to make meaning of this diagnosis, one expected in family history but unusually early in generating symptoms.

A mass of cream-colored paper makes up the midpoint of the binder. Each is a letter written by a physical therapist my parents brought me to shortly after diagnosis. Unlike the neurologists and neurosurgeons, who work through prescription and operation respectively, she wanted to preserve as much of my muscles as possible before they atrophied and before I grew in height. The detail of her medical expertise varies widely from the other providers. Their descriptions of my gait and strength are simplistic, only a few sentences with 05 scales of strength. This is a neurosurgeon’s description of me:

“When asked to run, Sam tenuously limps when placing weight on the left lower extremity, with associated decreased forward propulsion. He also tends to lock the knee in recuvartum to increase osteologic stability and therefore minimize muscle energy requirement.”

Her writing acknowledges the accommodating effort my body and brain make. Still, these descriptions of my body are strange.

Throughout the medical descriptions of me I’ve found, the interest is clearly on the pathological. Line after line of these letters isolate parts of me and force them to announce or renounce normality, to their eyes. I see these descriptions as consistent with a wider bias toward disability surveillance, whereby the disabled body is seen as particularly needing or deserving vigilant scrutiny (Saltes, 2013). They’re looking for disease but describing disability.

I had thought of my archive as a source of information, but doctors’ refusal to rely only on records is clear. As I’ve lived in new places, each new doctor feels the need to rediagnose me. I say I have no reflex in my left knee, my records says so, but they still test. The images they create from MRIs and audiologists provide a clear corroboration. Even then it’s like they’re working from dead reckoning: only the most recent previous records are worth using for comparison. Phantom disability is made real for them, through those images (Hagood, 2017).

Among these notes, however, I realize a strange feature of all the medical writing I’ve seen up until this point. There is no specific description of my case in plain language. I have patient brochures (see Figure 4), intended to describe the general case of NF2 patients. I have provider letters in which doctors describe me in jargon for one another, in ways weighted towards their specialty. None of these letters are addressed to me. Where is the information specifically about me, for me? I’m left to say that only my parents’ and my notes fill that role in this archive.
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Figure 4: Some of the non-personalized brochures within the archive. Note the images of calm information transmission and the seemingly unconnected melanoma brochure that’s found its way into the collection.

Alt-text: A collection of five brochures laid flat. The first is called “Brain tumors: Understanding your care” and depicts a doctor pointing to a computer screen of MRI brain scans while an older patient watches. The second has a blank, green cover and is titled “Neuro-fibroma-tosis: Information for patients & families.” The third is called “Neurofibromatosis: Questions and answers.” It was published by the Children’s Tumor Foundation and the cover shows a woman lifting a young girl with neurofibromatosis, type I. The fourth brochure, published by the American Brain Tumor Association, is titled “Stereotactic radiosurgery: Focusing on treatment” and shows several older patients reading. The last brochure, with an abstracted starburst cover, is titled “Dysplastic nevi: And risks of melanoma by the Skin Cancer Foundation.”

Studying the social elements of illness, Annemarie Mol (2007) describes how medical experts coordinate themselves around a disease. Radiologists only see disease in images, while pathologists can locate disease in severed limbs. Despite the incomparability of these types of knowledge, doctors act like they’re working together in response to a single pathology. They see what Mols calls “the body multiple.”

Mol shows the debate and uncertainty produced when the diagnostic tools of doctors and the embodied experience of patients diverge. Sometimes that divergence can be resolved or ignored:

“It is precisely because nobody expects there to be a linear relation between a patient’s physical disease and what we might call his ‘social disease’ that the latter deserves separate attention. Thus, the fact that different objects may be added together and thereby turned into one doesn’t depend on the projected existence of a single object that was waiting in the body. Singularity can also be deliberately strived after. It can be produced. The result of addition is a single object.” [10]

Imaging artifacts and perceptions of pain are both tools in the argument over treatment, but images and other media can be valued over the oral testimony of patients. In my radiologist reports, a phrase like “given differences in technique” does that work across hospital systems. In other places, a grumble about a radiologist’s superior skill compared to previous technicians does the same.
If we accept that both patients and care providers enact medical knowledge and labor, we can now explain
the heavy presence of annotations and notes in my archive. They are artifacts for the coordination of care
outside the hospital system. They take abstracted clinical descriptions and apply them to the symptoms I
experience. They locate potential allies (medical or political) and ensure the right questions are asked at the
right times.

