

Posthumanist Medicine:  
Participatory Healthcare, Medical Humanities, and Digital Media

by

Danielle Stock

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## Author's Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

## Abstract

This dissertation explores the construction of illness in the context of two interrelated processes that both propose a more empowered patient role and a whole person model for healthcare. Specifically, these contexts are the digitally mediated space of “health 2.0” and the medical movement toward humanistic practices, such as narrative medicine. This research identifies and questions some of the deeply ingrained humanistic leanings of these approaches to reveal how an essentialist understanding of the human perpetuates the modern biomedical conceptualization of healing. The concept of wholeness is deployed—in the sense of bodies, selves, and illness narratives—to continue understanding the sick body/ mind as broken and in need of mending by institutionalized medicine.

This same conceptualization is taken up online where individuals represent their experiences of illness. The space of health social networking sites serves as a reinforcement of the quantified self of modern medicine, a tactic employed to support commercial profitability. By critically analyzing the language and goals of medical humanities, the visual rhetoric, social use, and political economy of websites where online illness narratives are crafted, and the social contexts attached to the contemporary experience of illness, this dissertation argues for a posthumanist thought intervention in medical training, healthcare delivery, and digital health.

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*To my parents, Deb & Joe Stock.*

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*We're here to awaken from the illusion of separateness.*

Ram Dass, *How Can I Help?*



## Introduction

When I began this research project, I set out to explore the blogging practices of people with Alzheimer’s disease and related dementias (ARD), a topic that sent me down a path toward a more expansive exploration of illness, narrative, posthumanist philosophy, disability studies, and new media. Early on, when I would tell others about the research that I was engaged in, many reacted with surprise. The surprise seemed to originate, not from the fact that I had chosen such a field of research, but at the idea of a person with dementia writing a blog. For me, this was a clear sign that my research needed to be done. Why was it shocking that someone experiencing memory impairment would write about this online? No one seemed to question the other kinds of social media communities I had been researching—those made up of persons with cancer or multiple sclerosis. Why were my friends surprised that people with dementia were capable of blogging? These lingering questions speak to both the cultural construction of dementia, which has created a certain mainstream or stereotyped “dementia figure,” as well as the larger question that this dissertation asks: who is entitled to a voice – to the right to construct a self-narrative – both on- and off-line?

The questions I explore here are entangled with conversations happening within and between the interdisciplinary fields of medical and digital humanities. Not surprisingly for two emergent fields, both of these disciplines are engaged in vigorous debates over scope, aim, and methodology. Medical humanities currently attempts to define itself in the tension between the instrumentalization of humanities’ objects of study (using art, music, and literature to teach health practitioners how to be more humane) and the use of tools of critical inquiry (disability studies, critical health studies, etc.) to evaluate and intervene in medical relationships, practices, and technologies.

Similarly, in digital humanities disciplinary debates, we regard the tension between the creation of digital tools for the analysis of humanities object texts weighed against the critical analysis of digital culture and the use of humanities research-creation practices to intervene in the cycle of innovation and commodification (Raley 40-1). I do not think that these debates need to have either/or stakes and I am content to dwell in the messiness of both of these disciplines.

This dissertation aims to complicate the expectation that difference, such as illness or disability, becomes socially accommodated in digital cultures—that there is space online for the performance of such identities. In my first chapter, I ground this exploration in a social historical analysis of patienthood in various ages throughout history, in order to give texture and depth to an understanding of the issues and realities of contemporary patienthood. In chapter two, I examine the implications of the rhetoric of whole personhood that characterizes discussions of medical humanities and narrative medicine, both of which are aimed at reforming contemporary patient care. In chapters three and four, I explore how this desire to put the sick body and, with it, the sick narrative “back together” also persists in online instantiations of health management and patient (self-)care, where commercial forces actively construct social and cultural meanings surrounding illness and health. Lastly, in chapter five, I investigate how the social, cultural, and rhetorical space of the dementia blog embodies the expectations of stable selfhood that substantiate the stigmatization of dementia.

In a general sense, this work examines how digital media is imbricated within contemporary economies of medicine and healthcare, whether knowledge economies, social economies, or political economies. I explore the role that these processes, tools, and social spaces play in constructing or disrupting medical understandings of the body. The goal of this study is to serve as a foundation for future scholarly investigation

into the way in which digital tools might be reimagined to serve the best interests of individuals and communities whose lives are overdetermined by the medical-industrial regulation of bodily difference.

## Chapter 1 | Patrons, Patients, and Participants: A Social History of the Healthcare Seeker

We organize the world—that is, space and time and, within these, social roles, cultural paths, ways of living, moving about, getting to work, styles of communication, and habits of leisure—for a kind of average person, designated normal. This is a world that the person who cannot, or can no longer, move there comfortably threatens to modify and remake. The first is a fear of discomfort, a kind of strain that is imposed by the being who is no longer located within our familiar norms. . . . In us or around us, the onset of disability creates a disorganization that is both concrete and social. But from this vantage point we perceive yet another disorganization, much deeper and more painful: the disorganization of our acquired understandings, of our established values.

Henri-Jacques Stiker, *A History of Disability*

In April 2013, Health Canada issued a recall of the generic brand contraception pill Alysena-28, after manufacturer Apotex reported that one batch of the drug, rather than containing seven placebo pills, might actually contain fourteen. This mistake resulted in the replacement of a full week's worth of active pills by a non-contraceptive sugar pill, thereby drastically reducing the effectiveness of the prescription medication. Individuals who had been taking pills from the affected batch for the past several months discovered that their risk of unplanned pregnancy had been, unbeknownst to them, significantly higher during that time ("Birth Control").

This story of a drug recall, though unsettling, is certainly not uncommon in North America. We can add it to the lengthy list of pharmaceutical, food, and product recalls listed at any given time on the Health Canada Recalls and Safety Alerts Database

(“Advisories, Warnings, and Recalls”). What seems unique about this news item, however, is the way in which Apotex and its retailers chose to position the affected women and their sexual partners in relation to the event—that is, as *patients* passively subject to the actions and expertise of healthcare service providers. Despite the apparent urgency of publicizing such a recall, Apotex chose to inform wholesalers and retailers several days before issuing a public report or press release that would directly inform the individuals affected by the error. The report did not break on CBC News until three days following the initial recall.

In response to the packaging error, CBC interviewed John Tse, the vice-president of Vancouver-based London Drugs. Following the recall, the pharmacy directly contacted over 350 of its customers who may have been sold the botched drug and offered each customer a free pregnancy test or morning-after pill. The offer of a contraceptive pill that must be administered no more than 120 hours (five days) following sexual intercourse to women who had taken the defective medication *months* prior to this recall seems both absurd and alarming (“Morning-After Pill”). However, putting this quizzical detail aside to analyze Tse’s verbal response to the events, we see reflected a highly paternalistic conceptualization of the pharmacy in relation to a group of customers constructed as both victimized and dependent. In his comments, Tse articulates the pharmacy’s responsibility to its customers, but uses the paternalistic language of an arguably antiquated medical model, stating, “I looked at [the recall] and said, “there could be unwanted pregnancies out there . . . . We felt it was important to let the patient know so there can be a judgment call from the patient,” and further, “We felt we need to go and look after our patients, because who would fight for our patients[?]” (“Birth Control”). This characterization is germane to an exploration of the individual’s historical and contemporary relation to healthcare, particularly if—as this

chapter will explore—we broaden our notion of healthcare to include a series of both clinical and consumerist interactions.

Tse’s remarks in this article point to a persistent tendency by healthcare providers to place the seeker of healthcare products and services in the passive role of patient, in spite of a twenty-first century context of the healthcare client or consumer. Despite using the language of control, Tse’s comments at least point to an interest in allowing for “a judgment call from the patient.” The same cannot be said for Apotex. At a time when corporate entities have direct access to the end-consumer through various avenues of social media, the example of Apotex reflects the perpetuation of an arguably unnecessary and forced dependency of the individual upon the denizens of medical authority. The possessive way in which Tse, as a stand-in for the company he represents, thinks about the individuals with whom he does business—as “our patients”—extends the proprietary etiquette of doctor ownership over patients to the realms of the medical market and, perhaps, beyond. Indeed, his words reflect an historical and ongoing tension within the sphere of healthcare between professional control and patient self-determination, a tension that underlies the development of the unique social contract that this dissertation examines.

The world of online health consumerism, management, and social networking illuminates different, although not altogether dissimilar, issues with regard to the position of individuals who identify as having medical conditions. While the doctor figure may be absent from this world, she is, rather, *displaced* by the corporate entities that have assumed control of the neoliberalist health mandate. The promise that social media will empower patients to heal themselves and each other is undermined by the reality that powerful individuals serve to profit from the shared experiences of those who seek their services. The problematic idea of a private corporation “protecting its

patients,” as the CEO above pledges with regard to pharmaceutical sales, is similarly revealed in the case of a popular health social networking site called PatientsLikeMe (PLM) and its role in protecting user data.

In May 2010, PLM discovered that Nielson, a large media research company, had secretly copied individual patient profile information—including personal demographic, health history, diagnostic, treatment, and medication data—to sell to one of its clients. As I will elaborate in chapter four, PLM’s messaging overtly emphasizes its commitment to empowering patients and providing them with the tools they need to improve their wellness. However, when PLM chairman Jamie Heywood notes in his interview with the *Wall Street Journal*, in response to the data-scraping incident, “We’re a business, and the reality is that someone came in and stole from us,” he highlights the true issue at stake for the company (Anglin and Stecklow). As the *WSJ* article points out, the practice of data scraping is legally questionable, but not necessarily illegal. The incident reveals the troubling reality that virtually all information that individuals make available online can be scraped and sold for consumer market research. Again, the question arises as to who is truly empowered in this instance of twenty-first century patienthood.

I have begun this chapter by elucidating two contemporary healthcare narratives, largely in order to frame the underlying motivations of this critical look into the historical medical archive. Indeed, the act of situating individuals’ contemporary healthcare experiences within the long history of medicine and medical relationships relies somewhat significantly on first articulating the problematic of defining contemporary patienthood. While the entire dissertation will elaborate on this issue, this chapter isolates two central concerns in the wider context of defining the historical patient: what does it mean to be a patient, and, more specifically, how have the social,

cultural, technological, political economic, and epistemological arrangements of each 'age' of medicine continuously modified the concept of the patient? Perhaps more to the point, is the term 'patient' continuously applicable, over the course of medical history, to the individual healthcare seeker, or is this an unsatisfactory and partial term? These questions will be considered in the context of the larger problem around which the Apotex recall, the Nielson data scraping incident, and the wider problem of patients' suppressed self-determination, revolves: that is, the question of "patient autonomy." This controversial concept has been a central concern of medical ethics since at least the 1950s, appearing in debates that pit patient rights to information and decision-making power against the professional expertise of medical authorities. As Rita Charon notes in her chapter on the narrative roots of bioethics, "many of the early concerns of bioethics—informed consent, safeguarding patients' autonomy, and resource allocation—were powered by the suspicion that doctors, left to their own devices, will exploit patients or in some way harm them and that patients need defense against them" (204-5). This attitude is grounded in real historical abuses of power that have produced an understanding of clinical interactions as necessarily "adversarial," a quality that certainly seems to inflect much scholarly and popular discourse on the subject of practitioner and healthcare seeker relations (Charon 205).

In recent times, the growth of grassroots activism (fuelled in large part by the affordances of the web) that promotes participatory healthcare and the experiential expertise of patients, to my mind, signals an alarming situation—the perceived persistence of medical paternalism among patient communities and a continued search for a greater balance of power between individuals and their healthcare practitioners. In tandem with the work of constructing a more nuanced definition of patienthood in this chapter, I want to hone in on the emergence of the twin rhetorics of autonomy and



wholeness in the context of healthcare. As the following chapters will elucidate, the quest for greater patient autonomy has been accompanied by an equally prominent and undertheorized movement toward promoting, through teaching and practice, the ‘wholeness’ of the patient-figure within medicine. Both of these reconceptualizations can be regarded as late-twentieth and early-twenty-first century rhetorical strategies in response to a long history of what was increasingly perceived as a depersonalized, dehumanized, and dehumanizing Western medicine. While the ideas of patient autonomy and wholeness are important elements of the political activism of marginalized patient communities, their deployment demands a more rigorous grounding in historical and philosophical ideas about the figure of the patient.

The historical picture that I attempt to lay out here is, of course, only one interpretation of the lengthy and complex history of medicine, healthcare, and patienthood. I do not claim to construct the definitive narrative for how patienthood has evolved over the ages, nor do I desire to do so. As Jay T. Dolmage highlights in *Disability Rhetoric*, advancing a *mētis* historiography “characterized by sideways and backward movement,” historical accounts always necessarily leave something out (5); responsible scholarship must leave space for alternative, parallel, and conflicting possibilities. My goal here is to highlight some of the ways in which the role of patient has been construed throughout history, as well as the way in which the human at the centre of the medical question has been conceptualized. This does not preclude the existence of other modes of experience within the medical sphere; in fact, it would be virtually impossible, within this chapter, to account for the diverse subject positions from which individuals, over history, have interacted with healthcare providers. Therefore, the various interpretative lenses I employ here are meant to be generative, rather than exclusive.

With that in mind, in the next section, I explore how the healthcare seeker's role might take on all or some of the three sufferer roles that Digby highlights: patron, participant, and/or patient. Keeping these roles in mind, the rest of the chapter highlights how certain theoretical undercurrents for conceptualizing the body and disease have created at least four different ways of understanding the human in healthcare: as symbolic sufferer, as natural-philosophical subject, as historical text, and as scientific object. The end of the chapter works toward developing a conceptualization of the contemporary healthcare seeker as "expert patient," a topic I develop further in chapters three and four.

### **Patrons, participants, and patients**

The inhabitant of the domestic sickroom of the seventeenth century cannot be identified as occupying the same political space as the iPhone-wielding 'expert patient' of the twenty-first century. There are, however, resonances in the social and economic structures of the healthcare interaction throughout history, such that we can isolate at least three different modes of experience. Drawing upon Anne Digby's articulation of historical medical experience, these modes place the individual in one or a combination of the roles of *patron*, *participant*, or *patient*. While Digby uses the term "object of medical attention" rather than "patient" to describe the third role (305), this objectified position reflects precisely the definition which Michel Foucault ascribes to the patient in *The Birth of the Clinic* (83).

Following from my interpretation of Foucault's formulation, which I describe in more detail below, the healthcare seeker is a patient only in the context of the *clinical* encounter, when made the object of a clinical gaze. To the extent that the *acting out* of a role demands some *active* involvement, we can go so far as to say that the notion of a

'patient role' is inherently paradoxical, since this subject position is discursively tied to passivity, reflecting more of an inert non-role. The etymological roots of the term patient imply "one who waits"—waits to see the doctor, waits to see what will be his or her fate, waits for a medication to work, waits for the body to respond; one who is at the mercy of factors beyond his or her control. Indeed, the adjectival and noun forms of the word both have their roots in the mid-fourteenth-century French term *pacient*, from the Latin *patiens*, meaning "suffering" or "enduring without complaint" (Harper). It would seem that the term allows for only a distinctly disempowering and limited set of expectations for the individual, as it is both politically and ideologically bound up with issues of autonomy and self-determination. As Jay Katz argues in *The Silent World of Doctor and Patient*, his seminal text on patient autonomy and informed consent, one of the major historical objections to greater patient participation in medical decision-making follows the logic that when persons become patients, they enter the "caring custody" of physicians (2, 105). In fact, "since physicians have generally maintained that patients do not have the *capacity* to participate in decision making, patients' 'autonomy' was not a concept inscribed in medicine's vocabulary" (Katz 104).

The historical characterization of the patient as simply a case history or medical record helps to illuminate what I am calling the non-role of patienthood. While Foucault famously articulates how the ill person comes to be, in the clinic, "the accident of his disease, the transitory object that it happens to have seized upon" (59), we see how the term 'patient,' as far back as ancient Rome, denotes the dehumanized, inanimate 'case history.' Indeed, the renowned Roman physician Galen, in his infamous case histories, tellingly "refers to stories about patients simply as 'patients,' so that Hippocrates and Erasistratus 'write patients' or 'write up patients'; one might 'read this patient' or 'interpret this patient'; or he might refer to the 'beginning of a patient,' meaning of

course the beginning of his or her story” (Mattern 42). As Susan P. Mattern observes, Galen’s use of the term *arrhostos*, ‘patient,’ implies the essentially static and objectified position of an individual whose existence and participation has been reduced to “a unit of discourse” (42). Along these lines, therefore, I distinguish between the passive position of the individual as patient and the more actively involved role of the individual as healthcare seeker.

That said, however, there is certainly a counter-argument to be made that healthcare seekers are increasingly taking ownership of patienthood as a subject position, and in the process, transforming the meaning of the term by disrupting the traditional characterization of the passive patient figure. One could certainly argue that groups such as the Society for Participatory Medicine, forums such as the social networking site PatientsLikeMe, and individual patient activists like the well-known blogger Dave deBronkart, or e-Patient Dave as he is popularly known, are reappropriating patienthood. This activist stance could be seen as akin to other rights-related reappropriations, most notably the attempts of the disability rights movement to, rather than replace a stigmatized word, “control its usage,” and thereby transform mainstream understandings of disability (Davis xv).

On a less optimistic note, there is also, of course, the question of whether there truly exists any space for genuine nonconformity or individual action within what Foucault terms a system of disciplinary control, of which medicine is but a part. It would appear that even the participatory action of healthcare seekers, oriented toward self-determination and autonomy in decision-making, is nonetheless co-opted to serve the wider interests of the regulation of deviance—even this type of ‘democratizing’ activity winds up reasserting normative ends. I will tease out this question in greater detail in subsequent chapters, in which the theoretical approach of posthumanism may

serve to reassess the prioritization of particular human values that continue to perceive and assess human embodiment through the limiting value system of humanism.

In many ways, my posthumanist reading of the human in healthcare will require a reconsideration of how we understand human interaction within medicine. Indeed, my problematization or, perhaps, narrowing of the definition of patienthood, above, also affects how we discuss the healthcare interaction; consequently, the phrase ‘doctor-patient relationship’ is not necessarily accurate or useful in identifying the historical relationship that this chapter sets out to examine. Not only does the phrase impede a proper representation of the individual seeking care, it also only partially represents the ‘medical’ side of the encounter. As historian Sally Wilde argues in the context of the changing surgical landscape of the 1890s, there are two major reasons for problematizing the term ‘doctor-patient relationship,’ not only in the historical context, but also in relation to contemporary encounters:

First, focus on the dyad of a single doctor and a single patient is deeply misleading, because it erases from the picture the many other people involved in the process of seeking and providing medical advice. Secondly using these words obscures, and therefore supports, the false assumption that the content of the clinical encounter is constant, whatever the surrounding institutional and financial circumstances. (2)

The productive distinctions that Wilde makes are based on an analysis of the social and financial elements of medical interactions in the nineteenth and early twentieth centuries. Through Wilde’s analysis emerge two rather different arrangements. The first is the home visit wherein medical advisers “encountered patients in the company of varying numbers of friends and relations” who provided emotional, decision-making, and financial support (Wilde 15). As the historical

narratives below will illuminate, pre-clinical medicine might even be regarded as a predominately *public* affair, as dictated by social custom and the historically performance-oriented nature of the physician's profession. By way of contrast, the second arrangement involves the hospital interaction, in which "the patient may have had various friends and relations with them in outpatients, but on the ward, visiting hours were strictly limited and they were far more likely to encounter nurses and doctors on their own, more or less unsupported by friends and family" (Wilde 15-6). In this case, junior doctors, supervising doctors, and nurses were all, as they are today, along with social workers, bioethicists, and even chaplains, members of a team of practitioners providing health-related care.

In each case Wilde argues that to characterize the interaction as a 'doctor-patient relationship' "is to totally miss this complexity and variation" (16). Adding to this line of thought, historian Edward Shorter reminds readers that what we "understand by 'doctor' before the nineteenth century had little to do with university-trained physicians, implicating instead a wide variety of professions whose essential preparation had been the apprenticeship" (784). More accurately, 'doctors' before the nineteenth century included some elite professors of medicine but, for the most part, referred to a heterogeneous cluster of medical and paramedical barber-surgeons, frontier or countryside doctors, midwives, apothecaries, corn-removers, and so forth (Shorter 784). Returning to the introductory anecdote to this chapter, pharmacists, contemporarily (but also historically), belong to this network of health professionals, particularly in jurisdictions where they have the authority to give prescription medication directly to consumers without a physician's orders. We might also include the diverse range of specialist and subspecialist professionals that one might consult in the case of complex health issues, and while we are expanding this definition, the

diverse and often anonymous multitudes of health practitioners, expert patients, and caregivers who share support, advice, and personal experiences in online spaces.

Wilde traces the origins of the term ‘doctor-patient relationship’ to the shifting power arrangement that accompanied the transition from bedside to clinical interaction. Whereas the doctor’s attitude toward bedside care in the nineteenth century reflected a “desire to attract and keep a family’s custom,” and thus guarantee a longstanding business relationship, the clinical “waiting room experience” common by the 1950s denoted the prioritization of the physician’s, and not the patient’s, convenience (16). Interestingly, the doctor-patient dyad seems to have emerged directly out of the focus on “keep[ing] a family’s custom,” in combination with developing codes of medical ethics and etiquette. The growing competition over healthcare seekers in the 1890s made the articulation of a special relationship between the doctor and ‘their patient’ in private practice increasingly imperative” (Wilde 17). According to Wilde’s research, then, the phrase ‘doctor-patient relationship,’ which seems unproductively to dominate our discussions about individuals’ interactions with healthcare practitioners, is tied historically to a rhetorical tactic by physicians, deployed to support their own financial and professional self-interest.

Wilde proffers the term “patient’s clinical interactions” as a more representative terminological replacement for ‘doctor-patient relationship’ (22). However, despite widening the frame of reference in a useful way, this phrase nonetheless bespeaks an unaddressed need; it fails to distinguish between clinical encounters and those interactions that took place both before the emergence of the clinic and those that happen contemporarily, outside of the institution—that is, in non-clinical real world or virtual spaces. Indeed, as this dissertation will analyze, contemporary discussions about patienthood focus on the notion of a ‘networked patient’ whose ‘care’ is dispersed

across a range of individuals, groups, resources, and institutions, and is ever increasingly defined in terms of a consumerist model.

Interestingly, the articulation of the network of relationships that surround the experience of illness, most notably through the space of online social networks, is seen by many as working toward an ideal of autonomy for healthcare seekers.<sup>1</sup>

Paradoxically, this observation suggests that the more heteronomous our experiences of illness become, the more capable we are of attaining autonomy as patients. As I will discuss shortly, the long-standing debate over patient autonomy, tilted in the literature toward a promotion of this elusive goal, is problematic for the ways in which it ignores the non-autonomous co-dependency of our bodies and our sociotechnical environments.

Both historical and contemporary attempts to define the individual's role in relation to the healthcare sphere are complicated by several conflicting dynamics. The role of the healthcare seeker in the interactions that Wilde assesses is, in each instance, uniquely constructed within a context of competing forces. These may include intra-familial dynamics, the financial interests of doctor and patron, the social conventions of the consultation space, the professional or social standing of the practitioner, the cultural expectations of the parties involved, and the socioeconomic position of the individual or family. As Digby notes, "patients' class, race, gender, age, income, and status were balanced against medical expertise in the distribution of social, economic, and clinical power [...] This suggests that patients were sometimes subjects but at other times objects: as patrons or participants they might control or influence their destiny, or alternatively—as with many hospital inmates or surgical patients—they might be

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<sup>1</sup> Numerous studies and scholarly publications assert the value or potential value of virtual communities in the growth of participatory medicine. See, among others, Eysenbach (2008), Gibson, Britton, and Lynch (2012), Lorig, et al. (2008), Thompson, et al. (2012); Topol (2012); Vawdrey, et al. (2011).



subordinate to it" ("The Patient's View" 305). Hitting a decidedly less optimistic note, Katz has powerfully argued in his historical-sociological analysis of informed consent that doctors' historical 'ownership' over patients and the silent way in which physicians have, up until fairly recently, controlled individuals' medical decision-making, through both nondisclosure and even deception, has largely impeded true healthcare seeker participation in medical matters.

With an eye to grounding my in-depth analysis of the contemporary illness experience, as it exists in excess of the overly narrow terminology of patienthood, the rest of this chapter will lay some historical groundwork for our current conceptualizations of the healthcare seeker. Focusing on my slightly adapted version of Digby's 'sufferer roles,' this chapter explores how healthcare seekers within various paradigms of medical thought have occupied (or not occupied) the positions of patron, participant, and patient. In considering social, cultural, economic, and technological arrangements, this analysis will also take into account the various theoretical trajectories regarding pathology and physiology that have vied for primacy over the course of medical history. In this way, I hope to arrive at an understanding of how medical theories about bodies (whether 'normal' or 'diseased'), modes of biomedical investigation, and sociocultural conventions regarding healthcare interactions co-evolve in mutually constitutive ways, and produce a particular set of roles, opportunities, and challenges for the healthcare seeker. At the heart of this analysis is a need to establish how the notions of "patient autonomy" and "patient wholeness," specifically, have come to be the dominant, and in many ways, domineering, concerns of contemporary medical reform.

## **Theoretical undercurrents for conceptualizing the body and disease in medicine**

The tendency in narrating the history of medicine over a time period ranging from ancient Greece to the present day seems typically to focus on a chronological account of how medicine has evolved from a religiously based, supernatural understanding of human illness to the rational, empirical, technoscientific approach of contemporary biomedicine. *The Oxford Illustrated History of Medicine* is one of several texts to follow such a model, favouring an interpretation of the development of medical knowledge as a march of progress. One notable exception to this approach is Jaclyn Duffin's *History of Medicine*, which is organized around the historical narration of the various divisions within medicine: anatomy, physiology, pathology, pharmacology, epidemiology, and so on. In organizing her text in such a way, Duffin is able to parse out the various, often antagonistic, theoretical trajectories that characterize medical thought paradigms over time, and which result in specific approaches to the medical study of the body.

Usefully, Duffin isolates several key theoretical dichotomies that help to classify each model; the power differential between the theories in each pair shifts according to the dominant worldview of the time period in question. The most basic distinction that Duffin identifies, and one which lies at the heart of medicine itself, is between the organismic (or individual) and nonorganismic (or population-based) conceptualizations of disease. The organismic theory, central to the medical model of disease, is unquestioningly accepted within the present-day Western medical institution. This model relies on the assumption that diseases are undesirable, represent a rupture of 'normal' bodily experience, and afflict individual sufferers (Duffin 67). Conversely, the nonorganismic theory presents " a world in which disease is constant and cannot be eradicated—indeed, probably should not be eradicated—a world in which some disease

might actually be beneficial” (Duffin 96). While we may frequently accept the organismic theory as fact—or, the only possible option—its opposite also frequently emerges in contemporary discussions surrounding healthcare funding, social assistance programs, overpopulation, and other conversations that engage the problematic eugenicist discourse of natural selection.

Duffin’s important distinction between these theories of human disease, and especially her contention that the organismic theory goes unquestioned in biomedicine, resonates with arguments made by healthcare ethics scholar Jeffrey P. Bishop, as well as others before him, notably, the psychologist Ernest Becker. Both Becker and Bishop identify the problem of human mortality, and our abiding desire to overcome it, as central to the structures of our social and cultural systems. In Bishop’s case, the concern is Western medicine, which he argues in *The Anticipatory Corpse* is “founded in a dream as old as humanity itself: to defer death. For death and the disease that is its harbinger are the most brutal reminders of the radical finitude of human existence” (17).

According to Bishop’s articulation, medical history, and its basis in what Duffin identifies as an organismic theory of pathology, has responded to the violence and abjection of disease with a violence all its own. In its unflinching obsession with deferring death, Bishop says medicine carves a spiritually destructive path through history in which

dead anatomy begets physiology; physiology begets technology; technology—the replacing of a dead organ by a dead machine—begets a life worse than death. An over-technologized medicine begets a biopsychosocial medicine; a biopsychosocial medicine begets a biopsychosociospiritual medicine; but the holistic care of the dying comes to look totalizing, indeed, totalitarian. (18)

Bishop's interpretation of the medical model presents a powerful critique of a historical narrative of medical advancement, in which attempts to stave off the threat of mortality result in the continuous dismissal or supercession of the psychological, social, and, especially, spiritual aspects of suffering and death. These experiences, he argues, are unavoidable and perhaps even essential parts of human life. This idea attained mainstream recognition, of course, through the work of Elisabeth Kübler-Ross, whose research on the psychology of death contributed to the incorporation of more humanized methods of hospital care for the dying. In her famous work *On Death and Dying*, Kübler-Ross employs the stories of patients' experiences with dying in order to awaken healthcare practitioners to the needs, frustrations, and expectations of the terminally ill. While Bishop reasserts Kübler-Ross's observations regarding medicine's problematic and harmful unwillingness to come to terms with death, he is strongly critical of more recent manifestations of palliative care as "total care," which he regards as a continued retreat from the acceptance of mortality through the insertion of the healthcare apparatus into even the final, sacred moments of an individual's life (255). Care at the end of life is no longer facilitated by "family, nurses, nuns, or their counterparts; it is deployed, for the patient's own good, by experts [...] becom[ing] the venue of professionals, who are bent on mastering death and finitude and fear and grief" (258).

The Western cultural preoccupation with prolonging life and combatting disease—understood as a physiological/organismic problem—also obscures the ways in which disease is socially and culturally constructed. As medical anthropologists, sociologists, and disability studies scholars have argued, notions of disease and disability are intimately connected to social, cultural, and historical contexts. This is an obvious premise of my study, here, particularly in the current chapter's concern with

the historically- and socially-situated role of the healthcare seeker. At a very basic level, we can turn to ‘culture-bound syndromes’ to understand how particular sets of bodily experiences, complaints, or behaviours become characterized as disease patterns solely in one historical moment, cultural group, and/or geographical location (Stolberg 5). One well-known example is the disease of ‘onanism,’ specific to eighteenth-century Europe and North America, which was believed to cause epilepsy, blindness, vertigo, hearing loss, headaches, impotency, memory loss, rickets, and irregular heartbeat—a disease that has since been demedicalized, and which we today refer to as masturbation (Joralemon 3). Another example is the mental disorder observed in Malaysia and Indonesia since the nineteenth century, known as *latah*, a disease “present in certain lower-class women past middle age [and] characterized by involuntary compulsive utterance of obscenities, parodying of others’ actions or other socially or morally offensive behaviour” (Horne 332).

While culture-bound syndromes are frequently considered to be unconnected to structural or organic changes within the body, and based instead on non-medical and culturally-conditioned behaviour, which becomes pathologized, Stolberg is right to point out that “in certain respects, the term ‘culture-bound syndrome’ is a misnomer. All diseases are to some degree ‘culture-bound’, even if they are attended by ‘organic’ alteration. Culture has always had its share in the way diseases are perceived and described, let alone explained” (162).

Indeed, through the lens of post-structuralism, we can understand not only the so-called culture-bound syndromes, but also every biomedically categorized and controlled disease as socially and/or culturally constructed and belonging to a discursively-enacted system. As early as 1923, the epidemiologist and medical writer Francis Graham Crookshank critiqued Western medicine for its “vulgar” tendency “to

speak, write and ultimately to think, as if these *diseases* we name, these *general references we symbolize*, were single things with external existences” (qtd in Charon 29). Several decades later, psychiatrist and medical anthropologist Arthur Kleinman’s landmark 1973 essay entitled “Medicine’s Symbolic Reality” takes up this concept to spearhead an important social constructivist trajectory within the sociology of medicine. Kleinman insists that the medical system “is structured, like any other segment of social reality, by the regnant body of symbolic meanings. . . . From this view point, healing is not the outcome of diagnostic acts, but the healing function is active from the outset in the way illness is perceived and the experience of illness organized” (86). Kleinman’s challenge to scholars in this text is to attend to medicine as it reflects, not a biophysical reality, but a sociocultural system.

George Engel’s influential 1977 article in *Science*, entitled “The Need for a New Medical Model: A Challenge for Biomedicine,” importantly articulates an issue that, at the time of publication, had becoming increasingly more obvious to healthcare practitioners, that being a crisis within medicine “stem[ming] from the logical inference that since ‘disease’ is defined in terms of somatic parameters, physicians need not be concerned with psychosocial issues which lie outside medicine’s responsibility and authority” (129). In describing the dangers of this mentality, Engel cites a respected speaker at a Rockefeller Foundation seminar who argues that “the physician should not be saddled with the problems that have arisen from the abdication of the theologian and the philosopher” (129). While my work here does not take up the question of theology in relation to medicine, it is certainly concerned with the philosophical ideas that ground the conceptualization of the patient, as described by Engel’s conference speaker, and as we understand this individual and her rights, roles, and responsibilities today. This is not a question simply for the philosopher, however, but, as Engel argues,

for those directly engaged within the profession of medicine, whose practices are grounded in particular philosophical understandings of human life that shape the scope and nature of healthcare interactions.

Turning to the field of disability studies, the argument for the social model of disease and disability is articulated by a range of scholars. Shelley Tremain, in her chapter “On the Subject of Impairment” employs a Foucauldian theoretical framework to address what she sees as the false distinction between disability (as socially constructed) and impairment (as ontologically situated), arguing that historically and culturally specific conditions of possibility facilitate the interpretation of particular bodily states as ‘impaired.’ “As *effects* of an historically specific political discourse – biopower – impairments are materialized as unitary and universal attributes of subjects through the iteration and reiteration of rather culturally specific regulatory norms and ideals about human function and structure, competency, intelligence and ability” (42). In contrast to this, the medical model takes for granted that diseases and disabilities can be traced to bodily deviance, and that they exist as physiological lesions or psychological conditions; diagnosis seeks to isolate the connections between symptoms and disease entities, while treatment attempts to disrupt disease and rehabilitate the body (Good 65).

Of course, the biopsychosocial bent of contemporary medicine, for Engel, and the biopsychosociospiritual concentration, as Bishop later describes it, developed over a period of centuries, and was closely connected to the historically oppositional distinction between the ontological and physiological conceptualizations of disease, both of which, nonetheless, ground disease, for the most part, (magico-religious explanations aside) in a material, biological reality. While our present-day understanding—the one that Bishop critiques—relies on a combination of these two

theories, they were not always seen as mutually inclusive. Whereas the ontological theory of disease locates the cause of illness outside of the patient and conceptualizes its manifestation as entirely discrete from the form and function of the individual's body, a physiological understanding of disease proposes the opposite: that diseases and bodies are continuous and conditions derive from corporeal causes (Duffin 28). As I will explain shortly, the perceived location and origin of disease is closely tied to how the medical interaction becomes structured and, specifically, how the sufferer's role is defined—that is, the degree to which their subjective experiences, individual symptoms, and personal interpretations are invested with value. Contemporarily, the perceived need to integrate practices that facilitate or respect the healthcare seeker's autonomy is tied to a series of historical paradigm shifts regarding where in the body researchers, physicians, and laypersons have located “the seat of the disease” (Foucault), as well as the “source of blame” for disease (Sontag, *Illness*).

These models for understanding the human body, whether applied to the study of structure (anatomy), functioning (physiology), or suffering and disease (pathology), help to illuminate the socially, culturally, politically, and technologically situated role of the individual within the realm of healing. Exploring how these theories influence that role—the extent to which they institute practices of patienthood, patronage, or participation—reveals what I identify here as four different ways of situating the healthcare seeker. These include identifying the individual with an illness, as symbolic sufferer, natural-philosophical subject, historical text, or scientific object. These classifications are not meant to be limiting but, instead, to draw on critical approaches established by Digby and Wilde in the act of evaluating shifting power arrangements and interpretative frameworks, insofar as they position the ‘diseased’ subject. While the predominant mode of these characterizations is one in which the individual is *acted*



*upon* by a healthcare practitioner or healer, these cultural spaces were not without opportunities for acts of self-determination on the part of healthcare seekers. In many ways, however, this autonomy relied also on heteronomy and the presence of kinship, social, and/or medical(-technological) support systems.

### *The symbolic sufferer*

Come, let us consult some prophet or priest or some  
interpreter of dreams... and find out from him why Phoebus  
Apollo is so angry with us. He may be offended at some  
broken vow or failure in our rites. (Homer 1.60-4)

At several moments throughout history, the position of healthcare seeker has been one in which the individual and his or her illness together exist as the physical manifestation of a symbolic event. We can extend this observation to suggest that, within this thought paradigm, the body of the sufferer, itself, becomes symbolic.

Prior to the practice of “rational medicine” most famously signaled in Greece by the emergence of the seventy or so treatises of the Hippocratic Corpus (c. 420-350 BC), healers and laypersons in Mesopotamia, Egypt, and Greece frequently understood diseases as emanating directly from supernatural sources, whether malicious demons or the gods, themselves (Longrigg 25-6). Mystical, animistic, and magical understandings of illness were met with particular healing practices in each civilization, aimed at ridding the body of *dis-ease*, as opposed to a concretely or categorically understood *disease*. These included, but were not limited to, the casting of horoscopes, soothsaying and ‘systematized’ sorcery of Mesopotamia; the spells, incantations, amulet magic, and

pagan worship of Egypt; and the divine healing, exorcisms, divination, and shamanic rituals of ancient Greece (Porter 47-53). The pre-Hippocratic conception of illness as having supernatural sources is evidenced in a range of texts, from Homer's *Iliad* and Hesiod's *Works and Days* to the Bible and the writings of Roman encyclopedist Cornelius Celsus (Duffin 70, Longrigg 25-6). While this dissertation (primarily due to concerns of scope) is limited to the development of Western notions of patienthood, it is certainly worth noting that First Nations populations throughout North America, as well as tribal communities around the world, continue to practice traditional (non-scientific) medicine that views the body as intimately linked to the cosmos and to the spirit world, and that invokes healing rituals that interpret disease as, at least in part, symbolic.

In contemporary Western society, rationalizations of pain, disability, or disease as tests of faith or personal challenges to overcome extend this classical idea that disease "is sent by remote powers to punish or to test" the sufferer (Duffin 70-1; Nutton 39). One rationalization of physical 'abnormality' that may become adopted by parents of severely disabled children relies on the idea that the disabled child's existence serves to teach an individual parent or family about the virtues of patience, compassion, or empathy, as in *The Boy in the Moon*, Ian Brown's memoir about his son who was born with cardiofaciocutaneous syndrome. In this narrative, the child's life is portrayed as important or meaningful only insofar as it serves to improve the moral strength of those around him. A more canonical example of this narrative trope is seen in the American classic *Uncle Tom's Cabin*, in which Harriet Beecher Stowe's angelic, suffering child character Eva, spiritually enlightened by her illness, becomes a mouthpiece for the abolitionist movement and a lesson in grace and piety for the adults who surround her sickbed.

One contemporary example of the ‘punishment’ rationalization, compellingly addressed by Susan Sontag, is exemplified by the cultural narratives that, since the beginning of the AIDS crisis in the 1980s, continue to function as explanations for AIDS diagnoses. AIDS was initially (and perhaps continues to be) interpreted as punishment for ‘deviant’ behaviour, since public awareness of the disease in North America attached it to specific risk groups, particularly the already stigmatized populations of homosexual men and intravenous drug users. Along another vein, Sontag argues in her earlier text, *Illness as Metaphor*, that current-day diseases such as tuberculosis and cancer, “around which modern fantasies have gathered . . . are viewed as forms of *self-judgment*, of *self-betrayal*,” rather than divine wrath, as in the ancient context, or moral justice, in the AIDS context (39-40, emphasis mine). Nonetheless, the notion that the mind is betraying the body, or that the body is rebelling against the emotions (40), alongside the common misconception by the nineteenth century that an individual “willed” a disease—that it was an expression of one’s character or the inner identity (46)—continued the “punitive” tradition of placing blame squarely on the sufferer as the creator of his or her disease (57).

Returning to the context of ancient Greek medicine, importantly, not all disease was explained using a supernatural framework, and certain texts distinguish between diseases requiring straightforward medicinal treatment and those that demand the specialized knowledge of religious healers. In Homer’s *Iliad* (c. 700 BC), both Machaon and Podalirius are healers who perform medical actions such as wound dressing and diagnosis independently of divine intervention (Nutton 38). Similarly, in Babylon, cuneiform texts display two types of treatment for the same disease—cure by either religious rite or medical remedy (Nutton 42). Certainly, identifying the origins of disease, and the potential symbolism of such an event, was central to diagnosis and

cure. As historian Vivian Nutton notes, “the assumption that Apollo, Artemis, Zeus, or some other god might have sent a sickness on to a community or on individuals is one that was widely shared. But there are traces of another view” (39). In the example of Philoctetes’ abandonment by the Greeks due to his “stinking and excruciatingly painful ulcer” in Homer’s *Odyssey*, the affliction is attributed to a snakebite, and not to any moral or religious indiscretion (Nutton 39). Interestingly, as Nutton observes, in Sophocles’ tragedy *Philoctetes*, written approximately three hundred years later (c. 408 BC), after a natural explanation for the ulcer (a snakebite) fails to produce a remedy, the event is ascribed supernatural significance and deemed curable only through the divine healing of the god Asclepius (51). As Nutton suggests, the interaction between and equal explanatory force given to both natural and supernatural explanations of disease points to the embryonic and highly contested state of medical knowledge before Hippocrates and Galen and their medical treatises arrived on the scene. Medicine was part of an enduring debate that in ancient Greece was uniquely distinguished by its inclusivity; laypersons and medical experts alike engaged in discussions of medical ideas, even despite the presence of rival camps of physicians concerned with identifying “the true art of medicine” (Nutton 44). This democratic spirit is evident within the Hippocratic and Galenic practices, as well, pointing to a time during which medical knowledge was more “open to varied influences and accessible to outsiders” than it was in the Near East (Porter 55), and certainly more so than it would become by the nineteenth century in the West as a result of the professionalization of physicians, and the elitism attached to this venture.

I will return to the implications for the individual healthcare seeker of a robust and democratic Greek medical sphere in the next section, but first I would like to analyze the way in which diagnosis within a supernatural model of disease constructs

the healthcare seeker, both physically and socially. Because of the narrative frame within which the experience of disease as a spiritual, magical, or supernatural event is understood, the methods of healers and priests involved searching the patient's body for symbolic clues or signs that would explain the divinely ordained ailment. As Duffin aptly notes, "in this context, the patient's subjective opinion about the causes of illness are [sic] given serious consideration, including the possibility that the disease may have moral, spiritual, or pedagogic functions. Treatment is the maintenance or restoration of integrity—righting wrongs, keeping faith" (70).

The important distinction made here, in the assessment and treatment of disease, is between the search for *signs* versus the identification of *symptoms*. In the symbolic or supernatural interpretation of disease, the body is not a medical object through which a biological disorder expresses itself and becomes recognizable by way of empirically acquired evidence. Instead, the physical body and the experience of the sufferer is predominately symbolic; the problem is not attributed to material causes and its existence is purely emblematic of spiritual or moral disorder. Following from this, we cannot, then, classify the individual in the sufferer role as a patient; the sufferer is, more accurately, a participant. Further, this participation takes place, not in the context of a medical or biological frame of reference, but through the individual's engagement in an interpretative or a narratological mode of inquiry in partnership with a professional healer or priest.

By way of example, the first book of Homer's *Iliad* narrates the inauspicious beginnings of the Trojan War for the Greeks. In describing a ten-day plague symbolized by the wrathful arrows of "Plague-god" Apollo that "rained down on every part of the broad Greek camp" so that "day and night, packed funeral pyres burned," Homer's epic narrates the supernatural explanation of disease characteristic of ancient Greek

thought (1.49, 383-4, 51-2). In the narrative, the solution to disease is not to seek a physician to diagnose symptoms or to cure the afflicted using medical expertise, but to find a seer gifted with the faculty of interpretation who can identify the cause of the god's anger (and, consequently, the army's suffering) (Homer 1.60-4). By knowing the cause, the situation can be remedied through appropriate action.

Once "the matchless prophet" Calchas "account[s] for the anger of lord Apollo the Archer-god," Achilles learns that the restoration of health depends upon the safe return of Chryseis, the daughter of Apollo's priest, whom Agamemnon has kidnapped and refused ransom for (Homer 1.92, 72-3). As Calchas explains, Apollo "will not release us from this loathsome plague till we give the dark-eyed girl back to her father" (Homer 1.97-99). Interestingly, the entire army—through the death and destruction caused by Apollo's plague—is called to account for Agamemnon's transgression. While the physical pain and suffering is not inflicted directly upon Agamemnon himself, the attack on his army exposes the leader to extreme threat—and not just physically, since a military loss would constitute a direct attack on Agamemnon's oversized ego. Further, since Calchas's role as healer is to interpret the event as figurative, we must interpret illness in this context as understood through a particular set of sociocultural circumstances.

Indeed, the individual bodies of the sufferers do not even enter into the picture assessed by Calchas; instead, narrative details relating to social relationships, cultural customs, and religious practices are signposts along the route to explaining and remedying disease. Unlike contemporary biomedical knowledge, in which the discovery of causes rarely results in cures, ancient Greek healing relied on the notion that *within* the cause lay also the solution. As I will elaborate in chapter two, contemporary movements toward the teaching and practice of narrative medicine

demonstrate some overlap with a more symbolic interpretation of disease; in attempting to disrupt the explanatory authority of biomedical epistemological structures, largely through a focus on narrative creation and analysis, narrative medicine engages with bodily experience in a way that considers the medical alongside the narrative, symbolic, and sociocultural.

*The natural-philosophical subject*

The art [of medicine] consists in three things: the disease, the patient, and the physician. The physician is the servant of the art, and the patient must combat the disease along with the physician. (Hippocrates, *Of the Epidemics* 1.2.5)

The interpretation of disease as supernatural was gradually displaced by the introduction of philosophy into healing. This does not, however, mean that disease experience was entirely or immediately divested of religious or spiritual significance. According to Digby, “until the scientific (and more particularly the surgical) achievements of the nineteenth and twentieth centuries endowed Western medicine with an enhanced authority based on greater therapeutic effectiveness, a providential worldview—where disease could be seen as punishment for sin, and good health be seen as God’s work—remained resilient” (296). This appeal to providentialism was most likely to be applied in cases where medicine proved unsuccessful or inadequate (Digby 296).

However, historians note that during the classical age, there emerged a definitive rejection of religion as providing a default explanation for suffering. What came to be

the dominant attitude of Greek rational medicine followed directly from the influence of the Ionian natural philosophers of the sixth century BCE and their outright rejection of supernatural causes (Nutton 45). Instead, the world was understood as governed by discoverable laws. The Ionian stance that humans were a part of this natural environment, composed of the same material and subject to the same rules, strongly informs the medical literature of the fourth and fifth centuries BCE (Longrigg 29, 31). Reiterating such discourse, the Hippocratic Corpus asserts that diseases, too, are products of the environment possessing their own independent natures. The unifying theory beneath Hippocratic medicine interprets bodily health as resulting from a state of natural and originary equilibrium, while disease inserts itself as an upset, a subversion of the healthy body's harmonious balance of fluids (Porter 56). This idea, most clearly articulated in the Hippocratic treatise *On the Nature of Man* (c. 400 BCE), would remain dominant in medicine well into the Middle Ages. A glut of fluids or *chymoi* (humours) in a particular area of the body was believed to create a particular illness (Porter 56-7). The Hippocratic treatise expounds the classic theory of the four humours (blood, phlegm, black bile, and yellow bile), as they connect to the four primary opposites (hot, moist, cold, and dry), the four seasons (spring, summer, winter, fall), and the four ages of man (infancy, youth, adulthood, old age) (Longrigg 29-32), "thus afford[ing] a neat schema with vast explanatory potential. On the assumption, for example, that blood predominated in spring and among the young, precautions against excess could be taken, either by eliminating blood-rich foods, like red meat, or by blood-letting (phlebotomy) to purge excess" (Porter 57).

The empirical approach of the Hippocratic perspective emphasized the individuality of the patient and not the identification of a discrete disease entity (Porter 60). Despite acknowledging the recurrence of certain identifiable diseases in the body,



Hippocratic medicine principally followed a physiological conception, studying disease as manifested in *individual bodies*, so that each illness was unique and required an individually tailored treatment plan (Nicolson 802-3).

In the second century AD, the celebrated Roman physician Galen endorsed Hippocrates and the Corpus attributed to his scholarship as founding the basis of his medical practice (Longrigg 34). This included Hippocrates' work in both medical and ethical spheres—his articulation of the theory of natural equilibrium, as well as his ethical codes in *Oath, The Physician, Law, Precepts, and Decorum* that continue to define social expectations for medical practitioner behaviour. Regarding pathology, Galenic medicine also sought to describe, predict, interpret, and justify diseases and treatments based on individual clinical observation and reasoning (Duffin 71). In the empirical study of disease, the role of the patient centred on providing descriptive accounts of observed and subjectively experienced signs of illness. This participation in the healing process, under the guidance of the physician-philosopher, took precedence over interpreting the symbolic significance of disease. In intuiting the inner state of the humours, the Galenic physician monitored the sick individual's body for such biometrics as pulse, the colouring, density and composition of urine and feces, complexion, temperature, the presence or absence of vomiting, the appearance of the blood, and the feel of the abdomen over the liver, spleen, and bladder. In Galenic practice, effective diagnosis combined sense experience, received anatomical wisdom, and inductive reasoning (Nicolson 805). Further, in Galen's case histories, descriptions of the aforementioned indicators "are followed immediately by the patient's 'history,' an account of what had occurred on the days before the development of symptoms. . . . Medical issues overlap with social, cultural, and moral ones from which they cannot be easily distinguished; furthermore, the patients emerge as characters in the literary

sense, with their own history, perspective, and attributes” (Mattern 99). The uniqueness and individuality of each patient that Galen writes about, even if many remain nameless and unidentified, and even if they deviate from Galen’s implicit (and preferred) “standard of the adult, Greek male” (104), is one of the most “socially leveling ideas in Galen’s work” (119).

Galen can be said to have adopted the Hippocratic notion that “the art [of medicine] consists in three things: the disease, the patient, and the physician. The physician is the servant of the art, and the patient must combat the disease along with the physician” (Hippocrates, *Of the Epidemics* 1.2.5). This tripartite structure resonates with contemporary patient advocacy for participatory medicine that endorses the cooperation of doctor and patient in working toward a goal of wellness. Indeed, as Susan Mattern notes in her text *Galen and the Rhetoric of Healing*, Galen believed firmly in a democratic and open medical sphere, particularly promoting the notion that every aristocrat should be well-versed in medical concepts. In his writings, he “excoriates wealthy men who are crammed with erudition but do not understand their own bodies, who are incapable of examining and choosing physicians based on their skills and medical knowledge, and who lack the technical sophistication of their own slaves” (Mattern 25). Galen seems to have supported the medical self-education of non-aristocratic laymen as well, and Mattern notes that in his case histories, he sympathetically portrays those patients who are knowledgeable about medicine, unless they object to his own interpretations (137). The case histories often record a subtly competitive dialogue between Galen and his patient, in which causes and cures are negotiated. Or, rather, this negotiation happened only between men—that is, between Galen and the patient’s male guardian, in the cases of women and children. As with other parts of Greek society, Galen’s assertion that all educated individuals should have

some medical expertise actually refers only to the erudition of *adult male citizens*, certainly not women or slaves: “in stories featuring the head of household—a husband, a master, or a father—this man’s voice and point of view tend to overwhelm that of the patient or supplant it altogether” (Mattern 123). Even in the case of a female patient, however, the individual being treated by Galen is still involved in the telling of her illness experience. The case histories reveal a physician who is decidedly patient-centered in his respect for the healthcare seeker’s (or her guardian’s) perspectives and opinion, and yet unflinchingly forceful and paternalistic in his demand for patient compliancy, “dominating his patients, and . . . reducing them to servile passivity in their own homes” (Mattern 148). The importance of this show of domestic and professional authority cannot be overstated, particularly for a physician whose prolific work is overshadowed only by his enormous ego (Mattern 178; Porter 73).

