From Stories to Discoveries:
Patients' Narratives as Advocacy in Biomedical Research

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Abstract

Biomedical researchers are trained to use positivistic approaches to develop efficacious treatments and pursue cures for illness and disease. Accordingly, they rarely engage persons living with the disease in the development of research questions and protocols (Sacristán et al., 2016). Just as patient narratives can create therapeutic partnerships in delivery of treatment (DasGupta & Charon, 2004), they offer value to the research process as a means to emphasize the person with the disease, rather than the disease, in isolation. We are interested in the role of patient stories as tools for influencing the biomedical research process (Greenhalgh, 2009; Panofsky, 2011). Applying Ellingson's (2009) approach to crystallization in qualitative research, we explore intersections in the literature on patient advocacy, our own narratives, and those from biomedical researchers and patients. We seek to uncover the meaning of involving not only patients, but patients' *stories* (Hyden, 1997), in creating an agenda for research in healthcare.

Introduction

Adam:

Shuffling along, parallel to the buffet table, displaying gait instability and balancing a ceramic catering plate with my left hand, plagued by neuropathy and weakness, I steadied myself before hooking my cane over my left arm to grasp tongs in my functional right hand and serve myself salad. Feeling comfortable in my otherness, I shrugged when the diner before me offered to assist with assembling my meal. Whether motivated by pity, aid, or efficiency, she smiled with pursed lips and a sideways glance, lifted my plate from the table, and proceeded down the line. Although “patients included” is a recent and flashy biomedical conference trend, advances in biomedical research inclusivity remain passive and permissive rather than active and enabling.

The facilitator began the closing session by eliciting from the audience, “the most innovative developments you heard about or saw during the conference.” Augmented virtual reality microscopy was a crowd favorite. Participants continued, “gene editing!” another, “liquid biopsy!” Indeed, next followed structured “share outs” from prescribed topics to advertise all that we learned about genomics, biomarkers, and immunotherapies.

I wondered how this might be so: I was attending this conference by selection for a special scholarship and concomitant designation indicative of my role as a science-literate patient advocate. Though I knew only those 25 or 30 others I spoke with directly over the course of several days, ostensibly the program that evening, mandatory for those attending on scholarship, comprised a majority audience of others like me: other patients. Yet not a word spoken about the bedside. Not a topic for share out. Not a single line explicitly drawn between research innovation and patient experience. A buffet table of scientific expertise and a burden placed on the consumer to navigate, serving as a barrier to access.

Krista:

I read Adam’s narrative, and immediately felt the dialectical tension he describes.

Maybe the conference participants were more excited about the scientific researchers? Can you fault them? They are researchers, after all. At the same time, reading Adam's story puts me in the room. His point is made more salient by his metaphor--the inaccessible buffet of food and research findings. Adam was hungry for participation, just as the researchers were hungry for new discoveries. Reading this story, for me, as a scholar of communication, reminds me of the power of the narrative--how (re)storying the conversation of Adam's role at the biomedical research conference brought to the fore the isolation patients potentially feel when asked to participate without an acknowledgement of their ways of knowing (Pearce, 1989).

With the two narratives above, we seek to illustrate our entry points in this topic--as a person living with brain cancer and philosopher of science, and a teacher and researcher of communication in academic medicine. In this chapter, we seek to use a mix of our own narratives and literature review to illumine lessons at the intersection of biomedical research and patient narratives which are, at best, left implicit, and at worst, neglected. Our method is patterned after the theoretical framework we espouse: first, advance a patient narrative, and second, interrogate its role in biomedical research advocacy.