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Watchful waiting

I’ve said enough now that I can look watchful waiting in the eye. It’s the paradigm for how I receive
treatment, but what is it?

In my case, watchful waiting has meant yearly hearing tests and MRI imaging of my brain (every other year
for my spine). Those diagnostics are followed by appointments with neurologists and, less often, a
neurosurgeon. Although the harms of NF2 in my family have mostly been related to hearing, these tests are
conducted in expectation that one day their results will be worrying enough to merit invasive surgery. There
are scant mentions of watchful waiting in my archive, however. The early mentions weigh whether it’s an
appropriate treatment or not. The later ones simply re-confirm it as a descriptor of how I’m being treated.

My confusion over how to define watchful waiting, or medical surveillance (distinct from Armstrong’s
theory), is shared by the medical literature. It originated as a cancer treatment approach but it, and the
variant of “active surveillance”, aren’t used or defined in a consistent way. In fact, Rittenmeyer, et al.
(2016) found in their survey that many watchful-waiting patients don’t even realize that they are
watchful-waiting patients. They describe the stress that prolonged uncertainty creates, through the voice of another
patient:

“For many, certain adjustments and life style modifications
were necessary in order to live with watchful waiting. ‘I don’t
like how medicalized my life has become. It feels like every six
months I’ve got to do something and in the meantime I’m
supposed to be worrying about it, you know? Checking, trying
to be vigilant, and all of that ... whenever I go in, it feels like
calling [emergency phone number] when you don’t have an
emergency.’ While engaging in watchful waiting patients
wanted to feel that their healthcare provider was empathic to
what it was like to go through what most described as an
ordeal.” [11]

The researchers emphasize the complexity of choosing watchful waiting for treatment. Patients are often
under pressure, by themselves, relatives, and friends, to appear to be doing something to treat their illnesses.
In those cases, watchful waiting looks like giving up.

On the other hand, watchful waiting is also a promise of care extended indefinitely, as long as needed. That
recurring care can “unstick” patients from the perception of unending chronic illness and make the waiting
that’s so inherent to patient-hood feel manageable (Baraitser and Brook, 2021). So, we have a poorly
defined protocol that legitimizes the delay of invasive procedures, hopefully in a way that assuages patients
rather than making them feel neglected.

With watchful waiting, both doctor and patient await alike. We are both part of a “surveillant assemblage”
of people and objects that train their gaze on a shared body (Haggerty and Ericson, 2000). The watching,
however, differs. For my doctors, watching is the extraction of images from my body at fairly regular
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intervals. Those images, and the technicians’ reports that accompany them, are something they can see and understand.

I am, however, always monitoring my symptoms. I don’t know what I’m waiting and watching for. Did I always have this much trouble understanding speech in a crowded room? Did the pain always creep past that point of my knee? Why did that spark of pain suddenly reach from my calf, through my pelvis, up to my ribs? Is there a way I can sneeze without creating a corresponding burst of pain? These are moments when I flicker into what the disability community calls “crip time” (Samuels, 2017). Outside of my or others’ control, I have to listen to what my body is telling me.

While images and reports can only arrive as documents, my information can only be shared orally with doctors. In some cases, a physical exam can confirm what I say (such as a tie between the location of my pain and the location of my nerve tumors). Im constrained to the oral report by the confessional mode of patient-centered medicine (Silverman and Bloor, 1997) and the limits of human language to communicate and categorize pain (Scarry, 1987; Whelan, 2009).

I now know why I’ve been conscripted as a watchful-waiting patient. My first neurologist writes at the time of diagnosis of surgery as inevitable, since I was symptomatic:

“The second possible course [after watchful waiting] would be to pursue surgical extirpation. Given the size and smooth outline of the left tumor, I believe this would be the appropriate one to remove. At an experienced center, about 2/3 of patients with this profile will retain useful hearing after surgery but 1/3 will lose hearing. The Dibella family is familiar with this possible outcome as 3 other family members have lost hearing with vestibular schwannoma surgery. [...] Although I emphasized that no decision should be made today, it is important to move towards a plan of action over the next few months as chances of retaining hearing decrease if the tumor grows.”

All the concern is how to trade a tumor for “useful hearing” — Deafness is treated as if it were another pathological state. The sudden onset of Bell’s palsy after my diagnosis with NF2 set the stage and made the chances of harmless surgical intervention next to nil. Naturally, we had to wait for my nerves to recover before surgery could be considered. But waiting is a practice. There has never been a good moment to stop waiting.