Importantly, in the Galenic context, involvement in the sphere of domestic patienthood is not always as a patient, but also as a public participant, lay expert, or personal advocate for the patient. Part of the medical training that Galen suggests for educated men involves visiting sick friends and relatives at their bedsides to both “advise” and “aid in examining and treating [them]” (Mattern 25). In the context of the highly competitive atmosphere of Greek medicine at the time, in which physicians’ care and cure of patients in their own homes resembled the public spectacles of the stadium, we might slightly tweak Hippocrates’ statement about the art of medicine—that it, in fact, consists in the disease, the patient, the physician, and the *public*. Physicians competed for the opportunity to take on a particular case through public displays of talent and expertise; as Mattern observes through her reading of Galen’s case histories, “medical contests at the patient’s bedside—like the public debates and contests [between Greek physicians]—were not always calm; they could involve noisy

disputation and exclamation of amazement. The contest of deeds was essentially physical, and Galen sometimes conveys a sense of urgency or even violence” (77). Due to the culture of competition surrounding medicine, in which diagnosis, prognosis, and cure were framed within a narrative of “victory and defeat, glory and humiliation” (69), in the agonistic component of Galen’s medical practice, the healthcare seeker’s position reflects that of the passive object of medical attention—“a body upon whom Galen displays his superior medical skill” (71).

Despite the affinities between Hippocratic or Galenic diagnostic practices and the modern clinical consultation, particularly in their ‘patient-centredness,’ these perspectives should not be interpreted as having, in any way, a historical relationship or suggesting “a timeless scientific impulse”; instead, “Hippocratic diagnostics served purposes specific to the social role and status of the Hellenic physician,” the cultural context of medicine during the period, and the specific interests of practitioners (Nicolson 804-5). It is important to keep in mind that well into the twentieth century the relationship between the healthcare seeker and the physician was dominated primarily by what Jonathan Will terms “benevolent deception.” This term denotes a type of relationship in which doctors intuitively or deliberately withhold crucial information pertaining to individuals’ health status, diagnosis, treatment, and therapeutic options because, as Katz notes, “physicians have always maintained that patients are only in need of caring custody” (2). With regard to disclosure in the ancient Greek context, Katz points to the Hippocratic Corpus, which advises that physicians “perform calmly and adroitly, concealing most things from the patient while you are attending to him. Give necessary orders with cheerfulness and serenity, turning his attention away from what is being done to him” (qtd in Katz 4). Physicians did not condescend to engage in dialogue with slaves or the free poor, and, as mentioned previously, conversation with

wealthy patients was not an invitation for shared decision-making, but served the didactic purposes of preventive medicine or the therapeutic purposes of winning patients' trust. The ability to win the trust, good faith, and *obedience* of the patient was central to the physician's ethos and perceived therapeutic effectiveness; both relied on the idea that his interests and the patient's interests were identical. Thus, "there is no 'other' who requires an explanation, for both want the same things: recovery and cure" (6); in this case, shared decision making would have been viewed as unnecessary. I will explore Katz's work more thoroughly in the following sections and chapters, since his interpretations are central to exploring how the healthcare seeker's role has developed.

The "identity of interests" perceived to be central to healthcare seekers' relationships with doctors emerged from a belief that the two were united in *philia*, or friendship (Katz 6). Furthermore, a naturalistic, teleological understanding of the body in relation to the universe imposed a fairly rigid system for interpreting and treating illness. During the early history of rational medicine, the influence of philosophy, particularly that of Aristotle, is deeply relevant. Thus, in characterizing the physician as "the servant of the art," Hippocrates also suggests, not only a particular kind of collaboration between doctor, patient, and disease (and public), but also the idea that the practitioner is bound by allegiance to a certain set of philosophical principles. While these undoubtedly include the tenets of the *Oath*, notably the promise to act only "for the benefit of my patients, and abstain from whatever is deleterious and mischievous," the physician under Hippocratic or Galenic medicine is also tied to the prescripts of a philosophical worldview that reflects a naturalistic cosmology (Nicolson 803). Indeed, Galen "was committed to the integration of philosophy and medicine and believed that to be a good doctor one had to be a philosopher; that medicine presupposed all parts of philosophy" (Longrigg 39).

Aristotelian natural philosophy had an obvious influence on medical practice from antiquity into the eighteenth century. Several of Aristotle's best-known treatises, including *Physica*, *De Anima*, and *Meteorologica*, evidence the philosopher's deep commitment to the study of natural phenomena—particularly, his interest in asking, “Why?” Aristotle's explanations are intrinsically teleological because the answers to his questions seek to isolate final causality, that is, the function or purpose out of which something comes to be present or absent. While teleological explanations preceded Aristotle's philosophical writings, his perspective presents a critical innovation, since he dismisses extrinsic factors as primary causes in nature; rather than attributing purpose to divine will or intelligent design, Aristotle understands nature as an end in itself (Johnson).

As discussed above, Galen's inheritance of the Hippocratic diagnostic practice of “knowing the person” through thorough (sometimes days-long) empirical observation, applies this Aristotelian empirical teleology within the context of medical investigation (Nicolson 805). In his medical writings, Galen quips sarcastically, “It was, of course, a grand and impressive thing to do, to mistrust the obvious, and to pin one's faith in things which could not be seen!” (Galen, *On the Natural Faculties* 1.13). At the same time, he appeals to teleology in using pre-established theories of humoralism and natural philosophy to explain the final causes of bodily processes. In one line of inquiry in *On the Natural Faculties*, Galen explains why the humours of the body are attracted to one another. His explanation relies on the notion that, because of the greater purpose of nutrition—a faculty granted by Nature, which “is artistic and solicitous for the animal's welfare”—each part of the body possesses the faculty of attraction, which allows it naturally to draw to it the appropriate type and quantity of “its proper juice,” or humour (Galen, *On the Natural Faculties* 2.1). Along the lines of teleological philosophy,

Galen's thinking here justifies a theory of humoral attraction through the final cause of nature's beneficence in sustaining animal life. As Mattern aptly observes, for Hippocrates and Galen, "Nature is the original physician that creates and heals, and the doctor, in this ennobling view, is the assistant of Nature" (24).

Returning to the position of the individual healthcare seeker, then, in a naturalistic paradigm of medical thought, the body of the sufferer and the processes of the disease (the signs and sense observations induced from both) reflect the higher purposes and physical laws of nature. Thus, in a similar way to ancient, symbolic understandings of disease, the body is read for signs, but this time of natural—rather than divine—processes. Diverging from previous traditions, however, is the emphasis on the five senses of both practitioner and patient as providing empirical evidence; the tactility of such an interaction, as well as the holism of an approach that considers the individual's "way of life habitation, work, diet, and so on" is premised on a person-centred conceptualization of disease (Nicolson 802). While it is anachronistic to say that classical medical practitioners understood the role of socioeconomic, environmental, and idiosyncratic factors in what they regarded as disturbances in the body's natural state, their methods can be seen to constitute the original holistic, alternative, integrative, or complementary medicine, as it is variously termed. Adopting a non-canonical narrative of medical history, doctor of integrative medicine Bruce Hoffman proposes that

an integrated approach to healing is not a new idea. It has appeared in various forms since antiquity. In fact, what is now termed traditional or allopathic medicine has only been dominant for about 100 years, but the tendency to be focused only on outer ways of healing has been dominant for at least the last five hundred years. Alternative or complementary medicine is, in fact, *the true*

*traditional medicine.* ‘We have been calling genuinely traditional medicine—used for at least 2500 years—‘alternative’ only because today’s newcomer ‘traditional’ medicine has misappropriated that attractive word, and truly traditional medicine has not shouted theft. (2, my italics)

Certainly, many contemporary practitioners within so-called alternative healing circles endorse this interpretation, which traces their professional roots directly to Hippocratic medicine.

### *The historical text*

The historical embraces whatever, *de facto* or *de jure*, sooner or later, directly or indirectly, may be offered to the gaze. A cause that can be seen, a symptom that is gradually discovered, a principle that can be deciphered from its root do not belong to the order of ‘philosophical’ knowledge . . . .  
(Foucault 5-6)

Scientifically speaking, the strength of Galenic authority eventually waned, partially owing to the context of seventeenth-century ailments like the plague and syphilis that Galenic medicine was unequipped to explain or treat (Duffin 45-6). During this time and into the early eighteenth century both mechanistic and vitalistic theories of physiology competed for scientific precedence. The theoretical binary of mechanism versus vitalism is concerned with explaining the basic concept of life—how does the body maintain a constant state of animation, regeneration, and cohesion? Vitalism explains life by appealing to the notion of a “life force.” For German physiologist Georg



Stahl in the early eighteenth century, “a God-given super-added soul (*anima*) [was] the prime mover of living beings”; the ancient idea of a gaslike *anima* provided a useful model for articulating an “agent of consciousness and physiological regulation” (Porter 247).

While proponents of vitalism like Stahl, an evangelical Lutheran, have often believed in a theological concept of spirit or soul, a vitalistic philosophy of the body does not necessarily equate to divinity or religion (Porter 247, Duffin 41). Recently, Jane Bennett (2010) has articulated a theory of vital materialism that pays homage to the early-twentieth-century “critical vitalism” of some experimental scientists. While this theory does not endorse a “naïve vitalism’ of soul,” critical vitalism seeks out alternative understandings of materiality that reject a dominant “mechanistic or deterministic” bias in which materiality “is thus in principle always calculable to humans” (“A Vitalist Stopover” 48). As Bennett explains, “central to this vitalism was the idea that ‘life’ was irreducible to ‘matter,’ that there existed a life-principle that animates matter, exists only when in relationship with matter, but is not itself of a material nature” (“A Vitalist Stopover” 48).<sup>2</sup> Bennett’s work, and that of others in the area of speculative realism, will enter heavily into my philosophical reading, in chapter two, of how the human is currently conceptualized within medicine; the decentering of the human being through a focus on shared vulnerability and kinship networks among various forms of life allows us to rethink the human along the lines of a different value system that could revolutionize the way in which medicine is practiced.

In contrast to vitalism, the theoretical understanding of the body that has held the most sway since approximately the seventeenth century is that of mechanism—the

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<sup>2</sup> Both Timothy Campbell and Eugene Thacker have also engaged, contemporarily, with theories of vitalism, both within the context of biotechnology.

conceptualization of life as, indeed, reducible to physical and chemical forces. Unlike some versions of vitalism, it often “defines all existence in terms of tangible matter” (Duffin 41). Seventeenth-century philosopher and mathematician René Descartes’ mind-body dualism separated a divinely created soul from the operations of the physical body in order to explain bodily functions according to mechanical laws. Rejecting vitalism, rival camps of eighteenth-century scientific medicine, inspired by William Harvey’s mechanistic explanation of the circulation of the blood, sought to understand the body using models derived from mechanical and chemical processes (Porter 247; Duffin 48). Similarly, applying physics to medicine, Dutch scholar Herman Boerhaave “construed health and sickness as expressions of such variables as forces, weights, and hydrostatic pressures,” attempting to give scientific validity to the notion of humoral imbalance (Porter 246).

One way that mechanistic theories entered into practice, in this case through the application of chemistry, was through a refinement of Galen’s analysis of urine, called uroscopy; “charts were constructed to allow physicians to associate the colour, odour, turbidity, sweetness, and other chemical properties of urine with a specific diagnosis” (Duffin 74). At the same time, however, this diagnostic tool was only minimally illuminating and practitioners’ interests in reducing or ending suffering became more focused on remedying symptoms than reading signs. Hesitant to “invoke unknown causes for disease[,] instead, they built a new system of diagnosis, deliberately labeled nosology, based on the careful observation of symptoms. It was a self-conscious effort to avoid theorizing. A flurry of classic disease descriptions followed” (Duffin 74).

Although Galen’s writings had emphasized the importance of sense observation, the Galenic medicine of his predecessors (mostly university-educated physicians) “took upon itself the general characteristics of medieval scholarship, including a disdain for

manual work and a deference to textual authority. For the medieval and Renaissance physician, authority lay with the works attributed to Galen. But this exemplar was developed selectively, so as to endorse reason over observation, book learning over sensory experience” (Nicolson 805-6). Because of a renewed philosophy of sensualism, which pronounced the “importance of observation and the dangers of theory,” by the eighteenth century, dissection became more respectable (Duffin 74, 29). At the same time, however, sensualism cast anatomy in a suspicious light, since anatomical analysis permitted only post-mortem diagnosis; thus, greater energy was directed toward the development of symptoms-based methodologies (Duffin 32).

The sensualism of the eighteenth century found strong proponents in the Latin nosological texts of English physician Thomas Sydenham and the philosophical writings of his friend and colleague, John Locke. As Duffin notes, Sydenham did reference the humours, but endorsed the use of a defined and limited set of predetermined potentialities of each disease as the foundation for a strong diagnosis (74). Following Sydenham, “nosologists” began the task of creating disease maps, which organized pathologies “into conceptual trees with branches for classes, orders, genera, and species. Symptoms and their sequence were used to categorize diseases as if they were entities, or ‘beings,’ like animals and plants” (Duffin 74). Not surprisingly, the memorization of disease characteristics and classifications recorded in nosological treatises, rather than the experiential learning of bedside practice, formed the basis of medical training at this time (Duffin 74).

In the nosological approach to medical diagnosis, diseases were entirely ontological—that is, they originated from outside the patient and existed separately from the body, representing a drastic turn away from naturalistic conceptions of disease. As Stolberg illuminates through his examination of the letters and personal

testimonies of early modern patients and scholarly physicians, illness is described as something apart from and adversarial to the individual's body. These experiences are discussed through the language of occupation, invasion, and antagonism: "In the language of patient letters, . . . the disease or the 'morbid matter' was an 'enemy' that 'struck' you 'fell upon' you, 'assailed' you or 'attacked' you, as it was put innumerable times. It 'invaded' you or 'snuck into' you and 'exposed itself' like a secret agent after it had established itself in the body, or it proved to be 'rebellious'. In accordance with this martial, aggressive language, patients asked physicians for suitable weapons to 'victoriously attack' the illness, to 'wage war' on it, to 'exterminate' it" (24-5).

Michel Foucault in *Birth of the Clinic* summarily states that, when the ontological view predominated, the "individual was merely a negative element, the accident of the disease" (Foucault 14). Foucault characterizes this pre-clinical positioning of disease as a medicine of forms or essences. In *Birth of the Clinic*, he traces the historical conditions that made the clinic possible by describing how various spaces, each with its own genealogy, coalesced during a brief period in French history from 1760 to 1830. One of these threads describes the nosological classification of disease in France, which was characterized by the publication of two key texts: François Boissier de Sauvages' *Nosologie* (1761) and Philippe Pinel's *Nosographie* (1798) (Foucault 4). Between the publications of these texts, medicine began to position "disease as its primary object" (Bishop 39). As Bishop notes, Foucault's description of nosology as a medicine of forms uses 'form' in the philosophical, but not strictly Platonic sense; the classificatory table of diseases gave a formal arrangement to the act of diagnosis (Bishop 39). In line with Foucault's identification of space as the primary organizing principle in medicine, the space of the nosological table "treats localization in the organism as a subsidiary problem, but defines a fundamental system of relations involving envelopments,

subordinations, divisions, resemblances” (5). On the basis of a space “of projection without depth, of coincidence without development,” a “flat surface of perpetual simultaneity,” the physician abstracts the patient—“his predispositions, his age, his way of life”—to hone in on the formal characteristics of the disease, reading these signs in order to classify it ontologically, as one would a species of flower, which “grows, flowers, and dies always in the same way” (5-8).

The reification of this formal arrangement led to the belief that this organization of knowledge ordered reality and, in the process, uncovered an ultimate truth about disease that had previously been obscured (7). This contributed to the process described above, whereby an ontological conceptualization of disease emerged; the objects of medicine—the forms or essences of disease—existed in the conceptual space of the table. As Foucault writes, “the form of the similarity uncovered the rational order of the diseases” (7). We can understand this as a process of secondary spatialization, “in which vicinity is not defined by measurable distances [within the body], but by formal similarities”—that is, proximity within the nosological table; “when they become dense enough, these similarities cross the threshold of mere kinship and accede to unity of essence” (Foucault 6-7). In Foucault’s example, the relative “freedom” of the space of disease in classificatory medicine, as compared to the anatomo-clinical method, meant that the same single malady expressed as “a nosebleed may become haemoptysis (spitting of blood) or cerebral haemorrhage; the only thing that must remain is the specific form of blood discharge” (11).

Foucault’s description of pre-clinical medicine highlights the significance of a logic of similarity in diagnosing disease; similarities in the surface signs and symptoms of illnesses indicate that they belong to the same class of diseases, regardless of any anatomical relation (or lack thereof). Likewise, remedies functioned on a “doctrine of

signatures,” so that matter with healing properties could be deduced on the basis of its outward appearance; “a flower whose blossoms resembled the shape of liver thereby suggested that it might be good for healing liver diseases” (Stolberg 27). This understanding took its cues from the organizing principles of nature; because disease was accorded a place in the natural world (as in the case of Hippocrates and the Ionian philosophers), it should also be dealt with and allowed to progress in the natural environment of its host—the family home. The disease “must not be fixed in a medically prepared domain, but be allowed, in the positive sense of the term, to ‘vegetate’ in its original soil: the family, a social space conceived in its most natural, most primitive, most morally secure form, both enclosed upon itself and entirely transparent, where the illness is left to itself,” to follow nature’s course (Foucault 18).

Drawing on the centrality of the family and the home to seventeenth- and eighteenth-century medicine, Digby, notes the underrepresentation of this space in histories of medicine, while Stolberg points to the centrality of domestic space in continuing the open and quasi-public tradition of healing inherited from the Greeks. While observation of a physician’s healing finesse may have continued to be a significant element of this scene, particularly during a time when competing medical ideologies and the lack of systematized medical training fostered suspicion and mistrust among laypeople, social conventions also dictated the presence of family, neighbors, and friends at the sickbeds of their relations. “Certainly among the nobility visiting sick relatives was *de rigueur*, and one’s absence had to be explicitly excused and accounted for” (Stolberg 53-4). Among poorer, rural populations, friends, acquaintances, neighbors, and others conventionally assisted nurses and physicians at the sickbeds of those whom they visited (56). The communal nature of healthcare, thus, “created ideal conditions for the dissemination of medical ideas and practices far beyond the narrow

circle of the physician-patient relationship” (82). Patient and physician letters, Stolberg observes, record evidence of the transmission of medical know-how communicated by those who had been privy to the healing practices of physicians and other practitioners (82).

Alongside the vitality of medical conversation within the public sphere, another, and perhaps most significant, detail that influenced how individual healthcare seekers engaged with and experienced medicine prior to the birth of the clinic was the tentative, contestable, unauthorized (and pre-technoscientific) quality of medical theories and knowledge. Indeed, therapeutic techniques and theories about the body frequently varied from one physician to the next (Stolberg 73-4). These factors were particularly influential in emphasizing the patronage side of the healthcare seeker’s role. And, despite negative critical reaction to N.D. Jewson’s theory that medicine during this time was overwhelmingly dominated by the patronage model, as Stolberg notes, the economic side of the arrangement certainly exerted significant influence on how healthcare seekers and physicians interacted; the patron asserted significant power over both a practitioner’s economic success and reputation, and “their relationship was much more symmetrical than it is today. . . . The patients’ wishes and desires carried great weight simply because there was usually a wide range of other healers and healing practices at hand which they could easily resort to if they were not happy with a physician’s advice or treatment” (Stolberg 68). The letters that Stolberg examines in his book point strongly to the idea that healthcare seekers were quite comfortable with managing their own illnesses (74), taking or rejecting physicians’ advice and prescriptions, vocalizing their dissatisfaction when necessary (69), and consulting the readily available (and bestselling) medical reference texts, health handbooks, and plague pamphlets of the day (21).

Is this the first evidence of a pushback against the authority of the physician? An attempt by patients to assert decision-making autonomy and champion the value of experiential expertise against a figure that was increasingly seen as potentially threatening were the balance of power to tip even slightly? An assertion like this would likely require a significantly more in-depth look into the historical archive, which is unfortunately outside the scope of this paper. Allow me to gesture, however, toward the virtual nonexistence of patient participation in medical decision-making during this time. As Katz suggests, there exists no evidence in primary or secondary texts on medical ethics, prior to the eighteenth century, that healthcare practitioners involved patients in the medical decision making process. Instead, “conversations with patients served purposes of offering comfort, reassurance and hope, and of inducing patients to take the cure. Achievement of these objectives demanded an emphasis on the need to be authoritative, manipulative, and even deceitful. That emphasis was dictated less by self-serving interests than by a wish to be helpful to patients; for without respect for medical authority, there could be no cure” (7). This protocol reflects a general attitude of denial toward and non-disclosure of the stultifying uncertainty that characterized most medical decision-making prior to the rise of scientific methods in medicine. Unwilling to risk damaging their already-shaky authority, physicians mostly disguised the reality that doctoring was (and to some extent, still is) comprised of a series of educated guesses (Katz 166). Not only was this disclosure stonewalled by the belief that laypersons were incapable of comprehending the “esoteric complexity” of medical knowledge, but “cure, doctors believed, required professing certainty to patients” (45).

This is not to say that participation was nonexistent; the tradition of letter writing between healthcare seekers and physicians meant that literate individuals frequently participated in the recording and interpretation of their own illness experiences in their



correspondences. Physicians expected a wealth of specific information on an individual's diet, lifestyle, medical history, and "bodily constitution" so that they could provide a specifically tailored treatment plan (Stolberg 66). Interestingly, this routine practice reflects the sort of personalized healthcare that patient advocacy groups seek today, in the twenty-first century context. However, because medical nosology operated on the premise that specific sets of symptoms would point to a specific diagnosis and prognosis (with precision being the goal), "differential diagnosis" was nonexistent (Shorter 784). Further, the process relied upon the patient's involvement as a participant, not in decision-making, but through personal testimony and the co-construction of a narrative of disease; often, the patient was simply regarded as a source of objective information in response "to a series of 'yes-no'-style questions" and symptom-based inquiries (Shorter 792).

While healthcare seekers may have appeared to have a similar degree of involvement in health-related matters to their present-day counterparts, they were also entangled within a very different discourse about the body, which guided their experiences and perceptions. While the use of nosological classifications in pathology and clinical medicine persists today, the central difference between eighteenth-century and contemporary categorizations that "simplify the mass of information gleaned [...] in clinical experience by giving it order and structure" is the relatively recent primacy of anatomical and chemical observations in identifying disease (Duffin 75-6). For the most part, this change has been facilitated by technological advancements that collect internal, molecular, and genetic data. But before this could happen, the epistemological framework of medicine had to undergo a shift with regard to the social and bodily spaces where disease was identified, treated, and monitored. These changes eventually led to much greater success in diagnosis and prognosis. But, as Foucault and other

scholars of history and sociology have noted, these shifts also drastically altered the position of the healthcare seeker, particularly in terms of power relationships.

*The scientific object*

Disease is no longer a bundle of characters disseminated here and there over the surface of the body and linked together by statistically observable concomitances and successions; it is a set of forms and deformations, figures, and accidents and of displaced, destroyed, or modified elements bound together in sequence according to a geography that can be followed step by step. It is no longer a pathological species inserting itself into the body wherever possible; it is the body itself that has become ill. (Foucault 136)

By the beginning of the nineteenth century, scientists and doctors had begun to think beyond symptoms-based diagnosis and to connect disease to particular alterations in anatomy. Prior to this time, many doctors were interested in pathological anatomy, however, “they were baffled by its relevance to practice, since both diagnosis and therapeutics were predicated on symptoms. Methods of examination before death revealed little about the internal organs. To have a ‘disease’ in the eighteenth century, a person had to feel sick” (Duffin 78). As Foucault points out, the obstacle to anatomical thinking in medical practice during the classificatory period, was never an issue of social taboo—the proscription against opening up corpses was far from prominent in the 1700s, contrary to illusions perpetrated in medical history; “the conflict was not

between a young corpus of knowledge and old beliefs, but between two types of knowledge” (126). This epistemological shift had to happen gradually before techniques such as taking the pulse, thoracic percussion, or auscultation could be used to identify the existence of disease. In classificatory medicine, an irregular pulse or breathing was a sign of disease because it was a *symptom* that constituted the disease; thus, as Foucault elucidates, “it was natural that clinical medicine at the end of the eighteenth century should ignore a technique that made a sign appear artificially where there had been no symptom, and solicited a response when the disease itself did not speak. [...] But as soon as pathological anatomy compels the clinic to [...] bring to the surface what was given only in deep layers, the idea of a technical artifice capable of surprising a lesion becomes once again a scientifically based idea” (Foucault 162). By the nineteenth century, then, practitioners used the recent inventions of thoracic percussion and auscultation in service of “physical diagnosis” that connected symptoms to anatomical changes and identified signs where there were no symptoms (Duffin 78).

As a result of this marriage between anatomy and pathology, the physician’s concern shifted from “how the patient felt, to emphasis on what lesion could be found” and disease names changed to reflect anatomy, rather than symptoms (for example, “phthisis” or “consumption” became “tuberculosis”) (Duffin 78). As Foucault notes, “the space of *configuration* of the disease and the space of *localization* of the illness in the body have been superimposed, in medical experience, for only a short period of time—the period that coincides with nineteenth-century medicine and the privileges accorded to pathological anatomy” (Foucault 3-4).

The refinement and popularization of microscope technology in medical practice in the 1830s added fuel to the movement toward deprioritizing the patient’s subjective experience and emphasizing the doctor’s objective findings. With the added authority

of microscopic vision, the patient's subjective experience of illness could now be attached to a technoscientifically sanctioned, visually identifiable disease, signified by alterations at the level of tissue structures. This turning point is characterized by an understanding of disease that we maintain today, that is, as *sometimes* ontological, ascribed to a physical lesion that can be regarded as separate from the 'normal' body, and *sometimes* physiological, emerging from within the patient and possibly dependent on individual factors (Duffin 79-81). The fierce opposition of these two theories, represented by the ontologically-based germ theory, which emerged in the 1880s, and Mendel's physiologically-based laws of heredity, consolidated in 1900, continued the debate between scientists on the true source and 'location' of disease. This eventually led to the acceptance of both as concomitant; the current medical model offers a synthesis, incorporating viral and bacteriological alongside genetic and autoimmune conceptualizations of disease (Duffin 81-92).

While technological innovations seem central to the shifting gaze that transformed the body's position in medicine, from a collection of subjective experiences, signs, or symptoms to an object of scientific scrutiny, to pinpoint these innovations as solely responsible would be to adopt an unproductive standpoint of technological determinism. As Foucault's *Birth of the Clinic* analyzes, the transformation of the body within medicine emerges from, first and foremost, a discursive shift in the healthcare encounter. Foucault's archaeology focuses on how changes in the late eighteenth century and early nineteenth century—bound up with the political milieu of the French Revolution—introduced a new gaze to medicine that came to characterize the modern clinical encounter. This clinical gaze comprised a change in the conceptual space of both the disease and the body, which emerged alongside changes in political space—namely, the reorganization of the social infrastructure related to public health and curricular

reform within faculties of medicine. The collusion of these different histories signified the introduction of a “new, coherent, unitary model for the formation of medical objects, perceptions, and concepts” (51).

Clinical medicine, for Foucault, was partially a product of tertiary spatialization—that is, “all the gestures by which, in a given society a disease is circumscribed, medically invested, isolated, divided up into closed, privileged regions, or distributed throughout cure centres, arranged in the most favourable way” (16). In France, the transition of the ‘natural habitat’ of disease from the family home to the hospital—the institutional spatialization of disease in the interests of free, centralized healthcare—was connected to the liberatory ideals of the French Revolution. The political concern of ‘good medicine’ thus became a task for the state and the ensuing regulation of the medical profession led to both the centralization of knowledge and the governance of all medical activity (19, 28, 31-6). The new clinic focused on medical training in hospitals, where doctors “learn[ed] as they practice[d], at the patient’s bedside: instead of useless physiologies, they [would] learn the true ‘art of curing’” (70). This training would be heavily grounded in a systematized body of authorized medical knowledge based on pathological anatomy (72). As Foucault notes, “this conceptual transformation... gave the clinical field a new structure in which the individual in question was not so much a sick person as the endlessly reproducible pathological fact to be found in all patients suffering in a similar way” (97).

Central to the process whereby clinical experience becomes a mode of knowledge creation is the instrumentalization of language in the objective correlation of that which is visible and that which is expressible (Foucault 196). By this, Foucault suggests that scientific discourse authorizes the clinical gaze, so that verbally articulating what one sees becomes a way of knowing (196). The clinical gaze depends on a careful balance

between speech and vision, “a precarious balance, for it rests on a formidable postulate: that all that is *visible* is *expressible*, and that it is *wholly visible* because it is *wholly expressible*” (Foucault 115, original emphasis). As Bishop understands it, “medical practice conceived signs as speaking their truth without remainder or excess—no interpretation being necessary” (35).

Foucault’s analysis highlights important changes in the power dynamic between physicians and patients as enacted by epistemological and discursive changes that effectively objectified the patient’s body and provided the physician—rather than the subject—with a privileged perspective on bodily experiences of disease. The clinical mode of investigation positions patients as “cases” in the sense that it “proceed[s] initially to the diminution of individualities” and, in so doing, discounts the idiosyncrasies of subjective experience (168). While the individual is no longer “the accident of the disease,” as she was positioned in classificatory medicine, now the individual within medicine represents a scientifically defined instance of abnormality. While eighteenth-century medicine was concerned much more with health than normality and was generally uninterested in the ‘regular’ functioning of the body, “nineteenth-century medicine, on the other hand, was regulated more in accordance with normality than with health; it formed its concepts and prescribed its interventions in relation to a standard of functioning and organic structure, and physiological knowledge” (Foucault 35).

Indeed, as Lennard Davis notes in his 1995 text *Enforcing Normalcy*, the word ‘normal’ as we currently use it, to describe the state of conforming to a standard, did not enter the English language until 1840 (24). Davis argues, echoing Foucault, that the emergence of the “norm” at this point in history was directly connected to the growing field of statistics, which emphasized an average state of being—‘l’homme moyen’ (27).

As opposed to a previously dominant notion of an 'ideal' body or moral disposition, the notion of a norm "implies that the majority of the population must or should somehow be part of the norm. . . . When we think of bodies, in a society where the concept of the norm is operative, then people with disabilities will be thought of as deviants" (29). This medical bipolarity, pitting the normal against the pathological, came to infuse value judgments about more than just the individual body, but also about the lives of groups, societies, and races (Foucault 35). As Davis points out, statistics and eugenics co-evolved due to a mutually reinforcing assumption "that a population can be normed" (30). Thus, in conversations surrounding both disease and disability, the 'normal,' as a concept that grounds much of our thinking about embodiment (particularly in the realm of medicine) must be regarded as inextricably bound up with discourses of human perfectibility and progress; nationalism, capitalism, and public health; and the medicalization of 'abnormality' (49).

*The partner, the client, the consumer, the 'expert patient'*

Physicians' persistent and relentless demand that patients trust their doctors . . . should have alerted doctors to the fact that patients may not trust them, or that they trust them only with profound reservations. . . . Instead, the idea of informed consent suggests that trust must be earned through conversation. (Katz xiv)

As I have explained, socially constructed notions about normal human embodiment, along with the epistemological changes which lent authority to the

physician's observations, knowledge, and intuitions in the nineteenth century, silenced the voice of the healthcare seeker to the extent that exclusion from life-altering medical decisions became commonplace. While informed consent laws in recent times have placed legal checks and balances on this practice, the paternalistic approach of many physicians continued to reign (and, arguably, still does).

Beginning around the time of functionalist sociologist Talcott Parsons' theorization of the "sick role" in his 1951 text *The Social System*, there emerged a flurry of scholarly activity directed toward analyzing the social roles of doctor and patient and defining the overarching relationship between these two figures. Parsons' theory formulated illness as a deviant social position, characterized by a "passive-alienative" element and a mode of "dependency," which threatened to disrupt the social order if left uncontained (193). The sick role allowed for the "conditional legitimation" of illness experience and the conformity of the sick individual by constructing it as a period of temporary abnormality, part of a journey back to a normal state (197, 211). In this theoretical framework, physicians become representatives of a system that controls deviance: their emotionless, professional relationships with patients support an interpretation of illness as a valid state governed by institutional arrangements and their role is, thus, to guide individuals to social reintegration (296-305).

Arthur Frank offers a useful interpretation of the implications of Parsons's observations about patienthood when he writes, "I understand this obligation of seeking medical care as a *narrative surrender* and mark it as the central moment in modernist illness experience [as opposed to pre- and postmodern experience]. The ill person not only agrees to follow physical regimens that are prescribed; she also agrees, tacitly but with no less implication, to tell her story in medical terms..." (6). This notion



of narrative surrender comes heavily into play in contemporary attempts to reform medical care through narrative medicine, a point I will return to in chapter two.

Following from Parsons, in 1956, Thomas Szasz and Marc Hollender articulated a more nuanced interpretation of the sick role in their formulation of three “basic models of the doctor-patient relationship.” In this brief analysis of the philosophical preconceptions associated with particular medical scenarios, the authors suggest that doctors and patients conform to one of three frameworks for social interaction predominated by activity-passivity, guidance-cooperation, or mutual participation (Szasz and Hollender 586-7). Refraining from offering value judgments about any of these power arrangements, the authors argue that “each of the three types of therapeutic relationship is entirely appropriate under certain circumstances and each is inappropriate under others” (591). In situations where individuals are incapable of more active involvement in their care, whether physically, cognitively, emotionally, or logistically (due to circumstances such as surgery or treatments that *require* their passivity), physicians assume dominance; “psychologically, [the activity-passivity model] is not an interaction, because it is based on the effect of one person on another . . . . ‘Treatment’ takes place irrespective of the patient’s contribution and regardless of the outcome” (Szasz and Hollender 586). When both individuals in the clinical interaction are active, usually when the patient “is conscious and has feelings and aspirations of his own,” physicians may take a guiding or ‘parental’ type of role, in which the patient is expected to cooperate, but in a diminutive mode of obedience to doctor’s orders; “the main difference between the two participants [in the guidance-cooperation model] pertains to power, and to its actual or potential use” (Szasz and Hollender 586-7). The final model, Szasz and Hollender note, “is essentially foreign to medicine. This relationship [of mutual interaction], characterized by a high degree of empathy, has

elements often associated with the notions of friendship and partnership and the imparting of expert advice. The physician may be said to help the patient to help himself" (588). In this type of interaction, patients take primary responsibility for their own care and the ideal of 'equality' is upheld. The conditions necessary to this mode of interaction include the requirements that participants have equal degrees of power and interest in the situation and are mutually interdependent in some way.

Importantly, Szasz and Hollender argue that this last model of mutual participation is not morally more favourable than the previous two and, instead, is appropriate only under certain conditions, namely, "when the physician does not profess to know exactly what is best for the patient. The search for this becomes the essence of the therapeutic interaction. The patient's own experiences furnish indispensable information for eventual agreement, under otherwise favorable circumstances, as to what 'health' might be for him" (589). In other cases, they suggest, it is both important and necessary that doctors take a more guiding and paternalistic role in their practice. Ultimately, it would seem, the relationships elucidated in this model reflect three highly different ways of conceptualizing both the disease and the healthcare seeker. Of particular interest to my research is the question of *why* Szasz and Hollender's third model of mutual interaction, characterized by equality and partnership, is "essentially foreign to medicine"? While one might certainly argue that, since the time of writing in 1956, doctors and patients have come closer to achieving this elusive 'third way,' largely through the widespread accessibility of biomedical knowledge and the promotion of self-care within the health industry, closer examination suggests that true partnership is just as foreign as ever.

Certainly, however, since the publication of this paper, the interest in exploring the potential for healthcare seekers' greater autonomy within medical interactions has

only increased in both academic and popular spheres. In this context, one of the most noteworthy events of the latter half of the twentieth century was the creation of informed consent laws. As Katz explains, in the late 1950s, judges began to ask the as-yet unconsidered question: “Are patients entitled not only *to know what* the doctor proposes to do but also *to decide whether* an intervention is acceptable in light of its risks and benefits and the available alternatives, including no treatment?” (59). While the answer to this question may seem obvious and far from revolutionary by today’s standards, the question, as Katz documents it, was highly contentious and polarizing. Informed consent was finally introduced as a result of the 1957 legal proceedings of *Salgo v. Leland Stanford Jr. University Board of Trustees*, in which Justice Bray determined that “a physician violates his duty to his patient and subjects himself to liability if he withholds any facts which are necessary to form the basis of an intelligent consent by the patient to the proposed treatment . . . In discussing the element of risk a certain amount of discretion must be employed consistent with full disclosure of facts necessary to giving informed consent” (qtd in Katz 61).

While Katz discusses the individual legal cases that created precedence for the eventual establishment of the informed consent laws we have today, it is important to note, also, that the development of informed consent as a concept within medical practice took place in the context of a growing awareness of atrocities that had been committed by medical scientists against vulnerable persons. The largest such example in the twentieth century is the grievous breach of human rights against marginalized persons subjected to Nazi experiments during the Holocaust. But, as Davis notes, “we have largely forgotten that what Hitler did in developing a hideous policy of eugenics was just to implement the theories of the British and American eugenicists” (38). Indeed, forced sterilization of persons with inherited disabilities was endorsed in the

respected magazine *Nature* in 1933 (Davis 38) and actually carried out in North America in the twentieth century on those institutionalized for “mental illnesses,” which at the time included so-called pathologies such as feeble-mindedness and epilepsy (Shapiro 158-9). There are, sadly, a plethora of other cases that belong to this dark history. In 1956, children at the Willowbrook State Hospital were infected with hepatitis B, while in 1963, older adults at the Jewish Chronic Disease Hospital were injected with cancer cells, in both cases without the consent of the unknowing research subjects. In 1972, in Tuskegee, Alabama, six hundred black men were denied penicillin for treatment of syphilis so that scientists could study the development of the untreated infection (Charon 204). And, over a century prior to this, J. Marion Sims, the so-called founder of modern gynecology, performed unconsented painful and life-threatening gynecological experiments on seven enslaved African-American women in order to study the treatment of vesico-vaginal fistulae (Ojanuga 29-30).

This legacy of deception, misinformation, and exploitation forms a dark shadow over the relationship between healthcare practitioners, as representatives of the medico-scientific authority responsible for these atrocities, and those who have no choice but to disclose their states of suffering and vulnerability. As I mentioned in the introduction to this chapter, Charon suggests that the emergence of bioethics within this context has resulted in an understanding of doctor-patient relationships as adversarial or necessarily conflict-ridden. “The extreme focus on patient autonomy,” Charon believes, makes sense only “if the doctor is seen as prone to take advantage of the patient” (205). While this may be true, there are certainly other reasons one could enlist in support of greater patient autonomy, aside from the imperative to eliminate coercion or deception.

Indeed, while the patient-empowering rhetoric of Justice Bray’s words in the 1956 informed consent trial is certainly noteworthy, Katz suggests that the effects of the

law on actual medical practice have proven to be relatively underwhelming (Katz 60). In exploring the many ways in which informed consent failed to deliver on its promise of greater decision-making power for patients, up until the time of publication in 1984, Katz argues that the denial or occlusion of the unavoidable uncertainty inherent in medical diagnosis, prognosis, and treatment was an undeniable part of the problem. The lack of transparency over uncertainty in discussions with patients, Katz suggests, could have been prevented by the medical use of more scientific methodologies that would have emphasized clarity and openness between doctors and healthcare seekers regarding medical unknowns. Instead, feigned certainty and professional superiority on the part of physicians simply preempted any potential for an open, trusting, and equal relationship between practitioner and healthcare seeker (206). As Katz suggests, medical practice failed to acknowledge that

in the absence of any one clear road to well-being, identity of interest cannot be assumed, and consensus on goals, let alone on which path to follow, can only be accomplished through conversation. Two distinct and separate parties interact with one another—not one mind (the physician’s), not one body (the patient’s), but two minds and two bodies. Moreover, both parties bring conflicting motivations and interests to their encounters. . . . Silent altruism alone cannot resolve these conflicting tensions. (xviii)

The questions of paternalism and autonomy central to Katz’s study of informed consent are now, more than ever, at the forefront of a booming Health 2.0 movement, in which medical power and patient expertise meet (and sometimes clash) in the so-called democratizing networks of new media. However, even more recent scholarship continues to express doubt over patients’ capacity to participate in medical decision-making.

A noteworthy 1992 article by Ezekiel and Linda Emanuel enters into this debate to ask the pressing question: “what should be the ideal physician-patient relationship?” Expanding upon Szasz and Hollender, they propose a fourfold model of the interaction in question that isolates the paternalistic, informative, interpretive, and deliberative models, each of which put forth a different role for and conception of patient autonomy (Emanuel and Emanuel 2221-2). The paternalistic model echoes Szasz and Hollender’s active-passive model, while the informative, interpretive, and deliberative models fall somewhere between the guidance-cooperation and mutual participation models. The difference between the latter three lies in how the patient’s values enter into the medical decision-making process; while the physician in the informative model is merely a technical expert who presents information and a range of options that the patient then assesses according to his or her value system, the physician in the interpretive model offers technical information and then assists the patient in articulating or interpreting his or her values to determine which options best realize these. In the last model, the physician and patient exchange ideas in “deliberation about what kind of health-related values the patient could and ultimately should pursue” (2222). In this deliberative model, the physician’s role is extended to also reflect the interests of a teacher or friend and the “conception of patient autonomy is moral self-development; the patient is empowered not simply to follow unexamined preferences or examined values, but to consider, through dialogue, alternative health-related values, their worthiness, and their implications for treatment” (2222).

Emanuel and Emanuel argue that certain conceptions of patient autonomy, such as the informative model, unproductively disempower the *doctor* by reducing their role to that of a technical expert; as such, they endorse the deliberative model, because it reflects “the essence of doctoring [as] a fabric of knowledge, understanding, teaching,

and action” (2226). Indeed, recent scholarship emerging from medical sociology and clinical practice has noted that the ‘asymmetry’ of relationships between practitioners and patients—“the inescapability of medical authority and patient deference”—is crucial to “what doctors are there for” (Pilnick and Dingwall 1374).

In the end, Emanuel and Emanuel fail to explicitly define the ideal role of the patient, though their deliberative model seems still to reflect a perpetuation of predominant passivity on the part of the healthcare seeker: despite amplifying the patient’s voice, arguably, the model still places the doctor in a more active, didactic role. This ideal runs up against some problems when we consider health and illness outside of a narrow biomedical lens. If doctors are trained exclusively in the language of biomedicine, there is much that their “caring custody” will exclude from consideration. As Anne Jurecic notes in her reading of Margaret Edson’s play *W;t*: “patients give their bodies over to doctors and hospitals only to encounter inattention and indifference, not because [patients] cannot express their suffering, but because their language is unvalued and unrecognized in medical culture” (48). In a relationship model in which the physician is a friend or a teacher, that figure is in some ways no less domineering than a medical professional in a paternalistic role, particularly if the way in which he or she guides the healthcare seeker toward a decision enforces a biomedically framed interpretation of that person’s experience.

While changes in the field of medicine since the 1950s have converged around developments in understanding biochemical, pharmacological, and genetic processes, the position of the healthcare seeker continues primarily to reflect objectification under the clinical gaze (Shorter 793). The widening landscape of increasingly more refined testing equipment and visualization technologies extends the gaze in perhaps more invasive and alienating ways. In her cultural analysis of medical imaging, José van

Dijck analyzes the various imaging technologies that medicine deploys to make the body more transparent—X-rays, ultrasounds, endoscopes, computed tomography, magnetic resonance imaging, positron emission tomography, and electron microscopes, to name a few. These medical interventions amplify the process whereby individual bodies undergo the scrutiny of medical and information technologies that code, label, and assess biological structures and, thereby, ‘invade’ corporeal space. As these systems extend the Foucauldian medical gaze of the physician, patients are further alienated from identification with or understanding of their bodies, resulting in a sort of subjection as scientific scrutiny over the body works to isolate mutation and, incidentally, construct notions of normalcy and difference.

Despite scholarly involvement, for at least the past sixty years, in the conversation regarding paternalism and autonomy in healthcare, many patient activists, as well as proponents of person-centred care and medical humanism, take issue with the almost total dismissal of the patient’s story or perspective in the clinical encounter; they continue to suggest that the prioritization of information yielded from advanced diagnostic devices has resulted in a serious breakdown in the relationship between individuals and their medical practitioners. Despite doctors’ greater therapeutic power “in the last quarter of the twentieth century, as an ever-broader stream of antibacterial, anti-inflammatory, antineoplastic medications became available, patients [have become] increasingly alienated from the former ‘demigods in white’” (Shorter 794). Furthermore, patients continue to be unnecessarily denied greater influence and autonomy in medical interactions. My example at the beginning of the chapter of the birth control drug recall illustrates a perfect example of the continued authority of medical professionals—in this case, pharmacists—as paternalistic spokespersons for healthcare seekers and intermediaries between pharmaceutical companies and healthcare consumers.



Much recent criticism of the medical establishment and doctor training reasserts and responds to the Foucauldian analysis that I have favoured in this history of the patient. In her study of narrative within medical practice, Julia Epstein studies how patient stories are translated into medical records in a way that seeks to contain corporeal deviance within a manageable space by giving semiotic meaning to experience; this ensures that the individual body is constrained within what Foucault terms a system of regulatory control (Epstein 4). The medically authorized representation of individual experience is problematic because it relies on the idea that the body can be decoded, “at a remove from the individual’s production of meaning within that body as it operates inside culture” (Epstein 1). While the narrative medicine movement, since the 1980s, has been presented as an antidote to the reductive and dehumanizing medical chart, in the sense that it attempts to consider the individual healthcare seeker as a “whole person” and not just as a patient, there remains some danger, to my mind, that the healthcare seeker’s story will nonetheless be subjected to the kind of regulatory control that Epstein traces in her rhetorical study of medical records. The illness experience, as interpreted by healthcare professionals, will always be sculpted to serve the interests of a narrative of normalization that becomes defined and, in some ways, appropriated by the medical practitioner who hears and authorizes that story. This is a topic I will examine in more detail in chapter two.

A wealth of literature in the medical humanities field, a sibling to the narrative medicine movement, also articulates the desire for medicine to move away from the current accepted system, in which patients are merely cases, to a mode of engagement that ‘humanizes’ healthcare (Brody 2; Polianski and Fangerau 121; Shapiro et. al 192-3; Macnaughton 928). These models promote conceptualizations of healthcare seekers as “whole persons” and partners in care. While the proposed methods for effecting a

conceptual innovation of the healthcare seeker's position within (and without) the medical institution vary from the prescription of a "humanities pill for what ails us" to the humanities' "intellectual co-engagement with policy makers and clinical researchers," the most promising and, indeed, most challenging remedies prioritize empathy and compassion as necessary facets of the relationship between individuals and healthcare practitioners (Peterkin; Macnaughton; Pembroke). At the same time, these new directions, which appear undoubtedly positive, also fall victim to an embedded liberal humanist value system that prioritizes qualities like wholeness, autonomy, and agency in ways that actually undermine the positive goals—equal partnerships, more nuanced definitions of illness, empathic care—to which the movements strive. The philosophical question of the human is central to how contemporary North American medicine, through attempted reforms like medical humanities, narrative medicine, and participatory healthcare, conceptualizes the subject as healthcare seeker.

## **Conclusion**

As I have explored in this chapter, the role of the healthcare seeker is highly context sensitive and has developed in tandem with particular social and medical constructs for understanding the human body. Over history, and persisting to the present day, the person at the heart of the medical inquiry is at times regarded as an entity through which symbolic emanations, in the form of bodily 'abnormality,' are channeled and interpreted; at times, as a natural being out of balance with an interconnected natural world; at times, as a bodily container for diseases that can be classified and treated according to rational systems of categorization; at times, as an object to be scrutinized under a medical gaze that views the patient—mind, body, and

soul—as his disease; and, at times, as a combination of some or all of these constructs. Awareness of these various approaches to understanding the human over time can aid us in critically investigating which threads of these historical conceptualizations persist in our contemporary medical sphere in ways that, potentially, do not serve the goals of humanized healthcare.

In the next chapter, I use these foundations to explore how deeply rooted humanistic assumptions about life contribute to the perpetuation of some of the persistent issues introduced in this chapter, which prevent individuals from assuming an adequate level of involvement in the decisions that affect their emotional, psychological, social, and bodily well-being. These assumptions are at the heart of the philosophical questions raised by posthumanist theory. And they are the questions that, I argue, must be interrogated far more directly than they currently are within the medical humanities movement in doctor training and the burgeoning field of narrative medicine. Indeed, the shift toward a partnership model within medicine depends upon a more critical transformation of medicine’s philosophical conceptualization of the human.

## Chapter 2 | Conceptualizing the Patient in Medical Humanities: A Posthumanist Intervention

What if our understanding of ourselves were based not on static labels or stages but on our actions and our ability and our willingness to transform ourselves? *What if we embraced the messy, evolving, surprising, out-of-control happening that is life and reckoned with its proximity and relationship to death?* . . . And what if each of these things were what we were waiting for, moments of opening, of the deepening and the awakening of everyone around us? What if this were the point of our being here rather than acquiring and competing and consuming and writing each other off as stage IV or 5.2B? (89, my emphasis)

Eve Ensler, *In the Body of the World*

If the humanities has a future as cultural criticism, and cultural criticism has a task at the present moment, it is no doubt to return us to the human where we do not expect to find it, in its frailty and at the limits of its capacity to make sense. (151)

Judith Butler, *Precarious Life*

Claiming to be “no apologist for cancer,” Eve Ensler, in her memoir *In the Body of the World*, nonetheless credits the bodily trauma of the disease for allowing her a *return* to a body from which she had been exiled (8). I begin this chapter with a series of questions from Ensler, which are more aptly *challenges* to the clean, categorical imperatives of medicine, in order to introduce an idea that medical practice has been, thus far, unable to reckon with—that is, the idea of all embodied experience as both fragmented and existing outside of the permeable corporeal boundaries of the humanist self.