Biomedical researchers are usually trained to use positivistic approaches to develop efficacious treatments and pursue cures for illness and disease. Accordingly, they rarely engage persons living with the disease in the development of research questions and protocols (Caron-Flinterman, Broerse, & Bunders, 2007; Sacristán et al., 2016). Just as patient narratives can create therapeutic partnerships in delivery of treatment (DasGupta & Charon, 2004), they offer value to the research process as a means to emphasize the person with the disease, rather than the disease, in isolation (Greenhalgh, 2009; Panofsky, 2011). Applying Ellingson's (2009) approach to crystallization in qualitative research, we explore intersections in the literature on patient narratives in advocacy, our own narratives, and those from biomedical researchers and patients. We seek to uncover the meaning of involving not only patients, but more specifically, patients' stories. As Hyden (1997) argues, "[p]atients' narratives give voice to suffering in a way

that lies outside the domain of the biomedical voice" (p. 49). We offer tactics to close this gap and identify a role for narrative in creating an agenda for research in healthcare.

The roadmap for this chapter is as follows. In the first section, we discuss the extant research on patient involvement and narrative in the context of biomedical research, and explain our methodological approach. Next, we investigate the topic of expertise by considering the interplay of experiences and credibility as each informs the roles ascribed to "patients" and "researchers." We extend the conversation about experiences to promote narrative as a tool to introduce a non-positivistic way of knowing that undermines the presupposed objectivity of science. We survey limitations of our piece. Finally, we offer concluding remarks. It is our aim to consider carefully the role of narrative, expertise, different ways of knowing in the pursuit of biomedical research, and ultimately health and healing.

Patient Participation in Biomedical Research

An investigation of the historical relationship between biomedical researchers and patients is helpful to better understand how patient narratives can inform the biomedical research process. Over the past forty years, there has been a shift in discourse from understanding patients as subjects (merely one of many tools required to conduct biomedical research) to important participants in (and even powerful drivers of) biomedical research. This shift can be attributed to both scientific and social influences (Caron-Flinterman, et al., 2007; Solomon, 2016). As scientific problems have become more complex and connected to social forces (such as social determinants of health), scientists have sought to include more lived experiences of patients in the research process. Additionally, the public has increasingly demanded the applicability of scientific discovery to lay people's and patients' lives.

Scientists and scholars tend to use two primary arguments for including patients in the research process (beyond serving as subjects). The first argument is regarding improvement of the science itself. Since patients have a type of experiential knowledge, their expertise can serve as a foil to the professional and objective work of scientists, thus creating a more

complete research outcome (Entwistle et al., 1998). Alternatively, Collins and Evans (2002) contend that partnerships with patients in the biomedical research process enhances the moral and political legitimacy of the research, since they are ultimately the beneficiaries of this information.

Though recognized in the clinic, “health care can be delivered more effectively and efficiently if patients are full partners in the process” (Holman and Lorig, 2000, p. 527), the movement to involve more patients in the biomedical research process in the US is a relatively new phenomenon. In 2003, Zerhouni, a former director of the National Institutes of Health (NIH), argued for a shift in clinical research to include more patients, specifically via community-based physicians and organizations. While no mention of patient narrative is present, the author clearly advocates for privileging patient voices in the research process, mentioning “new models of cooperation between NIH and patient advocacy alliances” (p. 64). However, bridging the gap between patients and researchers is a hard-won process. Reporting for *Nature News* five years later, Butler (2008) questioned what the NIH had actually done to encourage the values they espoused. He explained,

> Over the past 30 or so years, the ecosystems of basic and clinical research have diverged. The pharmaceutical industry, which for many years was expected to carry discoveries across the divide, is now hard pushed to do so. The abyss left behind is sometimes labelled the 'valley of death' — and neither basic researchers, busy with discoveries, nor physicians, busy with patients, are keen to venture there. (p. 841)

As illustrated by this report, simply giving a mandate for scientists, clinicians, and patients to communicate more effectively and creating “networks” (Zerouni, 2003) were not enough to bridge the gap between these communities. With this example, it is important to note that disciplinary boundaries often shape the way that scholars understand a particular phenomenon. In the case of Zerouni’s (2003) mandate and Butler’s (2008) critique, these perspectives are legitimized in the biomedical research community, in part because of their affiliation with the NIH and the journal *Nature*. Despite Butler’s (2008) critique, some scholars contend that biomedical researchers and patients have seen some successful partnerships.