The only time the protocol has been threatened is when I’ve moved from one hospital system to another. Otherwise, as I learned in my last appointment, the only indicator for surgery would be if one of my imaged schwannomas appeared malignant or upon the verge of harming my brain. Now, remember, I have schwannomas throughout my body but only four of them are covered in the diagnostic images I receive. We’re pretending that only the four schwannomas visualized by a magnetic eye are capable of malignancy. I don’t know what kind of care that is.

Continuations

Here at the end, I’m going to be as concrete as I can.

First, I’m suspicious that access to patient notes alone will improve medical care. In the U.S., the 2021 Cures Act gave patients the right to access to their notes through electronic patient portals (Blease, et al.,
The “open notes” movement has argued that this will increase accountability, but I’ve hopefully shown that U.S. medical records, as they’re written now, are not intended for patient use. They are still created for collaboration between medical professionals, which means they are written using terms that make them hard to read for patients. I don’t think the return of the “patient story” to these notes will help chronic-illness patients much either — we know our stories and how to produce them.

Openness is admirable as a political value, but without care it can conceal just as much as it reveals (Tkacz, 2012). The openness that “open notes” and practices like lifelogging encourage implies an end of a process. I think the onus is on doctors to change their notetaking practice, to consider their notes as a useful tool for patients at all. Until these notes are meant to include patients in collaboration, I think they will remain primarily a resource for doctors (or those patients who can interpret those records alone or with help). Open your notes, just like cities are opening civic data portals and programmers are opening their code bases, some say. My attempts to unpick my own records show why I think they will remain closed.

Second, in my case, watchful waiting was not a treatment choice; I have experienced it as an abdication, although an abdication that I have maintained. The case is a fundamental way of organizing how a patient’s illness is seen. I think here of Frances Griffiths’ reminder that a changing case can sometimes be healthy, for the patient: “Being stuck as a particular type of case in medicine may well be an unhealthy state for an individual.” As my diagnosis became more set in records, it became harder and harder to ask doctors to revisit those judgments of my case (even as they recreated them through tests and exams, year after year).

Despite the minimal benefits of each test result, watchful waiting itself has been stressful: each set of appointments, I haven’t known whether now is the time when they will recommend opening me up. I’ve come to dread the obligation of self-surveillance, because I know that its results might be used to hurt me. More medical studies should consider the burden that watchful waiting puts on patients and acknowledge that most of the labor of waiting is done by patients, for themselves.

In her autoethnography of pain, Lara Birk writes:

“When pain is no longer understood as simply a private, personal matter, its political agency can be realized and its sufferers can embody more empowered narratives of endurance and strength. It has been my aim here to begin to give pain a voice, so that other persons in pain can come out from under the shadows of false shame, join their voices to the collective, and resist that which endeavors to secure their silence.”

I want to add my voice to hers. If you are an NF2 or watchful-waiting patient, I hope my voice has spoken to you. And if you need me, I’ll be here, waiting.

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Samuel DiBella is a Ph.D. student in the College of Information Studies at the University of Maryland, College Park. He previously completed an M.Sc. in media studies, with distinction, at the London School of Economics; his dissertation focused on the ethics of online identification. His writing has appeared in Public Books, Surveillance & Society, International Journal of Communication, and the LSE Review of Books. Sam has been a neurofibromatosis, type II, patient for 17 years and usually passes as able-bodied. E-mail: sdibella [at] umd [dot] edu

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Notes

References


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doi: https://doi.org/10.1136/bmj.n429, accessed 12 December 2022.


doi: https://doi.org/10.1111/1467-9566.ep10939100, accessed 12 December 2022.


doi: https://doi.org/10.1111/1467-9566.ep10491512, accessed 12 December 2022.


doi: https://doi.org/10.21983/P3.0185.1.00, accessed 12 December 2022.


doi: https://doi.org/10.1136/bmj.m4143, accessed 12 December 2022.

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Natasha Salletes, 2013. “‘Abnormal’ bodies on the borders of inclusion: Biopolitics and the paradox of disability surveillance,” *Surveillance & Society*, volume 11, numbers 1–2, pp. 55–73. doi: [https://doi.org/10.24908/ss.v11i1/2.4460](https://doi.org/10.24908/ss.v11i1/2.4460), accessed 12 December 2022.


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