After dealing with a painful post-surgical abscess following the removal of her uterus, ovaries, cervix, fallopian tubes, rectum, and sections of colon, Ensler recalls the lead-up to her eligibility for radiation and chemotherapy. Along with the guilt and blame imposed upon her by cold, detached physicians who cruelly comment upon her body's too-slow recovery—"I feel as if I have failed," she remarks—she also writes of the dismissal and judgment attached to something so dull and non-vital as a medical chart (70, 88). The brutality of having her body categorized within a particular stage of cancer—either IIIB or IVB, they tell her—reminds her of being placed in the 'stupid' group in fifth grade—5.2B, labeled one of "the wrong children, the fat, the pimply, the depressed, the painfully introverted, the ones with behavioural disorders, the broken and oily-haired girls, the aggressive, menacing boys" (86). The resonances between these experiences that each *imposed upon her a deficit*, prompt Ensler to ask the series of questions above.

Most notable of these questions, for my purposes in this chapter, is the challenge to "[embrace] the messy, evolving, surprising, out-of-control happening that is life" (89). Admittedly, when taken out of context, this line reads as a cliché, perhaps grandiose, observation on the unruliness of human life in a vast and mysterious universe. Indeed, I am not interested in defending an argument that "life is crazy—accept it" (an argument that I do not believe Ensler is making, either). Instead, I hope to uncover some of the insidious humanistic impulses that guide the narratives to which we turn when we attempt to think about the human experience of illness—impulses that lead us to overstate allegedly human qualities like agency, rationality, autonomy, and wholeness. In contrast to an illness journey depicted as a rupture and repair of body, self, and personal narrative—conforming to a medical master narrative, of sorts—in Ensler's memoir, for example, we see serious illness narrated through a different

frame. What Ensler describes as her emotional ‘emptiness’ and feelings of incompleteness derive from the violence of sexual abuse that divorce her from her body, as well as the emotionally damaging experience of having paid witness to the stories of sexual assault victims from many countries around the world. As I will explore in more detail below, her cancer, while ravaging, excruciatingly painful, and near-fatal does not create a ‘narrative rupture’ in the negative sense; it opens her to a world of interconnectedness in which she begins to see her suffering—and her joy—as belonging to, with, and in the world.

The first part of this chapter will examine the values and goals of medical humanism—its attempts to respond to a legacy of impersonal medicine—as it manifests in the writings and curricula of medical school educators, scholars, and other commentators. For the most part, the call for a humanistic revitalization of medicine revolves around the practice of narrative medicine and the related concept of “whole person care,” ideas that I will explore in detail through the writings of Arthur Frank, Rita Charon, and others. Narrative analysis of illness by researchers in literature, sociology, anthropology, psychology, philosophy, and other related disciplines tends typically to illuminate the complexities of the illness experience and the ways in which meaning is negotiated variously in context-specific and relational ways. However, literature promoting the study and adoption of narrative techniques within medical practice seems, often, to construe illness narrative in terms of a rehabilitative or, what Frank in *The Wounded Storyteller* calls a “restitution narrative,” figured through binaries in which health is aligned with wholeness and coherence and illness with fragmentation and chaos. Despite criticism of this limited mode of understanding the healthcare seeker’s story, the narrative of restored wholeness (and the doctor’s role in achieving this) seems pronounced in the literature, perpetuating a seemingly inescapable

conceptualization of the patient as no more than a collection of parts to be reconstituted. As I will argue, this reductive view is inextricably linked to the continued reliance of medical practice upon a liberal humanist value system.

Throughout the discussion I will return to Ensler's eloquent and complex account of her experience with cancer in terms of how her perspective can contribute to a rethinking of medical humanities' and narrative medicine's conceptualization of the human. In the last half of the chapter, I will introduce the phenomenological concept of posthumanism and explain its relevance within a contemporary medical sphere that seems intent on reforming its relationship to the human, but has yet to escape the confines of liberal humanism. This posthumanist intervention asks medical humanities scholars, medical practitioners, and medical students to think more critically about the rhetorics of holism, autonomy, and humanization endemic within current attempts to reconceptualize the healthcare seeker. Expanding on this idea through the work of Cary Wolfe, Judith Butler, and Jane Bennett, I explore how consideration of the body's incomplete, atomistic, and fragmentary nature poses an occasion for a more nuanced understanding of illness experience, based on the lived human experience of shared vulnerability. I connect this reading of human embodiment to the work of disability studies scholars, including Jay Dolmage and Margrit Shildrick, who critically deconstruct notions of wholeness, prosthesis, and the disabled body.

### **Medical humanities and narrative medicine**

Returning to one of the probing questions of Ensler's memoir—that is, what it means to be human in and through the embodied experience of disease—we are faced with a line of inquiry that sits at the forefront of ongoing conceptual renegotiation within the medical field. Beginning most notably, perhaps, with the work of French

poststructuralist Michel Foucault, modern medicine has been heavily criticized for its objectification of the patient and its reductive, atomizing view of the individual as merely a diseased body or medical case (Foucault 168). This situation is well addressed in literary form by Ensler when she recounts her oncologist's suggestion that she undergo radiation: ". . . he says the mantra of the end of the world. 'WE LIKE TO THROW EVERYTHING AT IT. That's all we know how to do.' And I say, 'The only problem is that IT is attached to ME.' And I swear he doesn't flinch. Me is irrelevant. Me is personal and specific. Me is what has to be passed through to get where he is going" (71-2).

Continuing from my discussion in chapter one of the history of criticism against the medical establishment for its reductionist, biomedically-oriented view of human functioning, I would like to focus here on medicine's reaction to that criticism. As discussed, early theorizing on how medical practice might reorient its perspective is seen in the influential work of George Engel whose 1977 article in *Science* was one of the first to blatantly express the need for a biopsychosocial model of human health—a model that extends the "somatic parameters" of the medical model to account for how psychological and social factors, such as mood, behaviour, lifestyle, philosophical worldview, cultural norms, etc., should be regarded *alongside* (and not secondary to) physical and biochemical "proof" of disease. Engel's argument, at this time, can be seen as intervening in an increasingly more technologically advanced medicine; the precision with which *data* had begun to speak for the patient (a precision considered infinitely more trustworthy than the experiential expressions of the individual, herself) made it all too easy for practitioners to overlook psychosocial influences on health.

The contemporary movement toward "whole person care" takes up the mandate of the biopsychosocial model in its interest in understanding the multifaceted way in



which all parts of a human life interact to produce our particular conditions of embodiment. As Tom A. Hutchison describes in his introduction to the edited collected *Whole Person Care*, “whole person care is not knowing all about the patient in all dimensions . . . . Such an undertaking is doomed to failure and would probably be perceived by patients as overstepping the bounds of the medical mandate and even as invasive. . . . [A]t the same time, nothing that comes up can necessarily be ruled out of bounds as a potential avenue for addressing the problem” (3). Central to understanding the practitioner’s role here, as Hutchison goes on to explain, is to see his or her purpose as serving both a curing and a healing function. While curing involves “eradicat[ing] disease or fix[ing] a problem,” “healing is a process leading to a greater sense of integrity and wholeness in response to an injury or disease that occurs within the patient” (4). Thus, as evidenced in other articulations of whole person care, the health professional’s investment in the patient’s wellbeing involves fixing or addressing the problems that contribute to somatization (the physical expression of ‘disease’), whatever that might be.

Here, in the language of whole person care, we see emerging the idea that medicine ought to repair the fractured wholeness of the patient; that along with physical disruption or disintegration comes a break in the previously integral body-self. In many ways, it seems that two approaches to teaching whole person care, both medical humanities and, within it, narrative medicine, also work to reinforce this notion of healthcare that heals the self or self-narrative, alongside the body.

### *Humanistic medicine*

In the midst of the debate over paternalism and autonomy, objectification and empowerment, the concept of medical humanities began to emerge in the United States

between 1960 and 1970 (Brody 1). In 1977, the Committee on Humanizing Healthcare, established by the American Sociological Association, “defined ‘humanized healthcare’ as ‘care that enhances the dignity and autonomy of patient and health care professional alike,’ through treating patients as unique, whole, and autonomous persons” (qtd in Mishler 436). Since then, professional and scholarly voices have coalesced to articulate a predominant desire for medicine to move away from the current accepted system, in which patients are merely cases, to a mode of engagement that implements this humanized brand of healthcare (Brody 2, Polianski and Fangerau 121, Shapiro et. al 192-3, Macnaughton 928). Prioritizing empathy and compassion as necessary facets of the doctor-patient relationship, much of the scholarship in this area revolves around teaching physicians-in-training how to be more ‘humane’ doctors—that is, more caring, more observant, and more invested than their forbearers. Presently, 69 of the 133 accredited medical schools in the United States list required courses in the medical humanities, while many of the 17 Canadian medical schools have started to integrate elective medical humanities courses (Banaszek 1).

Medical humanities curricula have taken a few different approaches to fulfilling this mandate and there is, of course, no consensus on the way in which the central goal of humanized healthcare ought to be achieved. For Dr. Allan Peterkin, head of the Program For Narrative and Humanities in Healthcare at Mount Sinai Hospital in Toronto, the medical humanities is as simple as “an experienced surgeon listen[ing] to the *Mahler Second* after a particularly difficult case” or a young internist asking her residents to discuss a poem rather than a medical case (648). Peterkin defines the medical humanities as a practitioner’s “exposure to literature, the fine arts, theology, history, philosophy and anthropology [that] broadens a doctor’s cultural competence and encourages the linking of both cognitive and affective approaches to the physician’s

task” (648). His definition seems particularly focused on how the addition of the humanities to medicine allows for an increased value placed on “curiosity and the role of aesthetics” (Peterkin 648).

In attempting to distill the various elements of a medical humanities approach like Peterkin’s, Howard Brody’s 2011 review of medical humanities education develops a tripartite definition that illuminates three recurring themes in scholarly discussions of the discipline’s role. His definition responds to an expressed uncertainty among health professionals, educators, and students with regards to what medical humanities means. Mirroring Peterkin’s definition, Brody’s notion of a robust medical humanities combines the three different conceptions he identifies, which include, first, medical humanities as a list of disciplines reflecting the ideals of a liberal arts education; second, medical humanities as a program of moral development, dating back to Petrarch’s humanistic philosophy of university education; and, third, medical humanities as a supportive friend, drawing on the work and life of renowned physician Sir William Osler, who sought the wisdom and beauty of the arts as a remedy to the emotional anguish of the physician’s duties (4-6).

What Brody, Peterkin, and others of the same pedagogical persuasion fail to address in their definitions is the problematic popular conceptualization of medical humanities as ‘tacked on’ to medicine, a critique that many humanities scholars level against an approach that unjustifiably dismisses the value of humanities-based forms of inquiry *within* medical practice itself. Indeed, both authors seem to endorse the notion, critiqued by Johanna Shapiro, et al. (2009), that the scholarly pursuit of medical humanities should be simply a disciplinary addendum or “an intriguing sideline in the main project of medical education” (193). Igor Polianski and Heiner Fangerau (2012) cite the findings of Shapiro, et al. that a large number of medical students respond to

the existence of humanities courses in their degree program as “pointless, boring, worthless, or just plain stupid” (192). They suggest that the negative reaction to medical humanities stems from dominant conceptualizations of the initiative that perpetuate a “two cultures” dichotomy; this approach continues the debate, which emerged in the 1960s, that polarizes scientific (hard) and humanistic (soft) educational pursuits in unproductive ways. They argue for a more integrated approach that simultaneously considers the culture and science of medicine and that is self-reflexive, rather than geared toward the goals that Brody identifies: liberal arts, moral development, and/or the mental health of the practitioner.<sup>3</sup>

This type of co-constructive mentality for envisioning the interaction between science and the humanities reflects the “Biocultures Manifesto” articulated by Lennard J. Davis and David B. Morris (2007) that centres around the following notion: “that the biological without the cultural, or the cultural without the biological, is doomed to be reductionist at best and inaccurate at worst” (411). Voicing what they observe to be “a grassroots, broadly distributed group of researchers who are treading the boundaries between science and the humanities,” Davis and Morris argue for the recognition of a community of researchers whose interpretations produce informed and engaged dialogue across disciplines. In this broad way, all articulations of medical humanities may be seen as partaking in a similar activity, however, as I have demonstrated, there are obviously vast differences in how each approach is conceived. Turning to explore the theory and practice of narrative medicine more closely, we can see how a *biocultural*

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<sup>3</sup> Schleifer and Vannatta offer a promising integrative model that uses “schema-based medicine” to complement evidence-based medicine and incorporate a “humanistic understanding.” One example is the practice of eliciting a patient’s chief concern, as well as her or his chief complaint, during the procedure of conducting the History and Physical Exam.

approach to healthcare interactions proposes to remediate an overly dominant *biomedical* approach to interpreting patients' stories.

### *Interpreting illness narratively*

The notion of a biocultural approach certainly resonates with the way in which narrative medicine has emerged within and without the medical institution. The narrative turn within various disciplines outside of literary studies began in the early 1980s. At this time, practice and theory within “science and technology, philosophy, the human sciences, sociolinguistics, sociology, and anthropology” all began seriously to incorporate narrative concerns (Engel, et al. 41-2). In his chapter “Tell Me a Story: The Narrativist Turn in the Human Sciences” Martin Kreiswirth describes “the recent obsession with narrative forms of interpretation and understanding as a response to . . . our current climate of anti-foundationalism, poststructuralism, and/or postmodernism—a response, that is, to the breakdown of transcendental truth claims, to various overturnings or assaults on formerly hegemonic logico-deductive and patriarchal models of reason and knowledge” (63). Narrative, then, becomes an access point through which to counter and critique what Jean-François Lyotard calls master narratives—in the case of illness, an understanding of that experience endorsed by the biomedical apparatus.

In the study of narratives of illness, within philosophy, psychology, sociology, medicine, and literary studies, similar concerns emerge, particularly in terms of understanding disease as socially and culturally constructed and illness as uniquely subjective. In the introduction to their edited collection, *Unfitting Stories: Narrative Approaches to Disease, Disability, and Trauma*, Valerie Raoul, et al. describe the three assumptions that provide common ground for the various interpretations voiced in

their text, assumptions that I believe guide the contemporary analysis of illness narratives across a broad range of humanities and social scientific disciplines: “The first is that disease, disability, and trauma, while often having physical or biological causes and effects, are socially and psychologically constructed and part of a life story which changes because of them. The second is that the exchange of stories is central to treatment, therapy, and advocacy for change. The third is that the stories exchanged (whether medical or personal, in the form of aesthetic or didactic accounts) are governed by cultural metanarratives that vary according to time, place, and socio-political context” (5). The editors highlight a decidedly postmodernist understanding of illness narratives (whether spoken or written) as simultaneously constructing and constructed by an individual’s personal life circumstances, psychology, and sociocultural environment, but also influenced by the wider cultural narratives which dictate the discursive and generic constraints of storytelling. Sociologist Arthur Frank also points out that our storytelling is conditioned by the “rhetorical expectations that the storyteller has been internalizing ever since he first heard some relative describe an illness or she saw her first television commercial for a non-prescription remedy, or he was instructed to ‘tell the doctor what hurts’ and had to figure out *what* counted as the story that the doctor wanted to hear” (*Wounded Storyteller* 3). These expectations are generic ones, defined by Carolyn Miller as recurring rhetorical situations, which become solidified and sometimes adapted as they are repeated. Recognizing the presence of these rhetorical demands is also key to understanding how our interpretation of experience, through its representation in narrative, participates in various different discourses about the body.

While narrators rely on certain generic conventions that are socially and culturally authorized, illness narrative as personal expression or testimony within a

medical encounter, argues Anne Hunsaker Hawkins, “returns the voice of the patient to the world of medicine, a world where that voice is too rarely heard, and it does so in such a way as to assert the phenomenological, the subjective, and the experiential side of illness” (12). Hawkins terms this type of narrative “pathography,” a form of storytelling that “restores the person ignored or canceled out in the medical enterprise, [placing] that person at the very center” (12). Similarly to Hawkins, Frank, in his text *The Wounded Storyteller*, argues that individual accounts of personal illness can serve as a form of postcolonial emancipation from the medical colonization of the body and of bodily experience: “As a post-colonial voice, the storyteller seeks to reclaim her own experience of suffering. As she seeks to turn that suffering into testimony, the storyteller engages in moral action. The themes of body, voice, and illness culminate in the ethics made uniquely possible in postmodern times” (18). The moral action to which Frank refers points to the way in which storytelling engages both teller and listener in a space that is “for the other,” the teller in offering forth her experience as a model or guide, and the listener in bearing witness (*Wounded Storyteller* 18).

Frank, in attempting to describe illness as actually *necessitating* narrative suggests that this experience is “a call for stories”; these stories are uniquely embodied narratives in the sense that they arise as a response to the phenomenological experience of illness. Frank identifies three different types of stories that illness sufferers tell: chaos narratives, restitution narratives, and quest narratives. Describing experiences which have not yet (or may never) take on the formal elements of an Aristotelian narrative, “chaos stories are antinarratives in that they are told from within *dehumanized* time—time without order and thus without meaning” (213). According to Frank, the act of narrating an experience through tropes such as restitution or quest “humanizes the chaos of what has happened to [the patient]” (213). Thus, illness narratives function as

empowering devices that allow “the ill,” as he refers to them, to “transform fate into experience”—to voice the bodily trauma and suffering of illness in a way that gives it meaning: that forms “empathic bonds” between teller and listener and thus has the potential to heal both self and other (xii). While restitution narratives, he argues, take up the dominant discourse of the medical establishment and its goal to return the body-self to the “normal” state of functioning that preceded illness, quest narratives may be more productive for the ways in which they configure the experience of illness as a transformative process that ideally leads to a new identity, one which may depart significantly from an individual’s past sense of self (prior to illness).

Throughout *The Wounded Storyteller*, Frank asserts a unique relationship or productive pairing between illness and storytelling, based on a few key arguments. First, he suggests that illness presents a unique opportunity to enter into the dyad of storyteller and listener, since the experience of illness facilitates a more acute receptivity to others’ suffering and a greater capacity for empathy. He argues that this is true in the case of illness “because the ill person is immersed in a suffering that is both wholly individual—my pain is mine alone—but also shared: the ill person sees others around her, before and after her, who have gone through this same illness and suffered their own wholly particular pains. She sees others who are pained by her pain” (36). Second, serious illness “is a call for stories” because being seriously ill causes damage to the suffering individual’s sense of identity, her life plan, and her illusion of both control and self-directedness. The sense of a whole narrative that connects past, present, and future becomes according to Frank, citing philosopher David Carr, disrupted, “as illness dislocates the relation of this whole: the present is not what the past was supposed to lead to, and whatever future will follow this present is contingent” (60). According to



Frank, narrative functions reparatively as “a way of redrawing maps and finding new destinations” (53).

### *Narrative medicine*

Narratives of illness exist all around us, mostly outside of the clinical setting where they attain medical corroboration: in exchanges between friends and family members, or between sometimes-anonymous strangers in online forums; in newspapers, magazines, blogs, radio, television, and film; in published personal memoirs; in unpublished, private forms. The narrative turn *within medicine* theorizes that the richness of detail and meaning offered by an individual’s personal account of illness has the power to present a holistic view of his or her health, by illuminating the various biopsychosocial concerns of a more ‘humane’ medicine I discussed earlier. Various scholars across disciplines have contributed to this narrative turn, including most notably physician and philosopher Howard Brody, physician and anthropologist Arthur Kleinman, literary scholar Kathryn Montgomery Hunter, sociologist Arthur Frank, philosopher Hilde Lindemann Nelson, occupational therapist and anthropologist Cheryl Mattingly, and physician and literary scholar Rita Charon, to name a few.

Drawing on this and other scholarship, narrative medicine or narrative health care is a disciplinary movement and healing approach—what John D. Engel, et al. call “both a philosophy of care and a set of skills” (54)—that emerged in conjunction with medical humanities in the early 1980s (Charon 4). Generally, these approaches to medicine take up the mandate expressed by Engel, et al. in *Narrative in Health Care* (2008) to

[stake] out a fundamental position on the relationship among *sickness, life stories, and personal identity*. With this ontology in place, narrative health care supports particular enactments of *patient-physician encounters* and overcomes *barriers between patients and practitioners* through emphasizing *narrative features of care/caring* and by encouraging the development and enactment of *narrative competence in a variety of health care contexts*. (55, original emphasis)

One of the earliest articulations of the narrative nature of medicine comes from Howard Brody in his 1987 text *Stories of Sickness*, in which he argues that storytelling is a central aspect of medicine, the repression of which has instantiated the endemic inattention to personal psychosocial considerations as an essential component of healing (2-5). He goes on to argue that there is no single way of understanding illness through a biopsychosocial model, instead “showing how important the specific details (the story of sickness) are to any meaningful comprehension of the impact of sickness on the person” (Brody 144). Brody highlights the power of the physician, because of his or her specialized knowledge and authoritative social position, “to construct stories and to persuade others that these stories are the *true* stories of illness” (182). To do so in a respectful and compassionate way, he argues, healthcare practitioners must be trained to be open to and accepting of personal, subjective stories about illness told by healthcare seekers, a capacity that he believes the study of literature provides access to (183). In Brody’s words, “physicians can properly exercise that power only when they attend carefully to the stories their patients tell them and engage them in meaningful conversation, within the broader context of the range of life stories made available to us by our society and culture” (182).

Since the discussion of literature and medicine began with the work of Brody and others in the 1980s, many implementations of narrative healthcare have emerged.<sup>4</sup> I will focus here on one of its most popular articulations, that being Rita Charon's Program in Narrative Medicine at Columbia University Medical Center. Charon, a medical doctor and professor of medicine who also holds a doctorate in English literature, views the narration of illness within the clinic as a therapeutic *and* diagnostic tool for *physicians*, rather than exclusively for patients. Her work in *Narrative Medicine: Honoring the Stories of Illness*, which describes the theoretical and practical basis for the Program in Narrative Medicine, pays particular attention to the rhetorical expectations and interpretive frameworks that determine how illness narratives are created and received. Charon's narrative medicine prioritizes the skills of "recognizing, absorbing, interpreting, and being moved by stories of illness" (4). It intervenes in the traditionally "impersonal, calculating" encounter to infuse the interaction between practitioner and patient with a higher degree of empathy, based on the assumption that "only when the doctor understands to some extent what his or her patient goes through can medical care proceed with humility, trustworthiness, and respect" (3).

For Charon, narrative knowledge balances out the universalizing tendencies of scientific and epidemiological knowledge by facilitating a means by which to understand individual experience (10). In this model, the health professional takes on the role of Homer's seer Calchas, who looks for subtle hints in the storyteller's words, "notic[ing] metaphors, images, allusions to other stories, genre, mood—the kinds of things that literary critics recognize in novels or poems,"<sup>5</sup> in order to interpret,

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<sup>4</sup> See: Engel et. al, *Narrative in Health Care*; Schleifer and Vannatta, *The Chief Concern of Medicine*; Harter, Japp, and Beck, *Narratives, Health, and Healing*.

<sup>5</sup> These observations are also central to a psychotherapist's assessment of patient stories, a connection that would be worth exploring in future analyses of narrative medicine theory and practice.

comprehensively, the scene of illness (66). Charon argues that the healthcare seeker's storytelling before a health professional constitutes an autobiographical act; that the narrative produced by such a telling can, and should, be read by the listener as a literary text. In this context, the practitioner is "the interpreter of these accounts of events of illness that are, by definition, unruly and elusive" (5). Importantly, a skillful approach to narrative medicine involves the clinician's ability to select the appropriate interpretative lens to read "a particular text or patient—for example, some texts need a forgiving reader instead of a skeptical one, and some patients need an authoritarian doctor instead of a collegial one. . . . The reader adopts his or her readerly stance toward the work—based in part on the makeup and behavior of the narrator but also based on the reader's own makeup and behavior. . . ." (110). Charon's attention to this point throughout the text is largely examined through the model of intersubjectivity, and her desire to promote medicine as "an ongoing intersubjective commitment in the face of vulnerability and trust" (215). This intersubjectivity is the defining element in the doctor-patient interaction that, she says, allows genuine understanding and empathy to arise.

Differently from Frank and other scholars who explore the varied narratives that patients, themselves, construct in response to the trauma of illness, Charon and other proponents of narrative medicine present narrative analysis and *creation* as a valuable exercise for health practitioners. She explains,

narrative medicine—and its cousins literature-and-medicine, relationship-centered care, patient-centered care, and the like—has developed means of encouraging clinicians to represent more fully what they learn about patients and about themselves. This new kind of writing . . . is not bound by the conventions of the hospital chart. It allows for the "I" of the writing subject. . . . What I have called the

'Parallel Chart' is an example of this kind of narrative activity—writing done in nontechnical language that captures the personal and metaphorical dimensions of meaning, for both the sick person and those caring for the sick person. (149)

She argues that attention to the multifaceted elements of a patient's clinical story is not fully achieved until it becomes manifested in representation—that is, through the use of a "Parallel Chart" to facilitate the act of reflective or creative writing on the part of health professionals. In this way, narrative meaning making can be instrumentalized in the service of clinical results.

Interestingly, in the creation of a Parallel Chart, the patient's story becomes rearticulated or interpreted through the authorial lens of the physician in the same way that the medical chart interprets a patient's story through a medical lens. Indeed, the goal of such an exercise is to permit the physician space to understand the patient in a more holistic way; however, the patient's story in this scenario becomes, problematically, appropriated by the medical authority figure. A more democratized approach to patient care might conceive of a "Parallel Chart" that is authored by the patient, himself or herself. While techniques, such as the ones proposed in Charon's version of narrative medicine, aim to renegotiate the relationship between doctor and patient by honouring the personhood of the healthcare seeker, the conceptualization of the "patient" as, in some way, more vulnerable or less vital than the doctor, continues to persist. I will elaborate on this point, below, by analyzing the language used to construct the healthcare seeker in medical humanities literature.

### **Humane medicine / humanistic medicine: the rhetoric of rupture and repair**

As discussed, both medical humanism and its sibling, narrative medicine, have attempted to intervene in a situation of dehumanized, depersonalized healthcare,

simultaneously with allopathic medicine's search for a more holistic 'biopsychosociospiritual' approach to understanding the functioning of the body-self. Despite the various ways in which medical humanities, as an emergent set of disciplines, is construed, one consistent thread that I argue seems to run through the various ways of understanding the project for more 'humanized' healthcare, is the way in which the individual at the heart of the question—the patient—is conceptualized. A literature review of the scholarship on medical humanities and narrative medicine—whether endorsing, justifying, or criticizing its inclusion in medical curricula—reveals that articles on the topic frequently begin with a reactionary approach that sees the figure of the “whole person” as the ideal antidote to the traditional objectification, dehumanization, and powerlessness of the patient. M. G. Kidd and J. T. H. Connor, for one, worry that “without a humanist perspective, a patient might easily be represented—and treated—atomistically, as no more than a collection of organs and systems” (46). Along the same lines, Alan Petersen et al. note that in North America and the UK, “the medical humanities are conventionally seen to redress a *deficit* in medicine” (2). This deficit, observes Jill Gordon results from the “relentless reductionism of the biomedical sciences. . . . History, philosophy, and sociology,” she notes, “warn that the person with the disease is all too easily reduced to the non-hygienic, non-rational, disordered ‘other’” (5).

Following from these observations, medical humanities professor Jane Macnaughton suggests that the movement is—or should be—focused on systemic change. The medical humanities field emerged “as a result of a growing sense that there was something inadequate about medicine's understanding of the human” (927). Macnaughton argues that despite challenging “depersonalization and molecular reductionism,” medical humanities have not sufficiently infiltrated medical teaching or

practice to achieve a more productive conceptual model of the human (930). The reimagination of the patient, these scholars note, must begin with a more robust, holistic understanding of the individual that extends beyond the physical markers of disease to account for the 'whole person,' an entity composed of idiosyncratic biological, genetic, emotional, psychological, social, and cultural aspects, and possessing highly subjective experiences of disease.

McGill University medical faculty Helen Mc Namara and J. Donald Boudreau observe that *whole person care* requires skills generally fostered by a humanities education, and involves meeting all physical, psychological, and spiritual needs. In this model,

healing involves reconciliation of the meaning(s) an individual ascribes to distressing events within his or her perception of personal integrity and 'wholeness.' This suggests that suffering may be associated with 'disrupted wholeness.' Whole person care is not limited to only what the physician sees; it must also strive to peer into the suffering patient's arrested, progressing, or otherwise evolving sense of self and wholeness. (Mc Namara and Boudreau 191)

Similarly, in his introduction to the edited collection *Whole Person Care*, Tom A.

Hutchison writes that the healing side of the medical encounter, which must be taught to future doctors, involves "a process leading to a greater sense of integrity and wholeness in response to an injury or disease that occurs within the patient" (4).

Likewise, Moira Stewart, professor of family medicine at the University of Western Ontario highlights the role of doctors in "help[ing] patients put the fragments of their lives back together into a whole" and stresses the importance of medical teaching that "avoid[s] the reductionist perspective of breaking down caring into minute skills and behaviours without also re-integrating the parts into a whole" (793, 799).

The rhetoric of restored human wholeness as the ultimate goal of the medical intervention also seeps into proposed practical applications of narrative analysis within medicine. As I explained previously, understanding and interpreting illness through narrative has come increasingly to structure the ways in which health practitioners are encouraged to know healthcare seekers as complex, individuated persons. While plenty of scholarship speaks to the theoretical benefits of engaging with patients through applied modes of narrative analysis, there is little discussion about the way in which patients' narratives within a clinical setting—despite their potential to infuse diagnosis and treatment with a more multifaceted perspective of the individual—nonetheless become *medical objects*, which continue to be instrumentalized in the service of understanding pathology. In this way, narratives, like bodies, are scoured for signs of pathology that are then diagnosed as causes or symptoms of the physical lesion. This situation is starkly illuminated by writing on illness narrative and narrative medicine, which consistently regards the 'brokenness' of the healthcare seeker's narrative as pathological, as a sign of the fragmented body-self; both of these—fragmented story and fragmented body—fall under the purview of the medical intervention, which becomes aimed at repair. The danger inherent within medicine's appropriation of an oversimplified form of narrative analysis, I argue below, stems from the potential for narrative to be integrated as simply another set of diagnostic criteria within an inescapably biomedical model.

In line with the larger project of medical humanities, a fixation on protecting or restoring the wholeness of the healthcare seeker is overwhelmingly apparent in the literature on narrative medicine. The notion of illness as precipitating narrative rupture and a call for narrative repair is perhaps foregrounded in Frank's writing in *The Wounded Storyteller*, the influence of which can be seen in subsequent literature



promoting narrative medicine techniques. For the most part, Frank's argument is productively directed toward thinking about illness storytelling as a therapeutic, but also a political tool, which asserts subjective, creative, interpretive ownership over one's own experience, much in the way that many patient activists currently assert this ownership in online spaces for narrating disease experience. However, in suggesting that the restitution of narrative wholeness through storytelling about personal illness experience can lead to 'humanization,' Frank's work in *The Wounded Storyteller* also makes a number of uninterrogated assumptions about 'normal' bodies and experiences as juxtaposed against 'ill' or suffering or remissional (those who "were effectively well but could never be considered cured" (8)) bodies and experiences.

Bluntly stated, I see a central contradiction in Frank's reliance on the idea of the illness story as that which creates or reintroduces wholeness (or a sense of coherence) in an individual's life. The argument for a return to wholeness during or after illness simply reinforces the values and narrative framework of a biomedical discourse that Frank wishes expressly to complicate. Indeed, even the quest narrative, supposedly a critical revision of the limiting restitution narrative, seems predisposed to an understanding of illness experience as an overcoming of fragmentation and chaos in favour of a restoration of wholeness (synonymous here with 'health' or 'normalcy'). The idea of a coherent life narrative, itself, is absurd and Frank, himself, even points this out when he cites Mill's acknowledgment "that even for the healthy person, 'the narrative coherence of events and actions' is never 'simply a "given" for us. Rather it is a constant task, sometimes a *struggle*, and when it succeeds it is an achievement'" (60). I think this idea is central to the major problem with Frank's argument, that being his assumption that 'normal' (read: illness-free) life experience is narratively coherent as opposed to the 'chaos narrative' of illness. It relies on a romanticization of the healthy life, and,

simultaneously, what one might call a ‘pathologization’ of the narrative of the ill person.

Indeed, there is also a risk, in subjecting a healthcare seeker’s narrative to medical scrutiny, that the very diagnosis of a narrative as broken could in some sense medicalize or pathologize *any* “broken narrative,” regardless of its status as a nonmedical problem. Preliminary evidence of such a tendency can be seen in the edited collection *Health, Illness, and Culture: Broken Narratives*, by Lars-Christer Hydén and Jens Brockmeier, in which (even as suggested by the title), the fragmentation, brokenness, or incoherence of narratives in various life spheres, including clinical experiences, but also the trauma narratives of 9/11 witnesses (Brockmeier), parents’ narratives about lost infants (Frank), and break-up narratives (Hydén), are all framed within the overarching disciplinary focus of *illness* and narrative (Hydén and Brockmeier, “Introduction” 1). The collection exhibits a tendency to view the narrative break or rupture as problematic, abnormal, and even dangerous, a tendency that idealizes the conversely unproblematic, unbroken narrative.

In a chapter from the same collection, written by Lars-Christer Hydén and entitled “Broken and Vicarious Voices in Narratives,” the author asks the important question—one that is certainly not considered frequently enough in theories of narrative medicine that operate on the assumption of a normatively communicative healthcare seeker—“what happens in situations where the teller or author has some form of communicative disability leading to an inability to fulfill the roles of teller of the story, and narrator and character *in* the story? In short, what happens when we are unable to tell stories?” (38). While Hydén seems initially interested in critiquing normative assumptions about the act of narrative creation, most of his chapter revolves around how the “broken” authorial voice, which results from “diseases or injuries of

the central nervous system” or the psychological inability to “[maintain] memories, perceptions, and experiences,” becomes articulated through a “vicarious authorial voice” (40). The chapter discusses the breakdown in narrative ability as a symptom of disease or disability, such that Hydén terms those persons incapable of independently constructing an autobiographical story as “narratively disabled” (50). However, I would argue that in discussions of narratives of illness or disability within the field of medical humanities, narrative disability is presented as an outcome of *any* kind of biomedical complaint. And, indeed, in the collection I have referenced above, narrative disability is also produced as a condition of various nonmedical experiences and presented as a sign of abnormality or deviance. In both cases, as disability is always, in part, socially and culturally produced, narrative disability is constructed through social, cultural, and even medical expectations of narrative coherence that correspond to a normative understanding of communicative proficiency (including, perhaps, the way in which narratives within the clinical space are expected to take on the rather inaccessible and exclusive terminology and epistemological structures of biomedicine).

Through the disability studies lens employed above, we might see how the perception of illness narratives as broken ones, in some senses, authorizes the stigmatization of illness as a deviant experience, that is only amplified by the framing of the ill person’s *narrated experience* as inadequate or fractured. It seems, also, to obscure the role of the listener in constructing a coherent story; indeed, the absence of an empathetic, invested, intuitive, active, or accommodating listener (or social/ cultural space) actively disables the narrator and his or her narrative. In a productive way, Charon’s account depicts the doctor as, not just a medical expert, but also a perceptive humanist who hears a fragmented, chaotic story and works with the patient-teller to produce meaning. She explains, “We clinicians donate ourselves as meaning-making

vessels to the patient who tells of his or her situation; we act almost as ventriloquists to give voice to that which the patient emits. I put it that way because the patient cannot always tell, in logical or organized language, that which must be told. Instead, these messages come to us through the patient's words, silences, gestures, facial expressions, and bodily postures as well as physical findings, diagnostic images, and laboratory measurements, and it is our task to cohere these different and sometimes contradictory sources of information so as to create at least provisional meaning" (132). Here, Charon explains the unavoidable way in which a clinician exerts influence upon the clinical narrative that gets voiced and, separately, the one that gets heard. She also, however, perhaps unintentionally exposes the ways in which narratives attain coherence and validation within the clinical space—that is, through the discourse of biomedicine, a meticulous, specialized language of which the practitioner, and, typically, not the healthcare seeker, has attained professional mastery.

To return to the central thread of my argument, the expectations of narrative and body-self wholeness, congruent with liberal humanist values of autonomy, bodily integrity, and self-determination are central to the narrative that Frank and other medical humanists believe must be constructed around illness in order for the self to remain stable. In his analysis of the various ways of understanding sickness as a phenomenological experience, Brody points to the tendency to view illness as a break in our experience of self; "if sickness leads us to see our bodies as being something foreign, thwarting our wills by their intransigence and unmanageability, then sickness has . . . introduced a sense of split and disruption where formerly unity reigned" (27). This understanding views illness as "an ontological assault, affecting our very being and not simply our activities" (29). While he disagrees with this assessment, stating instead that this reflects, specifically, Eric Cassell's enumeration of *suffering* (which is not necessarily

coterminous with illness), this same perspective of illness as ontological assault is expressed elsewhere in the scholarship on narrative medicine, for example, by Engel, et al. in *Narrative in Health Care*. In their discussion of what they curiously term the “narrative features of the patient,” the authors explain,

the person seeking care from the health care practitioner often approaches this relationship with some degree of brokenness or vulnerability, and in search of healing. Characteristically, such an individual has experienced disruption of what Bruner describes as the *canonical* baseline state of affairs in her life, typically as a result of illness or injury. . . . [The patient] approaches the caregiver with hope for redress in order that the state of affairs in her life might be restored, and that the plot of her life story might be reconstituted. . . . In the search for healing, the patient seeks to return to wholeness and a normal life, so far as that is possible. . . . The disintegrating force of crisis or illness in one’s life must be addressed in ways that restore the integrity of one’s living, as well as one’s meaning. (94-5)

Engel et al. suggest here, and throughout their text, that the illness narrative is a primary source for understanding the person seeking care, but also a strategic locus for intervening in and repairing the disrupted integrity of the narrator’s body-self.

A similar perspective is put forth in a recent *Journal of Medical Humanities* article entitled “An Anatomy of Illness” by David Biro, a clinical professor of dermatology. Biro provides an account of illness as an individual and social experience, emphasizing the status of illness as a wholly negative process—something that alienates us from our bodies, selves, and society, as “a part of the body [becomes] abnormal and compromises the integrity of the whole” (44). Lamenting the separation of “the ill” from the rest of society, and the “silence that has for the most part been imposed on them by the

outside, healthy world and that has prevented doctors and caregivers and policy makers from fully understanding and responding to their needs,” Biro argues that both society at large and physicians, themselves, have a responsibility to engage more compassionately and with greater awareness to the needs of “the ill” (52). Specifically, this must involve practices of narrative medicine, starting with a realization that “. . . we can’t heal patients with surgery and chemotherapy alone. We must also repair their broken selves and broken connections to the world. Most patients need strategies to cope with the uncertainties of illness, to find hope in desperate situations, to bolster their vulnerable egos, to remake their self-narratives, and to alleviate their loneliness” (53). And yet, confoundingly, the majority of Biro’s essay perpetuates the very isolating, ostracizing, reductive language that he critiques as stigmatizing the experience of illness. The question I can’t help but ask when I read this and other generalizations about the capacity for illness to break all aspects of a once-healthy life is, How does a characterization of illness as an exceptional state in which, both an individual’s personhood and body become fractured (and, thus, become markers of deviance), in any way help to put forward a more nuanced, compassionate, and empowering image of illness experience?

Admittedly, on the surface, it seems slightly absurd to suggest that the wholeness of the suffering individual—a goal supported by the long legacy of liberal humanism that infuses our understanding of human wellness—is an unproductive goal for medicine to cling to. I certainly do not mean to suggest that respect for an individual’s sense of personal ‘normalcy,’ based on her life needs, expectations, and goals, as well as her apprehension of what it means to live the good life, is a misguided focus for medicine. I believe that medicine is inextricable from these social, cultural, and highly individual conditions and must necessarily answer to them. The problem, I

argue, is in constructing this type of care—care that sees the individual as not merely a medical object, but a complex assemblage of interacting entities and forces—through the language of wholeness. This value system is just one frame, and perhaps a reductive one, through which to conceptualize the human subject, and specifically the one experiencing illness.

Importantly, Charon takes pains in *Narrative Medicine* to develop an understanding of patients as those who, far from broken-down, “enter whole—with their bodies, lives, families, beliefs, values, histories, hopes for the future—into sickness and healing, and their efforts to get better or to help others get better cannot be fragmented away from the deepest parts of their lives. In parts, this wholeness is reflected in—if not produced by—the simple and complicated stories they tell to one another, whether in medical interviews, late-night emergency telephone calls, or the wordless rituals of the physical exam” (12). However, while Charon avoids the problematic insinuation that those with illnesses live fractured lives that reflect normatively-scripted instances of deviance, arguing instead that the integrity and selfhood of the individual persist in spite of illness, just as much as the aforementioned writers, she relies on the notion of a *de facto* originary wholeness—the very idea that introduces the trouble of ability / disability in the first place.

I am particularly concerned, here, with the tyrannical way in which wholeness—allegedly ruptured by a crisis that affects *first* bodily integrity and *then* the integrity of the self (psychic, social, etc.)—becomes the central goal of humanistic medicine, the frame through which biomedicine recasts personal illness narrative. Certainly, Frank, Charon, and other medical humanists are eager to admit that, in Charon’s words, “human beings do not become—or create—theirself in autonomous and deracinated acts of will but instead develop over time in concert with others. Postmodernism’s

fragmentation here gives way to a quilt-unity of virtual wholeness made up of disparate but interweavable pieces” (75). And yet, they are all equally eager to elevate the status of the ‘whole person’—a *virtual wholeness* that Charon acknowledges—to the primary concern of a more ethical medical practice. My central question revolves around the possibility that a humanized understanding of the healthcare seeker is, conversely, *threatened* by the notion of a whole person.

*Eve Ensler’s broken narrative*

In this section of the chapter, I am concerned with critiquing the attitude within medical practice that views storytelling in the clinical setting as an opportunity to assert control over, not just a medicalized body, but, now, a medically appropriated life narrative. This approach to understanding healthcare seekers’ experiences, one that emphasizes the binary framework of broken versus unbroken, ill versus healthy narratives, seems radically divorced from the ways in which individuals speak about, write about, and think narratively about their own journeys with illness. Eve Ensler’s memoir *In the Body of the World* beautifully illuminates the way in which her illness experience cannot be extricated from the rest of her life story any more than it can be told in a way that reflects the orderly, structured, coherent narrative that Frank believes individuals must create in order to make sense of illness or to restore past wholeness. The memoir consists of fifty-three chapters that Ensler calls “scans.” Some present single memories of cancer or childhood, others are merely lists, such as “Here’s What’s Gone” or “Chemo Day Five,” and still others describe individuals from Ensler’s cancer journey, or from her work as a women’s rights activist in the Congo. While the reader may discern a loosely linear story of her cancer journey, the memoir is far from a tidy, organized retelling of her diagnosis, treatment, and survival. Instead, Ensler suggests,



“This book is like a CAT scan—a roving examination—capturing images, experiences, ideas all of which began in my body. Scanning is somehow the only way I could tell this story. Being cut open, catheterized, chemofied, drugged, pricked, punctured, probed, and ported made a traditional narrative impossible. Once you are diagnosed with cancer, time changes. It both speeds up insanely and stops altogether. It all happened fast. Seven months. Impressions. Scenes. Light beams. Scans” (9). The disorderly and disjointed time of cancer cannot meaningfully be translated into a form that reconciles the experience with a coherent life narrative. Instead, Ensler struggles with the various frustrations, confusions, suppositions, and rationalizations that arise as she *attempts* to fit this fate into a grand, overarching narrative of her life. Her scan entitled “How’d I Get It?” helps to illuminate her search for an appropriate way to understand the seemingly senseless appearance of cancer in her body, cycling through her own worries and paranoia about past mistakes and regrets, as well as the cultural myths that so stubbornly cling to our understandings of cancer. The scan consists of a series of questions:

Was it tofu?

Was it failing at marriage twice?

Was it never having babies?

Was it having an abortion and a miscarriage?

Was it talking too much about vaginas?

Was it worry every day for fifty-seven years that I wasn’t good enough?

...

Was it the city?

Was it the line of two hundred women repeated in hundreds of small towns for many years after each performance, after each speech, women lined up to show me their scars, wounds, warrior tattoos?

Was it suburban lawn pesticides?

...

Was it my father dying slowly and never calling to say good-bye?

...

Was it bad reviews?

Or good reviews?

Was it being reviewed?

Was it sleeping with men who were married?

...

Was it Froot Loops?

...

Not being breast-fed?

Canned chop suey?

TV dinners?

...

Was it in my blood?

Was it already decided?

...

Was it that I didn't cry enough?

Or cried too much?

...

Was it not enough boundaries?

Was it too many walls? (54-7)

Throughout the rest of the text, Ensler tries on some of these various lenses for focusing the perspective of her illness narrative, failing ever to choose just one as she reflects on the physical process of her body's transformation through cancer, which is at the same time an emotionally volatile and transformative process. Each moment brings a new assemblage of reminiscences, changes, relationships, emotions, gifts, and challenges that combine to make Ensler's articulation of a narrative entirely different in each "scan"; in documenting her imbrication in these mutating webs, she reveals how there is no single way to tell her story, no single narrative trope through which to string together a series of discrete but interconnected events. To my mind, this is the major revelation of her book, a way of articulating the complexity of the individual life that finds itself contending with a cancer diagnosis, the life that becomes no less multifaceted, messy, and complex through the experience of cancer and its telling.

While Ensler's memoir is certainly written at least partially in the sense that Frank understands illness narrative, that is, as a way of making sense of her experience with cancer, her diagnosis does not enter the picture of her life as a narrative crack that disrupts the serene, stable wholeness of her life pre-diagnosis. Instead, she presents herself as one already divided, already traumatized, already scarred, already broken (as, indeed, we all are in some way). She is a survivor of childhood sexual abuse, but she still carries the guilt and shame of this trauma, a hungering for human connection that is never properly satisfied and the feeling of having been exiled from her own body (1). She has made a career traversing the globe in pursuit of other women's stories of abuse and suffering, a career that landed her in the midst of the Congolese civil war, wherein extreme violence—systematic rape and torture in the pursuit of minerals and wealth—continues to be waged on the bodies of women and children (4-5). Carrying

the burden of these stories of violence alongside her own, she understands the Congo as having thrown her “deep into the crisis of the world”—the end of the body, the end of humanity (7). At the same time, her cancer throws her into the crisis of her own body—a body from which she has been radically dissociated (7). As she, herself, writes, these two crises merge in her narrative because they are, indeed, inextricable from the way in which she has experienced her life and positioned herself in relation to the world around her. I would suggest that, while she does not set these two crises up as analogies for one another—her heady and complex treatment of both carefully highlights the particularities of each situation, such that a simple body-as-microcosm interpretation does little justice to her work—instead, Ensler’s narrative presupposes that these life experiences cannot be easily or, at all, disentangled.

If there is any overarching way in which Ensler articulates this narrative of her life experience during a time of cancer, it is simply to focus on that experience *as* “messy, evolving, surprising, [and] out-of-control” (89) in a way that, for once, allows her to see herself as belonging to, with, and in a messy and chaotic world. In many ways, the time during which Ensler ‘battles’ cancer (she, too, is skeptical of this problematic metaphor), is rich and fulfilling in ways that do not get discussed in the oftentimes reductive narratives that circulate in our mainstream cultural spaces. Interestingly, we see how, in a completely realistic and unromanticized way, Ensler is transformed by her experience with cancer, an experience that, she says, turns her for that time into all “body, body, body” (7):

There is something about the exhaustion of being poisoned, of your body fighting off the attack or just surviving the attack. There is something about being clutched, clenched, chemoed that is so deeply strenuous and catastrophic that it takes you to a mystical place where you are so deeply inside your body, inside the inside of the

cavern that is your body, so deep inside that you scrape the bottom of the world.

That is where I began this burning meditation on love. (162)

Against a backdrop of failed romantic relationships, and sexual abuse by her father, all of which formed for her a detached and sterile understanding of what love should be—“something you succeeded or failed at” (163)—Enslar sees a new “alchemic dance” happening around her: “It was MC cooking me soft-boiled eggs at 5:00 a.m. to calm my stomach, Amy who I hardly knew stopping by unexpectedly to rub my feet, Susan appearing in my hospital room, my son sleeping on my couch, Nico coming from Italy for an entire month and turning my loft into a summer ashram . . . ,” and so on; “this daily, subtle, simple gathering of kindnesses, stretched out across the chemo days and months was, in fact, love. Love. Why hadn’t I known this was love?” (164-5). Indeed, the love that Enslar begins to perceive, profoundly, all around her helps to position the experience of serious illness as very much within the realm of ‘normal’ human experience. While the caregivers and friends she honours in this passage have always been present, caring for her in various ways throughout her life, it is only through the apprehension of her own vulnerability and the membrane of care that she begins to see forming *through* the understanding of that vulnerability as a shared experience, that Enslar truly sees this phenomenon for what it is.

I am discussing Enslar’s narrative approach at length here because I believe that it productively complicates some of the assumptions that Frank, and others following his formulation of narrative medicine, have not adequately questioned. For one, Enslar’s experience with cancer—the during, not the after—not that mythical “return to wholeness” of the survivor—actually reconnects her with a body from which she has been dissociated due to a violent and gaping tear in the *social* fabric of her life, a tear that also disrupts her emotional life and hurls her down a path of self-destructive

behaviors including substance abuse, anorexia, and sexual promiscuity. This is the tear caused by repeated incestuous rape. Cancer, she says, brings her back to her body and to the meaning of real connection in her life.

Certainly, her memoir is about violence and trauma, as well. Much of Ensler's writing is dedicated to the exploration of holes—the physical ones that relate to her biological experience of cancer, such as the chemo port and the stoma, but also (and perhaps more urgently so) the holes that rupture “the social membrane” around her. The metaphor of the hole is best represented by a reality made clear to Ensler through her work in the Congo, that is the staggering incidence of rape-induced vaginal fistulae among Congolese women; she writes, “so many thousands of women have suffered fistulas from rape that the injury is considered a crime of combat” (42). Speaking about the perverse political and social circumstances that make this reality possible, Ensler goes on to meditate on the way in which “humans have become hole makers. Bullet holes and drilled holes, hurt holes, greed holes, rape holes. Holes in membranes that function to protect the surface or bodily organ. Holes in the ozone layer that prevent the sun's ultraviolet light from reaching the Earth's surface. . . . Holes, gaps in our memory from trauma. Holes that destroy the integrity, the possibility of wholeness, of fullness” (43). This meditation on holes, gaps, and ruptures offers forth an understanding of human experience in general, but also of the experience of illness, in particular, as belonging to a deep and tangled network of absences and excesses. To say that the diagnosis of disease, itself—in the case of cancer, the presence of pathologically dividing cells in the body—is sufficient to effect a traumatic rupture in a supposedly otherwise unmuddled life narrative is to overdetermine the varied ways in which the experience of illness might influence a life or its narrative expression.