Caron-Flinterman and colleagues (2007) classified three categories of patient participation in biomedical research. They include (1) ithe lobbying of patient organizations, (2) ad hoc use of patients' ideas and demands through intermediaries, and (3) inclusion of patient representatives in existing decision-making groups (as described in Adam's story above). Although their study was conducted in the Netherlands, Caron-Flinterman et al. (2007) argue that their literature searches and participants give a "reasonable impression" of the landscape globally (p. 347). Wehling et al. (2015) also address issues of typology, arguing that, although classification holds value, the level of diversity in disciplines and approaches may limit social scientists' abilities to define the experiences of researchers' and patients' partnerships.

More recent work by Kaye and colleagues (2012) acknowledges that current biomedical research models fail to adequately include the perspectives of patients and research participants. The authors propose that new technology can facilitate participant-centered initiatives (PCIs), defined as "tools, programs and projects that empower participants to engage in the research process using IT (p. 4). They further argue that using PCIs through technology, such as patients sharing of data in social media and apps, can encourage ongoing interactions between participants and researchers. As Kaye et al. explain, this approach "can result in research that demonstrates high standards of research integrity but also an involvement by patients and participants that is more active and richer than more conventional approaches" (p. 5).

Imbedded in the models described above is a dialogic space between patients and biomedical researchers, where, in some cases, patient narratives are shared directly to the researchers and, in other cases, are shared via an intermediary (i.e. a researcher or physician sharing a patient's story on behalf of the patient, or more recently, an app sharing data with a researcher in which the researcher constructs the story of a patient's illness via the data received). In any case, narrative is at the center of the interaction. It is the primary tool patients have to engage with biomedical researchers. However, as illustrated by Wehling et al. (2012),

patients, researchers, and physicians each approach their interactions with illness and the storying of illness quite differently. One specific area where these epistemological differences manifest is in the context of objectivity. Writes Murphy et al., (2016), “the reality of patients is never directly encountered by a clinician, or anyone else, but is revealed gradually through the stories they tell” (p. 103). Murphy and colleagues (2016) remind us, “accumulating information about a patient is thus a hermeneutic exercise” (p. 103).

What is the problem with objectivity?

Biomedical researchers, even more so than physicians, are trained to privilege the perspective of objectivity. Randomized controlled trials are seen as the so-called gold standard of biomedical research, where the goal is to eliminate bias and control for as many variables as possible. When it is impossible to control for a variable, researchers treat this as a limitation of their work, caveating and listing these at the end of their studies. Conversely, most physicians acknowledge that the practice of medicine is both a science and an art (Charon, 2006; Greenhalgh, 1999; Solomon, 2016). Although many clinicians work within the paradigm of evidence-based medicine, Solomon (2005) notes that this term, itself, is political and subjective in nature. The term, at best, can give epidemiologic data about a particular disease, but fails to offer much solace to patients who do not fit into the standard narrative of a particular disease (p. 289). Narrative researchers move even further away from the objective paradigm. As Chase (2003) explains, “[narrative] researchers develop meaning out of, and some sense of order in, the material they studied; they develop their own voice(s) as they construct others’ voices and realities” (p. 657). The dialectic tension between objective and subjective are inherent in Japp and Japp’s (2005) investigation of the narratives of biologically invisible diseases. As they explain, “[t]he pervasive hegemony of the biomedical model of disease limits the stories patients tell as much as it does physician’s practices” (p. 122).

It is expected that these tensions may introduce significant worries for biomedical researchers for whom empirical evidence is the purported norm by which science progresses,

and it is only through these evidence-based methods that a proper objectivity toward a subject or domain of investigation is maintained. Though, the philosophy of science has long advanced the position that all observation is theory-laden (Hanson, 1958). More plainly, any observation or experimental design is selected with theory in mind. Theory selection itself is a social act. Philosophers of science Bertolaso and Sterpetti (2017) remind readers of the epistemic subjectivity of theory selection, favoring plausibility accounts replete with subjectivity rather than probabilistic accounts. When available evidence fails to adjudicate between rival theories, researchers employ so-called theoretical virtues to advance the preferred theory. Peter Lipton (2003) develops a robust account of theoretical virtues and their role in identifying scientific theories which are the most likely to be at least approximately true.