## **A posthumanist intervention**

What strikes me as important in Charon's representation of healthcare professionals as "meaning-making vessels" is her understanding of wholeness as *produced by* the narratives we construct around our experiences. I would like to bring this idea to the forefront in order to disrupt the reified notion of human wholeness as that which must be cherished, respected, maintained, or reestablished through medical humanism and narrative medicine. While the implication in narrative medicine scholarship is that 'chaos' or fragmentation—arguably rather unavoidable human experiences—are introduced into individuals' lives through illness and that this experience is essentially 'dehumanizing,' I would like to present a different view. This view is less concerned with the overbearing agenda to contain deviance within a manageable framework than it is with exploring how the individual story/self resists the systematized control of medicine. Medicine cannot, at once, view the person as a fixed, stable entity whose care can be managed both biomedically and narratively, while simultaneously understanding the person as produced by a complex interaction of both internal and external factors that may be social, cultural, environmental, molecular, genetic, biological, chemical, psychological, technological, and that are subject to constant flux and reconfiguration. Indeed, to put it another way, medicine cannot possibly produce a "coherent, whole" narrative on behalf of a patient, any more than it can assert complete control over the complex interaction of actants that produce a somatic lesion (try as it might).

It would be a trite oversimplification to remark that medicine must simply accept that death and vulnerability—the ultimate outliers it wishes to control—are always finally beyond medical control. Indeed, the entire biomedical enterprise is constructed around overcoming the body, and its goals are overwhelmingly positive ones; the

healthcare professionals that carry out this enterprise act out of an all-consuming compassion for suffering persons (regardless of how that care ultimately gets delivered), oftentimes, to the detriment of their own personal mental health.

Inarguably, we can say that biomedicine will always reflect this goal of overcoming, that it will always view mortality as the ultimate weakness of the human, the ultimate call for intervention. Perhaps, though, medical care could stand to let go of that which it cannot possibly control—that is, the life narrative of the individual who appeals for care. As I am arguing, the current call of humane medicine to promote liberal humanist ideals like wholeness, integrity, and agency as key defining traits of the ‘fully human’ person, is concerned with controlling exactly that. The next part of this chapter argues that this mandate of humane medicine belongs to the tradition of liberal humanism and a continued understanding of the human as a self-contained system, whose social, cultural, interpersonal, psychological and other facets simply work toward the illumination of a predominantly biomedically understood human organism. In this chapter, my response to the call, by medical humanities, for the “intellectual co-engagement” of science and the humanities, therefore, centres on questioning the humanistic focus of the articulations of medical humanism I have elucidated thus far.

Returning to the 1977 statement made by the Committee on Humanizing Healthcare that defined its goal as promoting care that “[treats] patients as unique, whole, and autonomous persons,” we see an unequivocally liberal humanist conceptualization of the individual in the healthcare context (Mishler 436). The question that I will grapple with throughout the rest of this chapter (and in subsequent ones) asks: is humanization necessarily the answer to problems in the healthcare interaction identified above, or is there another avenue through which to understand the human as healthcare seeker? While medicine is evidently about the patient, while it places that



figure firmly at the centre of its regime, can we productively decenter this figure without reverting to the cold, calculating medicine of earlier times? To provoke this a step further, is it possible to think about health and the practice of medicine in a non-anthropocentric way?

Without getting too caught up in the inherent contradictions between the competing value systems of “humane medicine” and “posthumanism,” I would like to entertain the possibly far-fetched idea that we can, in fact, fruitfully decenter the human in the medical encounter. I cannot reasonably proceed, however, without placing all of my cards on the table, so to speak, and acknowledging the overarching contradiction in my project as a whole—that is, I have placed the question of the human at the centre of a project that seeks to disrupt that very tendency. In her study *Vibrant Matter: A Political Ecology of Things*, a project upon which my exploration in the rest of this chapter will partially focus, political theorist Jane Bennett offers full disclosure of the same problem inherent within her own philosophical analysis of vital materialism. For Bennett, this problem manifests itself through “the perfectly reasonable objection that the ‘posthumanist’ gestures of vital materialism entail a performative contradiction: ‘Is it not, after all, a self-conscious, language-wielding human who is articulating the philosophy of vibrant matter?’ It is not so easy to resist, deflect, or redirect this criticism” (120). Bennett points to an overwhelmingly powerful drive—whether by way of “the voice of reason or habit . . . to again grasp for that special something that makes *human* participation in assemblages radically *different*,” a grasping that one encounters again and again wherever the question of the human arises (121).

While the human-as-healthcare-seeker is where this project begins, my motivation in writing is to think beyond the self-enclosed, self-determining, autonomous, and monadic entity that liberal humanism has constructed for us, and

upon which medicine has traditionally based its practices. This is a posthumanist gesture, even if the very questions I engage make it impossible to abandon the centrality of the human entirely. This reorientation could open up, as other posthumanist theorists have suggested, some vastly more promising possibilities for beginning to understand how our world operates on the basis of what Bennett calls “agentic assemblages”; how our health as individuals extends far beyond *the individual*; how, to say that disease is biologically, socially, culturally, and medically constructed is to talk about only part of the story. The theorists I discuss in this section all take a horizontal view of the reciprocal relationships that form the world as we perceive it; rather than locating or fortifying boundaries that bolster our sense of humans as unique and therefore privileged, they seek out affinities and commonalities across species lines, even across the not-so-vast chasm between the living and non-living.

Examining the philosophical leanings of liberal humanism, against which posthumanist theory reacts, we find an arguably quite admirable value system, one which evolved from Enlightenment thinking that sought to affirm the dignity and worth of each individual. Understandably, then, the impetus to reaffirm liberal humanist interpretations of the person as healthcare seeker extends from an equally positive aspiration to promote compassionate and empathetic engagement within medicine. Problematically though, upon closer examination, we see that humanistic “aspirations are undercut,” as critical theorist Cary Wolfe notes, “by the philosophical and ethical frameworks used to conceptualize them” (xvi). Indeed, through the assertion of allegedly ‘universal’ human qualities such as rationality and self-determination, humanism sets out rather narrow expectations for human behaviour. The same thinking that idealizes completeness, holism, and autonomy also produces the very conceptualization that medical humanities says must be reimagined—that is,

what Wolfe identifies as the “fetishization of agency” and a view of the diseased body as something that can be taken apart and put back together (138).

As disability studies scholars note, this “liberal humanis[t] preoccupation with autonomy and agency as conditions of human status and civic participation” excludes from the category of ‘human’ any body that fails to meet these criteria (Wolfe 138).

While humanized healthcare and narrative medicine seek to reestablish body-self ‘wholeness,’ no bodies, selves, or psyches ever will be—or ever have been—‘whole,’ in this sense, whether due to amputation, paralysis, cognitive impairment, developmental disability, psychological disorder, or any other ‘abnormal’ state (Sobchack 22). In addition to these categories, we might add what Frank calls the “remission society,” an idea he introduces in his book *At the Will of the Body*, about his own experience with cancer. The remission society

describe[s] all those people who, like me, were effectively well but could never be considered cured. . . . Members of the remission society include those who have had almost any cancer, those living in cardiac recovery programs, diabetics, those whose allergies and environmental sensitivities require dietary and other self-monitoring, those with prostheses and mechanical body regulators, the chronically ill, the disabled, those ‘recovering’ from abuses and addictions, and for all these people, the families that share the worries and daily triumph of staying well. (8)

Frank’s point is that we certainly cannot assume indefinite health after recovery, particularly from serious illness; indeed, in the remission society, “the foreground and background of sickness and health constantly shade into each other” (9). Indeed, in some ways, the vulnerability of all of our bodies and the biological inevitabilities stored in our genes imply that each of us belongs to the society of “the undiagnosed.”

As disability studies scholars remind us, mortality and aging are common to every body; even for those in ‘perfect health’ who are lucky to live long enough, ‘abledness’ is only ever temporary. The operating assumption within biomedicine, however, is that the ‘normal,’ ‘healthy’ adult person is whole, whereas the child or adolescent is ‘still developing’ and the older adult contends with the ‘slow decline’ of aging. Implicitly, then, the person with an illness or disability enters the category of the troubled or incomplete body that characterizes these so-called peripheral groups, both of which many of us will inhabit at some point. This is not to perpetuate a normative understanding of lifespan or bodily experience, but simply to trouble what we take to be even the most ‘uncomplicated’ body (that normative ideal which exists only in statistical form). As I will explain shortly, posthumanism provides the requisite framework to assert these important claims that no body—whether ‘normal’ or ‘abnormal’—can or should be labeled ‘whole.’

Following from these contradictions, I argue that the antithesis of this so-called ‘whole person’ model—that is, an atomistic view of the human—does not necessarily preclude or undermine the positive goals of medical humanities, particularly if it focuses on the shared vulnerability that is engendered through the very condition of incompleteness or fragmentation. This is not to say that the patient *should* be viewed, in the words of Kidd and Connor, as “no more than a collection of organs and systems” (46); indeed, as many scholars before me have noted, this narrow biomedical view of human functioning is far from productive. Instead, posthumanist theory can allow for the construction of a more nuanced model of the human being within medicine that deprioritizes goals of normative compliance and instead imagines the body as *never* complete in and of itself.

*What is posthumanism?*

To narrow in, briefly, on this potentiality, we must first and foremost ask the very question posed in the title of Wolfe's text *What is Posthumanism?* (2010).

Acknowledging that posthumanism continues to be a highly contested term, Wolfe distinguishes between the terms *posthuman* and *posthumanist*. The posthuman can be defined as that which comes *after* human embodiment has been transcended and the "ideals of human perfectibility, rationality, and agency inherited from Renaissance humanism and the Enlightenment" have been taken to their utmost extreme (xiii). This is not the line of thinking that Wolfe wishes to develop, nor is it, in my articulation, a responsible model on which to base medical research and patient care. Instead, Wolfe formulates a notion of posthumanist theory as a *critique* of humanism, particularly its "fantasies of disembodiment and autonomy" (xvi). For the purposes of this paper, posthumanism signifies: 1) "a historical moment in which the decentering of the human by its imbrication in technical, medical, informatic, and economic networks is increasingly impossible to ignore" (xvi); and 2) an acknowledgment and acceptance of human materiality, embodiment, and mortality from which liberal humanism has striven to escape.

Wolfe insists that to be truly posthumanist, posthumanist thinking must deconstruct itself in order to avoid reinscribing the hegemonic discourse and practices it rejects. However, I will focus here on what Wolfe's thinking means, specifically, for medicine's conception of the human. In contrast to the institutional imperatives of technocratic medicine that reinforce binaries and highlight the uniqueness of the diseased body as individuated through medical need, Wolfe's posthumanism seeks to topple binary oppositions between nature and culture in order to reveal our inextricable and "constitutive prostheticity" (xxvi). This theoretical turn asks us to recontextualize

the human in terms of how our entire sensorium is necessarily dependent upon and coextensive with our technical and social environments. According to philosopher Bernard Stiegler, our bodies and minds have evolved alongside our technical implements in a process of epiphylogenesis in a way that makes us *always already* decentered beings (175).

Semantics notwithstanding, at first glance, the ‘humanization’ movement within healthcare is entirely compatible with the posthumanist perspective in the sense that it, too, rejects the Cartesian mind-body split perpetuated by the medical model. The contradiction in terms within the discourse on medical humanities has emerged, however, through writers’, scholars’, medical doctors’, and other commentators’ demonstrable fixation on reorienting medical practice to focus on the ‘whole person’; indeed, endorsing the wholeness and autonomy of the body-self while, at the same time, attempting to assert the interconnectedness of our bodies and our environments is both problematic and counterproductive.

As Wolfe reminds us, the whole, autonomous human has never existed, despite the best efforts of liberal humanism to reject our vulnerability and other more ‘animalistic’ qualities. Working within the field of animal studies, Wolfe’s posthumanism affirms these qualities, largely by pointing to the human being’s ‘radically ahuman technicity,’ expressed through the co-constitutive nature of our psychic and social systems. This co-constitution is most evident through “our subjection to a technicity of a language that is always on the scene before we are, as a precondition of our subjectivity” (Wolfe 89). Both our dependency on that which is ‘external,’ language, for one, along with our inescapable mortality are, together, what Wolfe, through Jacques Derrida, calls our “double finitude” (88). Central to Wolfe’s

posthumanism, this double finitude is the shared condition that unites humans with other forms of life.

Within the medical sphere, both of these facets of human finitude are adamantly contested through what Jeffrey Bishop calls “a dream as old as humanity itself—to defer death” (17). To this I would add medicine’s equally powerful dream to deny the inescapable co-dependency and vulnerability that bring that mortality into awareness. Whether or not medicine can practically conceive of the paradoxes of death—for one, that the threat of loss also creates value, meaning, and connection—there is certainly much to be gained by practitioners in adopting a posthumanist perspective that destabilizes the foundations of hegemonic power structures (Bishop 3). “In the wake of this ‘after’ [of the posthumanist],” Wolfe suggests, “new lines of empathy, affinity, and respect between different forms of life, both human and nonhuman, may be realized in ways not accountable, either philosophically or ethically, by the basic coordinates of liberal humanism” (127-28). This perspective is central to conversations in animal studies, disability studies, and, to my mind, medical humanities—all areas in which hegemonic discourses of normalcy and difference result in the marginalization of particular experiences and voices. For the medical field, especially, the opening up of “new lines of empathy, affinity, and respect” is particularly pertinent, considering expressed criticism within the literature over a perceived lack of empathy in healthcare practitioners’ encounters with patients (Warmington 328).

### *Vulnerable bodies and agentic assemblages*

Interrogating many of the same questions regarding ‘humanity’ as an exclusive category constructed through the devaluation of that which we deem ‘nonhuman,’ in her book *Precarious Life*, Judith Butler seeks to identify the conditions that make a death

grievable, as well as the implications of such value judgments that place certain deaths in the category of “ungrievable.” In her compelling exploration of violence and mourning in the context of Western, and specifically American, anti-terrorist aggression, Butler assesses reactions to experiences of loss, specifically those produced by the World Trade Centre attacks in 2001. At the heart of her inquiry is a desire to question what other reactions are possible to the traumatic apprehension of vulnerability, aside from retributive military violence. Butler’s argument elucidates how, in the wake of 9/11, various factors, including imbalanced reporting, the “raw public mockery of the peace movement,” “the characterization of anti-war demonstrations as anachronistic or nostalgic,” and the ambiguous and egregiously non-self-referential use of the term ‘terrorist’ in public and political discourse, all worked to reinforce the message that “there is no excuse for September 11”—in other words, that there was no way in which the framework of American foreign policy may have created the global conditions of possibility for acts of terror such as this one (3-4). In this context, violent military responses were justified on the basis of fear and loss, with no critical attention paid to the status of that response, which “destroyed life and decimated peoples,” as, itself, an act of terrorism on the part of the US (6). Indeed, “the erasure from public representations of the names, images, and narratives of those the US has killed” establishes a “differential allocation of grievability that . . . operates to produce and maintain certain exclusionary conceptions of who is normatively human: what counts as a livable life and a grievable death?” (xiv-xv).

In this argument, Butler posits, rather controversially, that the so-called terrorist attacks of 9/11 provoke a “dislocation from First World privilege [that], however temporary, offers a chance to start to imagine a world in which that violence might be minimized, in which an inevitable interdependency becomes acknowledged as the basis



for global political community” (xii-iii). While my research here explores a different context for heteronomous relationships than does Butler’s, I believe the common ground between our work lies in the decentering of the first-person experience in favour of a broader view that understands our inescapable imbrication in various other lives.

In the subjective experience of bodily illness, the medical reaction is to shore up one’s defenses, so to speak, and, using a similar language of battle, deploy all potential resources toward the denial of vulnerability and the assertion of various liberal humanist values: self-control, agency, autonomy, self-determination, individuality, independence. Interestingly enough, the assertion of these values can be taken to such an extreme that—to return to Ensler’s discussion with her oncologist—the very “me” at the heart of the quest to protect or save is forgotten. When Ensler is forced to decide whether or not to subject her body to radiation when “it could destroy my intestines and make it impossible for me to eat or poop again,” a detached, unsympathetic doctor, in what the reader can only interpret as a feeble and ineffectual attempt to respect her autonomy as a decision-maker, merely gives her the hard data upon which to make a decision (71). In his response, “WE LIKE TO THROW EVERYTHING AT IT. That’s all we know how to do,” the body is understood as an object of medicine and the militant desire to eradicate the body of disease in order to restore prior integrity or wholeness may actually result in permanent disability (71). At the same time that medicine, itself, is hurting the body in the process of trying to heal it, the personal narrative of illness, as I have been discussing, is directed toward a therapeutic goal of restoring wholeness.

Thus, my work here, like Butler’s and Wolfe’s, is interested in a critical stance that “attend[s] to [the] frame” (Butler 5). The following long quote from Butler nicely

articulates the importance of examining the conditions of possibility that produce a particular understanding of the human and of human action:

The point I would like to underscore here is that a frame for understanding violence emerges in tandem with the experience, and that the frame works both to preclude certain kinds of questions, certain kinds of historical inquiries, and to function as a moral justification for retaliation. It seems crucial to attend to this frame, since it decides, in a forceful way, *what we can hear*, whether a view will be taken as explanation or as exoneration, whether we can hear the difference, and abide by it. (4-5)

Likewise, a frame for understanding illness and disability emerges through the language of a dominant medical discourse that precludes particular alternative narratives for conceptualizing the human in that context. "Attend[ing] to this frame" is central to "*what we can hear*" and what we can say about the experience of illness. And, in large part, this frame, as in the military context, considers vulnerability intolerable; rather than understanding it as an inescapably human experience that opens up a realm of possibility based on interdependence, medicine reads vulnerability, and its co-conspirators grief and fear, as that which we must guard against.

We can think about grief and mourning in the context of losing another to whom one is attached, as in Butler's exposition, but we can also think about it in the context of illness, of grieving or mourning a change or a perceived loss within oneself. When we become "dispossessed," as Butler puts it, from a particular place, community, or in the context of illness, from our own bodies, "we may simply feel that we are undergoing something temporary, that mourning will be over and some restoration of prior order will be achieved. But maybe when we undergo what we do, something about who we are is revealed, something that delineates the ties we have to others, that shows us that

these ties constitute what we are, ties or bonds that compose us" (22). Here, Butler is speaking about a condition that is not specific to the experience of vulnerability, itself, but that vulnerability makes clear to us because it illuminates "the ties" that at least partially construct who we are, ties that are nicely articulated in Ensler's meditations on love during her cancer journey. The tie is that which is "neither exclusively me nor you, but the way by which those terms are differentiated" (Butler 22). Butler explains,

What grief displays, in contrast, is the thrall in which our relations with others hold us, in ways that we cannot always recount or explain, in ways that often interrupt the self-conscious account of ourselves we might try to provide, in ways that challenge the very notion of ourselves as autonomous and in control. . . . I tell a story about the relations I choose, only to expose, somewhere along the way, the way I am gripped and undone by these very relations. My narrative falters, as it must. Let's face it. We're undone by each other. And if we're not, we're missing something. (23)

While Butler is largely concerned here with the notion of grief or mourning as instigated by a traumatic change in our relationships with others, I think that a similar emotional experience arises as a result of diagnosis. Particularly in the case of terminal or degenerative illnesses, diagnosis is described by many writers as an occasion for mourning, specifically mourning future losses and their inevitability. What Butler's account contributes, for the purposes of my exploration here, is the importance of vulnerability to a more nuanced understanding of the norms against which we judge the subject position of the healthcare seeker. While the loss and grief attached to illness may thrust our vulnerability and interdependence into stark view, this perspective merely illuminates a shared condition that transcends the medical binaries of healthy and sick.

What's more, the act of perpetuating a false ideal of normative wholeness and subjective integrity against the alleged disorder, disintegration, and vulnerability of illness simply widens the already-artificial gap between health and illness, in effect dehumanizing those whom we label 'broken-down'-bodies-become-'broken-down'-selves. Perversely, then, as Butler describes in the context of our self-definition against those we label morally and ethically different from us, the sick, too become casualties of a system in which "dehumanization becomes the condition for the production of the human" (91). Inasmuch as health, normatively understood, defines itself against illness, the affirming ideal of the wholeness and integrity of the well body produces the perceived fractured or disrupted wholeness of the sick body. To continue to emphasize the value of this illusory ideal within medical humanities is simply to perpetuate the dehumanization made possible by nineteenth- and twentieth-century medical practices, against which medical humanism has defined its mandate.

What Butler's argument fails to broach, a point which is also articulated by Wolfe in *Before the Law*, is the idea of shared vulnerability as an occasion for establishing affinities between human and nonhuman animals (Wolfe 18-20), and if we are to add Jane Bennett to this mix, between humans, animals, and non-living entities. Similar to Wolfe's conception of the externalized self, political theorist Jane Bennett's vital materialism sees the human actor as inextricably linked to his or her environment, and thereby both dependent upon and vulnerable to outside forces and processes. In her text *Vibrant Matter* (2010), Bennett expounds a theory of "thing-power," which—rather than viewing agency as a definitively human quality—seeks to understand matter, itself, as invested with agency—that is, with the qualities of "efficacy, trajectory, [and] causality" (31).

In the introduction to her text, Bennett writes, “instead of focusing on collectives conceived primarily as conglomerates of *human* designs and practices (‘discourse’), I will highlight the active role of *nonhuman* materials in public life. In short, I will try to give voice to a thing-power” (1-2). She goes on to propose her political purpose in articulating a theory of distributed agency, which despite presenting a decentering view of the human, nonetheless reveals how such a perspective might actually work in favour of human flourishing, rather than, as some have argued, jeopardizing our well-being by compromising our primacy in a hierarchy of life. Bennett explains:

Vital materialism would thus set up a kind of safety net for those humans who are now, in a world where Kantian morality is the standard, routinely made to suffer because they do not conform to a particular (Euro-American, bourgeois, theocentric, or other) model of personhood. The ethical aim becomes to distribute value more generously, to bodies as such. Such a newfound attentiveness to matter and its powers will not solve the problem of human exploitation or oppression, but it can inspire a greater sense of the extent to which all bodies are kin in the sense of inextricably enmeshed in a dense network of relations. And in a knotted world of vibrant matter, to harm one section of the web may very well be to harm oneself. Such an enlightened or expanded notion of self-interest is *good for humans*. (13)

In her argument, Bennett is speaking about political agency and, more specifically, about how we can understand global events as being engendered by dynamic processes rather than individual human actors. In an attempt to diminish the cultural power of the ‘blame game’—of “a moralized politics of good and evil, of singular agents who must be made to pay for their sins (be they bin Laden, Saddam Hussein, or Bush) . . .

[that] legitimates vengeance and elevates violence to the tool of first resort” (38)—she locates the source of “political responsibility [in] a human-nonhuman assemblage” (36).

Bennett seems to reinforce the argument that Wolfe advances for the originary prostheticity of the human in her assertion that “there was never a time when human agency was anything other than an interfolding network of humanity and nonhumanity” (31). Rather, human agency is only ever articulated in and through ‘agentic assemblages’—that is, “ad hoc groupings of diverse elements, of vibrant materials of all sorts,” each of which has its own vital force different from the agency proper to the grouping itself, but none of which autocratically governs the trajectory of the confederation (24). Bennett puts forward the Chinese concept of *shi* to describe the nature or ‘vibe’ of a potentiality that arises as a result of a particular spatio-temporal configuration. *Shi* denotes the “style, energy, propensity, trajectory, or élan inherent to a specific arrangement of things. . . . [For example,] a good general must be able to read and then ride the *shi* of a configuration of moods, winds, historical trends, and armaments” (35).

As I interpret Bennett’s argument in *Vibrant Matter*, it won’t do to say that there exists for any entity, force, or assemblage an absolute whole, composed of a combination of its discrete parts. It is equally impossible in her theory of vital materialism to posit that the whole always exists, even if its boundaries are constantly changing. The assemblage, according to Bennett, is “an indivisible continuum of becomings whose protean elements are not only exquisitely imbricated *in* a flowing environment but also *are* that very flow” (92). Therefore, each element or part of the assemblage is constantly opening out to other elements and none can act independently of the various confederations into which it forms. The creative activity within each member-actant is what characterizes the collectivity as what Bennett calls an “open

whole” (35). I take this to mean that because agency is distributed and therefore only realized through an opening out of any particular actant to the possibilities of action, then neither the collectivity nor the singular member is ever, in itself, whole. In the case of the human, then, the very idea of discrete, clearly defined boundaries is inimical to what it means to have a body-self whose agency is enacted through multiple, morphing assemblages.

Returning to Ensler’s *In the Body of the World*, we see oscillating perspectives that embed the various manifestations and understandings of illness within the vast, complicated assemblages of the contemporary world. Her rendering of her intra-abdominal abscess caused by post-surgical infection bleeds into her description of the Gulf oil spill, such that we begin to see resonances between the two simultaneously occurring incidents. Ensler writes:

At Sloan-Kettering they show it to me on the CAT scan screen: a huge pool of blackness in the center of me—the same day as the Gulf oil spill, the now poisoned Gulf of Mexico somehow inside me. Sixteen ounces of pus. Two point five two million gallons of oil a day. An intra-abdominal abscess. Contamination from postsurgery, postexplosion leaking, the spread of infection to the bloodstream to the ocean. My body is rupturing, shit leaking from where they closed it up, gushing out of me from every orifice, leaking and spilling, purging—same moment, same day BP exploding rising up, gushing out of me from every orifice. . . Symptoms may include abdominal pain, chills, diarrhea, oil penetration destroying the plumage of birds, making them less able to float in the water, less able to escape when being attacked, preening leads to kidney damage, altered liver function, ruptured digestive tracts, lack of appetite, nausea, dolphins spurting oil through their blow holes, rectal tenderness and fullness, seal fur

reduced in its insulation abilities, leading to hypothermia, vomiting, weakness.  
(68-9)

This description can be seen as a way of disrupting our traditional routes to understanding both traumatic personal events and devastating global catastrophes. While the tendency that Bennett highlights in *Vibrant Matter* is to point the finger at “singular agents who must be made to pay for their sins”—in Ensler’s example, BP—the author’s scan in this part of her book, as in others, is, I believe, a political act that draws the individual into the realm of the global, molecular, environmental, economic, and political through the parallel imagery of contamination and infection. In many ways, Ensler wishes to highlight how collectivities of forces that imbricate various actants, including “rapacious greed, the hunger for more and more, the tiny percentage of those who have everything, and the majority of those who have nothing[,] . . . corporations, industrial destroyers, rapists, corrupt leaders, and the arrogant and disinterested rich” (211), as well as the chemicals in our foods and cities, our good or bad intentions, the information in our genes, the microbes in our stomachs, the medical technologies that fuse with our bodies, and a vast multitude of other forces come together variously at different times to produce the conditions of both the individual body and the natural world. While she is strongly interested in targeting human responsibility for the declining health of the planet and its human population, for atrocities like the sexual abuse of thousands of women in the Democratic Republic of the Congo, her descriptions consistently invoke a cosmic view.

While vital materialism gives us an alternate set of terms for apprehending what healthcare has begun to understand as the biopsychosociospiritual approach to healing, I think that in the context of medicine, the notion of vital materialism is especially beneficial because it unseats notions of the ‘normal’ or ‘complete’ human body that



underpin the contemporary medical mindset. As Bennett notes, “vital materiality better captures an ‘alien’ quality of our own flesh, and in so doing reminds humans of the very *radical* character of the (fractious) kinship between the human and the nonhuman” (112). This conceptualization of the human allows us to do away with myths of absolute wholeness, agency, and autonomy that actually work to marginalize the experiences of those with illnesses and to medicalize such deeply personal, often organic, and sometimes subconscious behaviours as the formation of a life narrative.

This perspective is important to understanding the human in the context of illness and healthcare because it is interested in asserting the complexity of human embodiment and, as a result, I would suggest, the stubborn resistance of human experience to full expression or containment within the normative narrative tropes of a given society or culture. As Ensler says, “we make up stories to protect ourselves. I am not a cancer person. I am not someone who would die in a car crash” (158). However, the vulnerability of human life hurtles into view to remind us: “there are no rules or reliable stories. There is suffering. It is ordinary. It happens every day. More of it seems to happen the older you get, or maybe your vision for it just expands. It is as unavoidable as your ordinariness, your baldness, your [colostomy] bag” (Ensler 159).

### *Disability studies, wholeness, and prosthesis*

In my analysis above, the undercurrent of prosthesis—as both metaphor and materiality—must be acknowledged, particularly in order to bring important disability studies perspectives into the conversation. In particular, I want to emphasize the way in which the concept of prosthesis has been employed figuratively in critical theory as a way of thinking about connections between the body and technology, including Marshall McLuhan’s notions of media as extensions of the body, Donna Haraway’s

depiction of the cyborg, Bernard Stiegler's ideas of the originary technicity of the body, and so on. In her introduction to the edited collection *Artificial Parts, Practical Lives*, Katherine Ott observes this trend, noting that "many scholars use the term 'prosthesis' regularly, and often reductively, as a synonym for a common form of body-machine interface. . . . Such assertions, while intellectually provocative and culturally insightful, hardly begin to comprehend the complex historical and social origins of prosthetics. Cyborg theorists who use the term 'prosthesis' to describe cars and tennis rackets rarely consider the rehabilitative dimension of prosthetics, or the amputees who use them" (3). Ott, along with the authors of the essays that compose the anthology, situate the history, design, use, and evolution of various kinds of prosthetics within the space of their material reality.

While I agree that, as Ott notes, it is vital to ground discussions of bodily experience in the materiality of the body—to "[keep] prostheses attached to people" (4)—there is also an important critical valence to the concept of prosthesis. This crucial point is well elucidated by Jay Dolmage in his book *Disability Rhetoric* when he notes that the effect of post-Enlightenment medical science has been to extend disability "beyond actual impaired bodies to become an operative and essential element driving subject-object dualism—any body subjected to the medical gaze becomes disabled to some extent, through its positioning as passive object, and through the oversignification of bodily deviation" (28). As Ott, as well as David Serlin, Vivian Sobchack, and David Wills, elucidate, the materiality of prosthesis, designed as a physical appendage or device to compensate for a perceived bodily lack, is central to understanding how the disabled body has been constructed over time. However, the metaphorical and rhetorical meanings of prosthesis are also significant.

Dolmage notes in his exploration of rhetorical history and the contemporary uptake of classical rhetorical teachings that bodily norms are present even in the ways that we talk about rhetoric—what it is and is not, or who can speak, write, and learn. Rhetorical history enforces normativity by asking us “to ignore our embodied selves and constrain our expressions of subjectivity” (92); the rhetorical theory we practice and teach restricts the ways in which we can communicate, limiting our available means of persuasion. In exploring the ways in which rhetoric, itself, can be “enabled by its prostheses, by the incoherence of its histories and the awkwardness of its positions” (92), Dolmage asserts that rhetoric must affirm, not just the body, but specifically the disabled body. In his argument,

disability is a material state and identity, as well as a vital critical modality. This is not to say that we are all disabled, but instead to emphasize that no one is normal. . . . [and to advocate] for the view that the body’s partiality and completeness can be claimed as essential and generative. This is not to say that we are all disabled, or that rhetoric is disabled, but to embrace a nonnormative discourse/ materiality, modestly proposing that such signifiers be tabled, not as the inverse of a privileged wholeness in a normative matrix, but rather as a valorization of alternative fleshing out and potential resignification, a shift of meaning and value that might also mitigate the oppression of bodies with disabilities. (91-2)

In acknowledging that disability and prosthesis are both materiality and critical modality, Dolmage highlights disability as both a state of embodiment, as well as a conceptual lens through which to understand the way in which the normal body is a fictional and/or rhetorical construct.

As disability rights activists advocate, the unique subject position of disability identity is vital to political activism and social change, such that universalizing the experience of disability is not productive. Furthermore, denying the materiality of disability by challenging that all disability is socially constructed can, contradictorily, misrepresent or marginalize the lived realities of bodily difference. As Dolmage notes, and as I reassert here, a cultural turn in disability studies—not unlike postmodern analyses of disability—can maintain the materiality of disability, while at the same time “[trouble] the origins and sedimentations of this materiality” (100). In particular, the cultural turn is not just an alternative to other models—the medical, social, or postmodern—but one that both incorporates and critiques these perspectives by studying the central role of language as both constructing and constructed by bodies (100-1).

Disability studies researcher Margrit Shildrick also pushes for new approaches to disability studies, looking to recent developments in feminist theory involving the uptake of Maurice Merleau-Ponty, Jacques Derrida, and Gilles Deleuze. She suggests that the contributions of these “philosophers of difference . . . [push] the problematic far beyond conventional meanings of the human and [open] up a celebratory positioning of difference and transcorporeality as the very conditions of life” (14). Shildrick notes that critical disability studies can benefit from a move toward the idea of the assemblage, iterated in my reading above by both Butler and Bennett, that productively troubles all distinctions, “[throwing] into doubt the very sense of self and other as distinct entities” (14) and “[enhancing] our understanding of a fundamental hybridity that speaks to the coming together of bodies in difference that are never comfortably subsumed into a new unified whole” (16). Importantly, Shildrick suggests that there is no reason why one body should be any more absorbed within “the manifold interconnections and

transformatory entanglements. . . that mark all forms of embodiment” than any other body (16). Prostheses, she notes, are important signifiers, since they disrupt our illusion of the whole body, even as they attempt to reconstitute it (16). Usefully, she goes on to explain,

The significance of prostheses is far in excess, then, of either therapeutic or rehabilitative intentions, and prostheses should not be read as solely material additions to the body. On the one hand functioning as utilitarian material artifacts, on the other, prostheses are rich in semiotic meaning and mark the site where the disordering ambiguity, and potential transgressions, of the interplay between the human, animal, and machine cannot be occluded. (17)

I bring these disability studies voices into the conversation to acknowledge that, in order to dismantle humanist expectations of bodily wholeness or integrity, the notion of prosthesis is central. Cultural readings of disability by both Dolmage and Shildrick appreciate, not just the incompleteness of every body, but also the way in which the disablist lens we use to marginalize the experience of bodily difference is, in fact, counterproductive—or, rather, a dismissal of the potential of the disabled body to generate meaning. Instead, a fixation on wholeness sees disabled, or sick, bodies as only “surfaces reflecting the meanings of others” (Dolmage 95). Medical humanities would do well to acknowledge, just as feminist theory and critical disability studies have, that “a human body is not a discrete entity ending at the skin” (Shildrick 24). As Shildrick goes on to say, once we accept “that material technologies constantly disorder our boundaries, either through prosthetic extensions or through the internalization of mechanical parts, it is difficult to maintain that those whose bodies fail to conform to normative standards are less whole or complete than others” (24).

## **Conclusion: the posthumanist patient**

To say that the person—composed of body and self, corporeal and psychic, physical and cultural, social and environmental, personal and public—is never whole is not to say that there does not exist, for the individual, a ‘normal’ or habitual experience of the body. In the day-in, day-out embodied experience of the world, one comes to expect certain things from one’s body, to know its challenges and its desires, to maintain a certain status quo. Having eaten as a vegetarian for the past fifteen years, I can expect that my stomach is unfamiliar with processing the organic compounds of ground beef, that without the proper enzymes, digesting a hamburger is going to be a rather trying feat. But that is not to say that the composition of proteins in my stomach would not change were I to reintroduce such a food to my regular diet.

This is an overly simplified way of saying that, even at a very basic biochemical level, my state of embodiment is not a fixed or even a stable one. For one, the body is a permeable space, subject to the living organisms that surround it, that pass in and out; subject to the non-living entities of its environments: the pollutants, the pesticides, the chemicals, the pharmaceuticals. In addition, when considered over the span of a lifetime, however long or short that may be, my body can never be said to be “the same” at any two points along that trajectory. Indeed, we would be wise to reconceptualize our understanding of healthy or able bodies, as disability studies scholars and activists since the 1980s have, as temporarily healthy or able bodies (Shapiro 34).<sup>6</sup>

All of this to say that the act of ‘returning’ a person to wholeness, taken to be an ethical obligation of the healthcare practitioner within medical humanities, is simply the

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<sup>6</sup> Similarly, Deborah Marks uses the term “contingently able bodied” to describe the body’s ongoing vulnerability to impairment (18).

act of reframing or reformulating an individual's expectations of the body within the context of her social, cultural, and spiritual life—something which we do on an ongoing basis because the corporeal part of us is not—and never has been—constant. Illnesses or disabilities developed over the course of a life thrust this fact, this morphability of the body, into stark view. While each experience is unique, and of course qualitatively different, the idea of a previously whole body *before* disability or illness, or one that I must return to *after*, is illusory; indeed, this conception of a whole body-self seems continually to be reified in discussions of narrative medicine's role in healthcare. In addition to masking a biological reality of the physical body, this mentality also obscures the ways in which our personal, social, cultural, and narrative frames for understanding and living with and in the body are, likewise, unstable, evolving, contestable, negotiable, and non-totalizing.

Fragmentation is the only constant. So why do we insist on wholeness as an explanatory, therapeutic, or meaning-making narrative? It would appear that narrative medicine attempts to formalize a natural process whereby individuals make sense of their life experiences, but through the mediation of a health professional's guidance and expertise. In attempting to enrich medical practice through the application of narrative theory and analysis, narrative medicine oftentimes overshoots the mark to suggest that doctors are responsible for more than just the medical well-being of the patient, but should also come to understand the way in which this illness fits into the patient's life, including their relationships, career, leisure, spirituality, and so on, to the extent that all of these things enter into the service of explaining and understanding a biomedical process. In some ways, it seems that this movement reflects a neoliberal impetus, with its imperatives of self-management, personal responsibility, and consumer power, in demanding that we 'make use' of the experience of illness—that we fit it in to a grand

life narrative, in which the lessons learned make us better, stronger, more capable, and more productive people.

In a neoliberalist paradigm, the judgment attached to an individual's inability to maintain a 'healthy' body or to the individual actions that contribute to illness or to the 'poor choices' people make in the face of illness is connected to an understanding of health as the individual responsibility of an autonomous agent. Unfortunately, some practices within narrative medicine seem inflected with this approach; there is an element of judgment and alienation that enters into the discourse of narrative repair and the creation of narrative wholeness, since both concepts work to produce the idea of a deficit in an individual's personal attempts at meaning-making. In assuming that the life narrative, too, is broken, narrative medicine runs the risk of making this deeply embedded and complex process into another biomedical category to be scrutinized and healed.

In reaction to over-simplified, economically-motivated attributions of personal blame, Wolfe, Butler, and Bennett, along with Dolmage and Shildrick, can be seen, each in different ways, to illuminate how our lives and our agencies are dispersed across and through other lives—even across non-living matter—to argue that the vulnerability we have attempted to reject is in fact a shared condition of life (and non-living matter). This shared vulnerability introduces an element of chaos; it means that control is not ours alone; it frees us, in some ways, from the shackles of agency and autonomy, and in that way it is, perhaps, the enemy of the neoliberal agenda.

At the level of the healthcare seeker and her story, an attunement to the inevitably fragmented nature of human life could free the illness self-narrative from its instrumentalization in a 'healing process.' Instead, narrative might reflect the complex ways in which illness enters into a life, as in the example of Ensler's memoir *In the Body*



*of the World*. I think the importance of entertaining this complexity, of resisting the urge to fit all of the pieces of the story—a stand-in for all of the pieces of the patient—back together into a whole cannot be understated. Indeed this approach can be nothing other than reductive. There are many different illness narratives to be told, and many of these will not be about clinging to an illusory notion of wholeness. The most profound example for me, comes from the experiences of those with Alzheimer’s disease who see this process as producing, for them, a “new self” or a new identity whose freedom becomes limited or encroached upon by others who would have them fit a previous mold—expecting them to fulfill a perceived prior wholeness, based on former abilities, occupation, interests, and memories. I continue this discussion of the Alzheimer’s self-narrative in chapter five.

In addressing the problematic rhetoric of patient holism and autonomy central to many definitions of medical humanities, I have also attempted to open up new avenues for understanding the roles of healthcare practitioners and seekers. I have not sought to reject the laudable impetus of medical humanism toward promoting a higher degree of decision-making autonomy and freedom from paternalism for patients, which I agree should strongly guide the contemporary practitioner-patient relationship. However, as I have argued, the healthcare practitioner’s role should be, *not* to understand or maintain the patient’s wholeness or completeness, but to accept the philosophical implications of the human as always already incomplete, externalized, fragmentary, and coextensive with his or her environment. Disease does not mark a rupture in an individual’s wholeness and integrity; the vulnerability and ‘rupture’ are present, in each of us—patient and practitioner, alike—from the start.

Using the posthumanist theoretical foundation elucidated above as a springboard, my next chapter will examine how humanistic conceptualizations of

patienthood are being both reproduced *and* resisted in contemporary new media spaces. Increasingly, both health-related, but also generic, social media outlets are the primary spaces where individuals construct narratives about and thereby create meaning from their experiences of disability or disease. The user interfaces, generic conventions, political economic structures, ideological persuasions, and sociocultural norms that configure narrative creation in these spaces require critical attention since these elements exert insidious discursive control over the stories users tell about disease and disability, in terms of both *what* they tell and *how* they tell it.

## Chapter 3 | Patient 2.0: Socially Networked Narratives of Illness

Hopefully waving goodbye to chemo forever. Im [sic] not sure I can ever put my body through all this again. Time to stop cheating death.

Kate Granger (@GrangerKate), *Twitter*, 27 Feb. 2014

“Can Google Solve Death? The search giant is launching a venture to extend the human life span. That would be crazy—if it weren’t Google.”

Cover of *TIME*, 30 Sept. 2013

In its most basic form, participatory health looks something like this: a distressed parent frantically Googling the description of his child’s emerging full-body rash; a young woman entering the doctor’s office armed with PsychCentral discussion forum postings on an anti-depressant medication she has been prescribed; or an individual with hypertension using the HeartWise Blood Pressure Tracker iPad app to monitor his blood pressure levels over the course of several months. When combined, these examples paint a picture of the various, and relatively new, ways that individuals within a participatory model of health understand, react to, explain, and manage disease.

According to the Society for Participatory Medicine, participatory health can be defined as “a model of cooperative health care that seeks to achieve active involvement by patients, professionals, caregivers, and others across the continuum of care on all issues related to an individual’s health” (“Welcome”). This focus on collaboration represents a shift in the practitioner-patient relationship, which involves increased attention paid to patient perspectives, experiences, opinions, preferences, and knowledge. According to some enthusiasts, this ‘revolution’ is drastically changing the

ways in which health practitioners and patients interact within the healthcare system. As medical doctor Eric Topol notes in his book *The Creative Destruction of Medicine: How the Digital Revolution Will Create Better Health Care*, digital media provide new opportunities for a departure from the heavily criticized methods of evidence-based or population-based medicine toward an individualized or customized healthcare experience “characterized by the right drug, the right dose, and the right screen for the patients, with the right doctor, at the right cost” (32). Topol’s work asserts the notion that, in an era of constantly emerging technological solutions, “medicine for the common good is not good enough” (32).

More important than the biomedical paradigm shift currently underway are, perhaps, the changing conceptualizations of health and patienthood embodied by the emergent dynamics between healthcare practitioners and patients. In valuing the insight of patient knowledge acquired through personal, subjective experience, healthcare practitioners are en route to more fully adopting an understanding of disease as produced through a range of determinants, rather than conceived narrowly as individual pathology. This development is not solely connected to a changing technological landscape, but to a variety of factors that I introduced in chapter one and that I will explore in more detail below.

This chapter shifts the discussion from a focus on movements within medicine and medical education outlined in chapter two toward an examination of the activities of contemporary digitally-engaged healthcare seekers, whose participation might be seen as extending from a combination of web democratization and the broadly distributed and peripherally organized activity of patient activist groups beginning as early as the 1950s (Williamson 35). I turn to address the impact of new media developments on patienthood, and, conversely, the role that personal accounts of illness

play in shaping the structure of health-related new media. I am interested in critically assessing the interplay between new modes of patienthood and new, specifically, *social* media in order to develop a nuanced understanding of how technological and cultural change interact within healthcare. What new expectations, roles, affordances, and constraints arise for the individual healthcare seeker in the current technocultural milieu? In spite of the hype surrounding the democratization of medical information and the empowerment of the patient, what new limitations have emerged? Which established structures of power remain intact? These are questions I will begin to address presently, and return to repeatedly throughout the final two chapters of this dissertation.

I begin with a discussion of the technoenthusiast rhetoric that has surrounded the emergence of health-related social media, offering an attempt at briefly historicizing the development of such spaces. In chronicling the emergence of health-related social media, I establish a context for critically analyzing the language used to talk about online health communities in mainstream media coverage, by patient activist groups, and by the communities themselves, a discourse that is overwhelmingly celebratory, enthusiastic, and optimistic. The second part of this chapter will map the terrain of contemporary health-related social media, exploring the structures, discourse, and affordances of such media as they pertain to the creation of personal illness narratives. I will explore how the possibilities enlivened by such media might facilitate a more robust understanding of health, shifting the burden of disease to a collective or community concern and disrupting some of the problematic humanistic tendencies I outlined in chapter two. I am interested in how the creation of *alternative personal illness narratives*—narratives that unsettle received biomedical and mainstream media-endorsed readings of illness experience—proliferate in online spaces for narrative

creation, specifically on health social networking sites (SNSs), personal blogs, and individuals' Twitter feeds.

At the same time, there is evidently an insidious side to the operations of some online health communities, particularly those operating under a profit motive. In the next chapter, I will delve into the example of the “free” for-profit health SNS PatientsLikeMe to uncover how the potential to create alternative narratives of illness becomes constrained and contradicted in light of the website's techniques of data collection. In the case of PatientsLikeMe, the narrative creation facilitated on the site is overwhelmingly geared toward the management and control of deviance, introducing a drastic contradiction between the experiences of chronic illness articulated by members in the discussion forums and journals, and those visualized through the narrative devices of the site's patient profiles.

My overall motivation in critically analyzing health-related social media stems from the reality that, increasingly, these are the primary spaces where individuals construct narratives about and thereby create meaning from their experiences of disease or disability. The user interfaces that structure narrative creation require critical attention since the generic conventions and ideological persuasions of these frameworks exert varying degrees of discursive control over the stories users tell about disease and disability, in terms of both *what* stories they tell and *how* they tell them. Firsthand stories about illness, disability, suffering, and pain matter, not only for their writers who fulfill a human need to make sense of experience through communication, but also because they constitute a space where what it means to be human is negotiated. As Cheryl Mattingly writes in her introduction to *Healing Dramas and Clinical Plots*, “attention to human suffering means attention to stories, for the ill and their healers have many stories to tell... The need to narrate the strange experience of illness is part of the very

human need to be understood by others, to be in communication even if from the margins... Illness... reveals much about how a culture conceives of life in time, being as a kind of becoming marked by transitions, transformations, and the inexorable progress toward death" (1). The stories of illness that we find in various corners of social media are important for the function they serve in helping us to relate to and understand one another; but they are also important because they constitute a mirror that reflects back to us the imaginings, expectations, anxieties, and stigma that we construct around certain human experiences—in this case, the reality of bodily finitude.

In addition to the way in which "pathography... helps shape our mythology about illness," as Anne Hunsaker Hawkins asserts, it also "embodies dynamic constructs about how to deal with disease and treatment: its images and metaphors and myths are not just decorative and fanciful but highly influential models of how to negotiate an illness experience" (11). How these stories are narrated, what rhetorical situations they are produced in, who tells their experiences and who can exert ownership over them, when and where these stories are permitted to be told—all of these conditions of production influence the narratives that are produced and, thus, their meaningmaking power. Audre Lorde expresses this reality when explaining her motivation, as a postmastectomy woman and African American lesbian, for publishing *The Cancer Journals*. She writes, "I do not wish my anger and pain and fear about cancer to fossilize into yet another silence, nor to rob me of whatever strength can lie at the core of this experience, openly acknowledged and examined" (9). Since "imposed silence about any area of our lives is a tool for separation and powerlessness" (9), we must pay attention to the stories that are told about illness, as well as those that are silenced.

## Defining Health 2.0

As my participatory health scenarios reveal, increasingly, the contemporary mode of patienthood involves leveraging the affordances of digital media platforms, that is, implementing user-oriented, participatory strains of online media—whether free web-based or mobile applications, or consumer market proprietary software—to achieve objectives of “collaboration, participation, apomediation, and openness” (Eysenbach). The digital media saturation of the healthcare sphere is often referred to by the name Health 2.0, a trend that promotes the goals of participatory medicine by viewing individuals as healthcare consumers or ‘e-patients’ in the market for knowledge translation, health management tools, social networking opportunities, and so on, all of which promote the ideal of the empowered patient (Eysenbach). As Charlotte Williamson notes, however, the truly emancipatory element of patient activism—in this case through participatory medicine—is not about patients’ power as consumers, alone: “consumers or customers want sellers of goods to offer them access, information, choice, safety, representation and redress: the principles of commercial consumerism. But patients also want the health service to offer them support, equity, shared decision making and respect. These principles are irrelevant or antithetical to commercial consumerism” (2). The philosophy behind participatory health is about equality in power relationships between practitioners and patients, not simply the false freedom of consumerism, which is exploitative at its core.<sup>7</sup>

In this dissertation, I am specifically concerned with *social* media that fall under the Health 2.0 mandate. These media can include both generic and health-related social networking sites, blogs, vlogs, and microblogging sites, and, though I do not discuss

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<sup>7</sup> Williamson also notes that the persistent use of the term “consumer” in this context relates to the unfortunate lack of agreed-upon terminology for patients and those who support their interests (94-5).



them here, even online role-playing games (RPGs) or massively multi-player online games (MMOGs). I am not particularly concerned with health-related content made available through proprietary websites, but instead intend to examine Health 2.0 as a socially leveraged phenomenon characterized by personal illness narrative creation.

Indeed, in the spaces where illness experience meets social media, there occur not only the activities of social support and information sharing that have been thoroughly analyzed by researchers like Jenny Preece, Barbara Sharf, Michael Hardey, and others, but also the less-rigorously examined creation of personal illness narratives. I follow the lead of Shani Orgad in seeking to “expand the research focus on information seeking and social support, to include a significant activity that has been largely overlooked: storytelling, i.e. patients’ configurations of their experiences into stories” (“Patients’ Experiences” 3). This creative action cannot be separated from the aforementioned empathic and informational qualities of social media in the context of illness; but this is a component I hope to hone in on, namely, to determine what kind of cultural work these digital illness narratives perform.

But first, what are we to make of the so-called “digital media revolution in healthcare”? The language of revolution, of course, connects this discourse to other uncritical and overblown reactions to technological development in general, stemming as far back, perhaps, as Plato’s distrust of the recorded word and its potential threat to memory in *Phaedrus*. The byline of a March 2013 *Macleans* article entitled “The smartphone will see you now” declares, “Putting medical technology in the hands of patients could revolutionize medicine” (McMahon 46). Speaking about consumer health devices, medical diagnostic smartphone apps, and health-related social media, the author makes the grand, largely unqualified statement that “the days of relying on your family doctor to figure out what’s wrong with you—a diagnostic process virtually

unchanged for generations—are quickly coming to an end” (46). Indeed, the popular press would have us believe that our computers are outdoctoring our physicians; that in very little time “Dr. Google,” in combination with a burgeoning consumer healthcare industry, will have replaced the practitioner of family medicine altogether. Going to even greater heights of hyperbole, a September 2013 *TIME* article entitled “Google vs. Death” announces Google’s latest venture to “solve death,” by creating a mammoth pool of human health data through its forthcoming Calico project (McCracken and Grossman).

The opposite sentiment—one of alarmism and fear mongering—also proliferates in mainstream and scholarly writing at the prospect of handing so much information over to the patient. Writers warn of the potential dangers of inaccurate medical information found online or misinterpretation of the “real thing” (Benigeri and Pluye; Theodosiou and Green; Cline and Haynes; Shalom). Certainly, the picture painted at each end of the spectrum overstates the case; the language of revolution and risk attached to consumer health technology necessitates a more critical, historically situated reading of the current technocultural milieu.

Is it possible, for example, that the emergence of contemporary self-care practices, such as participation in online health communities represents, not a revolutionary change in patienthood or a risk-laden breeding ground for the spread of misinformation, but a technocultural-medical moment that is also a harking back to or reinstating of a historical mentality toward illness? One that viewed the responsibilities and obligations attached to suffering, caretaking, and curing as a communal burden, which extended beyond the realm of the nuclear family and productively blurred the line between public and domestic space? While this is not the central claim I am making, the historical account offered in chapter one might point to this possibility. I

raise the question because it, in turn, begs another question as to whether the Web 2.0 'self-help' approach to healing is really all that *new*. As Lister, et al. observe, "there is a strong sense in which the 'new' in new media carries the ideological force of 'new equals better' . . . . These connotations of 'the new' are derived from a modernist belief in social progress as delivered by technology" (11). Indeed, the use of the term *new media* to name the artifacts, tools, and strategies of our particular technocultural-medical moment is bound up with the technoenthusiast rhetoric of Health 2.0 discourse.

### *The digital revolution in healthcare*

Perhaps the largest issue with much of the rhetoric surrounding the emergence of new technologies is the way in which it subscribes to a technological determinist model of social and cultural change. Technological determinism asserts that the impetus of technoscientific innovation and the introduction of new technological artifacts are what drive revolution in other arenas of human life. It overstates the role of new technologies in transforming society, rather than understanding the emergence of technology as unavoidably embedded in cultural dynamics that shape and are shaped by the production of new media (Williams 5). This inclination is certainly present in much of the discussion surrounding Health 2.0 technologies, in the sense that media such as mobile applications, health records-related software, assistive devices, and social media in both personal and medical settings are heralded as tools that will revolutionize healthcare and improve the overall health of the populations fortunate enough to have access to such technologies.

Nowhere is this sentiment more apparent than in Eric Topol's *The Creative Destruction of Medicine*, which argues that the antiquated and historically slow processes of medical-scientific discovery will face an overhaul in the coming decades through

“the active participation of consumers” who will, essentially, be capable of “digitizing” themselves (vii). Topol argues that “we now have the technology to digitize a human being in the highest definition, in granular detail, and in ways that most people thought would not be possible” (vii). As he describes,

digitizing a human being is determining all of the letters (‘life codes’) of his or her genome . . . . It is about being able to remotely and continuously monitor each heart beat, moment-to-moment blood pressure readings, the rate and depth of breathing, body temperature, oxygen concentration in the blood, glucose, brain waves, activity, mood—all the things that make us tick. It is about being able to image any part of the body and do a three-dimensional reconstruction, eventually leading to the capability of printing an organ. . . . And assembling all of this information about an individual from wireless biosensors, genome sequencing, or imaging for it to be readily available, integrated with all the traditional medical data and constantly updated. (vi-vii)

With its obvious overtones of surveillance and control, this “digitization,” of course, depends upon the willingness of “consumers” (the term Topol consistently uses to describe health-conscious individuals) to adopt habits of compulsive self-monitoring and digital recordkeeping. Topol refers to this type of engagement as a “democratization of medicine” (vi), though it more likely reflects a future of overmedicalization—indeed, a dangerous retreat away from a posthumanist understanding of health and back toward a limited medical model supported by the promise of clean, unambiguous data.

Although there are a number of issues with the course that Topol navigates for medical-technological development, one of the main ones is his reliance upon the argument that the new technologies he glorifies—biosensors, imaging technology,

social media, etc.—are propelling changing modes of medical research and innovative dynamics in medical care, most notably through the allegedly revolutionary participation of patients in their own care. If we look at the way in which layperson involvement in medical settings has evolved over the past half century or more, we see that more active patient involvement emerged out of advocacy movements attached to questions of patient and caregiver rights, as well as issues of paternalism and consent—for example, rules surrounding parental visiting rights in pediatric wards, obstetric policies and practices, the policing of female sexuality with regard to contraception and abortion, and so on (Williamson 48-9, Dubriwny 18-9). This patient activism was certainly connected to technological developments, as well, such as the work of the UK patient activist group RAGE, founded in 1991 to protest unsafe radiation practices and advocate for the reduction of potential side effects (Williamson 52). However, in order for patient activism to emerge surrounding medical care, there also had to exist particular conditions of possibility and, for the most part, these were not technologically driven.

Understanding changes in patient roles and healthcare delivery must involve analyzing social and technological change in a more robust way. Some such approaches—antidotes to technological determinism—have been proposed by Raymond Williams, Daniel Chandler, Langdon Winner, and Andrew Feenburg, among others. Here, I take the methodology of Brian Bloomfield, Yvonne Latham, and Theo Vurdubakis in using the concept of “affordances” to navigate the problematic gap between “undersocialized and oversocialized conceptions of technology” (416). The authors argue that “the affordances of technological objects need to be understood in terms of the sociohistorically contingent folding(s) of the body and the artefactual world into one another” (417). We cannot understand the affordance(s) of a particular artifact

as emanating out of the materiality of the object, itself; instead, what we can do with an object is a product of “the ever-changing relations between people, between objects, and between people and objects” (420). Bloomfield, et al. use the example of fire as an element that we cook our food with; however, “‘cook-with-ability’ is not a property of fires; rather humans have developed practices and equipment for making fires which are ‘cook-with-able’ and, importantly, keeping them this way and thus preventing them from becoming house fires or forest fires” (417). The focus is on action *potentialities* that emerge from various and shifting assemblages of agents and materials.

According to this logic, then, it would be misleading to attribute a “digital revolution in healthcare” solely to the availability of new technology. Indeed, many of the contemporary changes in healthcare are far more complex than this, and stem also from a particular mindset toward the social dynamics of healthcare delivery, the status of patient and doctor, the accessibility, sanctity, or locus of medical information, the status of medical-scientific theories about the body, social and cultural views on the privacy of personal information, and so on. Recalling Foucault’s exposition on the shifting medical epistemology of the late eighteenth century (discussed in chapter one), we can see how the generally accepted theory of medical technological innovation only partially explains the emergence of the clinical gaze.

With regard to health-related social media, in particular, my analysis takes its cue from the language of activism surrounding patient use of social media and consumer health technology by commentators, but also by patients themselves. I understand this discourse as directly connected to the patient emancipation movement, the development of which Charlotte Williamson traces in her book *Towards the Emancipation of Patients*. According to Williamson, the movement began in, roughly, the 1950s when patients and their partners in care began to form groups in order to self-

advocate and to criticize certain unethical or paternalistic medical practices and policies. She argues that three simultaneous factors have contributed to the inception and continuation of patient activist groups: 1) a shift in social values, beginning in the mid-twentieth century that caused individuals to question traditional sources of authority; 2) the poor quality of medical care and disparaging writing on such issues by dissatisfied patients; and 3) critical sociological research on the medical institution beginning in the 1960s (Williamson 34-5).

While Williamson does not address this in detail, the women's health movement and the work of feminist health activists were a driving force in the growth of patient advocacy and the critique of expectations of, specifically, female (but also male) passivity in the medical environment. As Tasha Dubriwny writes in *The Vulnerable Empowered Woman*, through various actions, such as the abortion speak-out by radical feminists the Redstockings in 1969 and the creation of women's health initiatives in American universities throughout the 1980s, "the women's health movement laid the groundwork for significant changes in the U.S. healthcare industry" (19). And yet, the patient rights movement as a whole, as Williamson traces it, similarly to the dispersed activity of women's health activism, is characteristically undefined, varied, and informal in nature (3). Nonetheless, it is certainly an emancipation movement, since the dispersed activity of those seeking to strengthen the voices and decision-making power of patients are attempting to remedy a vast power differential between patients and health practitioners. As Williamson explains it, patient "emancipation does not mean rejecting what is good about a dominant social group, those of its ideas and actions that free people from hardship, want, fear, disease or pain. It means altering the relationship between dominant and subordinate social groups, lessening the opportunities for the

one to harm the interests of the other. . . . In that, it benefits the social group that is more powerful as well as the group that is less powerful” (1-2).<sup>8</sup>

Groups that promote patient empowerment through social media and information technology understand this kind of action as improving health management and social support for both patients and practitioners. The central conclusion of the e-Patient Scholars Working Group, founded by Dr. Tom Ferguson, reflects the idea that contemporary ‘e-patients’ are striving for greater autonomy, “managing much of their own care, providing care for others, helping professionals improve the quality of their services, and participating in entirely new kinds of clinician-patient collaborations, patient-initiated research, and self-managed care” (ix). The negotiation of these opportunities is an important concern in patient forums on health SNSs, where individuals share strategies for addressing antagonism in the clinical setting, preparing for medical appointments, and navigating difficult conversations with doctors. The twin mantras of self-education and self-advocacy are strong within these spaces, where individuals (some more vocally than others) challenge one another to be in control of what happens to their bodies.

According to Williamson’s work, the discussions and concerns of pre-Internet patients were strikingly similar to those found online today; what we are likely witnessing then, is the mainstream adoption of what were once radical attitudes toward health and healthcare. In part, these conversations have flourished because of the availability of online spaces to connect, but the adoption of Internet communication and digitally supported self-care strategies certainly does not mark the origin of patient participation in healthcare. Taking the patient emancipation movement into account, it

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<sup>8</sup> The disability rights movement might be seen as equally integral to the movement for patient emancipation, since it challenged the medicalization of deviance and sought to critique ableist attitudes regarding health and rehabilitation (see Shapiro, Charlton).



could be argued that the social circumstances generated by early patient activist groups created an opening for other modes of patient engagement to emerge and that, in combination with developments in networked information technology, an affordance (or set of affordances) arose. If we look at this history alongside that of social media, we can see how the social opportunities presented by networked technologies assembled with the social needs of individual patients and patient activist groups.

Listserves, for example, are one of the earliest Internet-enabled social media through which patients connected and formed communities. Barbara Sharf's early study of the Breast Cancer List (BCL), based on research conducted between 1994 and 1995, offers insight into the way in which listservs facilitate information exchange, social support, and personal empowerment among list subscribers. As Sharf notes, the BCL was created by Canadian molecular biologist Jon Sharp as part of his work on the advisory committee for the Atlantic Breast Cancer Information Group, a grassroots patient advocacy organization (67). Users of the BCL consisted of individuals with breast cancer, their friends and families, physicians, and researchers, and the mandate of the list reflects its origins in patient advocacy. Indeed, the description of the list, as it appears to new subscribers, reflects the focus of many such patient communities:

While some of the list will be devoted to discussions of medical advances, as well as possible therapeutic treatments, both mainstream and alternative, the list should also have a less rigorous side to it. . . . It will also be a forum for breast cancer patients and their loved ones to vent frustrations and offer alternative strategies in dealing with the patriarchal [sic] medical-industrial complex, and to offer help and insights into the psychosocial management of the disease. Finally, the list will offer a venue for the discussion of the work of various grassroots breast cancer advocacy groups worldwide, to announce events, to

exchange ideas related to breast cancer activism, and, more broadly, to discuss the politics of breast cancer and health care. (Qtd in Sharf 67)

As Sharf notes, the advisory group had been seeking out a way to connect its diverse audience and engage them in information sharing, and discovered the value of a listserv strategy in meeting these needs. This form of interaction, with its clear framework for participation, quite obviously lays the groundwork for the development of web applications like discussion forums and social networking sites, which developed simultaneously to users' desires to connect with one another in more contextually rich ways.

Another early way in which healthcare seekers connected online was through the Whole Earth 'Lectronic Link (WELL), popularly documented by Howard Rheingold in his book *The Virtual Community: Homesteading on the Electronic Frontier*. The WELL was "a computer conferencing system that enable[d] people around the world to carry on public conversations and exchange private electronic mail (e-mail)" ("Introduction"). As Rheingold notes, this "virtual village of a few hundred people" in 1985 had expanded to eight thousand members by 1993, becoming a space where people, identifying with various subcultures, met to share special interests and hobbies, discuss news and ideas, play games, and find and offer support. In her 1997 discussion of electronic narratives of illness, Faith McLellan studies the exchanges of one such discussion group on the WELL. Also mentioned by Rheingold in his book, McLellan's focus is on the conversations that emerged, and were ongoing for more than three years, when Phil Catalfo, the father of a ten-year-old boy from California, posted a topic called *Leukemia* to the parenting conference, announcing his son Gabe's diagnosis. Between the creation of this initial topic in January 1991 and the three subsequent topics

that Phil opened on the subject of his son's illness up until September 1994, there are over 1500 postings (89).

McLellan analyzes the narrative qualities of the co-authored story of Gabe's illness, noting that such electronic narratives disrupt traditional expectations of authorship and genre, allowing for a powerful narrative and supportive community to form around an experience of illness. While this way of writing may have been new, the way in which individuals came together on the WELL to support the Catalfos can be understood as a virtual instance of a support group. The desire to reach out to "expert" strangers is, indeed, not new or revolutionary—though the platform, scope, and "virtuality" are.

In another of the early studies of illness life writing in online spaces, Michael Hardey analyzes personal home pages created by individuals and their family members to share information about their illnesses. While the decline of the personal home page can perhaps be attributed to the explosion of the blogosphere in the late 1990s, beginning in the mid-1990s, the web provided access to more user friendly web-based publishing tools from AOL, Tripod, GeoCities and other companies, resulting in "tens of millions of personal home pages, with photo galleries, flashing text and graphics, personal journals, and lists of noteworthy links to other sites" (Standage 225). In his analysis, Hardey creates a fourfold typology to categorize how and why people create thematic homepages on the topic of their illnesses, all of which resonate with the ways in which users contemporarily create illness narratives in online spaces like SNSs, blogs, and Twitter: 1) in order to familiarize readers with the various emotional, physical, social, and other challenges they face because of their illness; 2) in order to provide advice to others diagnosed with their condition; 3) in order to advocate for particular healing philosophies, treatments, or procedures; 4) in order to promote business-related

interests, such as selling consumer health products (34). In her study of women's breast cancer home pages, Victoria Pitts critically analyzes another aspect of self-disclosure in such spaces, looking at how writers "create personal web pages on the Internet as sites for generating new forms of knowledge, awareness and agency in relation to the illness" (34). Specifically, she wonders whether Internet spaces might allow for more subversive forms of illness representation to emerge, a question that I, too, pose in relation to personal blogs.

Awareness of the history of writing and community-formation surrounding illness on the Internet, as well as the persistence of such scholarly concerns, I think, helps to disrupt the notion that "new" twenty-first-century modes of carrying on such conversations, through social media like Twitter or online communities like DailyStrength, have emerged independently, detached from any history of remediation, to propel changes in contemporary patienthood (Bolter and Grusin). Indeed, such mutually constructive changes in the social role of patients, the development of medical technologies, and innovations in communications media far pre-date the first uses of the Internet by healthcare seeking individuals and communities. We could say that the keeping of "a well-stocked medical chest, and its adjunct the household book of medical recipes" with its "miscellany of medicinal and culinary recipes"—a fixture in many homes since the beginning of the seventeenth century—is one early, though anachronistic, example of participatory medicine (Digby 292).

In the twentieth century, the growth of the consumer health industry was both a cause and symptom of increased self-care; in some instances, consumer, and not market, pressure strengthened the role of individuals in the medical sphere. As Jeana Frost notes in her article on the blood glucose monitor as an innovation in participatory medicine, this historical example "illustrates how technological developments and

patient advocacy combined to produce a treatment breakthrough that represented a major improvement in the life expectancy and quality of life for the millions of people living with insulin-dependent diabetes” (“Innovations”). Frost chronicles how changes in diabetes care emerged, not because of technological developments in blood glucose monitoring, but because of the activism of one individual with diabetes, Dick Bernstein, and his advocates. Bernstein’s efforts to combat medical paternalism eventually led to legally sanctioned patient access to the technology and its widespread distribution.

In the case of the “digital revolution in healthcare,” the driving force for such change (whether it is, indeed, revolutionary or not) is not the digital technology itself, and neither is it solely the social movement of patient activism. The technologies we use to write about, track, manage, and understand our health do not exist in a vacuum, independently from the ways in which they are produced, used and, in turn, manipulated by human actors. Many of the new opportunities for patient participation in health-related settings are connected to the technologically-facilitated activities of seeking out sympathetic others on a site like DailyStrength, accessing hard-to-find medical information through WebMD, storing and analyzing personal health-related data on PatientsLikeMe, purchasing genetic sequencing and connecting online with other sequenced users through 23andMe, or monitoring one’s vital signs, including temperature, heart rate and blood oxygenation level through the palm-sized Scanadu Scout device. However, none of these affordances would be such without the social and cultural space for this kind of activity. Beyond this prerequisite are economic concerns; for, perhaps if our healthcare systems functioned flawlessly and our physicians had the time and resources to provide highly attentive and focused care to each healthcare seeker, individuals would not feel personally responsible for or compelled to self-advocate for their health. Beyond economic concerns, an epistemological shift (such as

the one that may currently be underway) to understand health as far-reaching and multifaceted, rather than merely biomedical, is spurring greater individual awareness of personal wellness that involves mental, emotional, socioeconomic, and physical health—an awareness that may encourage some people to spend more time trying to understand their unique, individual needs. The more insidious side of this shift is, of course, the neoliberal strategy to capitalize on the dictum of individual responsibility for wellness, so that health self-management and the reduction of risk become commoditized activities (Dubriwny 27-8).

Furthermore, there are specific social realities that must be acknowledged in relation to how technology becomes integrated into pre-existing cultural practices. For example, while healthcare seekers are now only a few keyboard strokes away from a cornucopia of health information, the result may be information overload. In some ways, doctors now function as medical editors. As Toronto physician Dr. James Aw writes, “My patients tend to come into the examining room overloaded with health information. It’s my job to act as the trusted translator, to filter the signal from the noise.” Of course, what counts as “health information” also changes in the complicated contemporary health-media landscape I am attempting to describe. What we find when we look more closely is that the “health information” individuals exchange online does not necessarily equate to *medical information*, the alleged purview of the medical doctor, but instead to *personal illness experience*, embedded in its complicated biopsychosocial context. In the quotation above, Aw betrays his allegiance with the old vanguard, in suggesting that he continues to represent the “trusted” authority. In reality, he can only call himself an expert on the medical side of things, while the rest is the domain of the “expert patient,” a figure whose emergence is tied to the affordances of a moment at

which meanings of health, access to information, and notions of expertise are being renegotiated.

Turning now to look at some contemporary developments in social media, as they are deployed to represent, discuss, or understand illness, I draw from the affordances-based analysis of sociotechnological change in healthcare to explore what new opportunities have arisen in and through the context of health-related social media. The rest of the chapter introduces how three kinds of spaces—health social networking sites (SNSs), blogs, and Twitter—function as arenas for the negotiation of experiences of illness and, specifically, for the construction of personal illness narratives.

### **Socially networked narratives of illness**

When then-29-year-old British doctor Kate Granger was diagnosed with a rare form of terminal cancer in 2011, she decided to use the experience as an opportunity to talk about illness, suffering, and death in a public forum. These topics, she had observed, were particularly taboo in modern-day Britain, a fact that was made apparent to her on a daily basis in her role caring for the medical needs of the dying. In an interview with *The Times*, Granger describes her motivation for tweet-broadcasting the personal ins and outs of her cancer journey, and her plans to, eventually, share the final days of her life on social media: “I tweet what I’m feeling now, like when I am going through scans, but it would be really interesting to tweet how I am feeling at the end and how it is going. I think that people don’t want to accept that dying comes to us all. There is this reluctance and inability to contemplate dying” (3). Her decision to tweet from her deathbed under the unsanctimonious hashtag #deathbedlive emerged from one of the many irreverent Twitter conversations between Granger and her legions of

social media friends and followers. For her pragmatic and public approach to her own death, she has been called “morbid” and “dark” (Fitzharris, “Dying the Good Death”). Indeed, the proposed hashtag campaign made international headlines for its profane treatment of what is most often regarded in Western cultures as a deeply personal, serious, emotionally-charged, and, therefore, necessarily private event. But, according to Granger, echoing the message of renowned critics Elizabeth Kübler-Ross and Philippe Ariès, the avoidance of topics like cancer and death, deemed unmentionable by implicit social norms, is preventing us from experiencing these for what they are—inevitable and deeply human experiences. NPR broadcaster Scott Simon echoed a similar sentiment in 2013 when he, controversially, tweeted his experience of the last seven days of his mother’s life (Bisceglia). The resistance to opening up the conversation surrounding illness and dying, Granger notes through her tweets and on her personal blog, is also preventing us from approaching our own deaths like other moments in life, as times during which we can make certain deliberate, albeit limited, decisions about the nature of our experience—about how and where (if not when) we will die (Granger, “A Good Death”).

While Granger’s concerns are certainly tilted in the direction of patient activism (her viral hashtag campaign #hellomynameis reminds doctors to introduce themselves to patients, as a gesture of humanity and compassion), I am interested in how Granger’s Twitter narrative represents a particularly high profile instance of the personal illness narrative authored via social media. Of course, Granger’s story has attracted media attention for her intentionally outspoken approach to her experience, as well as her unique perspective as a specialist in elderly medicine whose job often involves easing her patients’ transitions into death. (Indeed, there is also an element of irony in her story that may account for a great degree of the visibility she has received.) She is also



an active blogger and commentator, and has written two self-published, fundraising e-books about her journey. But, this sort of self-disclosure is certainly not unique or new. It is happening on the ordinary Twitter feeds of ordinary sick people who have chosen to share, rather than to omit, their experiences of illness and vulnerability. These ongoing narratives are, likewise, present on social networking sites and online communities where individuals participate specifically for the purpose of talking about illness-related concerns.

There are two things to address with regard to what I am calling the *alternative personal illness narratives*, like Granger's, that emerge in social media spaces. First, as I have partially developed above, what sorts of affordances establish the necessary conditions for these narratives to come to life on social media? And, secondly, what is new about these narratives, by which I mean to say, how are these different from the ones that Arthur Frank elucidates? (And, indeed, how are they uncategorizable by his terms?) More generally speaking, in the relatively new context of Twitter and other social media, what sort of cultural work do these particular illness narratives perform, both online and offline? My argument is that spaces like health SNSs, personal blogs, and Twitter constitute fertile ground for, first, the expression and representation of non-normative experiences and, second, the opportunity for those shared non-normative experiences to become occasions for conversation that is stifled or difficult to accommodate in other spaces.

My work continues the discussion taken up by Victoria Pitts in her research on the potential for subversive illness narratives to be constructed on women's breast cancer home pages. As she explores, while "women's web pages might offer potentially critical opportunities for women's knowledge-making in relation to what are often highly political aspects of the body, gender and illness . . . , the Internet is not an

inherently empowering technology, and it can be a medium for affirming norms of femininity, consumerism, individualism and other powerful social messages” (Pitts 34). Pitts concludes, ambivalently, that the tendency toward the reassertion of hegemonic ideas about femininity and a female “sick role” persists in women’s online representations of their illness, as well as in Internet marketing geared toward individuals with breast cancer; but, at the same time women seem to be empowering themselves through the “taking in and re-distribution of medical power” (53). Here, I take up Pitts’ conclusion that “the prospect of health and illness empowerment through the Internet is far from certain, and calls for more thinking and research about how people actually use the Internet for ‘empowerment’” (53-4). Specifically, I look at how the construction of personal narratives about illness experience, in an important way, allow conversation and community to emerge surrounding the marginalized subject position of sickness. As I will explore, those conversations are valuable, in spite of the way in which corporate interests often intercede or weaken the potential power of such online action.

The social, emotional, and informational support present within patient communities is noteworthy for many reasons, and has been discussed extensively in the literature. Expanding on this research, I argue that the transgressive space created by the existence of such groups allows different narratives of illness to emerge—ones that are not necessarily geared toward “getting better” or “being normal” (although these are certainly expressed concerns), but toward a whole range of other goals, the most radical of which, perhaps, in contrast to medical narratives of overcoming, is the goal of living (well) *with* a particular, sometimes undiagnosed, incurable, or chronic, condition. As I discussed in chapter two, there is little opportunity, even within newer approaches to healthcare delivery, for the emergence of personal illness narratives that accept

sickness or disability as a tolerable, expected, or unavoidable part of life. Certainly, we all wish to minimize the pain, discomfort, suffering, and loss of perceived autonomy that come along with bodily ‘abnormality,’ however, in many people’s lives, this is not possible. It is simply a reality of day-to-day experience. We need space for life stories that reflect this reality—that don’t filter experience through a trope of normalization or overcoming. These stories exist variously on online patient communities, blogs, and non-health-related social network sites like Twitter. In the following sections I discuss the specific generic expectations, material affordances and constraints, and social contexts of each medium that create slight variations in the ways that illness narratives are authored and received, and the social functions they serve.

#### *Personal illness narratives on health SNSs*

Since Pitts’ study of personal home pages in 2004, much research in the field of health studies has emerged to address the social use and function of health social networking sites (SNSs) in the context of disease management and social support, mostly for the ways in which they facilitate a wide sharing of knowledge across geographical, social, and economic boundaries that is virtually impossible offline or in interactions with physicians (Hoch and Ferguson; Preece; Gallant et al.; Fox and Jones; Ancker et al.; Frost and Massagli; Foster and Roffe; Bonniface and Green). Some examples of popular health social networking sites include PatientsLikeMe, Alliance Health Networks, Inspire, DailyStrength, CureTogether, and PsychCentral, among many others. The makeup of these sites is varied but, generally, all are structured according to various ‘disease communities’ that an individual may join for free once he or she creates a profile. Profiles usually allow users to share their diagnoses, track their health, and connect with other users. For persons with disabilities or persons

experiencing illness, whether temporary or terminal, health social media represent unique arenas in which users can safely transgress ableist norms and engage in emancipatory activity.

In more mainstream spaces, such as Facebook and Twitter, individuals with illnesses, physicians, and partners in care come together to share emotional support and knowledge through designated Facebook groups or hashtag communities. The latter “community interactions are made possible by use of the simple # symbol (known as a hashtag) that is used to indicate a topic, conversation, or event on Twitter [or Facebook]. This allows connections to be formed, for example, in disease-oriented communities such as the rheumatoid disease group that Kelly Young organized around the hashtag #rheum” (Young and Harmel). These hashtags may be used when the occasion arises, but are also deployed to generate “‘conversation communities’ for a concentrated hour-long ‘Twitterchat’ that can develop into an ongoing discussion about the topic” (Young and Harmel). Similar conversations and communities emerge in the comments sections of blogs about personal illness, which are often networked through blogroll links, followers’ and commenters’ blogs, and so on.

The kind of collaboration happening in health-related uses of social media falls under the purview of much new media scholarship, particularly that of Henry Jenkins and Jane McGonigal. Both researchers provide valuable approaches for considering how participatory media, crowdsourcing, and grassroots movements help to combat hegemonic discourse present in mainstream, commercialized cultural sites. As in the case of online disease communities, participatory media can create spaces where difference can be safely enacted or where subjective experience and ‘unauthorized’ individual expertise can be translated into what Pierre Lévy terms “collective intelligence” (quoted in Jenkins, *Convergence Culture* 4, 26).

According to enthusiastic commentators on the digital revolution in healthcare, online spaces for disease management and community formation provide a platform through which healthcare seekers can empower themselves against the highly technologized medical sphere discussed in chapter one, which functions best when individuals' bodies—their complaints and symptoms—are interpreted by diagnostic machines that look deep inside the body to places that subjective experience may neither conceive of nor understand. Thus, in this narrative, socially-leveraged media, characterized by bottom-up processes, experiential expertise, individualization, networked communities, personal relationships, and easily accessible, mobile information, combine to produce what Kate Lorig and colleagues at the Stanford Patient Education Research Center call the “expert patient,” popularly termed *patient 2.0* (Lorig et al. 248). This individual becomes the source of expertise on her own illness as it is lived subjectively—that is, as it exists in a world of particular social, cultural, familial, psychological, economic, and environmental conditions that are unique to the individual, and that no medical diagnostic machine can meaningfully interpret.

In addition to knowledge creation engendered through the aggregation of patient-reported experience, sometimes informally and sometimes more empirically (as we will see in the case of PatientsLikeMe), health social media also attend to an emotional need that may be unaddressed elsewhere in patients' lives. In her 1998 study of online communities, Jenny Preece coined the term “empathic communities” to describe the nature of online interaction between groups of individuals seeking, not just informational, but also emotional support during particular *shared* life circumstances. In her review of over one hundred online communities, Preece “found that empathy is a key ingredient in many support groups covering a wide range of topics” (“Empathic Communities: Reaching Out,” 33). These empathic communities are different from

more factually concerned or information-based groups, in that they “generally have a strong focus on medical or personal problems, and their members want empathy and emotional support” (33).

Within health social networking sites (SNSs) like PatientsLikeMe (PLM), Inspire, and DailyStrength, one inevitably finds (in most, if not all, sub-communities that are organized around a particular disease or condition), discussion posts in which members express their gratitude for the support they have found on the site, often using the language “family” and “friends” to describe fellow community members. In addition, online disease communities have the potential to be spaces where the “biopsychosociospiritual” approach to understanding health, endorsed in current articulations of patient-centred and whole person care can be accessed, articulated, and realized by healthcare seekers, themselves. While physicians are increasingly trained to interact with patients according to a holistic health paradigm, in which factors like income and occupation are just as, if not more, powerful determinants of health than genetics or physiology (see chapter two), there are many important conversations that can happen only *between* healthcare seekers, for these conversations require access to shared experience. Such conversations involve side effects and/or determinants of illness related to personal relationships and day-to-day living; for example, in a PLM discussion post about the emotional strain that Christmas creates, the topic creator shares with other MS community members her stressful experience with the holiday season, prompting others to share their own difficulties and to offer strategies for lessening the emotional strain during these times. Interestingly, in this thread, when one user interjects to offer medical diagnostic opinions that are peripherally related to the topic creator’s problem, the poster’s words are met with hostility; it would seem that in conversations like these, members are looking for specific kinds of advice that

are *not medical*, but based in personal experiential knowledge regarding social, emotional, and psychological health.

Occasionally, online conversations between healthcare seekers are ones that physicians, while they may have the required knowledge base, do not have the time, to address; for example, problems relating to socioeconomic barriers to health or the difficulties of negotiating the financial side of the healthcare system. In a PLM discussion thread of over 2,000 posts, on the topic of living alone with MS after age 65, members converse about the financial and social issues associated with aging independently with MS, discussing strategies, financial assistance programs, assistive technologies, and personal successes, failures, worries, and goals. The struggle to qualify for disability among persons with MS is also a constant topic of discussion on the PLM group; using the search string “SSDI” (Social Security Disability Insurance) at the time of writing brings up 1,396 discussion threads. These discussions reveal the intricate ways in which social, economic, personal, and cultural circumstances interweave to produce the particular conditions of an individual’s illness.

Perhaps because of the way in which user belonging to or participation within the online group is predicated upon the uniting force of ‘difference,’ SNS members’ discussion contributions, journal entries, and personal biographies disclose a high degree of unqualified vulnerability. By ‘unqualified’ I mean that writers do not seem compelled to justify their admissions, or even to attribute narrative significance to these moments. In large part, this is related to the temporal conditions of self-disclosure on these sites, which is oftentimes not subsumed under a primary goal of representing experience for its own sake, but of sharing relevant details as they pertain to the concerns of the community as a whole. Nonetheless, a narrative emerges for each user, fragmented though it is between journal entries, discussion posts, status updates,

images, etc. Looking at a user's profile on PLM, for example, one can understand her story (as much of it as she has chosen to disclose) by viewing an aggregated, hyperlinked feed of all of her contributions to the site. But following discussion threads on health SNS forums also tends to produce a disjointed narrative for each contributor. Narratives extend beyond any one site, as well, as in the case of members posting journal entries that link to their personal blogs and reference listserv, Twitter, and Facebook presences.

On SNSs, self-narratives appear, as Gillian Whitlock and Anna Poletti observe, as "auto-assemblages," rather than traditionally written narratives (xiv), since they emerge out of the technological structure of the space. As Aimée Morrison notes in her study of the Facebook status update function, "to account for the 'auto' of this 'assemblage'" means that

we must begin to consider the style sheets that organize display of user-generated materials; the input prompts that coax and restrict user action by turns; the ever-shifting privacy settings that dramatically and continually reset the boundaries between personal narrative and public dissemination; and the automated algorithm-driven recitation of users' actions across their social graphs. Each shapes the resulting digital life writing 'text' as much as do the more traditional authorial practices of a typing subject deliberately arranging her life into a story. ("Facebook" 113)

In this context, Morrison suggests, individuals' self-disclosure on SNSs is sculpted by what she calls "coaxed affordances" that are "both discursive and material" ("Facebook" 117). As I will explore in greater detail in the context of PLM, the commercial interests of the website create particular material conditions that coax the sharing of specifically biomedical data that tells a patient's story. This also influences



the discursive space of the site, which is constructed differently on the form-focused profile than it is within the open-ended “free space” of the community discussion forums.

As I describe in chapter four, while the design of a space like PLM may be heavily guided by the company’s financial motives in ways that are, to my mind, unethical, such online spaces are nonetheless highly engaging and valuable to users. Health SNSs are significant for their role in *validating* the various and highly individual aspects of illness experience. This affirmation is socially produced through the discourse of communities whose members are mutually invested in a process of understanding, coping with, *living well with*, and, sometimes (when possible), overcoming their illnesses. Above and beyond the lauded access to medical and health-related information made possible by the internet, spaces designed or used specifically to negotiate the complicated ins and outs of personal or familial illness can be seen as transgressive, in the sense that they create space for certain kinds of dialogue, personal expression, and narrative creation that are socially impermissible in other cultural spaces. The notable exception to this point is, of course, the genre of published illness or disability memoirs, which bring marginalized experiences into mainstream cultural spaces (although these narratives cannot always be classified as transgressive portrayals of illness or disability). However, the creation of these narratives is limited to those with the writing ability, financial freedom, professional connections, and/or education necessary to access this relatively exclusive field of cultural production.

Certainly, access to the Internet and to socially networked platforms that facilitate the creation of personal illness narratives is also restricted by cultural and socioeconomic constraints. The fallacy of describing the Internet as a democratized sphere of communication with equal access for all has been thoroughly critiqued in the

literature and I do not wish to replicate that same mistake here. While not everyone possesses the resources required for participating as an “expert patient”—including Internet access, digital device ownership, free time, and technological literacy—the opportunity for narrating one’s personal experience online is certainly available to greater numbers of writers than the contemporary publishing industry can accommodate. This is particularly true in the context of digital life writing (on blogs, vlogs, and SNSs), “a realm,” as Morrison notes, “with no gatekeepers, editors, or canons, producing texts to excess on a scale of production and publication that completely overwhelms the boutique reading practices of literary scholarship” (“Facebook” 112).

Keeping these important limitations in mind, I contend that the online story-writing of persons with illnesses (and their partners-in-care) certainly belongs to the transgressive space created by online disease communities, which opens up opportunities for otherwise silenced conversations. While those who join social networking sites like PLM, CureTogether, DailyStrength, and Inspire do not necessarily set out with the goal of writing a personal illness narrative, the interactions on these sites are predominantly story-based. The community forum exchanges of individuals on these sites are rooted in the idea that personal illness experience is a powerful source of information. Sharing experience in this way—whether through brief anecdotes or lengthy expositions—becomes a way for writers to craft a particular interpretation of their own experience that may then become a source of new knowledge for the reader. Stories told on health SNSs cannot be described as narratives in the traditional sense, partially because the explicit intentionality of “writing the story of my illness” is not present. However, the goal for individuals who (depending on the affordances of the site) share profile information, author journal entries, and write and respond to forum

posts is to fully represent their illness journey. This representation becomes articulated in narrative ways and it also becomes interpreted narratively by the reader/viewer.

### *Blogging illness*

While similar conversations happen within the comments threads of blogs as those that take place in community forums, there is a very different dynamic at play on personal blogs. On each of these sites, one individual's story comes to the fore, and the genre reflects autobiographical life writing; the writing is directed equally toward therapeutic self-reflection and documentation for both personal and altruistic purposes. On the blogs of persons with Alzheimer's disease and related dementias (ADRD), examples I will discuss in chapter five, many writers indicate having started a blog to support readers, specifically those experiencing similar life circumstances, using their own personal stories.

As other scholars have argued, social media like blogs (and, as I will discuss below, Twitter) create new opportunities to productively tweak or navigate certain social conventions, in this case those related to personal illness. As danah boyd notes, the asynchronicity of some social media can act as a social buffer. For an HIV-positive man, she writes, keeping a blog where his friends could go to read about

his ups and downs of his illness . . . allowed him to negotiate social boundaries with friends in new ways. He no longer had to gauge the appropriateness of the situation to suddenly declare his T-cell count. Likewise, his friends didn't have to overcome their uncertainty in social situations to ask about his health. He could report when he felt comfortable doing so, and they could read when they were prepared to know. This subtle shift in how he shared information with friends and how friends consumed it eased all sorts of tensions. (75).

boyd uses this anecdote to suggest that “technology doesn’t simply break social conventions—it introduces new possibilities for them” (75). In this example, it becomes possible for the individual writing about his illness to manage both information and relationships in a way that minimizes social anxiety and maximizes social support.

The counterargument to boyd’s view posits that these so-called affordances of social media—asynchronicity and the resulting alleviation of social burdens, such as the face-to-face, “real-time” expression of care—actually weaken our social and emotional ties, holding people less accountable to one another. This line of reasoning suggests that an asynchronous exchange in an individual’s blog comments does not carry the same supportive value as, say, a face-to-face conversation, ostensibly because of the way in which such communication is mediated. This is the line of reasoning Hubert Dreyfus pursues in *On the Internet*, in which he argues that

when we enter cyberspace and leave behind our animal-shaped, emotional, intuitive, situated, vulnerable, embodied selves, and thereby gain a remarkable new freedom never before available to human beings, we might, at the same time, necessarily lose some of our crucial capacities: our ability to make sense of things so as to distinguish the relevant from the irrelevant, our sense of the seriousness of success and failure that is necessary for learning, and our need to get a maximum grip on the world that gives us our sense of the reality of things.

(6)

Dreyfus argues that online interaction is physically detached, written (and, thus, more calculated or “editable”), and far less socially and emotionally risky. Indeed, because of the mediation of potential discomfort (because the stakes are much lower), online interaction is “easier” in a negative way; according to Dreyfus, it could signal the decline of important human emotional and psychological capacities. On the contrary, a

face-to-face social encounter, because of the potential for discomfort, also carries with it the capacity for a greater reward.

Sherry Turkle expresses similar anxieties in her latest book *Alone Together*, in which she suggests, “Virtual places offer connection with uncertain claims to commitment. We don’t count on cyberfriends to come by if we are ill, to celebrate our children’s successes, or help us mourn the death of our parents. People know this, and yet the emotional charge on cyberspace is high. People talk about digital life as the ‘place for hope,’ the place where something new will come to them. . . . Now, when there is a lull, we check our e-mail, texts, and messages” (154). Turkle makes the case that technology preys on our human vulnerabilities—our loneliness, our fear of intimacy—and presents us with an appealing offer: “the illusion of companionship without the demands of friendship” (1). The implication in Turkle’s work is that relationships founded on digital modes of togetherness are necessarily weaker than those that rely on physical proximity.

In the context of illness-based online communities, and the relationships that form around the shared experience of illness, I am particularly struck by the way in which “cyberfriends” *do*, indeed, “come by [our virtual ‘homes’] if we are ill,” just as they celebrate with us and help us mourn our losses. Perhaps these relationships should not serve to *replace* those based on “in-the-flesh” interaction, which is the point I believe Turkle makes; however, there is certainly evidence in these friendships of true care and interdependence, an idea that I will expand upon in the next chapter in light of the SNS communities that form around shared disease experience.

In terms of the cultural work that blogs about personal illness produce, beyond their functions as coping mechanisms, arenas for knowledge dissemination, and ways to mediate difficult conversations with acquaintances or loved ones, these are spaces for

ongoing reflection and narrative writing that chronicles the illness journey in ways that necessarily disrupt conventional narrative structures, such as those outlined by Arthur Frank, whose work I will return to shortly. While writers self-consciously construct a narrative about their experience, using many of the same tropes of battle and overcoming, the way in which a narrative evolves temporally—that is, the way it is written in serial fashion—pre-empts the kind of deliberate framing of the overall illness journey and its reduction to a simplistic story of re-normalization. As Jill Walker Rettburg notes, although we are used to episodic narrative in formats such as television shows, comic books, and novel series, blogs do not create the same kinds of narrative effects (such as “the cliffhanger,” for example), because of both the brevity of blog posts and the conventional lack of continuity between posts (112). In addition to this is the potential boundlessness of a blog; it does not really have a conclusion, unless it reflects what Rettburg calls a “goal-oriented narrative,” which sets out a particular project, parameters, and conclusion for the blog (113). Indeed, even in personal journal-style blogs, some writers may decide to delete a blog, “conclude” it by signing off, or be unable to continue writing because of illness or death. In this last scenario, if he or she was the only author, the blog will no longer be updated, although a friend or relative may publish a post to inform readers about the blogger’s status (Rettburg 119). Unless the website is removed, though, the blog will continue to generate hits, perhaps even be linked to or commented on. The hyperlink could be seen as a way in which a blog becomes a part of other stories on the web and continues to generate a narrative of sorts—to be implicated in others’ illness journeys or to serve as a space for continued conversation. In a way, the story goes on and on, even after it loses its author.

More to the point, however, structurally speaking there is no defined end to a blog, and indeed, no need to conceive of an ending, a generic convention that cannot

possibly be sidestepped in a traditional memoir or autobiography. The pressure to produce any kind of narrative “arc,” then, is relieved. As Rettburg notes, “When blogs tell stories . . . that story is usually partial and incomplete, and does not form a narrative whole as well-formed stories in mainstream literature and cinema do. Instead, the overall story as gleaned from reading a blog is likely to be pieced together from fragments, perhaps supplemented by bits of stories from other places” (115). These other places could be social media spaces, such as the writer’s Twitter feed, PLM profile, or another personal blog.

Certainly, the fragmentary quality of blog narrative does not preclude smaller episodes within the larger fragmented story from adopting classical narrative structures. Furthermore, there is an unavoidably high degree of self-fashioning on blogs, as is the case on other social media like health SNSs, Twitter, LinkedIn, Facebook, Instagram, and so on. Writers of blogs self-consciously project a particular vision of personal identity when they represent their experiences online, and they may even work to realize a particular narrative framework or mythology for their illness experience. However, attending to the generic qualities of the blog reveals that the piecemeal nature of the medium constitutes space in which to tell a story that does not reach a resolution, that dwells in the messiness of human life, and that articulates the complexities of an experience like cancer or multiple sclerosis or Alzheimer’s disease. This very open-endedness, even if it is limited by the unavoidable narrative expectations we impose on our own experiences and identities, nonetheless influences stories of illness, particularly since they are told as works-in-progress.

In her discussion of the *Leukemia* journals on the WELL, McLellan makes an observation that could apply equally to the personal illness blog:

the *Leukemia* journals, like many on-line narratives, are a long work in progress, presumably finished only when participants stop posting. For the participants, the ongoing nature of the story is crucial. There is a rawness and emotional power in these postings that is hard to sustain on the printed page, especially considering the usual lapse of time between experience and book publication. The freshness and lack of self-consciousness of electronic postings can provide rare glimpses of less-mediated experience. While deceit is certainly possible, vulnerability can also be magnified when the masks and defenses of on-line writers are all but absent. In that respect, the on-line narrative may come closer to actual experience than any other kind of illness story. (103)

While this sort of narrative form has been assessed by some critics as, indeed, anti-narrative—a product of what “[Frederic] Jameson predicted [as] the loss of narrative resolution and the descent into cultural schizophrenia at the hands of highly informed capital” (Bassett 6)—Caroline Bassett argues that new media have not, in fact, replaced “the logic of narrative” with “the logic of information” (2). Indeed, the alignment of narrative as inherently human against information, which is inherently technological, institutes a false binary. Despite the nature of contemporary narrative as characterized by fragmentation, discontinuity, rupture, in-process-ness, and non-linearity, Bassett argues, “narrative *lives* because it is contingent and mutable, because it is changing and transforming rather than fading in response to alterations in the material conditions under which we live . . .” (3). I will return to the nuances of this discussion in chapter five when I analyze the blog writing of persons with Alzheimer’s disease.



*Illness “auto/tweetographies”*

The affordance to author online narratives of personal illness, of course, happens in a moment when the social exigence for public self-disclosure about personal illness experience (for whatever reason—empathic support, information sharing, therapeutic writing) arises, in combination with the capacities of networked technologies to provide user-friendly and accessible web applications for self-publishing. A similar set of circumstances has produced the chronicling of illness experience on the social networking site Twitter. The medium has been referred to as “micro-blogging” for the technical constraint of permitting writers only 140 characters per tweet and the reverse-chronological ordering of posts; the differences between a blog and a Twitter feed, however, seem substantial enough that such a designation demands reconsideration. More so than the blog, perhaps, the medium of the tweet seems to draw out amplified anxieties and suspicions, namely the argument that the predominance of fragmentary snippets of information over the longer, cohesive, sustained, and self-enclosed narrative heralds the rise of information and the demise of narrative. Indeed, this observation has been met with alarm by commentators such as Nicholas Carr who calls the Internet “an interruption system, a machine geared for dividing attention” that has already begun to produce a waning of human capacities for sustained attention, complex thought, and deep concentration (131).

At the forefront of this debate are thinkers like N. Katherine Hayles and Bernard Stiegler whose work theorizes the ways in which contemporary technoculture infiltrates, disrupts, and rewires cognition. While debate over the effects of our dominant cultural form—the information tidbit—are ever-expanding in importance, it also seems imperative that we explore how narrative does, indeed, persist despite the ongoing and radical changes to how we receive it. The production of illness narratives

in online spaces reflects a desire, on the part of the individual, to make sense of an experience through written representation, and also to make that experience widely available to an audience of, oftentimes, anonymous readers for a variety of reasons. This particular use of a space like Twitter complicates disparaging analyses of the medium as dumbed-down, easily digestible drivel that chronicles the mundane and inconsequential details of users' lives. It makes possible an understanding of this space as facilitating important, socially engaged modes of self-representation, a possibility that becomes illuminated through the example of Dr. Kate Granger's widely publicized use of Twitter to broadcast her illness journey.

As in the case of the personal blog, it is, perhaps, the very open-endedness of Twitter—it's framelessness—that establishes the conditions for this kind of self-disclosure. Of course, this "framelessness" creates a kind of frame: the writing of a tweet is an occasion to say something—*anything*; an entreaty for frequent, excessive, sometimes obsessive sharing. In many ways, Twitter sharing differs from blog writing because, as Antti Oulasvirta et al. observe in their study of microblogging on *Jaiku* and *Twitter*, the practice is defined by frequent sharing of "current activities and experiences," which "creates pressure to continue sending status updates even at very mundane moments, as the sender's presence is constantly being created and recreated through these messages" (238). This means that the content of tweets often reflect what is happening at the moment of writing, although this is not always the case. Laurie McNeill surmises that "blogging remains popular, and is the place for longer entries (and not the banal), while microblogs and social networking sites call for these rapid-fire but often quite trivial life installments" (150). Writers, of course, selectively decide which of their life moments are worth sharing and, by doing so, they "may be constructing the social meaning of those events" (Oulasvirta et al. 248). Twitter,

Facebook, and other social media have built-in systems for responding to and affirming the sharing of others, so through “favorites,” “likes,” “retweets,” “tags,” and “mentions,” other users decide which topics receive favourable attention, thus “engag[ing] in a communal act of auto/biographical reflection and affirmation” (McNeill 150). In this way, sharing is sculpted by the user’s social circle of followers and takes place according to whatever expectations arise as a result of the culturally embedded nature of such communication. These “auto/tweetographies,” as McNeill calls them, also alter our offline practices, “with users on the alert for the ‘reportable,’ thinking of how to shape experiences into status updates or tweets” (151). This is connected to “the communal pressure to keep producing and consuming” these micro-stories, which helps to “embed auto/biographical acts in cultural consciousness. The modes of auto/biography become part of millions of people’s daily routines” (151).

As the technology continues to define itself, conflict arises over what is the “appropriate way” to use it, the proper etiquette, and the acceptable topics of discussion and contribution. This, as Gitelman and Pingree elucidate, is the case for any new communication medium: “new media, when they first emerge, pass through a phase of identity crisis, a crisis precipitated at least by the uncertain status of the given medium in relation to established, known media and their functions. . . . [T]heir place is at first ill defined, and their ultimate meanings or functions are shaped over time by that society’s existing habits of media use, by shared desires for new uses, and by the slow process of adaptation between the two” (xii). It would be naïve to argue that Twitter does, in practice, fulfill its function as a forum in which to “say anything.” A person’s participation in any Internet space is unavoidably susceptible to real-world social norms, including the same (or more pronounced) harassment, discrimination, shaming, bullying, and any other kind of violence that exists in offline spaces (Dery 1). When

other Twitter users and journalists report that a user like Kate Granger is breaking a taboo about “what we should talk about online,” they are both identifying and questioning the authority of those proscriptions. The viral nature of this sort of activity on social media means that if enough individuals decide that they, too, see the importance of demystifying the experience of illness and death online, then a small space opens up for that kind of conversation to happen (conversations that are, of course, already happening in niche social networking sites and communities like PatientsLikeMe and DailyStrength).

The importance of this discussion happening in a generic, mainstream space like Twitter cannot be understated. While the attention paid to human vulnerability and the sharing of empathic support is certainly valuable on health-related social networking sites, the subversiveness of such a space is limited in the sense that the transgressive activity is confined within a community of (generally) likeminded people with similar experiences; the site name “PatientsLikeMe” aptly demonstrates this point. When these conversations shift to mainstream spaces, the potential arises for wider attention to be paid to human vulnerability. In a small way, this fissure, this provocation, might represent an alternative to understanding the Internet as a space for shameless self-promotion, posturing, and narcissism, as some critics have figured it. At the same time, the sharing of any kind of personal experience, whether negative or positive may be construed as a way of seeking to validate the ego through Internet conventions like the Twitter “retweet,” the Facebook “like” or “share,” or the blog comment or “trackback.” I will attempt to address this tension in chapter four through my discussion of PLM users’ deployment of the concept “new normal.” Here, the discussion of personal illness-related challenges serves as an opportunity for individual and social acceptance

in the face of radical life changes and not necessarily narcissistic attention-seeking behaviour (though there is the possibility that both motivations might be at play).

### **Kate Granger and #deathbedlive**

Thus far, I have sketched an outline of how the structural and social affordances of SNSs, blogs, and Twitter, each in their own way, carve out space for the performance of difference and for the construction of alternative personal illness narratives that disrupt received thematic frameworks. Returning to my discussion of Arthur Frank's *The Wounded Storyteller* in chapter two, these traditional frameworks include: chaos, quest, and restitution. Frank's theory presupposes that, as individuals think about, talk about, write about, and otherwise creatively express their experiences of illness, we assert an overarching narrative about what the illness means in the grand scheme of our lives. This framework helps us to cope with the perceived loss of control, self-direction, and autonomy that comes along with any threat to 'normal' living. As I argue, the approach that Frank forwards—that is, the restitution narrative—still heavily asserts a reading of illness or disability as a temporary, abnormal state that needs overcoming; it accommodates neither the experience of chronic illness, nor terminal illness, nor the simple reality that human beings are unavoidably susceptible to pain and suffering—experiences that are consistently framed as negative, undesirable, and even unusual in the received narrative structures.

Where does a tweet narrative about personal illness fit into Frank's model, taking, for example, Kate Granger's ongoing self-narration of her cancer journey? Granger has expressly reacted against the metaphor of battle, expressing on her blog, as well as on Twitter, that the notion of a person losing her battle against cancer "somehow lays blame with the patient and seems very unfair. . . . [W]hen I die I will be

turning in my grave if anyone says ‘she lost her brave fight’. I would like to be remembered as a fairly successful, fun-loving and ambitious individual, not as a loser” (“Cancer in the Media”). As a scientist and doctor, she notes, “I quite admire my cancer” for its beauty and mystery at the cellular level (Granger, “Is cancer inherently evil?”). She has made very public her ambivalence toward aggressive treatment, after experiencing the destructive effects of chemotherapy, and has shared with readers her difficult choice to continue chemotherapy, despite her apprehension (Granger, “Dear Chemo” and “Dear Chemo Part 2”). And she repeatedly turns to humour to spread her positive outlook because it “normalises this huge life event that is approaching for me” (Granger, “Dying – can it ever be a laughing matter?”). Her narrative takes its overarching structure from the axiomatic appeal to live in the present, to enjoy the moment, to make each day count for something. As a physician, Granger is in a better position, at least than the average cancer patient, to know the biological intricacies of how her own story is likely to end. And while the decision to tweet her illness is certainly “to open up discussion,” it is also a definitive provocation of social media-related anxieties surrounding what is an appropriate topic for a 140-character tweet or Facebook status update; how personal, how “morbid,” how bodily, how human are we permitted to be in these spaces?

When scholars theorize about illness narrative, they often position it as a therapeutic form of storytelling—a situation of crisis that may be resolved through creative expression (see Frank, Kleinman, Lorde). In the context of Twitter, however, we see illness become embedded in what is already a pre-existing stream of self-disclosure. Illness is not necessarily a call for stories, but it becomes a *part* of the story. Looking at Granger’s Twitter feed, we see that her more autobiographical tweets shift between anecdotes about day-to-day living, work, family, special occasions, mundane moments,

and noteworthy events, some of which include hospital visits, chemotherapy, scans, medical procedures, and sick days.

These individual tweets can be strung together to produce a narrative, though the immediacy and real-time nature of these 140-character “blurbs” mean that they are generally not imagined by the writer to belong to a larger, overarching telos. Instead, the cohesiveness of these pieces of text might owe itself to the conscious way in which individuals construct an online identity and conform to social expectations about their online contributions. The reader may be likely to connect the dots of a friend’s serially received tweets to understand his or her experience narratively. Indeed, an individual’s profile of tweets and retweets composes a micro-blogged story, one that is read live, or nearly so. However, the format of the Twitter profile certainly does not lend itself to backward narrative analysis. Attempting to dig months and years back into the archive of Granger’s tweets during my research made Twitter’s status as a compulsive and always-on technology abundantly clear. Indeed, the structure of the interface compels a live or only moderately asynchronous reading, especially on the profile pages of heavy users who tweet several times daily.

And yet, the micro-stories that combine to form larger stories on Twitter are often unavoidably narrative and autobiographical in nature. Kate Granger’s Twitter presence is explicitly constructed to represent her experience—it is a space of sharing and self-expression. This is, of course, an unsurprising way to use social media. Perhaps obviously, the attention surrounding Granger’s narrative choices on Twitter is not a result of her being a woman with cancer who tweets, but a result of her being a woman with cancer who tweets *about her cancer* (and her eventual death); the controversy is over her decision *not to omit* the taboo details of her life from her Twitter presence. Indeed, as I mentioned before, in the “wild, wild West” of newer social media spaces,

the boundaries are constantly being defined, negotiated, and renegotiated, so discussion over “should we really talk about *that* online?” seems prominent in the popular imagination. One of Granger’s expressed goals is to push the envelope over what we consider to be the appropriate way to deal with, understand, and manage dying and death. This is undoubtedly a subversive move, particularly in a space where the focus is on *life*-logging, defined (though implicitly) against the alternative—mortality, or reminders thereof (suffering, illness, injury, bereavement, or anything that might be characterized as a threat to one’s vitality). If, as Marcel O’Gorman argues in *Necromedia*, using the work of Ernest Becker and others, contemporary technoculture serves as an immortality engine through which to reaffirm the uniqueness and worth of the individual, then Granger’s powerful campaign can be read as subverting this collective hallucination. At the same time, Granger’s tweets about death serve as a memorialization of the final years of her life in the form of an archive that will outlast her earthly presence, just as individuals’ blog and SNS presences function. Granger’s archive of the self, while it certainly works toward a goal of demystifying the human experience of dying, nonetheless serves as a means of immortalization that may protect Granger (and others who document their experiences of terminal illness) against the finality of death.

Granger’s use of Twitter reveals an interesting interplay between the expected ways in which users engage with a platform like Twitter and the more subversive appropriations of the space. In this case, a writer like Granger is able to act provocatively, through the emergence of affordances that are created when various elements converge: a social network, an interface for self-documentation, a social exigence to share one’s personal experience, and a cultural taboo that needs deconstructing. A similar assemblage of factors establishes affordances for writers in



other Internet spaces to engage in this kind of activity. Many of the personal narratives of illness that I will discuss in the last two chapters, authored by individuals living with illnesses, self-consciously assert the importance of rejecting hegemonic understandings of what it means to live a normal life. Their narratives provoke readers to reorient expectations surrounding the performance of a “sick role” and to question prefabricated narratives of overcoming and renormalization, particularly in the case of chronic illnesses like multiple sclerosis (chapter four) and degenerative ones like dementia (chapter five).

Of course, even in the Twitterverse, where Kate Granger offers forth her personal story of human vulnerability, there exists a baffling contradiction that originates deep in the core of the corporate social media. That is, even as Granger in her own small way takes a swing at the behemoth of death anxiety that lurks in every shadow of human cultural activity, the denizens of the corporate Internet lay out their plans to “conquer death.” Indeed, the attempt to do so, according to commentary on Google’s forthcoming public health project Calico, capitalizes on the very user-contributed data that Tweeters, Facebookers, Googlers, bloggers, YouTubers and all the rest of us, Granger included, make so readily available (Farr).

In another display of the limitations to user expression in commercialized Internet spaces, in this case on Facebook, we see the repeated censoring of the mastectomy photo, an attempt to shame women’s bodies (particularly those physically scarred by illness) and suppress the conversation surrounding the politics of breast cancer.<sup>9</sup> The case to which I’m specifically referring occurred on the Facebook page of

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<sup>9</sup> A user named Scorchy Barrington used the social justice website change.org to create a petition to Mark Zuckerberg entitled “Facebook: stop censoring photos of men and women who have undergone mastectomies.” As of 27 Feb. 2014, the petition was declared a victory, despite the deletion of photos on The SCAR Project website that day.

The SCAR Project, a photography project geared toward the documentation and destigmatization of post-mastectomy bodies. Facebook deleted images displaying the mastectomy scars of a woman who had passed away that very day; as the first person to be photographed for the project, the post was meant to memorialize her life and pay tribute to her courage. As the moderator notes, “It was the sight of Vanessa’s remaining nipple (the entirety of her other breast having been removed in a mastectomy) that sent Facebook’s censors into an infantile frenzy to protect the public from the horror of seeing a female nipple” (The SCAR Project). After users protested the decision, Facebook authorized the reposting of three of the deleted images—but only the ones depicting Vanessa after her remaining breast “and its offensive nipple” had been surgically removed (The SCAR Project).

This tension, between subversive cultural action and our entanglement within the deep commercial and ideological substructures of the web, is a concern I take up in greater detail in the next chapter in the context of the health-related SNS PatientsLikeMe.

## Chapter 4 | “Big Power and Big Money”: Social Networking the Clinical Gaze

je participe  
tu participes  
il participe  
nous participons  
vous participez  
ils profitent

Atelier Populaire (1968)<sup>10</sup>

The odds are always good that big power and big money will find a way to control access to virtual communities. . . . What we know and do now is important because it is still possible for people around the world to make sure this new sphere of vital human discourse remains open to the citizens of the planet before the political and economic big boys seize it, censor it, meter it, and sell it back to us.

Howard Rheingold, *The Virtual Community* (1993)

Accessibility in the context of the Internet has traditionally examined how online media have the potential to overcome socially constructed barriers to communication, social participation, and access to information. This is the approach taken by Paul T. Jaeger in *Disability and the Internet*, wherein he contextualizes the enthusiasm with which the emergence of the web was met by disability rights activists who envisioned this virtual space as ripe with potential for individuals who were (and are) limited by ableist restrictions in the public sphere (40). Interestingly enough, a similar sort of emancipatory rhetoric characterizes the discourse on patient activism and participatory

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<sup>10</sup> This text belongs to a poster created by students who formed the *Atelier Populaire* during the May 1968 student and worker protests in France.

medicine in relation to new media. Much of this activity has catalyzed around the use of social networking sites, Internet forums, web-based or mobile health management applications, and e-patient communication tools. These media are seen as avenues for “patient-driven medicine” whereby individuals can empower themselves with knowledge, community support, and individualized health plans, all of which, enthusiasts suggest, will amplify patient voices and facilitate the creation of collaborative partnerships with health practitioners.

In the same way that Jaeger problematizes the rhetoric of emancipation related to disability and the Internet by revealing how a whole host of real-world barriers to participation for persons with disabilities have simply been replicated online, I also wish to problematize the technoenthusiast, emancipatory rhetoric of patient activism in the context of digital media (60-61). On the one hand, the manifesto of the e-patient movement as articulated by the Society for Participatory Medicine states: “Participatory Medicine is a movement in which networked patients shift from being mere passengers to responsible drivers of their health, and in which providers encourage and value them as *full partners*” (“Welcome,” my emphasis). On the other hand, some online spaces that claim to support participatory medicine continuously reinforce the identity of the individual as patient. This designation perpetuates the positioning of users under the scrutiny of a clinical gaze, separating body from subjectivity and creating a new entity—“the object of the gaze” (Foucault 83). Furthermore, on sites where the rhetorical exigence is explicitly connected to narratives of normalization, user involvement, in terms of how individuals can communicate and discuss experiences of disease or disability, is undoubtedly restricted.

Therefore, I am concerned here with a different kind of accessibility, something we could perhaps call discursive access. By this I mean the degree to which the

discursive and rhetorical framing of a site of participation affirms the needs and identities of its users. This is an important type of accessibility that measures the rules of engagement according to which users can participate against the expressed or implied goals of that group. The design of a site of participation is crucial to this analysis since it dictates the generic structures, frames of reference, and modes of interaction that are available to users in that space.

While online health-related media achieve this objective with varying degrees of success, in this section I turn to the example of the health social networking site (SNS) PatientsLikeMe (PLM) to explore how the commercialized health social network frames and solicits user participation in ways that constrain the lived experience of disease or disability. In light of the palpable benefits of health social media to facilitate transgressive conversations about illness experience, some of which I discussed in the early part of this dissertation, in some instances, the potentially emancipatory activity that takes place on commercialized health social networks—PLM, for one, and others that may develop as health social media proliferate—is paradoxically, subject to rigidly defined boundaries. These spaces, where the “sick role” and the patient identity are enacted, allow for the *temporary* subversion of norms only insofar as user involvement corresponds to ableist logic and maintains a goal of eventual normalization. Furthermore, user practices within these spaces are rooted in the notion that the body is a source of data that will provide potential answers to physical ailments. As Olivia Banner notes in her study of the “informatic subject” on PLM, “these sites are points of biomediation, where a digital representation of an illness is accepted as corresponding to the truth of the body,” while at the same time, they are also sites “where the social construction of an illness is contoured as well as challenged by people with the illness” (198). Banner connects this biomediation to the obsessive practices of lifelogging, self-

tracking, and the “transformation of affect into data” that “advance a process of informatic subjecthood” (199).

While this is currently not the case with most other online personal health forums, such as Inspire, DailyStrength, and CureTogether, the framing of user experience within the coordinates of a biomedical norm or ideal is unavoidably persistent on PLM, currently the largest health SNS, where the cultural space of the site is susceptible to the governing logic of its commercial agenda. Thus, my argument in this chapter takes quite seriously Eric Topol’s concern “that online health communities will be exploited or controlled by entrepreneurial interest or the life science industry” (237).<sup>11</sup>

Indeed, the nature of the participatory space on PLM is highly influenced by the involvement of various corporate customers, the presence of which establishes an environment of Foucaultian disciplinary control. The central question that persists throughout this investigation must be examined in light of the heavily political economic influences of the site’s existence and growth, that question being: is PatientsLikeMe a locus for the democratic sharing of information, or instead, an opportunity for large corporations to voyeuristically monitor consumer behaviour and attitudes? Perhaps even more importantly, can it be both? On one hand, the arguably useful tools designed for tracking and monitoring health function to prescribe user disclosure through a myopic focus on soliciting information that can be leveraged as sellable data. This greatly impedes the emergence of a productive dialogue surrounding experiences of ill health or disability because it restricts the expression of personal

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<sup>11</sup> The health SNS CureTogether is one example of an ethical approach to Health 2.0 that could be compromised by its recent acquisition by the genetic testing corporation 23andMe. CureTogether is a two-person startup, described on its website as a “social business, currently funded by its founders and angel investment” that shares aggregated, anonymous user data for free with only a handful of reputable universities and research groups. Unlike PLM, the website shares only aggregated, anonymous user data with other users of the site and individual profiles are kept private.

experience to the confines of biomedical categories. By contrast, the site's discussion forums seem to reject the enforced normalization that occurs in other parts of the site, namely the patient profile.

In her study of the chronic fatigue syndrome and fibromyalgia communities on PLM, Banner observes that the "practice of self-quantification" required by the patient profile tool "amplifies a dynamic whereby together patients generally accept the terms offered by biomedicine through which to understand their illnesses" (200). In this study, however, I turn to a different PLM community—the multiple sclerosis (MS) forum—to explore how individuals generally *resist* this dynamic. Indeed, the content of members' contributions and their responses to others' experiences on the SNS reflect a transgressive understanding of illness as a "newly normal" state of being. Therefore, in the first part of this chapter, I focus on the member profiles and activity of the MS community. I chose this segment of the PLM user population because it represents a high percentage of the total members and posts on the site as a whole.<sup>12</sup> In addition, because of my interest in analyzing how communities facilitate an individual's negotiation of his or her "new normal," it was important to study the disclosure of a community of healthcare seekers and partners in care whose lives were affected by an incurable, chronic, and poorly understood, not to mention highly idiosyncratic, illness. Because of these characteristics, discussions of normalcy—both social expectations and personal norms—are important to the MS illness community on PLM.

As the Multiple Sclerosis Society of Canada explains on its website, MS is a highly variable and, in many cases, unpredictable disease of the central nervous system. While little is understood about what precipitates MS, it is a process whereby the myelin, which protects the nerves of the central nervous system, begins to break down.

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<sup>12</sup> As of 29 Nov 2013, the PLM MS community has 35,714 members and 946,913 discussion forum posts.

Current research on the causes of MS points to a complex interaction between environmental and genetic risk factors, although it is believed that neither is the *sole* contributing factor. While MS occurs at any age, it is typically detected between the ages of 15 and 40, and is three times as likely to occur among women than men. Because it disrupts the functioning of the central nervous system, MS can result in problems with balance, mobility, hearing, vision, and memory—however, each individual will experience these symptoms differently (“What is MS?”). Due to this reality, much of the discussion surrounding the disease on PLM is focused on dealing, not only with symptoms, treatments, and procedures, but also with the total disruption that the illness creates to one’s illusion of control and sense of normalcy.

Following this analysis, I discuss how the affordances and constraints of the website, itself, can also be seen to account for the sorts of conversations that are permitted to thrive in these online spaces. The second part of the chapter seeks to expose the complexities and ambiguities generated by the various interests represented on the SNS—the individual users, the corporate partners, and the corporation, itself—with an eye to uncovering the ways in which individual experiences of disease and disability are constructed in the online sphere of PLM. If patient care under the participatory health rubric tends toward a holistic approach, does a site like PLM, which uses a predominantly biomedical model in framing user experience, contribute to or hinder the amplification of the individual patient’s voice?

#### *A note on methodology in cyberethnography*

Current standards in new media studies regarding the analysis of user-contributed content from SNSs, online communities, personal blogs and homepages, and so on are at the centre of ongoing debates in academic research. As the contributors



to Annette Markham and Nancy Baym's edited collection *Internet Inquiry* explore, these are, of course, related to much larger grey areas regarding 'personal' space, privacy, intellectual property, and participation on the Internet, the boundaries and definitions of which remain under negotiation. My research on the MS forum of PLM has taken the form of what is popularly known as 'lurking,' in which I am neither a participant, nor an identified observer of the community. My choice to study the SNS in this way is related to the nature of my research—that is, grounded in textual analysis and close reading of users' written contributions, as well as rhetorical analysis of the web interface, including its layout, structure, and visual composition.

The analysis that follows is not a social scientific study, in which I factor in personal data about contributing participants in order to make conclusions about the users, themselves. Through humanities-based methodologies, I engage in what Shani Orgad calls qualitative Internet research: "the study of the multiple meanings and experiences that emerge around the internet in a particular context. These meanings and experiences can relate to contexts of use (by individuals, organizations, networks, etc.) and/or contexts of design and production processes. The task of a researcher is to inquire into those meanings and experiences and explore their significance" ("Question Two" 34). In my study of the PLM MS discussion forum, I focus on the substance of users' contributions—that is, their writing, image sharing, and other interactions with the site's tools—as representative of their experience; I am studying the way in which they construct their experiences through the structures of PLM, and how they respond to each others' self-disclosure. I assume that the individual writers on the sites that I study are, indeed, who they say they are and have not attempted to collect data on these writers because I see their participation as representative of their experience.

The obvious downside to this online-only methodology, as Orgad notes, is its impact on the sample of participants, since it “is limited only to those who actively participate (e.g., those who post messages) and therefore are visible. However, many online participants are lurkers, but their participation and practices can be extremely significant and highly consequential for understanding an internet-related context. Yet from a discursive point of view, the ‘silent’ are difficult to incorporate into the analysis, as they leave no observable traces” (“Question Two” 43). Obtaining more information on these sorts of users would require contacting participants directly and using surveys or interview questions to discover more about their use practices on PLM. For the purposes of my research question in this chapter, however, I do not believe that this extra contextual information is pertinent or necessary. While it might provide an interesting additional layer of meaning to a larger study, my interest here is in critically analyzing the discourse of participants and the way in which that discourse is framed by the website for various intents and purposes.<sup>13</sup>

The user-contributed content on this site, considered collectively, produces a particular shared experience; it also reinforces or denies certain portrayals or understandings of illness experience, through social processes of validation or dismissal (i.e. what gets written online, but also what goes unwritten or unresponded to). While I certainly do not consider this space as divorced from the other ways in which illness is lived (but, instead, as a part of this process), my scope is limited to the space and content of the PLM website. Like Orgad in her study of breast cancer patients online, I have no interest in comparing and contrasting online narratives with offline ones, since this move simply “reproduces the conceptual and methodological separation between

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<sup>13</sup> Although, it would certainly be valuable to know why users choose to lurk and what value they extract from the website, since they are not concerned with its storytelling and relationship-building components.

the online and the offline. It also constrains our ability to recognize the potential distinctive qualities of storytelling online that are not necessarily comparable to other modes of storytelling” (69). Instead, I understand individuals’ participation on PLM as one of many spaces in which they live the reality of their illness and construct meaning around it. Indeed, the structures of the website and the contributions of participants are deeply connected to and “embedded in a wider culture of health and illness” (Orgad, *Storytelling* 20).

With regard to the issue of user privacy, I have chosen to de-identify user-contributed content by altering usernames and paraphrasing (instead of directly quoting) users. Not only is this necessary because of the corporate control that PLM has over user content (over which it claims ownership), it is also important to the privacy of individual users who most likely regard the spaces of their profiles and disease communities as safe spaces, separate from more public parts of the Internet. Therefore, all usernames that I include in this study have been replaced with fictional ones and, as such, they do not reflect the actual names of participants. Additionally, since direct quotations are searchable and could potentially identify users, all original phrasing has been reworded, albeit with great care, to express the substance of each user’s writing. While I have made these methodological choices in the interests of respecting users’ rights to privacy, PLM is quite transparently a space where user involvement is subject to various kinds of “eyeballs,” including PLM’s corporate partners, as well as other industry representatives who may be lurking on the site. This suggests that the SNS is actually a semi-private space, in which users are required to register, but *anyone* can register and the surveillance of users is considered a part of the site’s governing agenda. It is, therefore, important to keep in mind how users’ awareness of the “lurking researchers” (like me) might influence how they participate and what they choose to

share, since, as danah boyd aptly notes, the collapsing of social contexts online “change[s] the rules about how people can and do behave” (“A Response” 30).

### **Negotiating a “new normal” on the PatientsLikeMe discussion forums**

A significant amount of discussion in the MS forum stems from the uncertainty and fear experienced by individuals with new diagnoses or symptoms. Thus, my analysis of users’ contributions to PLM MS discussion forums centres around the deployment of the term “normal,” as users attempt to redefine the shape of their lives after diagnosis.<sup>14</sup> The recurring question, particularly in MS communities, is: “is this [my experience] normal?” In the case of MS, the notion of “normalcy” is particularly complicated, in the sense that there is no single predictable or even “average” way in which persons experience the illness. At the same time, there are a range of expected symptoms that people with MS often deal with, as well as a common cache of medications, procedures, and treatments that individuals may be prescribed. These introduce secondary sets of side effects and symptoms that MS sufferers may experience in common.

A frequent type of discussion thread on the MS forums on PatientsLikeMe might begin with an individual expressing concern over a new symptom or impairment that they are experiencing and issuing an open question to other forum participants asking whether or not this phenomenon is normal. That is, is it something that others have experienced or been warned about? Is it a sign of something else? In these types of threads, respondents often provide accounts of their own similar experiences, offering advice or a story about how they coped. The response may give practical guidance about a symptom, treatment, or side effect, or simply serve a sympathetic and

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<sup>14</sup> As of 4 December 2013: 10,136 results from PLM, MS group topics.

supportive function. In one such example, only a few users respond to Antonia's concern over an unusual recurring arm twitch, and all seem to agree, based on their own experiences, that Antonia simply overexerted herself and that, unless it gets worse, she does not need to see her doctor. In typical fashion, another user, Maria, provides links to further information, in this case on the topic of twitches typically associated with MS. Of course, Maria self-consciously places quotation marks around "usual" when she refers to these symptoms, in an effort to signal the unsuitability of such a term in the context of MS.

It would seem that a large part of the anxiety surrounding MS in the discussion forums is the very nature of the disease *as* multiplicitous, unpredictable, and idiosyncratic. While other types of illnesses might allow the afflicted at least the minor comfort of 'normalcy' through group belonging to a legion of similarly 'abnormal' bodies or psyches, diseases like MS are perhaps even more stigmatizing in the sense that they prohibit group identification to a large degree—instead, sufferers are joined by the confoundingness of an illness that, at times, alienates them even from one another.

*"New normal"<sup>15</sup> and "living with"*

While metaphors of battle are, of course, central to the way in which many health-related SNS users understand their experiences of illness, a counter-rhetoric also emerges in stories in which members empower one another to think beyond the notion of mere survival. Particularly in the case of diseases like MS, a chronic illness for which there is no cure and no definitive way of predicting the speed of progression, members seem particularly attuned to the necessity of finding a way to live with their condition—

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<sup>15</sup> Many thanks to Natalee Blagden for directing my attention to this terminology.

and, even, to thrive in spite of it. One discussion thread in particular, created as a way for individuals to talk about their hobbies and talents, provides a fitting example of this positive group psychology. Posters to the thread share anecdotes and photos that describe the skills, activities, and creative projects that they either continue to practice or have newly taken up since their diagnosis with MS. These include activities as diverse as painting, photography, home renovation, carpentry, piano-playing, cake-making, acting, crafting, juggling, camping, gardening, cooking, writing, and so on. The topic originator's goal is blatant from the beginning—to combat the dangerous and self-defeating fixation on the overwhelming physical and/or cognitive losses sustained by those diagnosed with MS. The thread presents an opportunity to refocus attention on personal success and to promote the self-worth of contributing members. While the space of the PLM discussion forums certainly provides an arena in which it is okay to be 'broken-down,' 'sick,' 'unproductive,' and 'whiney' (all deprecating, culturally constructed labels that sufferers of chronic illness contend with), this space also presents an arena for asserting alternative (and perhaps decidedly non-Western) values regarding what it means to live well.

These two dynamics of the MS discussion forum on PLM are mutually reinforcing, in the sense that they allow contributors to: 1) acknowledge the way in which their new bodily or cognitive states pose a threat to socially acceptable ways of living in Western society; 2) share personal stories about sickness, frailty, unhappiness, disorder, alienation, confusion, and frustration that are unacceptable or unwelcome in other, more mainstream spaces of daily life; and 3) collectively imagine and promote alternative modes of living and finding self-actualization that may resist master narratives of success. All of these affordances are accessed through the conceptual lens

or framing device of a “new normal” that users define for themselves through the reflective and interactive community space of the PLM discussion forum.

Indeed, as I discovered through countless hours of reading through discussion threads in the MS forum, many contributors to PLM couched the experience of reorienting their lives in relation to an MS diagnosis in the language of normalcy and difference. The ever-shifting terrain of MS, as lived by those diagnosed with the illness, has led many to refer to new sets of symptoms (or even the very unpredictability of symptoms) as constituting their “new normal.” This deployment of the concept of “normalcy” is worth investigating in greater detail, since it actively disrupts the very notion of a norm. It implies that normalcy is, indeed, as idiosyncratic as the experience of MS. It points to the notion that an individual body dwells in its own, individually articulated realm, in which there persists the reference point of a *personal norm*. This doesn’t square up so nicely with the notion of a hegemonic norm against which, socially and culturally, we delineate the boundaries between ability and disability, normalcy and deviance. I suggest that use of such language represents a political stance. Indeed, in referencing “my new normal,” individuals actively resist the expectation that their bodies, their minds, their work, their relationships, and so on, conform to the accepted and culturally endorsed standards that define the norm.

Therefore, I argue that the deployment of the term “new normal” is a subversive move that works to disrupt the notion of bodily normalcy. The new normal that users describe is, in fact, a resistance to the norm—it acknowledges the idiosyncratic nature of the body (in this case, the body with MS), the flexibility and mutability of bodily states from day to day or month to month, and the lack of control that one can assert over one’s embodiment. That is to say, the new normal is an ongoing process of continually adjusting one’s expectations of the body, of self, and of others according to constantly

shifting (and unpredictable) conditions of existence in a way that honours personal values and wellbeing. In contrast to the personal profile charts that I will discuss in the next section, which unilaterally assert a biomedical norm, users' personal stories communicate the importance of asserting and accepting the abnormal (that is to say, doing away with the norm altogether).

In one telling discussion thread, Sankavi writes about her resistance to thinking about the future or trying to make sense of what is happening to her. She comments that every time she seems to grasp a new understanding of her reality, it quickly changes once again. The unpredictability of the illness, as well as the feeling of loss that accompanies a diagnosis—particularly a loss of hope for the future—is an experience that many posters write about through the language of bereavement. Stacey observes that she and her friends with MS experience the grief of a lost sense of self and the disruption of future plans. Henrietta writes of her life before MS as a former life that she now mourns. Maria notes that each new change brings about this same experience, so that, as Ankita expresses in a different thread, the grieving process is ongoing as physical and emotional states fluctuate. As many point out however, this is a “normal” part of the experience of, not just MS, but of life itself. As Roisin elucidates, all humans must accept change as an unavoidable condition of existence—it just so happens that those with MS face the threat of mortality at an earlier life stage than most of us expect.

This “dilemma,” as Roisin aptly describes it, of facing how to function in a transforming body, is prevalent in many of the MS threads. In one revelatory example, in a discussion thread about embracing one's “new normal,” Wenchao describes the difficult decision she made to donate all of her clothes and shoes that she could no longer wear due to MS-related changes. She had been holding on to these personal items for the past five years, with the hope that her body would one day return to its



former state. As she explains, the act of giving away these possessions felt symbolic of having given up her determination to be an “old self” and moving toward acceptance of her new reality. At the same time, she sees this new self, who cannot fit into her clothes and shoes, as a stranger whom she is still getting to know.

Wenchao’s self-disclosure regarding her experience of abandoning an obsolete sense of self highlights the tensions at play in many individuals’ experiences of MS—the desire to protect the sense of a stable identity, while at the same time finding the flexibility to adapt certain parts of oneself, including those markers by which we often define “the self,” to new physical and cognitive states. Her discussion thread and other similar ones create a space in which writers can negotiate the constraints and opportunities that arise in the gap between an “old” and a “new” self. Pat opens up about this process of redefining in the context of her retirement, explaining how she once saw her work as a large part of her identity. The transition to retirement is challenging both because of her self-judgment and because of the ways in which she feels others regard her. The crisis these individuals describe is not simply one of health, but also of compromised identity and a flagging sense of self-determination.

The uncomfortable space between an “old” and a “new” normal can be seen as a product of the social category that Susan Wendell suggests young and middle-aged people with chronic illnesses inevitably inhabit. In an article that puts forward the necessity of understanding chronic illness as disability, Wendell, a disability activist/scholar and chronic illness sufferer, explains that this social group is not easily understood or accepted. We are considered too young to be ill for the rest of our lives, yet we are not expecting cure or recovery. We cannot be granted the time-out that is normally granted to the acutely ill (or we were given it at first and have now used it up, over-used it), yet we seem to refuse to return to pre-

illness life. We are not old enough to have finished making our contributions of productivity and/or caregiving; old people with chronic illnesses may be seen to be entitled to rest until they die. And we are not expected to die any time soon, so we are going to hang around being sick for a long while. Cheri Register calls us 'the interminably ill.' ("Unhealthy" 164)

The discussion forum participants in the PLM MS community repeatedly grapple with their status as "interminably ill." In their journey to understand their experiences and to continue to live well with MS, many of the posters to the MS forum are collectively working through the social, emotional, interpersonal, and psychological challenges that are attached to the unstable conditions of their embodiment. As their bodily states collide awkwardly with the normative structures established within their physical and social environments, environments that produce new kinds of disability in their lives, the individuals who seek community interaction on the PLM threads are also actively involved in resisting ableism. They question the norms that may have, at one time, been applicable to their lives—or that they failed to meet when their bodies, prior to diagnosis, manifested mysterious symptoms; the ones that continue to carry the oppressive weight of a past instantiation of the self, of some ideal but unachievable way of being.

Negotiating a new normal means not only adjusting one's expectations of self, but also managing others' expectations. As Jorge points out, contemporary Western society does not exactly cultivate an attitude of caring compassion among its members. In one thread, the user suggests that this situation relates to empathy, or a lack thereof—a failure by those "outside of MS" to understand the challenges of the illness. Indeed, one of the most painful challenges is not the physical, phenomenological

experience itself, but the social alienation produced by deeply ingrained ableist biases that friends and family members may hold.

In a discussion related to managing social stigma in the transition to medical retirement, Aren begins the conversation with a relatable anecdote about one person's naïve question: what does Aren, who is medically retired, do with all of his free time? This discussion thread is noteworthy because it begins with a mostly ironic question. The central problem is that "free time" is an illusion with MS, since meeting one's own basic needs becomes a full-time job and activities that may once have occupied one's free time are oftentimes inaccessible. As Aren explains, his daily activities revolve around managing his extremely tight disability income, attending medical appointments, preparing insurance paperwork, sleeping, grocery shopping, and doing a host of other mundane tasks that are now extremely time-consuming and physically or mentally strenuous because of his illness. The thread evolves into an interesting discussion about the sick role, in particular, allowing users to express a shared understanding of the daily limitations to 'normal' productivity that MS instates.

For some, success is measured by "just surviving." Others communicate the importance of performing daily tasks according to one's own schedule in order to protect physical and emotional wellbeing. As Maria notes, her day is very average, except that she does not work in a "real job" and all of her daily tasks must be done at a pace that is healthy for her. As Andrzej expresses, everything on his "daily chores" list takes much longer than it used to and this is something he and those around him have simply had to accept.

Evidently, much of the anxiety expressed in the discussion stems from having to answer the questions "what do you do?" or "what have you been up to?" and not having anything acceptable to say. While the thread certainly becomes a space to vent

about a lack of support from self-interested, naïve, or willfully ignorant friends and family who don't understand the often-invisible symptoms of MS, more solutions-oriented contributors encourage other members to focus on meeting personal goals and to disregard what is socially acceptable in favour of what is personally necessary. Many posters encourage positive psychology among the group, choosing to interpret their illness experience as an opportunity to slow down and enjoy the elements of their lives—friends, family, pets, nature—that they consistently took for granted during their hectic pre-MS lives. Buddy suggests that the obligatory slowed pace of life with MS allows for new opportunities to take a leisurely stroll through life—something that the “old normal” did not permit. Sharon, reiterating Buddy's sentiment, says that although she would never wish for an MS diagnosis, she chooses to interpret it as a blessing that has allowed her the freedom to enjoy life at a relaxed pace, observing things she might otherwise have missed.

The acknowledgement by some MSers of their counter-cultural ways of living in the world vocalizes one of the greatest challenges of chronic illness, while also facilitating a discursive space for reimagining ideals of success and happiness. At the same time, they face the pressure—which they often regard as a pragmatic social need—to fit in, to “pass,” to be accepted as capable, to have others respect their limitations without dwelling on them. Wendell addresses this pressure by pointing to the tendency within disability activism to resist medicalization through various strategies, one of which is “to downplay the realities of fluctuating impairment or ill health” (165). This tendency to promote the figure of the ‘able-disabled’ and the “reluctance among disability activists to admit to weakness or vulnerability” only helps to perpetuate the “pressure to conform to an inspiring version of the paradigm of disability. Those people with disabilities who can best approximate the activities and

appearance of nondisabled people (that is, those who can make others forget they are disabled) will be allowed to participate most fully in the activities of their society” (Wendell, “Unhealthy” 165). Ultimately, this also influences the chronically ill, those who straddle the tenuous line between “illness” and “disability” that many disability activists wish strongly to assert. As Wendell notes, the step to distinguish one type of vulnerability (illness) from another (disability) only works to further stigmatize the subject position of those with chronic illnesses, including chronically ill disabled people.

In the discussion threads, individuals share their anecdotes about their ongoing efforts to manage how family, friends, and strangers perceive them and their abilities (a distinction that seems difficult to make when so much of personal identity seems subsumed by “what we do”). Many put forth stories that trace conflict to others’ faulty assumptions about the storyteller and his or her illness. One extremely popular thread is full of examples of individuals facing expectations that are incongruent with their abilities. The discussion is one of the longest threads in the PLM MS forum, with over 6,000 posts since its inception, when it was originally created as an all-purpose space to “say anything” about MS. In his introductory post, the topic creator suggests a number of writing prompts, one of which challenges respondents to discuss how others react to their MS. One respondent writes of her frustration over the inappropriate expectations that others have of her, which are sometimes overly high and sometimes insultingly low. She relates an anecdote about a friend for whom she’d promised to bake a birthday cake. Having sold her cakes for many years, Margy takes pride in this work and considers it one of her special talents, an activity that she continues to pursue happily in spite of numbness and tremors in her hands. When her friend attempts to cancel the order, worrying that Margy has too much on her plate, Margy is forced to convince her friend that she can and *wants to* create the birthday cake; her friend’s paternalistic

attempt to ease her burdens instead becomes a stressful conflict in which she must defend her abilities. Margy writes about the frustration of having to prove herself. She writes of her desire to be given the opportunity to make her own decisions about what she is capable of achieving, noting that her limitations change from day to day. Having a goal to accomplish, even if it causes a degree of physical or mental struggle, seems more integral to Margy's personal wellness than the admonition to rest. The gist of her post addresses the problem of negotiating a sense of normalcy with other people in her life while she adjusts to MS. Her friend's well-meaning attempt to support her actually creates an obstacle to her efforts to live well. Margy expresses the root of the issue well when she identifies the enforced invalidism that her friend seems to promote; however, there is evidently a drive on Margy's part to prove herself capable—undefeated by her MS. Ultimately, her own expectations of herself, and not others' expectations, based on normative social roles, will determine the shape of her life with MS.

The persistent tension in MSers' web forum stories, between defiantly asserting their right to be 'unproductive' (in a capitalist sense) and their social prerogative to pass as normatively able-bodied, is especially salient when probed in relation to the structure of the PatientsLikeMe website, in particular, its system of data collection. This is mostly for the reason that the focal point of the site—the users' entered data in the form of profile charts—attempts to map illness relative to the common or average user's experience of a disease. In certain parts of the profile, PLM is also interested in comparing an individual's emotional or physical state to “unstated but determining norms” (Garland-Thomson 7). In this context, problematic questions arise. For which metrics is it important that a user compare herself/himself against an “MS norm” and when is it important to compare oneself against a “healthy norm”? While users express some appreciation for the PLM tools that allow them to track their own personal

medical record—flareups and regressions, new symptoms or relapses—there also exists some tension between the “norm” that individuals allegedly deviate from and the fact that there is no “normal” MS. Another important question regarding the profile charts is, how well or poorly (to what degree of effectiveness or holism) does the data actually reflect the full experience of an individual’s illness? Comments in the discussion forums suggest that the profile chart data is heavily tilted in favour of biomedical metrics, to the detriment of other data related to personal, social, and emotional states—factors which, users assert, are equally instrumental in determining well-being. In one thread, Martina compares how she feels on a day-to-day basis to how PLM asks her to rate her disability, noting that she would rate herself entirely differently if the scale reflected her personal sense of wellbeing, rather than a medical one. Similarly, Andy writes that, while he reports his MSRS<sup>16</sup> for the purposes of PLM, there are other rating scales he uses, such as the subjective ‘good MS days’ versus ‘bad MS days,’ or, at a more spiritual level, an everyday ‘rating’ of feeling blessed.

As I will discuss in the next section, the picture reported by a user’s profile charts, then, is a rather incomplete account of their illness experience, tied to a biomedical understanding of illness. The PLM profiles reflect an instance of what, in 2007, *Wired* magazine editors Gary Wolf and Kevin Kelly heralded as the “Quantified Self” movement (Wolf). This perspective on the body’s functioning upholds an antiquated model of health, in which the human body is seen as a complex machine or computer that can be monitored, tuned, modified, or even hacked. Indeed, the PLM profile charts might be seen to mimic the medical notes of a mid-twentieth-century

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<sup>16</sup> Multiple Sclerosis Rating Scale, a tool developed by PLM to facilitate “patient-reported assessment of functional status” that would “accurately quantify the level of MS-relevant disability experienced by patients across a range of domains affected by demyelinating lesions” (Wicks, Vaughan, and Massagli).

doctor. As I will argue, this is a backwards step and a missed opportunity for PLM to support its users' needs—a decision made to protect neoliberalist economic interests.

### **Producing a statistical “norm” on the PatientsLikeMe profile**

PatientsLikeMe is a social networking site directed specifically toward the end of accruing a vast body of collective intelligence; by linking individuals experiencing various forms of ill health or disability, the site has become a veritable data pool of experiential expertise. While the marketing of the site to individual users most strongly emphasizes its social purpose, ostensibly, its primary function as a for-profit organization reflects, more accurately, this data collecting impetus. The statistical collation extends far beyond the social networking needs of its users in the sense that data disclosed by patients is collected for commercial profit—that is, sold to various partners, including research, pharmaceutical, and insurance organizations. While PLM is fairly transparent about this practice of anonymized data sharing,<sup>17</sup> the site's economic imperative suggests that the tools and methods for communicating information that are provided to 'patients' on the site are developed, not necessarily to facilitate the sharing of experiential knowledge, but first and foremost, to maximize profitability.

PatientsLikeMe was co-founded in 2004 by Benjamin Heywood, James Heywood, and Jeff Cole, all engineering graduates from MIT (“About PatientsLikeMe”). At the time of writing, PLM is a free service composed of over 250,000 members. Prior to 2013, user profiles on the site used one of two privacy levels: “visible” (only PLM members could see the user's profile and contact them) or “public”

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<sup>17</sup> In its “Openness Philosophy” and associated “Privacy Policy” linked from its homepage PLM informs users that “Shared Data” (from profiles, forums, and other places on the site) is de-identified and shared with third parties.



(any visitors to the site could see the user's profile, but only members could contact them). However, in August 2013, PLM 'closed' the site by requiring all visitors to register an account in order to access its content.<sup>18</sup> Prior to this, unregistered visitors also had access to a plethora of community information, including: 1) public profiles; 2) treatment reports that evaluate specific drugs, equipment, therapies, procedures, lifestyle modifications, etc.; 3) symptoms reports that discuss prevalence and common treatments; and 4) information about ongoing research and clinical trials. The public nature of these pages allowed nonmembers access to a significant amount of disease-specific data and the opportunity to gather information without directly participating in the activity of the community.

Now, upon required enrolment, the new user is asked to identify as a "Patient," "Caregiver (and want to track someone else's health)," or "Clinician or Research Scientist" ("Join"). If the new user selects "Patient" or "Caregiver," he or she can, optionally, identify with one or more "conditions." As a user types his or her condition (or that of the person he or she supports) into the search bar, a list of options based on predictive text technology appears. The user then selects one of the existing patient communities from this list. Users may also provide basic demographic information if they wish; however, the site recommends that users remain as anonymous as possible. After users register, they are initially prompted to provide an immediate report using the "InstantMe" option which asks, "How are you feeling now?" and, optionally, "Why?" The goal of this feature is to attract immediate user participation following initial registration and to compel daily user participation, with the suggestion that "answering this one question every day can help you discover how your well-being changes by the time of day, the day of the week or the seasons" ("My Profile"). Users

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are then prompted to provide a basic profile (age, sex, location, biography) and disclose health information (condition history, treatments and therapy, symptoms and side effects, weight).

The result of this rather time-intensive and methodical data collection is a series of clear, coherent and visually appealing graphs representing various aspects of the patient's health status that henceforth appear on the user's main profile page. A "patient icon" also functions to represent the user's experience, displaying data quality, health status, and time since diagnosis. Data quality is measured, using a star rating system, according to the level of patient commitment to the site, with three being the highest level; one star is awarded for background disclosure, currentness, and completeness, respectively. Essentially, this functions as a ranking system as well as a compulsive icon urging users to participate as actively as possible (ideally, inputting data on a daily basis) in order to increase and/or maintain this symbol of expertise. The patient's health status is represented by a small stick figure that may be colour coded according to mood (i.e. for mood disorders like anxiety or depression) or dissected into sections corresponding to motor functioning and colour coded according to severity of symptoms in each region (i.e. bulbar, arms, chest, and legs in the context of amyotrophic lateral sclerosis). Hovering over an "i" (info) symbol expands the patient icon to reveal the patient's age, sex, location, disease-specific health indicators, and latest "InstantMe" report.

Use of the PLM site demands, at a very basic level, that users identify or define themselves as "patients." From the outset, this designation positions users under the scrutiny of the clinical gaze that Michel Foucault analyzes in *The Birth of the Clinic*, separating body from subjectivity and creating a new entity—"the object of the gaze"—the "patient" (83). This categorization exists regardless of whether or not members are

actually patients, implying that use of the site as a form of cyber-healthcare automatically inserts individuals into this passive role. Similarly, the role of patient also situates individuals in a particular realm of “difference” in which they are defined by the physical or mental “abnormalities” they experience. All parts of the profile are specifically dedicated to characterizing, classifying, and depicting impairment; extending from this, users’ identities on the site are defined by their experiences of disease. This is not to say that the site should, or even could, fully represent an individual subject; our online representations are almost always fractured and incomplete. However, this system certainly contributes to a hegemonic discourse of disease in which individuals with illnesses or disabilities become defined by a quest to regulate difference and normalize the body.

Despite the rhetorical framing of the site, I do not wish to suggest that the sharing and community-building that takes place here is exclusively negative; much of the interaction on PLM, as my discussion in the first part of this chapter revealed, is invaluable to both emotional well-being and disease management. However, the very notion of finding “patients like me” implies the pre-existence in users’ lives of a status quo of alienation or difference that requires them to seek out solidarity among others with similar experiences. In this way, the site reinforces the notion that illness or disability equals exclusion from other conventional avenues of group belonging; that in order to find empathic others individuals must seek out people “like them.” While a certain level of personal experience may be a prerequisite to genuinely understanding a person’s situation and to providing useful advice, at the same time, the language of similarity and difference embedded in the very name of the site subscribes to the notion of disability and illness as experiences that take place outside of the realms of “normal” experience. The language of similarity is further emphasized in the “My Conditions”

tab of the user profile, which encourages users to “enter all of your current, resolved, and misdiagnosed conditions to find patients more like you” (“My Conditions”). Interestingly, the goal is not to find *more* patients like you, but to find patients who are *more like you*. The underlying implication is that individuals with similar groups of conditions are better equipped to support one another and to share the *right* kinds of information. While this perspective may be true from a purely pragmatic, medical, or symptom-based standpoint, it contradicts evidence on other parts of the social network that experiential knowledge sharing and empathic support happen between individuals with vastly different medical diagnoses.

In attempting to understand their past and present situations, users are also invited to judge or weigh their experience of illness or disability against the “average experience” of other users with similar conditions. This element of disease management, in appealing to statistical evidence regarding what is normal or exceptional in terms of disease symptoms, treatment side effects, etc. further perpetuates normative discourse. In his analysis of the construction of disability in *Enforcing Normalcy*, Lennard Davis traces the development of the “norm” from which the disabled body allegedly deviates. As he elucidates, this fixation on normalcy developed in close conjunction with the field of statistics, which emphasized average or mean states of being (Davis 27). The heavy prominence of line graphs as a way of charting patient experience on PLM is certainly relevant here. In the “Treatments” tab, for example, users can compare their reactions to a treatment using a graph that compiles data reported by all site members who used the same treatment. Davis notes that, in statistics, “the average becomes paradoxically a kind of ideal” (27). While individuals would likely prefer to deviate from the average in these graphs—to exhibit an exceptionally positive reaction to a treatment or to be experiencing fewer side effects

than average—the “norm” that the average instates introduces a sort of “normality,” even in the midst of “abnormality.” The very reliance of the site on linear, statistical modes of narrating disease experience is problematic for the rhetorical weight that these modes carry in reinforcing the binary of normalcy and difference.

The impetus to reject impairment in order to achieve an average, moderate, or middle state is further emphasized by member profile charts that provide “InstantMe” and “Quality of Life” reports. The “InstantMe” component asks users to rate how they are feeling at any given time on a five-point scale from “very good” to “very bad.” The “Quality of Life” indicator chart presents user-entered data regarding social, mental, and physical qualities of life; users are asked to “think back over the past 30 days” and report answers to over twenty symptoms with the following responses available: none of the time, a little of the time, some of the time, most of the time, all of the time. The symptoms are all negative, for example, “how much has your health limited you in accomplishing as much as you would like to?” An answer “none of the time” corresponds to a green happy face, while an answer “all of the time” is signified by a red sad face. Not only are these rankings based on “unstated but determining norms, a hypothetical set of guidelines for corporeal form and function arising from cultural expectations about how human beings should look and act” (emphasized by the use of emoticons), they are also entirely subjective (Garland-Thomson 7). As a result, the data that these graphs contribute to general statistics about patient symptoms and overall health is inevitably skewed by the inescapable subjectivity of such reports.

The cycle of normativity that the site promotes reflects an orientation toward and reinforcement of what Judith Butler refers to as a “pure body” (Butler qtd in Tremain 34). Through the use of categories—conditions, symptoms, treatments, and side effects—and their various subcategories, the site implicates and reinforces this pure

body—one that does not, like the diseased or disabled body, “[inaugurate] an explanatory need,” but “eludes [explanation] by virtue of its physical anonymity” (Mitchell and Snyder 60). The spectre of this elusive (because illusory) body is ever-present on the site, and is reinforced as users weigh themselves against it. More importantly, from the perspective of the biomedical industry, the site’s efforts to enforce a pure body dwell at the core of the company’s profitability, as well as the financial success of its corporate customers who also depend for survival on the disciplinary power of normative discourse about the body. In implying a pure body through the documentation of ‘anomalous’ bodies, PLM engages in the political discourse of Foucaultian biopower, a point that I will expand upon shortly; symptoms or conditions function in the same way that Tremain notes impairments emerge, “as unitary and universal attributes of subjects through the iteration and reiteration of rather culturally specific regulatory norms and ideals about human function and structure, competency, intelligence, and ability” (42).

In the same way that the site attempts to regulate—to reinforce the ideals of liberal humanism—it also conceives of the deviant body as fragmented or incomplete. The body, considered “broken” itself, is broken down into manageable sections; indeed, an image that exemplifies this movement toward fragmentation quite well is the small stick figure on the patient icon of persons with amyotrophic lateral sclerosis (ALS) that attempts to represent the degenerative nature of the disease. As mentioned previously, the stick figure’s dissected pieces represent motor functioning and severity of symptoms in each region. This approach to representing and understanding the “abnormal” body as broken down at the same time implies that the body of the “normal” subject is constituted by an originary wholeness; that the body becomes fragmented only as it becomes anomalous. While many scholars, including Vivian

Sobchack, David Wills, Jane Bennett, and Cary Wolfe have elucidated a posthumanist understanding of embodied subjectivity and agency as unavoidably fragmentary, the antithesis is promoted on PLM, where the notion of fragmentation is *only* deployed in the context of a physical body that is constructed as fragmented, faulty, or malfunctioning.

Arguably, PLM reinforces the same sort of “hegemony of normalcy” that Davis identifies in the novel, a form of writing that he says “promotes and symbolically produces normative structures” (41). Davis’s observations are particularly insightful in the context of the illness narrative tropes of overcoming and rehabilitation—narrative structures that seem to be replicated through the PLM framework for sharing one’s personal illness experience. On PLM, the desires to track progress and monitor health status contribute to a goal of normalization, whereby the deviant elements of the narrative, as represented by the linear graph, will eventually be resolved by the imposition of normalcy. In this cyber-representation of the clinic, disease sufferers and disabled individuals view their bodies as mechanical systems to be repaired, rather than complex organisms that operate according to, not only biological, but also social and cultural structures. In subscribing to normative categorizations about corporeal health and wellbeing, PLM overlooks factors beyond the site of the individual physical body that might create, aggravate, or skew perceptions of disease or disability.

The simplicity that profile visualizations offer, in categorizing and defining, functions to elide the complexities of human corporeality and the intricate ways in which notions of health and disease are socially and culturally constructed. Further, in the sense of the website’s economic motives, the affordances provided through data processing and profile visualizations must be seen as, first and foremost, compulsive technologies that encourage users to share more data in greater detail in order to take

full advantage of the platform's disease management tools. The site's interest in containing corporeal deviance within a manageable space and its basis in Foucaultian clinical epistemological myths to give semiotic meaning to experience ensure that the individual body is constrained within a system of "regulatory control" (Foucault qtd in Epstein 4). While the social networking tools that the website provides facilitate community formation and individual disease management, the central profile visualizations limit the frame of reference for discussion to the categorizations and normative values of a medical discourse that, paradoxically, seeks to neutralize and objectivize personal disease experience.

#### *Commodification and disciplinary power*

The regulated nature of user disclosure in the patient profile is directly related to the surveilling gaze of corporate customers, which monitors even discussion board activity. The role of commercial interests in determining the cultural function of PLM cannot be underestimated. As I will explain, the marketing of the site to particular audiences of researchers and industry partners exposes a rather different perspective with regards to how PLM views its users and the ways in which it prioritizes, not culturally or socially productive "sharing," but commercial opportunism.

While information about the use of sold data is not immediately offered to users when they register for their free accounts, several links from the PLM homepage make explicit the company's "Openness Philosophy." This component of the site emphasizes the importance of sharing information in order "to effect a sea change in the healthcare system" ("Openness Philosophy"). The manifesto goes on to explain the site's belief "that the Internet can democratize patient data and accelerate research like never before. Furthermore, we believe data belongs to you the patient to share with other



patients, caregivers, physicians, researchers, pharmaceutical and medical device companies, and anyone else that can help make patients' lives better" ("Openness Philosophy").

On a dedicated "PatientsLikeMe for Partners" website, a very different story is told about the function and purpose of the activity that happens on the SNS. The "Products & Services" section advertises a rather explicit agenda: "PatientsLikeMe collects such a rich amount of patient data – including genotype, individual genetic mutations, phenotype, quality of life measures, treatments and symptoms" and "sells access to our comprehensive research platform, which contains a real world population of 115,000+<sup>19</sup> patients with over 1,000 conditions" ("Custom Research"). Rather than endorsing activities like sharing and connecting with likeminded others, the site directed toward corporate partners invites customers to surveil and exploit users, or to use the language of PLM, to monitor activity, access data, and identify market demands and opportunities. From this end, users of the site are merely opportunities for access to a rich store of market data. Here, not only is patient opinion assessed to determine the viability of potential healthcare products and services, but users also fall into the cycle of commodification as they, themselves, become the substance of products and services sold to corporate partners. Further, despite the rhetoric of openness that the site endorses, the information that it collects is not open to any research group with the means and inclination to advance knowledge on a particular condition; it is open only to those groups willing and able to pay.

This situation also means that the site is ripe with potential for unethical use by commercial organizations that create fake profiles on the site in order to scrape valuable

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<sup>19</sup> The current number of registered users on PatientsLikeMe, at the time of writing, is approximately 250,000, suggesting that this page contains outdated information.

patient data. In May 2010, PLM caught media research firm Nielsen using sophisticated software to copy conversations between users in disease community forums. Nielsen works with a variety of clients, including major pharmaceutical companies, to monitor the online activity of clients' consumer bases. The company collects relevant data and sells it to its partners. PLM discovered three other fake accounts linked to Nielsen that were actually computer programs extracting data and shut them down immediately, sending a message to users via the PLM blog to inform them of the security breach (Angwin and Stecklow). A *Wall Street Journal* exposé on the data scraping incident interviews legal experts who say the practice is legally questionable, but not necessarily illegal. The incident reveals the troubling reality that virtually all information that individuals make available online can be scraped and sold for consumer market research. When PLM chairman Jamie Heywood notes in his interview with *WSJ*, "We're a business, and the reality is that someone came in and stole from us," he highlights the true issue at stake for the company (Anglin and Stecklow). In light of this reality, CBS MoneyWatch commentator Jim Edwards argues that PLM is "more villain than victim" in the Nielsen scandal. In his article, Edwards reminds readers that PLM "makes its money by persuading patients to give up the kind of private data that once rested securely in a locked filing cabinet in your doctor's office." Edwards highlights the worrisome bottom line of such a privacy breach: "There was no privacy violation. Rather, Nielsen found a way to extract PatientsLikeMe's data without paying PatientsLikeMe to do so."

Adding to the website's emphasis on commercialization, the very activity made available to corporate customers falls all too easily within the bounds of Michel Foucault's theory of disciplinary power. Tremain elucidates Foucault's concept of biopower in relation to what she sees as unstable (or illusory) boundaries between the

categories of 'impairment' and 'disability.' Discussing the ways in which the category of impairment was created to enable the continued regulation of 'deviant' bodies, Tremain notes that "technologies of normalization are instrumental to the systemic creation, classification, and control of 'anomalies' in the social body. Foucault argues that the function of these techniques is to isolate so-called anomalies, which can in turn be normalized through the therapeutic and corrective strategies of other, associated technologies" (36-7). This explanation is remarkably apt in the context of PatientsLikeMe, the work of which directly contributes to the development and proliferation of "other, associated technologies" like pharmaceuticals, medical devices, health plans, etc.

While some might argue that the data mining taking place on PLM simply leverages the built-in affordances of networked social media platforms, it is imperative to understand these practices as also actively constructing narratives about disease and disability through the information PatientsLikeMe requests from users and the ways in which it frames this disclosure. As discussed earlier, the categories and visualizations displayed on patient profiles conform to particular notions about 'normal' versus 'deviant' bodies. Opportunities for sharing in this context force users to compare their own conditions or levels of wellbeing to some unstated, yet agreed-upon norm or ideal.

At the heart of this situation is the question of who decides upon the categories through which users are asked to identify their experiences. When adding a condition to a PLM profile, users are asked to enter the first few letters into a search field and then select the appropriate label from the list of results. A user cannot simply identify with Depression, but must select what *kind* of depression from a lengthy list: Reactive Depression, Major Depressive Disorder, Postpartum Depression, Mild Depression, Dysthymia, Seasonal Affective Disorder, Bipolar I, Bipolar II, Atypical Depressive

Disorder, or Schizoaffective Disorder. Corresponding to each item in the dropdown list is the number of users who have listed this condition on their profile, as if this information might affect the user's choice. After indicating a condition, users are expected to select symptom information from a default list. As the information box on this page indicates, "All PatientsLikeMe members start with five symptoms: Anxious Mood, Depressed Mood, Fatigue, Insomnia, and Pain. They are good indicators of your health regardless of your condition(s)" ("My Conditions"). Depending on the condition you add, other 'common symptoms' will be listed; for example, the dysthymia condition adds eleven additional symptoms to the list, and users can add new symptoms or remove non-applicable ones. These default lists represent another manifestation of disciplinary power, whereby a finite number of authorized conditions or symptoms indicate to users which of their ailments are valid, how they should be named, and what they mean. This component is an extension of the obsessive need to categorize and differentiate that propels the commercial pursuits of the healthcare industry and the epistemological regime that supports this commodification.

A noteworthy example of such activity—which also perfectly represents the clashing dynamics of users and the corporation—is seen in a thread where a woman humourously, but also rather despondently, catalogues the physical changes MS has caused. In her post she lists various consequences that she connects to her illness, including loss of self-esteem, dry skin, hair loss, abnormal hair growth, weight gain, and other bodily changes. In the list, she suggests that her breasts now resemble banana peels and, as the algorithm does when an individual references a certain drug or treatment like Tysabri or Tylenol, PLM tags "banana." This means that the word is now hyperlinked to a PLM treatment page about bananas where users can see which other members with MS are eating bananas as part of their treatment regimen. Because the

data-collecting algorithm cannot detect the context of the word's usage, it cannot distinguish between a user creating a metaphor to describe her experience and a user discussing her treatment regimen in a literal way; this example, itself, is perhaps a useful metaphor for the reductive way in which PLM and the quantified self movement envision health.

Added to the regulatory power of normative biomedical language, the seemingly omniscient voice of PLM, which communicates through regular notifications, reminders, and instructions, also works to enforce a sort of disciplinary control. For users who withhold information about symptoms, for example, the following finger-wagging notification appears: "You haven't filled out a complete symptom survey in over 30 days. To make your symptom and treatment reports meaningful, it is important to report on all of your primary symptoms regularly" (PatientsLikeMe). If a user attempts to add treatments before entering details about her condition and condition history, she receives the following notification: "Sharing a bit more about your condition will help put your information in context." ("My Treatments"). Similarly, the "My Conditions" tab encourages users to share as much as possible: "Enter all of your current, resolved, and misdiagnosed conditions to find patients more like you" ("My Conditions"). At the same time, however, upon registration the user is informed politely of the freedom the site allows: "you can share all your conditions, or just the ones that you are most interested in exploring at PatientsLikeMe" (PatientsLikeMe).

The work of trolling moderators also functions in a similar way; this panoptical brand of surveillance watches hawk-like over user activity, rewarding excessive sharing and discouraging neglect of the site's opportunities. This mechanism is persuasive, since it convinces users that their participation is directly related to their ability to extract "meaning" from their situation. In the Multiple Sclerosis community, this

presence is most clearly evident through the postings of the moderator who oversees all activity in the message boards to ensure that participants are using the website as they should. Often, this means posting messages like the following, a response to a thread about side effects from the drug Tecfidera, used to treat relapsing remitting MS. In the post, a PLM moderator reminds respondents who report side effects and reasons for stopping treatment to complete a “treatment evaluation” for those searching the database. The moderator is not diagnosed with MS, but is instead an employee of PatientsLikeMe whose participation is guided by the interests of the corporation. Indeed, for this reason, the moderator’s gaze comes across as helicopter-like, a sort of control mechanism that disciplines user behaviour on the site.

While the site’s mission statements promote a system that works to facilitate the needs and interests of patients, the overly regulated structure of PLM betrays the actual motivations of the site to acquire *statistically* meaningful information, rather than findings that are meaningful to the individual. This preoccupation is quite clearly voiced by co-founder and CEO Jamie Heywood in his lecture “The Big Idea My Brother Inspired,” in which he pronounces that user information on PatientsLikeMe is “a story until we convert it to data.” This telling statement suggests that subjective user experience is relatively useless until it is made objective, empirical, and scientifically relevant by the site’s conversions. However, to the individual using the site, meaningfulness is entirely subjective. Perhaps the user had no need to update her data over the past thirty days because her condition is stable; perhaps she feels the need to update only when something personally significant happens in her life; perhaps the site is a way for her to monitor only one aspect of her condition, or simply to access discussion forums. In all of these cases, significance is entirely relative, and, as many users make clear, the “story” is, in fact, the most important part. Along the lines of the

PLM business model, however, meaning is dependent upon scientific and economic value.

A quick survey of the patient profile reveals that even the design and capabilities of the user interface correspond primarily to data collection. There is no space on the profile for unprompted, open sharing of information and opportunities for unguided narrative writing are limited. The “Biography” section of the profile consists of three sections: 1) “Interests” (a list of ten selectable reasons for being on the site, i.e. advocacy or research); 2) “Bio” (a text box where users are to “describe [themselves] in a few short sentences”; and 3) “About Me” (a text box where users can “describe [their] medical history to another patient like [them]” (“Profile”). Ostensibly, these areas present a one-time opportunity; while they can certainly be updated, the range of disclosure that they afford is relatively restricted.

Perhaps to respond to this need, PLM recently added the “Journal” feature, which tracks users’ activity on the site in a similar way to the Facebook Timeline. While the ability of users to comment on these automatically-generated journal entries or share a link in their journal provides a degree of authorial control, for the most part, the “Journal” is not a journal at all, but instead an aggregated “News Feed” (to use more Facebook terminology) that is created by a computer algorithm that documents the user’s activity on the site, which may include writing comments, responding to posts, sharing new personal medical information on one’s profile, and so on.

## **Conclusion**

Despite the economic interests of PLM, the outcome of which is the regulation of user disclosure to facilitate the acquisition of statistically significant data, there are components of the site, namely the discussion forums, that allow for more complex and

nuanced narratives to emerge than those found on patient profiles. While the desires to track progress and monitor health status—in effect, to work toward a visualizable normalization of the individual—are the primary exigencies of the profile interface, the discussion forums meet a predominately social need. Rather than tracking and isolating the otherness or deviance of the individual’s experience, the forum marks a place of co-identification or community building wherein users seek to relate their feelings, experiences, findings, or questions, as well as to build affective, interpersonal relationships, rather than statistical ones. In this way, the forums allow a space for alternative, non-normative narratives to develop. These spaces reveal illness or disability to affect individual lives, not simply as medical conditions, but as complex sets of cultural, social, environmental, and other factors that influence individuals’ ways of being.

Interestingly, the forums also allow an opportunity for users to express criticism of the very structures that enable their participation on PLM. While analyzing the MS discussion forum, I became aware of the extent to which users are, indeed, conscious of the various gazes to which the information they share is subjected. In one thread questioning PLM’s data selling practices, one user links to a CBS News report about the Nielsen data scraping scandal in order to make other users aware of the presence of pharmaceutical representatives who use the website as moles, short-circuiting PLM’s commercial structures to scrape data about patients and also to plant information encouraging them to use certain drugs and avoid those sold by competitors. The conversation goes on to discuss the issues of privacy and exploitation of users on PLM, with some users expressing concern and others explaining their willingness to accept the terms and conditions of using the site. While some respondents share techniques by which they use the site subversively, such as intentionally not providing certain



personal information, others communicate their willingness to provide ‘free labour’ to PLM because they believe the rewards of participating are greater than the potential drawbacks. These justifications echo PLM’s claim that patient sharing on the site will further research on their diagnosed condition(s). While this may be true, it also furthers a highly exploitative agenda; if PLM were truly concerned about helping people, they would operate as a not-for-profit organization, acknowledging that the personal illness experiences of their users—and not their own data collecting mechanisms—are at the root of their value as a corporate entity.

Indeed, complicating my discussion in the first part of the chapter of how users contest, redefine, and recreate a “norm” that resists the norm—their new normal—is the way in which some users talk about their participation in the data collection and forum discussions on PLM as a form of productive, empowering, and self-validating labour. This is complicated for a few different reasons, firstly, because of the way in which activities like ‘disease management’ and social interaction become validated through their framing as labour. Even as forum participants attempt to “re-engineer” their lives against a norm, in ways that accommodate their particular disabilities, they nonetheless interpret their own use of the site, normatively, as a form of productive contribution within a neoliberalist system. In this light, the user sees herself as, in Banner’s words, “a potential ongoing source of data, which becomes a gift to the health commons” (199). Secondly, the situation is fraught because of the way in which this labour works ultimately to support a medical-technological industry that, itself, profits from the biomedicalization of all illness.

As I have discussed, the ability to frame illness biomedically is PLM’s greatest asset as a corporate entity; however, this framework has implications for the wider cultural context in which the website is embedded. In her text, *Reading and Writing*

*Disability Differently*, Tanya Titchkosky draws attention to the ways in which disability exists as a concept created by and between people, “made meaningful by the ways we say it to be and live its being” (12). If the user profile can be seen as another text through which illness is enacted, then seeing this text as an adequate representation of an individual’s disease means conceptualizing that embodied state as, predominately, a problem to be solved, rather than a mostly unavoidable condition of human embodiment. Titchkosky reinforces a point argued by Joan Scott that “we do not discriminate because we have noticed a difference. Rather, within a hierarchicalized techno-bureaucratic capitalist culture we discriminate and thereby enact difference” (24). On PLM, the user profile relies on the categorization of the individual and the documentation of his or her health status; in the space of this text—in its systems of measurement and visual techniques—difference comes into being. On discussion boards, however, the textual engagement is strikingly different. Even diagnostic categories are erased, as users with various disease experiences interact on message boards that fall outside of their ‘assigned’ positions on the site.

Discussions between differently diagnosed ‘patients’ work to break down the boundaries that enforce regulatory controls upon bodies. Similarly, many forum conversations on the site also help to complicate normative understandings of what it means to be sick or disabled. While user profiles work toward normalization—the solving of a problem—discussion forums not only accept the existence of problems (symptoms, side effects, limitations, impairments) as normal, they also treat them as indefinite realities. While users’ lives are often negatively impacted by their diagnoses, an individual’s self-disclosure can reveal the staggering complexities of these ‘undesirable’ experiences—for one, that persons with illnesses or disabilities are, nonetheless, capable of participating in a full range of human experiences and

emotions, including happiness, contentment, success, love, creativity, etc. This is equally true in the MS forum, where the degenerative nature of this illness looms large over any and all forum discussions, but not to the detriment of members' abilities to live complete and fulfilling lives, to which their forum posts testify.

Casting a heavy shadow over the highly constructive and meaningful exchanges that happen on the PLM site to reorient perspectives on 'normalcy' is the insidious nature of its economic position. While use of the site is technically free, the site's business model employs user-disclosed information to further enmesh individuals as consumers in an already highly commoditized healthcare sector. As I have discussed, the forums, although they, too, fall within the category of data available for purchase, nonetheless offer a space where users actively construct their illness experiences in non-normative ways. They are a site where users can critique the system, offer alternative options, and become informed and empowered co-creators of knowledge, rather than passive and complicit consumers. Here, the discussion works to expose the medical and economic construction of biomedical 'conditions'—of disability and disease, in general— to renegotiate how these states of being are understood as lived realities outside of their definition by hegemonic models. Indeed, user activity on PLM forums allows for resistance against commodification and subjugation within and through the healthcare industry, since it provides a space for users to question and discuss potential options for care, treatments, and solutions, beyond the information that is, perhaps, promoted on the site or in consumer literature. This space allows for subversion of traditional narratives of illness or disability or hegemonically dictated methods of dealing with bodily "abnormalities."

This chapter has intended to expose a central tension or contradiction in the way that the PLM site structures user engagement and the way that individuals appear to

participate. Centrally, this analysis helps to expose how the movement toward so-called patient-directed healthcare, despite its laudable impulses, carries forward epistemological and economic structures that keep patients in the passenger seat, while exploiting them for their personal data. Indeed, troubling is not a strong enough word to describe the highly opportunistic nature of a PLM brand of commercial pursuit. And, certainly, the stakes are much higher than mere corporate gain or loss. The rhetorical framing of persons with disabilities or diseases on PLM, in perpetuating the hegemonic discourse of biomedicine, works to reinforce a problematic understanding of individuals with illnesses and disabilities as abnormal or deviant. Users' opportunities to construct their own narratives about their experiences are limited by design structures that sculpt and retrofit *stories* to reflect *data* that meets the categorical imperatives of the scientific process, and financial profitability in general.

While PLM occupies a relatively minute space within the vast realm of web-based health tools and technologies, its rapid growth and increasing number of industry partners (sixteen and counting, including Merck, Genentech, and Novartis) ("Partners"), raises some cause for concern as to the direction in which our allegedly 'democratized' spaces of online participation are headed. Above all else, this chapter attempts to present a cautionary perspective amidst the din of the zealous, and oftentimes industry-sponsored, enthusiasm over 'Health 2.0' and participatory medicine. If health-related social networking sites are to adopt the business model endorsed by PLM, in which patient activism and empowerment are co-opted to support commercial interests, then we really are witnessing the promulgation of real-world power relationships throughout Internet spheres.

## Chapter 5 | A Butterfly in a Jam Jar: Self-Narrative in Dementia Blogging

...I am not sure I am brave, I often feel like a butterfly desperate to get out of a jam jar and sometimes think that maybe I write to mask anything is wrong with me. Perhaps it is more that I am saying, 'here look, I am fine, I can write these words, so I must be ok. Maybe I will never get any worse.'

Mrs. Hsg, "Who am I?" (comments), *Before I Forget*<sup>20</sup>

One of the themes I have highlighted throughout this dissertation is the resistance of many narratives of illness, particularly in the online spaces I have studied, to metanarrative structures like quest or restitution. While personal narratives of illness in social media often contain aspects of these framing devices, there are other important organizing concepts that writers employ in order to convey their experiences of illness. In the case of the dementia blogs that I will discuss in this chapter, this writing is less fixated on the goal of articulating a totalizing or mythologized interpretation of experience than it is on chronicling a series of moments, continually anchored in the present. The goal of such narratives is to respond to not just the existential and physical crises that illness introduces, but also particular social expectations surrounding illness.

Of course, all illness life writers tell their stories as a way to find meaning in the midst of change, trauma, confusion, pain, isolation, and so on (Hawkins 10). But because many examples of life writing in social media spaces are not beset with the demands of narrative resolution—they offer forth a series of both reflections and perpetual presents—they must be considered separately from narrative frameworks

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<sup>20</sup> All quotations by blog writers in this chapter are the writers' words, directly copied and unedited.

of illness in published, printed form. For example, in my last chapter, I discussed the organizing concept of a “new normal” narrative that emphasizes the ever-evolving and contingent “normalcy” that persons with chronic illness, specifically multiple sclerosis, experience. Stories told by individuals on PatientsLikeMe, while their writing may not necessarily be treated in the same way as a blog-style narrative, repeatedly highlight the contingency and uncertainty that characterizes all human experience, particularly in illness. This is a deliberate reframing of illness that is untied to a teleological trajectory.

This chapter will turn to explore the blogs of persons with dementia and the narrative techniques they employ as they craft their stories of illness. I will demonstrate how the narrative perspectives presented in two exemplary blogs respond to social constructions of Alzheimer’s disease and related dementias (ADRD). The power of social expectations surrounding ADRD is the single greatest influence on how dementia bloggers understand their experiences and write about them, and for the most part, this is framed through the narrative trope of reasserting selfhood against an anticipated loss of self.

Certainly, these narratives are similar in some ways to Kate Granger’s Twitter reflections on her cancer journey or the “new normal” stories of MS patients in the PLM discussion forum, particularly for the way in which they carve out subversive space for the performance of disability and illness. Firsthand stories of ADRD are also, however, quite distinct from other illness narratives in social media because of the social context out of which they emerge. The degree of dehumanization to which those with cognitive disability are subjected creates a rhetorical exigence for blogging rooted in the protection of selfhood, particularly through the assertion of the

autobiographical identity. I will first chronicle how the fear and dread surrounding this loss of self in dementia are socially produced through the endemic stigmatization of persons with dementia in Western society. The response by an individual diagnosed with ADRD to blog his or her status as “someone with dementia” is, at least in part, a conscious reaction to threatened selfhood. I will explore how the blog becomes a space to contend with a medically and socially overdetermined end-of-life story, paying particular attention to the generic qualities of the blog that facilitate this narrative response. The fixation on coherent selfhood appears to be the source of much suffering in these blogs, even as writers employ their narratives to continue proving their status as self-aware and self-determining. I will conclude by ruminating on the expectations of narrative medicine, in general, and the socially enforced obsession over the self in dementia, in particular. My aim is to add to the discussion about personal illness narrative by exploring how the theme of stable selfhood in dementia blogging emerges as a response to social constructions of ADRD.

### **Dementia in context**

Social expectations of coherent and stable selfhood establish a particular blogging context for persons with ADRD who chronicle their dementia-related experiences online. Writers frame their stories in ways that attempt to assert the self, while at the same time questioning the fairness of, validity of, and need for such expectations. In my preliminary research on the topic, I noticed that blogs about ADRD are typically authored by: 1) an individual in the early stages of dementia; 2) an individual with dementia together with a supporter (family member or friend); or 3) an individual who is a personal support worker, or lives with, or otherwise

supports a person with dementia. ADRD is an umbrella term for a cluster of progressive conditions, including Alzheimer's (AD), frontotemporal (FTD), Lewy Body (LBD), mixed, and vascular dementias, that over time and at varying rates, diminish an individual's capacity to form new memories and access old ones. While the symptoms of these kinds of dementia vary, as the diseases progress, possible symptoms also include mood and behavior changes, physical impairments, and difficulty speaking and writing ("What is Alzheimer's?"). Thus, eventually, all bloggers with ADRD will likely require assistance in order to continue writing—to navigate the steps of operating a computer and navigating a website, as well as recalling words, phrases, or memories and translating these into a written narrative. Some may simply stop writing altogether if they do not have the support of collaborators or partners-in-care to facilitate their continued blogging practice. This helps to explain why all of the bloggers whose writing I discuss in this chapter are individuals who were diagnosed and began writing about their experiences during an early stage of dementia.

It is worth noting that the number of bloggers who identify as "caregivers," or what we might term in more empowering language, partners in care, far surpasses the number of those who identify as persons with dementia. The discrepancy in numbers between these two groups likely speaks to the inaccessibility of such a platform to those undergoing cognitive changes, varying in degree and kind, but which most likely affect linguistic abilities and fine motor skills. While my work in this chapter analyzes the narrative constructs employed by bloggers with dementia, more work is needed to assess the value of blogging for persons with dementia and to design more accessible blogging platforms. This is particularly imperative, since the potential



therapeutic effects for individuals with dementia of engaging in regular brain activity like reading and writing are currently of great interest to researchers. As Alzheimer's Disease International explains in its *World Alzheimer Report 2014*, "cognitive stimulation may be beneficial for cognitive function in old age in both people with and without dementia" (57). One study conducted by researchers at Rush University observed the cognitive abilities of 300 healthy people, connecting cognitively stimulating activities, including reading and writing, to a less marked cognitive decline in the six years before death (Wilson et al.). While the consequences of these findings for adding to our scientific understanding of why and how different types of dementia develop are certainly exciting, my work in this chapter will focus more on the narrative side of personal experiences of dementia. As discussed, the dominant cultural myths surrounding dementia negatively overpower any compassionate or humane response we might have to persons diagnosed with the disease. In the interests of supporting the right to live well among those with dementia, we can benefit from hearing those individuals' stories and understanding their motivations for telling them.

Many campaigns to support Alzheimer's awareness and research have been aimed at "ending the silence" surrounding the disease. In February 2014, actor and comedian Seth Rogen attracted a great deal of publicity for ADRD research and his Alzheimer's fundraising organization, Hilarity for Charity, when he testified at a Senate hearing on the subject. Tellingly, while Rogen's viral YouTube video has 6.6 million views ("Seth Rogen Opening Statement"), only two of the eighteen senators on the hearing subcommittee stayed to listen to Rogen's speech. In this context, Rogen's words ring even truer as he states, "Americans whisper the word Alzheimer's

because their government whispers the word Alzheimer's. [...] And although a whisper is better than the silence that the Alzheimer's community has been facing for decades, it's still not enough. It needs to be yelled and screamed to the point that it finally gets the attention and the funding that it deserves and needs" ("Seth Rogen Opening Statement").

Importantly, however, a lack of conversation is not the only issue; simply speaking about dementia is not necessarily the solution to destigmatizing it. When we do speak, we must choose our words with wisdom and compassion, a response that seems to be desperately lacking in emerging conversations surrounding ADRD. Examples of this lack of compassion appear in the mainstream media on a regrettably regular basis. By way of example, a recent piece in the *New York Times* by physician Danielle Ofri, framed as a discussion about the silence of doctors surrounding AD, rather serves to perpetuate the image of the illness as both shameful and horrific. Describing her experience observing a patient—"an accomplished sculptor and intellectual contrarian" who is nearing the end of his life with dementia"—Ofri writes, "to see him now, with hardly a sliver of his personality left, encumbered with physical injustices you wouldn't wish upon your worst enemy, was beyond heartrending." She goes on to say, "There was something almost shameful in bearing witness to a fellow human being's profound indignities. I was embarrassed *for* him, for how embarrassed *he* would likely be, if his former self could see his current self. That his current self lacked the capacity to be aware of his state offered little comfort." Ofri proceeds to speculate on the clinical silence surrounding the subject of AD, suggesting that it could be due to "the invisibility of the illness, especially in its earlier stages," or the fact that "all the top 10 killers in America are potentially preventable or at least

modifiable – all except dementia.” Both of these facts make the illness enigmatic and frustrating. Ofri’s conclusion points to doctors’ own existential fear over a loss of cognitive capacity as the true reason for the lack of conversation surrounding AD in the clinical setting, suggesting that “the idea of the mind vanishing is more petrifying than much of the bodily devastation we are privy to.” Ofri is certainly correct in asserting that physicians need to be mindful of their own emotional weaknesses in order to provide responsible and compassionate care, and she also raises many of the issues that create a particularly negative social environment for thinking about dementia. However, the premise of her article confoundingly serves to reinforce the notion of AD as a dreadful disease, particularly in the way that it describes the individual who inspires such ruminations. This frustratingly irresponsible approach on the part of medical professionals to discussions about dementia is an important point that Ofri leaves out of the conversation, perhaps because she does not realize the power of her own words to construct a stigmatized view of dementia.

The same insidious portrayal of dementia is found in other articles that profess a concern for ending the stigma surrounding ADRD. In just one of countless examples, a CBC article reporting on a new “dementia buddy program” at Northwestern University that pairs persons with dementia and doctors-in-training, explains that the program is aimed at reducing the stigma of ADRD among physicians (“Dementia Buddy Program”). In the same breath, the article describes Alzheimer’s as “a devastating illness” and the program as providing patients “a sense of purpose [...] before their illness eventually robs their minds.”

With such media portrayals of ADRD that perpetuate responses of fear and horror, it is hardly surprising that when, in January 2014, Ohio State University made

its Self-Administered Gerocognitive Exam (SAGE) available to the public on its website, the level of interest in the test was so high that the website crashed temporarily. While Ohio State researchers say the test—described in the media as an “Alzheimer’s online test”—can identify cognitive impairment as effectively as more detailed clinical tests, it cannot isolate Alzheimer’s or dementia as the cause of poor test results (Knapton). The public reaction to the test clearly speaks to the level of fear and anxiety surrounding the disease. In part, this is due to the growing statistics we regularly hear reported on the illness. In Canada, there are over 450,000 people living with ADRD (Norris). In America that number is 5 million, where 1 in 3 older adults die with ADRD, making it the sixth most common cause of death (“Alzheimer’s Facts”). According to Alzheimer’s Disease International, as of 2013, there are 44.4 million people with dementia worldwide, 62% of whom live in developing countries (“Dementia Statistics”).

That such a scientifically misunderstood disease could be so frequently diagnosed is certainly cause for a rational degree of concern. The mystery surrounding the science of AD, in particular, at least partially establishes the popular perception of the illness as terrifying because it is believed to be indiscriminating. However, conversations of ADRD also take on a distinctly emotional tone of existential dread, largely in connection to the other popular association of dementia with the destruction of self or identity. As I have mentioned in previous chapters, certain illnesses, by way of the cultural meanings that have developed around them in North American society, have the power to evoke extreme reactions of fear and stigmatization. Susan Sontag’s pivotal works *Illness as Metaphor* and *AIDS and its Metaphors* chronicle the cultural histories of tuberculosis and AIDS as carrying this

sort of weight within the popular imagination. Contemporarily, Alzheimer's disease and other progressive dementias, such as fronto-temporal dementia and Lewy Body dementia, comprise the most salient examples of such an illness. As D. J. Jolley and S. M. Benbow note, like other stigmatized diseases such as cancer, tuberculosis, AIDS, and leprosy, AD "commands fear before sympathy, because it has been marketed largely through its most debilitating, demeaning and despairing features" (117). Arguably, the most demeaning of these features, as presented in mainstream media and popular culture, is the power of dementia to rob individuals of their *selfhood*.

In his book, *Self, Senility, and Alzheimer's Disease in Modern America*, Jesse F. Ballenger traces a cultural history of AD by treating "the dread surrounding dementia as a historical problem" (3). In tracing the beginnings of this reaction back to a mid-nineteenth-century American context and chronicling the discourse on senility and AD since that time, Ballenger suggests that we might better understand dominant attitudes toward the disease and learn how to "respond with wisdom and compassion" (3). I am most interested in Ballenger's observation that "the loss of the ability to independently sustain a coherent self-narrative—a loss that dementia entails—has come to be considered the most dreadful of all losses" (9).

Related to this fear of a broken self-narrative is the tendency in North American society for individuals to resist states of vulnerability and dependence because they transgress neoliberal expectations of individual responsibility and self-determination. We see this discourse emerge in discussions of euthanasia in relation to dementia, in which the fear of being a burden on one's friends and family becomes a central justification for assisted suicide. One recent example of such a dialogue is provided by Gillian Bennett, an 85-year-old B.C. woman and retired psychotherapist

who ended her own life in order to avoid the implications of advancing dementia symptoms (Ryan). Bennett created the personal website DeadAtNoon.com to explain her choice and present a series of arguments in favour of physician-assisted suicide. Her justifications for suicide appeal to both anxieties I discuss here: the fear of being a burden on one's family members or society and a refusal to face the vulnerabilities of impaired cognition. In the opening to the personal essay on her home page, Bennett writes, "I will take my life today around noon. It is time. Dementia is taking its toll and I have nearly lost myself. I have nearly lost *me*." Describing dementia as a "typical" and "boring" disease, her rational approach to her illness reflects the worldview of a bright intellectual whose life has revolved around ideas and relationships. Thinking ahead to an increasingly more debilitated state, Bennett envisions herself as simply a "mindless body," "carcass," or "empty husk," the care of which (because she sees herself not as a person by this point, but merely an "it") will be financially costly and emotionally burdensome for her loved ones, an option that she sees as "ludicrous, wasteful, and unfair." Bennett even presents her desire to "cost Canada as little as possible in my declining years" as one reason to end her life. Her pragmatic arguments are based on what Bennett sees as the ethical choice for persons of increasing age and declining health. Discussing the economic burden of a disproportionately large elderly population, she notes, "There are many ethical issues here: life extension radically alters people's ideas of what it is to be human—and not for the better. As we, the elderly, undergo manifold operations and become gaga while taking up a hospital bed, our grandchildren's schooling, their educational, athletic, and cultural opportunities, will be squeezed dry."

I respect the pragmatism of Bennett's approach and her right to choose the conditions for her own death—to ensure that they are personally validating and ethical. However, in the interest of interrogating her central concern here—the notion of how our treatment of older adults might alter our concept of what it means to be human—we must ask ourselves how the elimination of such occasions for vulnerability to exist in the world might also negatively impact human relationships (see Stephen Post). Discussions of physician-assisted suicide, like Bennett's, become occasions to consider and assess the humanist values that sometimes overdetermine our expectations of our own lives and our relationships with others. Indeed, as Ballenger's work illuminates, this tension stems in large part from the shame we have attached to states of vulnerability, such as cognitive disability. Unsurprisingly, many of the dozens of dementia blogs that I investigated in my research for this chapter begin with posts that articulate bloggers' apprehension over what they foresee as their eventual burdensome dependency on family members and friends.

I am interested in this area of illness narrative authorship because I think it brings to light a few different concerns regarding illness writing online and the representation of Alzheimer's disease in the wider cultural arena. Specifically, in the work of Alzheimer's supporters and self-advocates, there is a concerted push to break down the damaging stigma attached to an Alzheimer's diagnosis and to reshape public thinking about the illness. Indeed, for many sufferers, the social alienation produced by the lack of support from misinformed friends and family is one of the greatest challenges of the illness. Characterizations of persons with dementia as "the walking dead" or "demented" abound in popular media representations. The promotion by groups like the Murray Alzheimer's Research and Education Program

(MAREP) of public awareness and the breaking down of Alzheimer's myths focuses on self-advocacy among persons with ADRD as one route to generating a more accurate and compassionate understanding of the disease. It mirrors the disability rights mantra "nothing about us without us."<sup>21</sup>

The goal of such projects is to disrupt the long legacy of stigmatization attached to a diagnosis of dementia. And doing this means understanding, from a cultural historical standpoint, how and why this particular perception of the disease—as dreaded and dreadful—has come to overshadow our capacity to think humanely and compassionately about the experience of dementia. In his history of senility and Alzheimer's disease, Ballenger attempts to locate what set of conditions in American culture generated the "fearful line" (3) "between the normal and the pathological, between a coherent, stable self and the incoherent, chaotic dependency of dementia" (2). Ballenger suggests that the fear attached to the threat of dementia cannot be explained by simply the greater attention paid, in recent times by both scientists and journalists, to Alzheimer's disease. Instead, the fear of dementia (or "senility" as it has historically been called), is deeply tied to changing perceptions surrounding selfhood and the life stage of older adulthood. Ballenger contends that the anxiety surrounding dementia within the American cultural imagination did not emerge until the late nineteenth century, and further, that the physical and cognitive decline often associated with aging have not always been regarded with dread. While eighteenth century tracts tend to describe older adults, problematically, as burdensome, they do not, Ballenger observes, see cognitive or physical changes as an unnatural or fearsome transition (5-6).

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<sup>21</sup> See David Charlton's *Nothing About Us Without Us* for the history of this term in the context of the disability rights movement (3).



Ballenger's central line of inquiry concerns the evolution of cultural ideas surrounding selfhood, specifically the moment at which selfhood became understood as something that one was personally responsible for—something that one must construct (9). Ballenger highlights a shift from the late nineteenth century discourse surrounding aging, in which “the senile man [was] the epitome of failure because his decaying brain collapsed under the pressure to produce in a modern industrial society” to the mid-twentieth century conception of the senile man as the epitome of failure because he could not “adjust to a consumer-oriented leisure society. Deprived of meaningful work, the aging man needed to find in leisure activities the means of creating a self. Senility was the failure to accomplish this” (59). Ballenger refers to this mentality toward aging as the “gerontological persuasion,” which focused on reforming societal attitudes toward older adulthood to reflect a norm or goal of “successful aging” (59). Ballenger argues that in the 1940s and 1950s in America, “the organizational infrastructure of aging,” including academic, medical, social service, and business campaigns, worked to address “middle class anxiety about the coherence and stability of the masculine self, but a self that now had to be established and maintained less through work than through leisure” (58). Marked by notions of aging gracefully, having a leisurely retirement, remaining healthy well into older adulthood, and maintaining a generally optimistic attitude toward aging, “the gerontological persuasion made dementia stand out much more clearly as a pathological condition” (60).

Ballenger's work builds on that of Elizabeth Herskovits whose 1995 article on subjectivity and AD observes the various political and social agendas that changing formulations of dementia have supported. The emergence, in the 1970s, of our current

Alzheimer's construct, damaging as it may be to persons diagnosed with ADRD, "has served specific political-economic interests, such as researchers' and research institutions' needs for funding and legitimacy, and solved certain clinical, pragmatic, and psychological problems, such as the need to create order out of chaos and to legitimize a range of therapeutic responses and sites" (Herskovits 147). Herskovits discusses how the act of demonizing those with AD reflects a widespread societal fear over the aging process. By categorizing what was once termed "senility" as, instead, a diagnosable pathology called Alzheimer's disease, this medically abnormal form of aging could thus be contained through treatments, medications, care regimens, and research. In terms of the social context, the medicalization of senility has led to the popular conception of Alzheimer's as a dreaded way to spend the final years of one's life; the stigmatizing discourse used to describe those diagnosed with the disease "has led to an implicit debasing of the 'self'" in dementia (152).

Several other studies of the damaging discourse of dementia highlight the power of language to shape social relationships and actions that have real implications for those diagnosed with ADRD. Susan Behuniak's (2011) analysis of the zombie metaphor to describe those with dementia exposes the implications of such dehumanizing terminology as "the walking dead" or "the living dead." This trope serves to infuse popular understandings of the illness with both terror and disgust, sentiments that perpetuate misconceptions and poor treatment of those with dementia. Sam Fazio (1996), Gloria Sterin (2011), Steven Sabat et al. (2011), Kate Swaffer (2014), and others also draw attention to the power of language to shape thinking about dementia and the attendant need for a linguistic reframing of the illness. As Gail Mitchell, Sherry Dupuis, and Pia Kontos summarize in their review of

literature on this topic, “It is our experience, in bearing witness to persons with dementia, that a significant amount of suffering is linked with the way the tragic and the horror-filled words and images, that are common place in social and medical literature, get imposed on individuals living with dementia” (8).

When looking at the voices of Alzheimer’s disease in the blogosphere I observe the presence of a movement to reshape popular ideas about ADRD, but I also see language that perpetuates stigmatization and, unfortunately, this is ever-present on the blogs of those who support persons with ADRD. Some of this stigmatization is immediately apparent through the titling of blogs, such as *“Had a Dad” Alzheimer’s Blog*, *Missing Jim :: Confessions of An Alzheimer’s Wife*, *My Demented Mom*, *demention*, *Alzheimer’s is a Bitch*, *Alzheimer’s is horrid!*, *Living in the Shadow of Alzheimer’s*, *Living with a Thief named Lewy Body Dementia*, and so on. In the case of titles like *“Had a Dad”* and *Missing Jim*, the subjects of these blogs were (or are) still alive at the time of blog creation and writing, suggesting that these writers appeal to the trope of persons with dementia as “already gone.” Even persons with dementia, however, seem to internalize the derogatory language and imagery attached to their diagnosis, with blog titles like *Slip Sliding Away* and *Watching the Lights Go Out* and blog post titles like *“Future? What Future?!”* (Silverfox).

### **Selfhood in dementia**

In addition to a critical rethinking of the language attached to dementia by healthcare practitioners, partners in care, the wider public, and even those with dementia, much work has been done by scholars in health studies and gerontology to create “a re-visioning of the self in Alzheimer’s disease” and to “strongly challenge

the assumption that the loss of self is a direct consequence of a degenerative process in nervous tissue" (Mitchell, Dupuis, and Kontos 7). Instead of understanding the identity issues that persons with Alzheimer's experience as being connected to the physical deterioration of the brain, Mitchell, Dupuis, and Kontos, Herskovits, Sabat et al., Tom Kitwood, Stephen G. Post, and others "purport that the debasement of personhood is more likely affiliated with the ways persons relate with those diagnosed with dementia" (Mitchell, Dupuis, and Kontos 7). Indeed, the accepted standards for what constitutes a "self" are too narrowly defined, predominately due to a fixation on autonomy as a marker of selfhood, conventional modes of communication as the only vehicles for self-expression, and clinical diagnostic interpretations of the Alzheimer's experience as measures of quality of life. In thinking more inclusively about the cognitive changes that persons with dementia undergo, researchers have begun to explore embodied forms of self-expression as also constituting "responsive behaviours" that individuals employ to communicate aspects of their identities ("Understanding Responsive Behaviours"; Dupuis, Wiersma, and Loiselle).

The notion of responsive behaviours deploys the concept of embodied selfhood to understand self-expression among persons with dementia as "consist[ing] primarily in their essential corporeality of being-in-the-world" (Mitchell, Dupuis, and Kontos 7). As Kontos (2004) elaborates, we typically expect that the "self" is enacted through cognitive processes, particularly linguistic acts. However, as she argues, persons with dementia have deeply ingrained and unique forms of physical expression that can also be seen as extensions of the self. Embodied selfhood emerges from both primordial and socio-cultural sources. Using Maurice Merleau-Ponty's

concepts of non-representational intentionality and the primordial body, Kontos suggests that the self originates in the primordial body, “whereby selfhood emanates from the body’s power of natural expression, and manifests in the body’s inherent ability to apprehend and convey meaning” (837). Drawing on Pierre Bourdieu’s idea of *habitus* as the link between bodily dispositions and the social world, she then argues for the corporeal foundations of the socio-cultural dimension of selfhood, suggesting that social practices become internalized in bodily habits at a pre-reflective level (837). Mitchell, Dupuis, and Kontos echo these findings when they note that “many life patterns and ways of relating continue to be expressed in the presence of dementia because fundamental aspects of selfhood are embodied and not defined by cognitive function” (7).

Ultimately, questions over the persistence of selfhood and self-awareness in dementia are entwined with broader questions about what it means to have, enact, express, or construct a self. As Herskovits points out, “representations of and debates about the self in Alzheimer’s attest to the very meaning and essential nature of the self and what constitutes subjectivity” (158). While Kontos and Mitchell, Dupuis, and Kontos challenge the cognitive foundation of selfhood as a way of rehumanizing cultural attitudes towards persons with dementia, this tactic might be seen as problematic for the reason that it continues to assert the coherence of a self. Is it possible that such a strong emphasis on the stable self, in fact, contributes to the problem of stigmatization? Why are we fixated on the notion of selfhood, or the *coherence* of self, as being the indicator of value, personhood, or humanness? Is it possible to retain one’s humanity and personhood while embodying a definitively

incoherent, perhaps chaotic, presence in the world? Is this state of discontinuity, in fact, a closer approximation of what it is like to enact a self over time?

In her study of persons with dementia at a long term care facility, Kontos argues that residents' abilities to manage "the social demands of eating in the dining room," such as using utensils, napkins, and condiments signals "the coherence and consistency in the residents' mastery of their social world" (842). This fact is related to embodied behaviour that results from a lifetime of socio-cultural priming. She suggests that residents' interactions were not a deliberate response to the rules of the social environment. Instead, "the taken-for-granted, pre-reflective nature of their practices flowed from embodied selfhood" (842). I am sympathetic to the notion that selfhood is expressed and manifested in various ways and support the argument that all modes of relating with the outside world are grounded in the phenomenological conditions of embodiment. However, there does come a time in the journeys of some persons with dementia when the utility of a spoon or fork is no longer automatically apparent or the typical manners of polite society no longer resonate. In these cases, the presence of other residents, nurses, recreational therapists, and health care aides remind individuals of social norms for behaviour, essentially serving a disciplinary purpose. The fact that these embodied social practices will likely weaken as memory loss advances seems to reduce the validity of Kontos' argument for embodied selfhood as the basis for the continued personhood of the individual with dementia. When embodied practices change, when they no longer express internalized social or personal norms, is selfhood compromised? When immobility increases and physical movement is impeded by cognitive changes, does the self begin to fade away, leaving us with the same philosophical problem?

The central problem with Kontos' argument, and others that propose embodied selfhood as a resolution to the debate surrounding the self in dementia, seems to be the presumption of a stable self that persists even in the presence of cognitive dissolution. Her paper expresses an obvious desire to see the threads of individuality and selfhood that connect pre- and post-dementia states of being. This approach understands the self-expression of individuals with dementia through a normative framework—that is, it sees embodiment as creating the conditions that uphold ideals of coherence, autonomy, and individuality. My critique of this approach stems from the possibility that it is a too-convenient response; it doesn't force us to do the difficult work of rethinking our definitions of personhood or what it means to be human. It doesn't force us to see incoherence as a reality of human life, and the stable self as an illusion. We instead spend energy trying to locate where and how persons with dementia are like "us," rather than *making space* for diverse and unconventional modes of subjective experience.

A similar but distinct approach suggested by Mitchell, Dupuis, and Kontos is to redefine selfhood to see it as relational and intersubjective. As discussed in my second chapter, Judith Butler has also advanced this perspective, though in a different context, to show the many ways in which we are bound to one another. What Mitchell, Dupuis, and Kontos so skillfully highlight is the nature of selfhood as something that is produced in and through relationships. Thus, if we see the self as "breaking down," the locus of such a break encompasses all actants and all relationships that interact with the individual; social contexts, environments, and individuals may be unequipped to support cognitive changes or not flexible enough to accommodate a person's continued expression of a consistent self. As Kitwood has

argued in various places, the loss of self or personhood that we associate with dementia signifies a flaw in the social fabric and a failure of personal relationships, rather than a structural change in the brain (“Personhood” 239, 241). This reflects a failure on the part of supporters to nourish the experiential self of the person with dementia—the part of the person that relies on “I-Thou relating” (“Personhood” 239).

The crux of this conversation can be articulated as such: the enacting or construction of self through *writing* or *speech* is a normative method by which one asserts one’s human presence in the world. These forms of communication allow others with similarly normative communication approaches to support, co-construct, or validate those expressions of selfhood. When normative modes of communication become less accessible, for example, for persons experiencing the cognitive changes of ADRD, the ability of their supporters to affirm, relate to, understand, or intuit expressions of self seems put to an insurmountable test. The incompatibility of these systems is, perhaps, what leads to a perceived loss of self. In reality, selfhood may persist—its expression hampered by a language barrier of sorts. Along these lines, scholars argue for the continued presence of an autobiographical, or what Kitwood calls an adapted self, that is still expressed through communicative, narrative means. As L.-C. Hydén and L. Örvulv argue in their case study of storytelling by persons with AD, individuals use linguistic and non-verbal practices to express their identities. Despite the fact that stories told by persons with dementia are voiced in temporally discontinuous or repetitious ways that may be problematic for listeners (people without dementia), the fragmented nature of the story does not disrupt or interfere with the teller’s self-awareness or sense of identity. Hydén and Örvulv point to the



need by researchers and partners in care to recognize a wider spectrum of communicative acts that serve to express identity.

In another sense, Kitwood argues that persistent selfhood can be supported by the notion that “a person with dementia still has an emotional and relational life, even though without the stabilization and compensation that cognitions ordinarily provide” (“Personhood” 241). He presents several strategies for supporting the experiential self, one of which is “‘celebration’: simply sharing in the beauty, the fun, and the joy of living. . . . Strikingly, it is often in episodes of celebration, such as parties, outings and dances, that people who have dementia behave most ‘normally’, and the us-them barriers dissolve away to nothing” (241). The act of sharing an experience can allow individuals to connect at an ontological level, a point I will return to nearing the end of the chapter.

Once again, these approaches continue to assert the centrality of persistent selfhood as that which proves the humanity of persons with AD/DRD. While one route to defending the personhood of those with dementia is to widen the criteria for what it means to have or express a “self,” a posthumanist move would be to deprioritize the notion of stable selfhood altogether, because of the way in which it is bound up with expectations of autonomy, self-determination, and personal responsibility—those “core cultural values” that the person with dementia transgresses (Herskovits 153). Changing the way that we perceive the construction and expression of self means also questioning the permanence of selfhood. As memory loses its power to shape identity—as it becomes unseated as the primary determinant of “self”—the self may be understood, personally and relationally, along different lines and according to different determinants. This might be akin to what Mark Freeman calls an *ontological*

or *spiritual self*, connected to the present moment and defined more by natural inclinations, preferences, or feelings, rather than an *autobiographical self*, defined by the referents of past experience. The larger question is, of course, even if selfhood, or awareness of self, *does not* persist, should this matter in our treatment of persons with ADRD? Notably, Stephen G. Post has argued for a treatment of persons with dementia based on moral solidarity—a principle that relinquishes the priorities of our “hypercognitive society” and rejects value judgments based on cognitive capacity.

As I will explore in my analysis of dementia blogs, online expressions of selfhood are connected to the autobiographical self and represent a symptom of our fixation on the individual self-narrative. In the blogs that I investigate below, the desire to produce a coherent self-narrative is tied to serious anxieties over the loss of selfhood in dementia, interpreted as a loss of social worth and an obstacle to personal well-being.

### **Dementia blogging: genre and rhetorical situation**

As Hydén explores in his discussion of narrative and selfhood in dementia, the apprehension or construction of a self or an identity has been intimately tied, in Western culture, to the ability to recount past details about one’s life—to the capacity for having or recalling memories. Hydén asks, compellingly,

What happens in situations where the teller or author has some form of communicative disability leading to an inability to fulfill the roles of teller *of* the story, and narrator and character *in* the story? In short, what happens when we are unable to tell stories? Or, when we as tellers are unable to create,

elaborate, revise, and scrutinize our own lives by telling stories? Does such a person lack an identity and a sense of self? (39)

In his study he explores the function of “vicarious voices” that aid in the sounding of an individual’s story, explaining how co-tellers can honour the identity and personhood of individuals who are “narratively disabled” by helping to tell their stories. As my discussion in chapter two pointed out, I am hesitant to accept such a designation as “narrative disability” for the way in which it pathologizes non-narrative modes of experience. However, like Mitchell, Dupuis, and Kontos, Hydén explores narrative creation as a relational act, which helps to alleviate the pressure exerted on the subject to construct a coherent self and life story. At the same time, Hydén’s article, alongside the voices I cited previously, expresses obvious anxiety over what cognitive disability and the inability to communicate normatively might mean for an individual’s subjectivity. Do individuals with memory problems still have selves? Do they still have identities if they cannot recall events from their lives, cannot talk to others about who they are or were? As I will discuss below, this preoccupation over questions of the self is not restricted to philosophical ruminations in academic journal articles. We must also consider how this obsession actually impacts those diagnosed with cognitive impairments; indeed, this same anxiety weighs heavily on the early stage dementia bloggers who write about their experiences online.

One goal of this chapter is to answer the question: what do the narrative structures, or myths as Hawkins refers to them, of firsthand dementia blogs tell us about how the disease is experienced subjectively? The desire to reassert the presence of the self (“I’m still here”) *through* the act of writing is a direct response to the

silencing and stigmatization that all persons diagnosed with dementia inevitably face in their day-to-day lives. Secondly, the appeal to live in the present, and the mythology attached to this dictum that manifests itself in dementia bloggers' writing, directly counters the culture of dread surrounding dementia and seems to be used self-consciously by writers as a framework for ordering their narratives. Persons with dementia who blog about their illnesses do not do so by accident. They make a deliberate choice and often commit, in a disciplined way, to the maintenance of their blog. It follows, then, that there are specific reasons why a blog, in particular, meets the rhetorical needs of writers who decide to share their stories online.

In my analysis of the major narrative tropes of individuals who blog about their ADRD diagnoses, I rely on Carolyn R. Miller's definition of genre as social action that emerges from recurrent rhetorical situations. In her 2005 article with Dawn Shepherd, "Blogging as Social Action," the writers argue that the defining feature of the personal blog is its role as a site where a stable self can be expressed. In exploring the *kairos*, or social and cultural context, for the emergence of the blog, as well as its generic features—semantic content, formal features, and pragmatic value—the authors conclude that, above all else, "the blog-as-genre is a contemporary contribution to the art of the self" (n.p.). Blogging's cultural moment is defined by "mediated voyeurism," best exemplified by the phenomenon of reality television and the societal obsession with celebrity culture, that has led to a breakdown in the boundaries between private and public spaces. According to Miller and Shepherd, the act of expressing intimate details about oneself in the public space of the Internet is an outcome of a culture in which "voyeurism and exhibitionism have been morally neutralized" (n.p.). Because the semantic content of personal blogs is predominately

about constructing and validating “an identity that [writers] can understand as unitary, as ‘real,’” the authors regard the rhetorical convention of the blog as intimately connected to the desire to assert subjectivity in the midst of change and instability (n.p.).

Miller and Shepherd’s observations are particularly useful when brought to bear on dementia blogs, and the important rhetorical exigence—or “objectified social need” (Miller 157)—of self-validation in these spaces. Indeed, writers’ self-professed and implicit rhetorical needs are met by the generic features of a blog. I will address three of these features below—temporal structure, imagined audience, and literariness—as serving the rhetorical needs of writers with dementia to reassert their selfhood against the perceived threat of loss.

#### *Temporal structure*

The writing of persons who blog about their experiences with ADRD disclose a similar kind of philosophy of “living in the present” in the face of a medically overdetermined, but subjectively uncertain, future. In some ways, these stories come close to what Arthur Frank calls “chaos narrative.” As he explains in *The Wounded Storyteller*, the chaos narrative is a story that “traces the edges of a wound that can only be told around. Words suggest its rawness, but that wound is so much of the body, its insults, agonies, and losses, that words necessarily fail” (98). The chaos narrative escapes from the lips of patients in what Frank describes as rambling “and then”-style utterances—unorganized, incoherent, and non-linear in fashion. Individuals experiencing the chaos of illness have been unable to find meaning or narrative significance in their experiences, or have yet to understand their pain

through the lens of a narrative trope like quest or restitution. Because of the nature of life writing in new media spaces, many writers who chronicle experiences of illness online may appear to tell their stories in the chaotic way that Frank describes—forever cycling through a series of present moments. This is a convention of social media genres that emphasize a perpetual present, chronicled in serial fashion. However, many of these storytellers, on Twitter and PatientsLikeMe, for example, in disclosing the vulnerability and rawness of *right now*, nonetheless reflect meaningfully on their experiences as a way to make them useful to themselves or to others. More so on blogs and social networking sites, writers also frequently record past experiences in narrative form and imagine possible future narratives.

Despite the oftentimes chaotic nature of illness, blogs on this topic have been crafted to reflect an individual's experience of reality in some way. As such, they are not true chaos narratives. Even if they reflect a chaotic present, bloggers and social media users have usually taken the time to sit with their stories and contemplate them as they record them. Nonetheless, these stories are also not always framed in terms of restitution or quest, or in Hawkins' mythological frameworks of battle or journey, rebirth, and healthy-mindedness. In many ways, these narratives are profound because they take up the contingent, frightening, and vulnerable sides of illness that are central to Frank's chaos narratives. The stories I describe in this dissertation—Kate Granger's Twitter reflections on cancer and the dying process, the contingent state of the new normal among PLM users with MS, and the search for selfhood in the face of progressive dementia among bloggers with ADRD—all profess, and do not shy away from, human weakness. In the examples I study, this weakness does not simply represent a challenge for the narrator to overcome in her quest for health, but is,

instead, an expression of human experience. These stories also reject the fantasy that our lives, selves, and self-narratives could ever be immune to change, since they are a testament to the limits of human agency. And in this way, they comprise important cultural artifacts for understanding the value of posthumanist theory to medicine.

Part of the reason why online narratives revel in “nowness” has much to do with the rhetorical framework of the spaces in which they are created. As discussed in chapter three, Twitter compels up-to-the-minute sharing of life details, with a particular focus on logging life as it happens. The brevity and informal nature of tweets facilitate a kind of on-the-fly, uncensored, and capricious form of communication. Though entirely different in terms of rhetorical function, the same temporal structure is true of blogs in which a backwards-chronological listing of posts enforces continuous prioritization of the present moment. This is not to say that the *content* of blog narratives is stuck in a perpetual present. Indeed, many bloggers reflect on the past and ruminate on the future, expressing their fears over the losses that their illness might eventually entail. In this way, blogs certainly travel back and forth in time. However, the temporal structures of the blog reinforce a present-focused orientation.

For one, as I mentioned, the presence of the most recent post at the top of the blog home page signifies various conditions: a diminution of past posts in favour of the most recent and relevant information; the expectation that a reader will follow along and be up-to-date with reading; and a sense of “live-ness” or open-endedness, that reminds us that blogs (unless writers deliberately conclude them) are perpetual works-in-progress. Other temporal signifiers include the date and time stamp on each blog post that anchors every entry along a linear trajectory. This feature recalls the

generic conventions of a journal, diary, or personal organizer, providing writers with a primary organizational structure that is temporal, rather than thematic, spatial, relational, or otherwise. The organizational feature of the “previous posts” section of most blogs, which allows the reader to find individual posts according to year and month also reasserts the blogging function of keeping time.

In the context of blogs by persons with dementia, the structure of a backwards-linear narrative ordered in time is central. Indeed, for these bloggers, it seems that the act of blogging is a conscious attempt to stay in the present moment, even as they recall past memories and speculate about the future. The temporally based organization of a blog certainly supports the rhetorical need to reaffirm one’s continued presence as writer and stable self, acting as proof that “I’m still here.” In the example of the blog *Slip Sliding Away...*, co-authored by Ed, a person with Early Onset Alzheimer’s Disease, and Mindy, his wife and partner-in-care, Ed frequently returns to the blog after months-long absences, each time remarking that his hiatus has not been due to cognitive impairment. On one such occasion, he writes, “Gee, ...despite being away from this site for over nine months since last posting... and despite what some of you may have surmised... no, I am not crazy yet...” (Ed, “Still Crazy...,” original ellipses). In another post later that year, he writes once again, “Several of you have asked me in separate emails why I have not posted in the last few months... the answer is... no, I am not any more crazy than before” (Ed, “Sinner’s Prayer,” original ellipses).

The feature of dated and timed check-ins via the blog becomes particularly imperative in the context of dementia, as individuals who are diagnosed with ADRD must contend with the collective social anxiety of “loss of self” that has, over time,



become attached to this group of illnesses. In this case, the liberal humanist expectations of self-determination and autonomy become threatened and individuals with dementia feel immense pressure to cling to self in the face of worsening cognitive impairment. The way in which blogs mark time, reflecting a weekly or monthly report, supports the rhetorical need to make one's status as "not yet crazy" known. The weight of this burden is evident in the blogging of persons with dementia, raising questions pertaining to the trauma inflicted, not by the physical disease, but by our social construction of it, a point I will turn to nearing the conclusion of this chapter.

### *Imagined audience*

The conditions of production and consumption of the blog are also important here, since writing within this arena is not intended for the writer alone, as would be the case with a personal journal. The fact that blogs represent a form of *social* media implies that bloggers writing about their own dementia diagnoses are interested in placing their stories somewhere that they will be read by others, commented on, and generally situated in a social space where new connections and social validation may manifest. In analyzing the then-emergent genre of the blog, Miller and Shepherd focus their paper on the rhetorical situation created by "the peculiar intersection of public and private that weblogs seem to invite" (n.p.). While individuals speak to their communities of readers, Miller and Shepherd note that on blogs, the writer also engages in a dialogue with himself or herself. They observe that, for bloggers, "self expression serves the intrinsic self-disclosure functions of both self clarification and self validation, enhancing self awareness and confirming already-held beliefs. The blogger is her own audience, her own public, her own beneficiary." As I will explain

below, taking into account the social dimension of blogging may support the idea that dementia bloggers write, at least in part, to prove their continued selfhood to others and, in the process, to themselves.

Some bloggers profess to writing for their friends and family as a way to keep them informed about the details of their diagnosis and their journey with dementia. As Kris writes in the first post of her *Dealing with Alzheimer's* blog, "My son has set up this blog for me. I'm hoping to use it as a journal of sorts to not only help me but my friends keep up with me. I have many many wonderful friends and family that keep up with me. I know it is as hard for them as it is me. They don't know how to ask how I'm doing and hopefully this will help them to understand" ("Christmas Eve 2003"). However, some comment that people in their real world social circles are too busy, disinterested, or in denial to follow their blogs. Over the course of five years of blogging, Silverfox writes that he sees his blog as a "lifeline," noting, "It is like I am writing to a very close friend" ("This blog"). However, at earlier moments he expresses frustration over a lack of interest from his friends and family when he posts difficult or upsetting news and "no one has tried to contact me, help me deal with this shock, or even reacted to my posts!" (Silverfox, "The emotions of disappointment").

At other times, bloggers are explicitly speaking to the "normal people" against whom they are defined as Other. Truthful Loving Kindness writes on her blog, in a plea for understanding, "My battle is the same as it is for you; to be the best "me" that I can be, despite dwindling resources. My sacrifice is my self; MY all – because that is the known outcome of this war. It will cost every single thing that I hold most dear, and my memories and connections with every being that I hold most dear. Eventually it will cost my life" ("Alternative to Consumer Terminology"). In this case, the writer

envisions the “you” reader as a cognitively “normal” person to whom she attempts to relate. At other times, the blog becomes an opportunity for writers to respond in a controlled and calculated way to frustrating experiences and attitudes they have faced in their daily lives. In this case, the writer envisions the audience as antagonistic, ignorant, or ill-informed and the blog is a space for mediating conflict or criticizing those who perpetuate dementia stigma. One image in a blog post from @mason4233’s blog *Dementia survivor, so far...* is a succinct, but powerful, example of the way in which dementia blogs sometimes address an antagonistic audience. The image reads: “I am a PERSON, not just a diagnosis,” followed by the blog text, “And you don’t have to raise your voice when speaking to me” (“I am a person”).

This imagined audience, then, is evidently not a reflection of the community of readers who follow and comment on bloggers’ writing.<sup>22</sup> As blog comments reveal, these readers are consistently supportive, likeminded, and, often, fellow persons with dementia. The imagined audience seems to function more flexibly for the writer as whomever—in the moment of writing—the blogger wishes to address. This flexible audience is important in the function of the blog as a space of self-validation.

Indeed, the act of sharing one’s experience of illness through blogging is not only to make sense of it in the ways that Frank and Hawkins contend that we do when we write about sickness—that is, by using narrative as a way of “redrawing

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<sup>22</sup> In this way, the perceived audience of the dementia blog seems to differ quite markedly from other blogging communities. By way of contrasting example, we can look to Aimée Morrison’s study of personal mommy blogs, in which she surmises that “the intimate public of personal mommy blogging” produces “direct emotional reciprocity among its participants” and communities that are small in scale, both features of which produce the conditions for a trustworthy, intimate, and likeminded audience (“Suffused” 38). Because of the political motivations—whether explicitly stated or not—of most dementia bloggers to, at the very least, contribute to the conversation about attitudes toward ADRD, and at a more political level, to campaign for better ADRD care, funding, and research, dementia bloggers seek out and expect a wide and diverse audience. However, for the most part, dementia blogging communities actually remain quite small.

maps and finding new destinations” (Frank 53). Because of the social nature of public blogs, these stories could also be about spreading awareness in the face of misinformation about dementia, or even connecting with others in an exchange of mutual support. Both of the bloggers I write about in the case studies mention these as central motivations, and other scholars have presented these as reasons for blogging about other kinds of illnesses (see Hardey, Orgad, Pitts). However, there is clearly more to the situation, and this “something more” is related to the writer’s need to assert her selfhood in the face of various challenges and obstacles, some of which are socially constructed. Certainly, writers have the need, simply, to say: “Hey! This is happening to me. This moment of human vulnerability is real and raw and, because I’m a social creature, I need to tell you about it.” As in traditional illness memoirs, “the ill person needs to reaffirm that his story is worth listening to by others” (Frank 56). At the same time, writes Frank, “he must also reaffirm that *he is still there*, as an audience for himself,” a point that certainly resonates with dementia bloggers’ writing (56).

I will discuss this idea in relation to both of the bloggers below, but for now, I draw on an illustrative example of the flexible audience in the case of a blogger with fronto-temporal dementia (FTD) whose blog posts often take the form of free verse or prose poetry. Bruce Bane, the author of *Living With Dementia*, writes on his “About Me” page, “I am writing this blog first of all for myself – to try and understand how my dementia affects my life. And if this helps others better understand the effects of FTD, so much the better. I am trying to find my way through this wilderness of a disease and I invite you to travel with me. It’s always better to travel together instead

of alone.”<sup>23</sup> The motivation of connecting with others in order to “travel together” is central to Bane’s writing. However, his goal is also, quite clearly, to put his words “out there” as a way of speaking to himself, about himself in the way that Miller and Shepherd observe. Many of his posts are explicitly on the topic of reconciling the changes in personal identity that he is experiencing with his sense of self. In one post, entitled “Who Am I Becoming,” Bane very explicitly employs the blog as a space to voice an interior monologue, writing:

If life is the process of becoming who we are meant to be / And then being who we are (no more, no less), / What does that mean for me? / Gradually it feels like I’m becoming less of who I am / This thing called dementia is draining me of myself / So I wonder, “Who am I becoming?” / When all is said and done will there be nothing left of me? / Or will there still be a spark that others can point to and say, / “Yes, that’s Bruce. I’d know him anywhere.”

At the same time, Bane has an obvious sense that he is speaking to an imagined audience of others who are going through this experience with him. In his post “The Liar,” he characterizes dementia as a liar that “tells me lies about myself / About the people around me / Lies like, ‘You have no worth’, ‘People see you as a burden’, ‘Everyone would be better off if you weren’t around’ / Believing these lies gives dementia power” (Bane). He ruminates on the dangers of accepting these lies, opting instead to believe the truths spoken by those around him that affirm his sense of self. Bane closes by saying, “Because when I listen to the lies I live them / And that becomes a burden for all of us / One that none of us deserves” (“The Liar”). In this post, the “us” that Bane addresses seems to refer to a general “us”—denoting society

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<sup>23</sup> The blog has been deleted since the time of writing.

or the collective—but it might also refer more intimately to his imagined readers, the ones who he sees as traveling with him on his journey with dementia.

*Literariness (and literacy)*

Connected to the generic affordance of the blog as a place to speak publicly to an imagined audience is the function of a blog as a manifestation of a normative communicational mode. While all of the dementia blogs that I researched, at various points, exhibit two of the narrative tropes that Frank highlights—chaos and quest—the blog, *itself*, also becomes a diagnostic test of sorts. It is, as each blogger self-consciously attests, a way to prove (to oneself? to the world?) that one has not yet “lost one’s mind.” The writing of a blog becomes a way of “passing” for normal, in spite of a cognitive disability. While each blogger chronicles his or her journey as it is marked by physical and mental changes that bring about both struggles and joys—even as each blogger is meticulously documenting her difficult symptoms or social embarrassments or “dementia moments” as they are affectionately called—she is also struggling to prove her continued presence *as herself*. The importance of the blog genre to such a project is central, since it provides the resources to construct an ordered, up-to-the-moment narrative.

The expectation that one articulate one’s illness story in such a way, or the desire to do so, reflects a highly normative expectation of how one should process, cope with, and communicate one’s experience. This reality is an oversight that I believe Frank makes when he writes of illness as a call for stories. The social expectation that we mobilize our experience to serve a greater good of self-discovery, social connection, or heightened awareness, and that we do so through narrative means is based on the premise that we all have the resources to perform such an act of

self-disclosure. The choice by those in the early stages of ADRD to chronicle their experiences through blog writing becomes a way of proving one's continued membership in this group of "normal people" who can communicate in conventional ways about what they are going through.

Among other reasons, these bloggers write as a kind of rebellion—however diffident—against the knowledge that this ability is a temporary one. Upon reaching his 100,000th view, Silverfox writes, "As I have said before, I will continue to write as long as I can. And, I am sure you recognize that my journey is speeding up and gaining intensity. No big deal! I am still here. Maybe a little more grouchy, fuzzy, unstable, or disoriented, but still here. And, as long as spell check works, you will be able to figure out what I am typing for a while!" ("100,000 Views!"). Truthful Loving Kindness speaks often of her diminishing writing abilities, providing a metanarrative to writers, in one post, about her struggles to actually bring her "bits of brilliant insight" into a cohesive piece of prose writing. She writes, "I typed these pieces of notes from my cell phone, hoping that I could later finish and connect the thoughts. It has been over eight hours and I can't seem to even grasp what I was talking about, let alone get to the point where I could continue thoughts or bring threads together like I had hoped. Posting as-is..." (Truthful Loving Kindness, "Efforts to Gather Clarity"). The determination to "write anyway" can be construed as an unwillingness to accept the imposed silence that social constructions of dementia present. Along the same lines, the act of blogging, itself, supports the narrative trope of "proving oneself" that is persistent across many ADRD blogs, and which I will discuss through my analysis of two representative blogs by persons with dementia. The first, entitled *Before I Forget*, is a blog about Early Onset Alzheimer's Disease (EAOD) written by a British

woman who calls herself Mrs. Hsg. The second blog, *Watching the Lights Go Out*, chronicles physician David Hilfiker's first year of an Alzheimer's diagnosis and the year following his doctors' retraction of that diagnosis. I will explore how the narrative point of view of *self-validation* in each of these blogs is connected to the dread over loss of self that contemporary cultural imaginings of ADRD perpetuate. Bloggers' writing oscillates between a desire to continue reasserting the self and an acknowledgment of the unstable nature of identity in dementia.

### **Mrs. Hsg, *Before I Forget...***

Mrs. Hsg wrote her first blog post in May 2012 when she began to notice that problems with memory were affecting her day-to-day life. After writing a few posts that month, she took a hiatus from posting until Christmas Eve 2012 when she announced her official Early Onset Alzheimer's Disease (EOAD)<sup>24</sup> diagnosis (Mrs. Hsg, "Christmas eve.."). One post shortly following this announcement reads, "I am thinking a lot today of what it means and how long I have before I am not me anymore. I lie in bed at night and can't believe..no..don't want to believe it. I want to die before I am a burden because my mind has gone" (Mrs. Hsg, "Leading Up to Christmas").

Like many of the ADRD bloggers whose words I read in my research for this chapter, the diagnosis of dementia brings with it, first and foremost, a crisis of identity—or, rather, a crisis pertaining to identity loss. Mrs. Hsg first expresses anxiety over eventually not being "me anymore." Unlike some of the claims that

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<sup>24</sup> The term EOAD is used to label a rare form of dementia that affects individuals under the age of 65. Most cases of EOAD are linked to genetic mutations in three different genes, although some people who are diagnosed with EOAD have the "common form of the disease," just at an earlier age than usual ("Early-Onset Alzheimer's").



Frank makes about the vulnerability of the body and the embodied nature of illness storytelling, for those with dementia, the mind, the self, the intangible “me” is at the core of the trauma. For the bloggers who set out to document their journey post-diagnosis, the act of blogging becomes many things—an opportunity to vent, a way of finding perspective, a forum for ADRD advocacy, and a vessel for memory keeping. Importantly, the blog also becomes an assertion of the self against the threat of dissolution, incoherence, forgetting, confusion, and so on. I find it noteworthy that, for the most part, the blogs I have read show very little evidence of an ADRD online community; the bloggers I write about (aside from Hilfiker) rarely receive more than one or two comments on their posts, if any. As mentioned in my discussion of the blog audience, at times, each of these bloggers seems to be speaking to an imagined reader reminiscent of a medical authority or suspicious caregiver—someone to whom the writer must prove his or her competency. At times, it seems that the writer is speaking to herself—to her own fear that she is becoming “someone else.”

Over the past two years of blogging, Mrs. Hsg has posted several times per month and the majority of posts relate, in some way, to her diagnosis with EOAD. As with all of the other blogs I will discuss, the point of the blog is very overtly to provide a space to write about the experience of dementia, functioning as a personal journal where Mrs. Hsg can share her life with readers. She is candid about her strong relationship with her adult daughter, whom she raised as a single parent for many years, and her fears over that relationship changing as new symptoms emerge. She openly discusses the strain that the diagnosis places on her marriage, expressing the mutual decision by she and her husband that he will not be the one to provide in-home care when the time comes. She also shares her experiences with the frustrating

bureaucratic intricacies of filing for early retirement and her disillusionment with the social support system (or lack thereof) for persons with EOAD in Britain, where she lives.

In the “Who Am I?” section of her blog, Mrs. Hsg writes, “I want to record my daily life and thoughts to look back on when I no longer remember. I hope I have 15 years at least before I am no longer me. So I will try and write as long as I can.” The page that Mrs. Hsg has titled “Who Am I?” carries a special kind of significance in this context. The blog is heavy with the weight of her attempts to express a seemingly compromised self. This notion of feeling compromised or divided is emphasized by Mrs. Hsg in her interpretation of a quotation by Terry Pratchett, reflecting on his own EOAD journey:

There have been several quotes by Terry Pratchett that I can identify with.

*‘It occurred to me that at one point it was like I had two diseases – one was Alzheimer’s and the other was knowing I had Alzheimer’s.’*

This is probably the quote I that strikes me most. Knowing you have Alzheimer’s is like being secretly give [sic] the date of your death and not being able to stop it or control how you will move towards it. It is like watching yourself in an out of body experience and not being able to intervene. The main thing is that nobody around you can imagine for one second how devastating it is to understand, and feel your own mental cognitive breakdown. (“The End Game”)

In this passage, Mrs. Hsg positions herself as an observer, seeing evidence of her mind slowly changing as a result of her illness. In a sense, this is her position as the writer of a blog in which she is her own subject; her role is to maintain a stealthy gaze on any

signs of herself “slipping away.” She notes in one blog post that her tendency to “‘catalogue’ anything new publicly is to hopefully educate as many as I can about the world of living with Alzheimer’s and Dementia. Maybe I feel that I am on some kind of mission, if so the very act of writing this is supporting me by getting rid of the worms in my head :)” (“Living with Early Onset...,” 31 Jul. 2014). However, the way in which she thinks through and interprets the physical and cognitive changes that she catalogues *also* reflects an obvious desire to prove that, for as long as she can make these observations, she might maintain the upper hand on her illness. As I referenced in the epigraph to this chapter, Mrs. Hsg writes of feeling “like a butterfly desperate to get out of a jam jar,” supposing that she writes “to mask anything is wrong with me. Perhaps it is more that I am saying, ‘here look, I am fine, I can write these words, so I must be ok. Maybe I will never get any worse’” (“Who Am I?” (comments)).

Mrs. Hsg’s reflections on linguistic ability are one example of this perpetual self-monitoring. She writes, “Language has not left me but has become more important as I notice the demise of tiny parts of language that become dysfunctional in my brain. Language is communicating who you are, if you no longer have language do you fail to be you?” (Mrs. Hsg, “Language and Me”). Her answer to this quasi-rhetorical question is that, indeed, “who she is” persists in spite of language difficulties because “who you are is much more than language or communication.” Nonetheless, a nagging question remains: “why do I feel that the more I forget and the less words I have, parts of me slip away?” (Mrs. Hsg, “Language and Me”). In another post, her struggles with grammar in her writing—particularly what she begins to notice as her newly acquired misunderstanding of the comma—also propel her to reflect on how the breakdown of linguistic ability affects her expressions of self. As

someone who is obviously inclined toward the literary—she also maintains a blog where she posts book reviews—a sudden difficulty with writing mechanics arrives as an assault to the very core of her being.

In her blog post on “Punctuation malfunction in my brain and my increasing fear of commas,” Mrs. Hsg notes, “As I write now I am having great difficulty in knowing if I am putting commas in the correct place and it has suddenly become a real issue. I have no idea why I am stressing about it so much... I am also misspelling words more frequently... Lately what I think is not what my fingers are typing, how can that be?” She brings up this issue mostly to voice her worry that she is becoming “less literate” and to communicate her awareness “of these small changes that I cannot do anything about.” She expresses her embarrassment over these mistakes, noting that, in the past, she has judged other bloggers for their errors in spelling, grammar, and punctuation. With great humility, she remarks that her new writing challenges have helped her to see “that it is what people are struggling to say that is more important.” Her sense of worry over what might be the implications of altered communication abilities is clear in the last line of the post, however, when Mrs. Hsg asks her readers: “but are people less likely to read a blog that has grammatical errors in even if the content is interesting?”

Her fear over *not noticing* changes in her own abilities or expressions of selfhood also becomes apparent in a blog post chronicling a trip to the memory clinic to assess her driving capabilities. Her discussion with the doctor eventually comes to the topic of post-mortem brain donation, and Mrs. Hsg is eager to have her brain donated to research after she passes away. Thoughts of her eventual cognitive deterioration and death are clearly amplified by her trip to the memory clinic, and this

leads her to reflect on her fears. Although she wants to be “a person who accepted things as they were so that I could focus on everything else,” she acknowledges her instinct to “fight this” (Mrs. Hsg, “Memory Clinic”). The anxiety underlying her words is palpable, as she writes,

When the problem is in your brain, you may not be aware of the rate the cognitive decline is happening, your thoughts will simply change without it seeming odd or wrong. I am scared that with cognitive decline I shall not be *aware* that dementia is increasing, because then I can no longer fight it. (Mrs. Hsg, “Memory Clinic”)

The act of taking an inventory of symptoms on her blog is one way that Mrs. Hsg self-monitors in order to stave off what she fears will be her eventual ignorance of her own dementia. This inventory taking is a framing device that each of the ADRD bloggers that I discuss uses at some point on her or his blog. Generally speaking, this tendency to “check in” is characteristic of the personal journal style of blog. In the case of ADRD, it also becomes a way to track evidence of symptoms as a personal medical record might. While Mrs. Hsg’s posts certainly do not report on daily, or even weekly, symptoms—her posts appear only about two or three times per month—her writing self-consciously announces its purpose, at least in part, as a kind of diagnostic test or form of self-monitoring.

### **David Hilfiker, *Watching the Lights Go Out***

On October 19, 2014, in a post titled “The Last Post ... (?),” blogger David Hilfiker writes:

Some of you will have noticed that I haven't written in almost a month; you may be wondering what's happened to me. I'm fine, but I just haven't had anything new to say. My cognitive lights are no longer winking out. True, some are still burned out and unlikely to return, but it seems I've written everything I've had to say about them. So it's time to end this chapter in my life and close "Watching the Lights Go Out."

Hilfiker's experience with Alzheimer's disease (AD) is a rather unique one, in the sense that his original diagnosis of cognitive impairment (probable AD) in September 2012—his reason for having started his blog—was revoked and downgraded to subjective cognitive complaints (SCC) just over a year later. A diagnosis of SCC means that the individual reports memory problems, however, these do not show up "objectively" through neuropsychological testing (Hohman, et al. 125-6). As the first year of Hilfiker's blog testifies, his life became consumed by the fears, stigma, and uncertainty attached to an AD diagnosis. After doctors reassess this decision, Hilfiker's blog gradually begins to examine the jarring process of readjusting to a life *without* Alzheimer's disease.

Hilfiker's blog is one of the more publicized examples of ADRD blogging, due to his prominent position as a socially conscious physician and author. In the '80s, Hilfiker practiced what he called "poverty medicine" in economically disadvantaged rural and urban communities in and around Washington DC. In 1990, he and his wife Marja founded Joseph's House, a residence for homeless people with AIDS and cancer. He is the author of the 1982 book *Healing the Wounds*, a collection of candid reflections on his career and the medical profession; the 1994 memoir, *Not All of Us Are Saints: A Doctor's Journey with the Poor*; and the 2003 book *Urban Injustice: How Ghettos*

*Happen*, a social history of poverty and critique of contemporary policies of social assistance in America. Hilfiker's decision to publicly chronicle his journey with AD received media coverage from several different outlets, including the *Daily Mail* (Peterson), *Washington Post* (Vargas), *Huffington Post* (Hall), *Policy Mic* (Adams), *Mashable* (Wertheim), and *New York Times* (Span). This degree of visibility is certainly not the case for the other dementia bloggers I write about in this chapter, so we can conceive of Hilfiker's readership as being significantly wider than that of the average dementia blogger.

Hilfiker is extremely candid about his experiences with cognitive impairment and repeatedly vocalizes his unwillingness to feel shame for the neurological changes that are producing new, different, or disappearing behaviours. His openness about his symptoms and cataloguing of these changes are voiced in an overtly activist tone, as well. Like Mrs. Hsg, Hilfiker sees his blog as a space to clear up the misconceptions about his disease that have insidiously found their ways into the cultural imagination. The emphasis on activism and paying witness to the truth of living with dementia are important ways in which these blogs form a kind of collective voice. Their explicit agendas to combat dementia stigma are a response to the fact that all individuals diagnosed with ADRD, without exception, find themselves on the defensive, forced to contend with dehumanizing attitudes and incorrect assumptions about the disease that derive from a deep-rooted collective fear over cognitive breakdown.

Uniquely, Hilfiker's observations on his illness also, quite clearly, emanate from the medically oriented perspective of a doctor who is perpetually on the lookout for signs and symptoms. He notes repeatedly that many small incidents about which he writes that would have meant nothing to him before his diagnosis, now activate his

“medical mind” and cause him to search for connections between the occurrence and his impairment (Hilfiker, “The Forward Lean”). His professional training can partially account for his meticulous journaling of these symptoms. However, this tendency appears across the spectrum of personal blogs by individuals with dementia and relates to the totalizing nature of such a diagnosis. When an individual receives an ADRD diagnosis, every small change in temperament, behaviour, or personality enters into the service of validating that diagnosis. As Mitchell, Dupuis, and Kontos observe,

Once diagnosed with dementia, persons and their feelings, actions, and expressions become symptoms within a problematized field of possibility. If persons with dementia express feeling healthy and well, they are judged as being in denial. If they are having trouble remembering details but fill in the gaps to save face, they are said to be confabulating. If they get angry with the way in which health workers are providing care, then they are labeled as aggressive and may end up being restrained and isolated. Other scholars have also noted this totalizing process of labeling and problematizing that engulfs a person’s entire life and relationships with others. (4)

Dementia blogs, while they are complex narrative spaces containing multiple rhetorical exigences, seem to serve this function by placing the subject under self-scrutiny. Hilfiker’s blog is a prime example of such self-scrutiny, as he spends just over one year defining his life experiences through the lens of dementia, only to have this lens shattered when the diagnosis changes.

The notion of an Alzheimer’s “identity” and how the self becomes redefined in the wake of a diagnosis become central foci on Hilfiker’s blog as he chronicles both



transitions—internalizing his diagnosis and then de-identifying from it. Hilfiker’s first three posts connect to three of the major concerns of this chapter. His blog begins as many dementia blogs do, with the announcement of a diagnosis. Entitled “Now It Begins,” Hilfiker writes, “Yesterday, the cliché goes, was the beginning of the rest of my life.” Similarly to Mrs. Hsg and other bloggers as they ruminate on their diagnoses, Hilfiker describes the path of his future as predetermined, tainted by the anticipation of sadness, loss, and dependence. He writes, “Alzheimer’s has always seemed like the worst way to go out. [...] Curiously, I feel more sad than scared: sad that I’ll not see much of my grandchildren’s growing up, sad that people’s last memories of me will be of a body unable to recognize anyone or speak cogently, sad that Marja and I won’t grow old together and that she’ll be burdened with taking care of me.” The vision of this predetermined path is bound up with the medical diagnosis, but also with every image, story, metaphor, or sentiment about ADRD that we’ve seen, read, heard, or felt—what Herskovits refers to as the “public consciousness of Alzheimer’s—a consciousness that is produced by the totality of discourse [...] about Alzheimer’s” (147). This consciousness is infused with the stigma, dread, and fear that I discussed in the first part of this chapter, meaning that those who are handed an Alzheimer’s diagnosis are also handed the weighty burden of our cultural constructions of the disease.

In line with my focus for this chapter, Hilfiker’s next post is on facing the loss of self—that most dreaded loss according to Western cultural understandings of ADRD. As he will continue to do throughout his blog, Hilfiker turns to Buddhist wisdom to remark that “suffering arises just here in this identification with ‘self.’ My identity is as an intellectual and I’m going to lose it” (“Spiritual Questions”). What he

understands as his eventual loss of self causes him anxiety, and yet he realizes that if he can deprioritize this fixation on “self,” then he can circumvent much of the suffering that the “predetermined path” of Alzheimer’s portends.

His third post questions the situation I have just described following an Alzheimer’s diagnosis, in which all life circumstances become connected, in some way, to pathology. He writes, “I’m interpreting so many mistakes I make in light of the dementia: typing mistakes, skipping words when I write, forgetting where I put stuff. In the past, I have sometimes used my diagnosis of depression as an excuse to avoid things, to pull back from life’s challenges. I don’t want to repeat that mistake here by interpreting everything through the eyes of this illness” (Hilfiker, “Is Every Mistake Alzheimer’s”). This is even more of a concern for Hilfiker because he has not actually received a firm diagnosis of AD—this does not come until approximately January of 2013. And, yet, as his blog unfolds, we see this urge being very difficult to resist. In his subsequent posts, he returns to this question—to the nagging desire to reframe his world according to Alzheimer’s disease: “Every day I notice something more that is amiss in my mind. I’m typing slower and with many mistakes; I’m so easily distracted; I’m so slow in getting things done; my memory seems to be getting worse by the week. Are those things evidence of worsening disease or am I beginning to imagine things in order to conform to the diagnosis?” (Hilfiker, “Fear”). Again and again, Hilfiker returns to this problem, and he does indeed continue to seek out connections between his memory, mood, and behaviours and his diagnosis.

Over the course of his first year of blogging, several daily and major life events become framed in the context of Alzheimer’s. Small changes that become preoccupations include: getting lost and disoriented in a well-known part of the city

(Hilfiker, "Lost"); an uncharacteristic disinterest in the presidential debate ("Uncertainty"); difficulties socializing at a conference ("Speaking at a Conference"); offering "bread" from the collection basket at church ("Learning to Laugh at Myself"); trouble following tech support instructions ("Why Am I So Happy Within My Alzheimer's?"); an inability to memorize directions ("Losing My Life"); repeating the same information on his blog multiple times ("God's Humour"); difficulty following the rules of board games ("Receiving Help"); and repeatedly forgetting the same intention to do something within seconds of having it ("Little Things").

There are larger changes, too, like memory problems that interfere with his duties as church bookkeeper and eventually force him to resign ("Losing Self"; "Confusion"; "A Huge Mistake") and "difficulty in writing and a general mild apathy" ("Life Lessons"). He also chronicles some positive changes, like spending more time with his children and grandchildren, finding more joy in "living in the present" rather than the future, and greater comfort in being emotionally open and vulnerable with others, which has resulted in deeper interpersonal connection.

Most noteworthy, with regard to the processes of self-monitoring that Hilfiker's blog takes up, is perhaps a palpable (and rather immediate) shift in his sense of identity (or identification) with this illness. At an early stage, he seems willing—even eager—to take on an AD advocacy role, remarking, "There are parts of me, I find it hard to admit, that are actually excited about this diagnosis, [...] parts, in fact, that even want it. It's not the prospect of real dementia or lying drooling in a nursing home bed, of course, but there is something titillating about the present, about being that person who can shock others, who talks honestly about his illness and helps others relate better to it. [...] How strange! ("Standing Out"). Very quickly,

even before his diagnosis is confirmed, Hilfiker feels that he has “in some real way integrated the diagnosis into my self-image” and that this letting go of uncertainty over the diagnosis has been a freeing experience (“Telling Karin”). In a blog post titled, tellingly, “Why Am I So Happy Within My Alzheimer’s?,” Hilfiker discusses the improvements he has experienced in his life since accepting that he has AD: “Gone is the sense that I should be doing *more*. [...] I don’t feel the same necessity to live in the future, fearing the judgment that will come if I don’t do it right.”

In taking on an advocacy role, Hilfiker finds purpose and empowerment through a diagnosis of AD. While he sees this as a shift in selfhood, I would argue that Hilfiker more likely fits the diagnosis into his sense of self, so that he can continue to be the person he was before—the person who doesn’t shy away from confronting difficult realities, like medical mistakes, social injustice, and, now, cognitive impairment. His blog, despite his reflections on letting go of self, is actually a manifestation of his desire to keep being the writer, the intellectual, the free thinker, the analytic mind, and so on.

Perhaps the real trouble with Hilfiker’s experience is that, even if he had accepted the need for a Buddhist-inspired process of detachment from ego, his “journey with Alzheimer’s” ends rather abruptly. For the first year of the blog, Hilfiker writes about his symptoms and dementia-related experiences a few times per week; however, some doubts begin to surface about his diagnosis and, in September 2013, he is finally cleared by a neurologist (“Waiting”) who tells him there is “no good evidence of brain dysfunction or cognitive impairment” (“Letting Go --Third Time Around”). Hilfiker reflects on what this means for his rather tenuous sense of self: “It’s true,” he writes, “a year ago, as I was getting used to the diagnosis of

Alzheimer's, I wrote about having to [let go of self](#) and I've mentioned it a lot since, for instance, [here](#) and [here](#). The Buddhists point out that hanging on to one's sense of self is a sure recipe for unhappiness because our self is always changing" ("Letting Go -- Third Time Around"). He notes that he had started to let go of his "self-image as an intellectual, as the independent, competent one who needed no help"—though, as mentioned, there is little evidence on his blog that he has truly given up these markers of identity. He goes on to explain his renewed crisis of self, now that he feels the weight of expectations to "return to normal":

Now I have to give up the self who is the Alzheimer's patient, the one who would create much suffering for his family as he declined, yet also the one who is losing his intellectual capacities but accepting it with grace, [...] and the one who is willing to speak and write about his disease publicly. That identity was an attractive self that I had become very attached to over the past year. It's hard to let it go.

The Buddhists are right again: In spite of the overwhelming good news of the last several months, I have felt almost cheated, suffering this loss of identity, unable to embrace the good news in all its fullness. ("Letting Go -- Third Time Around")

With this last visit to the neurologist in January 2014, Hilfiker remarks that he begins to feel a release, once again, from the Alzheimer's identity, a "freedom from that tension between who I am and who I thought I was" ("Letting Go --Third Time Around"). And yet, it seems almost with sadness and regret that he ends his blog in October 2014. He expresses guilt over feeling as though he has misrepresented himself. The blog has not served the purpose he had originally intended, and this is

difficult for him to accept. He feels as if he has “promised one thing and delivered another. It’s an irrational sense that I have something to apologize for” (“The Community Responds”). Despite having continued for the last year of his blog to chronicle symptoms that were no longer Alzheimer’s, but some other form of cognitive impairment, the erasure of a diagnosis makes his complaints feel less purposeful—without a diagnosis, he is actually *unable* to rally around a coherent new sense of self in illness.

Hilfiker’s writing in this post and elsewhere points to the profound power of a diagnosis to shape an individual’s expectations of self and the world. One of the major themes in his blog is to explore how he reacts to what he believes will be others’ expectations of him *as* someone with Alzheimer’s disease. His writing is enlightening in countless ways, but with regard to my purposes in this chapter, Hilfiker’s work to expose the social expectations that we create around selfhood in ADRD is noteworthy. The burdens that social constructions of ADRD place on individuals with cognitive impairment are clearly real and endemic.

### **Moving beyond narrative?**

In our conversation I told my husband that all I understood were the first phrase of the paragraph and the last phrase of the paragraph, so all the sentences in the middle might just as well have been “blah blah blah.” He took me in his arms and his reply was, “Okay, are you listening?”

“I love you blah blah blah ... forever.” (Truthful Loving Kindness, “I was going to write”)

The blogs of Mrs. Hsg and David Hilfiker both reveal, in their own ways, how self-narratives—the stories that we tell ourselves, and others, about who we are—can be the source of great anxiety in the face of progressive cognitive impairment. Both blogs serve as a way for writers to assert coherence in response to threats of the dissolution of self—they are spaces where a life narrative can be articulated meaningfully. They are also archival spaces where writers record evidence of who they are—or were. The blog becomes a vessel or time capsule, or in some articulations, a prosthetic memory for writers who hope to record as much as possible about their lives before their neural structures are no longer capable of storing memories. This perceived need to construct a prosthetic self of sorts can be construed as an anticipated need for defense against future silencing and dehumanization. The prosthetic blog-self can provide affirmation of selfhood once writers cross the so-called threshold into critical memory loss.

The urgency of such a project for both Mrs. Hsg and David Hilfiker emanates from the discourse of dread and fear over ADRD that sees the illness as, ultimately, one of narrative trauma. Ostensibly, in dementia, the rational, autonomous, self-determining person becomes one who, while clinging to old and weakening ties to a self—that is, to the autobiographical markers of identity—is simultaneously losing the faculties of memory that would allow her to effectively continue to be that self. This attachment to narrative—or, more specifically, to the need for a coherent self-narrative—is central to the suffering that a diagnosis of ADRD brings.

In his essay “Beyond Narrative: Dementia’s Tragic Promise,” Mark Freeman describes the experience of his mother who has dementia, observing that her most

traumatic moments with the illness occur when her desire to assert her identity crash into the realities of her cognitive impairment. She self-identifies as the “office manager and check book balancer, able to do just fine, thank you, on her own” (172). But interruptions to the story that she tells about herself come as a profound and painful shock. While she is able, mostly, to get by on her own, the overwhelming experience of trying—and failing—to recall a schedule of social appointments and the desire to continue working, driving, and managing her own finances as these abilities decline, send her into crises of identity that compromise her happiness and sense of stability (169-71). On the other hand, life “becomes most worthwhile for her precisely when *she*—qua autobiographical identity—isn’t there. Or, to put the matter somewhat differently, if paradoxically, her healthiest and most life-affirming experiences as a self, a vital self, are precisely when her autobiographical identity, and narrative, are in abeyance” (172). As Freeman notes, “the self who loves music” and “the self who loves Sophie [her granddaughter]” remain ever-present during these times, “but it is a self that is rooted mainly [...] in the living moment, in relation to what is *Other*. Her identity at these moments, therefore, is not so much a *narrative* identity, born out of the particulars of her history, as what might be considered a kind of ontological or spiritual identity, born out of her being” (172).

Freeman draws our attention to two distinctly different subjective experiences: that of autobiographical identity, which is temporally situated within the trajectory of past, present, and future, versus “what Iris Murdoch has referred to as ‘unselfing,’” made possible by complete absorption in the present moment (173). Murdoch’s concept of unselfing, as Freeman describes it, involves “putting aside one’s ego and thereby letting in the world, in all of its profound otherness” (182). Murdoch uses the



example of great art to explain the moment of unselfing, during which we observe and admire an object without needing to possess or instrumentalize or appropriate it “into the greedy organism of the self” (64).<sup>25</sup>

The importance of these moments of “unselfing” lies in “the very energy and vitality they are able to generate[, which] may well tell us something about the limits, even the dangers, of narrative” (172). Citing both Murdoch and Crispin Sartwell, Freeman notes that, although we may be “*narrating* animals,” we are also filled with anxiety over the production of narrative. Furthermore, while the absence of narrative has been said to characterize certain types of psychosis, an excess of narrative may be another kind of madness (Sartwell 67). Freeman’s exploration of this possibility in the context of dementia questions how a release from the expectations of autobiographical narrative might lessen the psychic and emotional trauma of the disease. He wonders if “by moving beyond narrative, beyond the confines of storylines that do not serve her, [his mother] too will experience something like liberation” (175). Moving beyond narrative implies opening up space for those with dementia and their supporters to be situated in a present moment that is free of expectations of narrative significance.

In terms of the loss of autobiographical selfhood for Freeman’s mother, he writes, “The end of narrative would thus spell the beginning of oblivion, of the very *absence* of Other, or world” (179-80). However, it may be the case that after this autobiographical identity dissolves, an ontological or spiritual self may remain—and this “core self” may be continually affirmed through its encounters with the world (180). This is certainly not to idealize progressive dementia or frame it as a kind of

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<sup>25</sup> What Freeman doesn’t acknowledge when he critiques Murdoch’s use of the word “detachment” to describe this process is the connectedness of her theory to the Buddhist philosophy of nonattachment. This state is very much relational, while at the same time an abdication of the ego’s power to cling to desire.

mystical experience (183). Instead, and I think for the purposes of our response to those with dementia, this problematization of the self-narrative in ADRD might lead us to more compassionate relationships, at both individual and societal levels. This acknowledgment of the different modes of experience available to human beings is the ultimate opportunity for what Mitchell, Dupuis, and Kontos, citing James H. Olthuis, refer to as “knowing other-wise”—“an opportunity to see difference as potential wisdom instead of something to be changed or fixed” (13). The mode of subjective experience described by Freeman—similar to what Kitwood calls an expression of the experiential self—productively complicates normative expectations of self-expression.

Thinking twice about the primacy of narrative to govern our understanding of ourselves, each other, and the world provides an occasion to see how meaning might be produced in other ways. Various scholars have critiqued the predominance of traditional narrative in our methods of reasoning, critique, interpretation, and historicization. Sartwell, although often labeled anti-narrative, rather challenges its authority over our meaning-making activities, drawing attention to non-narrative ways in which we express ourselves and relate to one another, such as through the circular movements and structural repetitions of blues music. Other scholars, particularly in disability studies, have highlighted the power of narrative frameworks to perpetuate normative attitudes. Lennard J. Davis reveals how the novel form, itself, reinforces ableist attitudes through the use of traditional narrative structures. Jay T. Dolmage, in his recent text *Disability Rhetoric*, compellingly asserts the rhetorical tradition of *mētis* as an undervalued approach to scholarly analysis, suggesting how new knowledge might emerge from addressing research questions moving

nonlinearly—sideways and backward—and layering hegemonic conceptions of history with alternate interpretations. This approach recognizes that “getting the story straight” is a tactic that reinforces the “straight body”—a “body that is itself a fantasy. To get these stories crooked, we should also shift our view to bodies that exceed and challenge norms and affirm that history comes from the body’s crookedness, too” (8). These scholarly voices enrich our understanding of human meaning-making and interpretation, and they also help to illuminate the ways in which the logical, rational approach of linear narrative might be limiting—even dangerous.

In this chapter, I investigated the narrative structures employed by bloggers who write about their firsthand experiences with different forms of dementia. In exploring the motivations of individuals with dementia to maintain a blog, I also discussed how bloggers’ attitudes toward their illnesses are an obvious response to the discourse of dementia that frames the disease as ultimately a loss of self. Indeed, blogs by persons with dementia reveal a tendency to internalize the cultural anxiety over selfhood in ADRD. Writing a narrative about this experience is, itself, an act of self-validation and a means by which to insulate the self against dissolution. In dementia, this tactic might act as a buffer against the expectations that individuals come to hold surrounding their dementia diagnoses—expectations that emphasize the dementia journey as one of tragedy, loss, and eventual oblivion. The fact that narrative functions to psychologically protect individuals in this way might make it an effective coping strategy. This possibility is perhaps best left for researchers in the social sciences and health studies to interrogate.

While I do not believe that this activity is dangerous in the least, I do harbor a degree of concern over the narrative structures that persons with dementia employ on

their blogs. My misgivings surrounding the use of narrative as a *tool* by persons with dementia to combat dehumanization emerges from the worry that it distracts attention from the very need for such a response in the first place. While Frank suggests that all illness is a call for stories—that bodily trauma is psychic trauma that needs the voice of narrative—I worry that illness is a call for stories because of the culture of fear and stigmatization surrounding most, if not all, illness. This culture establishes the conditions that make narrative writing necessary, as a defense mechanism and a safe space for voicing experience. The rhetorical situation from which dementia blogs originate seems to be one of fear, judgment, and negative self-scrutiny. I bring these concerns into the context of scholarship on narrative medicine, not to deny the power of storytelling and the importance of subjective experience in medicine, but to complicate the understanding of narrative and the need for it within a healthcare setting. In the context of blog writing by persons with dementia, the creation of narrative is not a solution to the problem of why those narratives become urgently necessary in the first place.

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