Thus, the lines distinguishing subjectivity from objectivity in research are blurred, and clinging to the notion of purely objective science is unhelpful, particularly for patients and clinicians who experience the messiness of disease on a daily basis. Patient narratives should not be rejected out of hand for fear of their socially constructed nature. In order to move beyond the question of legitimacy of patient narrative in the understanding of biomedical research, it is useful to delve into the notion and definition of expertise.

Who is an expert?

When considering the role of patients and patient narratives in biomedical research, expertise becomes a significant area of contention. In the traditional biomedical model of medicine (as embodied by most biomedical researchers), patient experience is often defined as “lay knowledge,” implying that it is epistemologically inferior to the expertise of researchers (Wehling, Viehover, & Koenen, 2015). This perspective is situated in the larger grand narrative of the biomedical model (Epstein, 1995; Japp & Japp, 2005; Morris, 1998), where the primary actor is the researcher using science and technology to discover and cure the patient. In this context, patients are objects of study upon which science is acted, rather than participants or co-creators of the outcome.

We suggest this model is mistaken on two accounts. First, the transactional model of care seeks to cure, assuming an acute intervention, which is poorly suited for the management of chronic illness (Carel, 2008; Holman & Lorig, 2000). Second, viewing patients as end-users, or more crudely, “consumers” and “customers,” fails to notice that clinicians, for their part, are similarly caught up in the biomedical model, treating patients in the clinic or at the bedside, as mere “providers” (Montori, 2017, p. 79ff.) This model leaves little space for inclusion of the patient narrative. Clinician narratives further punctuate the loss of autonomy experienced by both “providers” and “consumers” of healthcare.

When patients have engaged with biomedical researchers, the language of biomedicine is privileged. Epstein’s (1995) participants in the AIDS treatment movement described this as learning a foreign language. His participants noted that, once they had access to the language of biomedicine, they could access and influence the institutions. In other words, “Once they could converse comfortably about viral assays and reverse transcription and cytokine regulation and epitope mapping, activists increasingly discovered that researchers felt compelled, by their own norms of discourse and behavior, to consider activist arguments on their merits” (Epstein, 1995, p. 419). As Wehling and colleagues (2015) explain, it is in this space where the definition of expertise becomes most murky. The authors state, “...to what extent and in what circumstances is patients’ knowledge complementary to and instrumental for scientific knowledge production, and how far is it opposed to it, contesting its background assumptions and conceptual approaches and transforming the latter?” (p. 5). Shapin (1990) notes that the constitution of the expert/lay divide is defined by the question of who possesses cultural competence; thus, asking researchers to posit what a space for productive exchange of experience and ideas between biomedical researchers and patients might look like.

As earlier mentioned, Japp and Japp’s (2005) discussion of legitimacy of patients’ experiences offer a grim description of the current space for conversation. Because patient narratives are told within the social and political context of the grand narrative of biomedicine,

patients are simultaneously constrained and enabled when telling their stories. Technical rationality is privileged, leaving patients who do not fit into the traditional narrative often feeling lost and delegitimized. In this postmodern perspective, counternarratives emerge from patients who question the dichotomy between illness and cured, seeking a space of demedicalization of their experiences (Harter, Japp, & Beck, 2005). Pearce's work (1985) on coordinated management of meaning is potentially helpful here, to both biomedical researchers and patients, to explain how these tensions have been created. As the author contends, each communicative community holds its own set of resources and practices, that are often not easily accessible to those outside the group. When this happens, conflict emerges and conversation can often devolve. As Pearce (1989) explains,

> In speaking to those who logics of meaning and action are similar to their own, persons use a sophisticated vocabulary, acknowledge the dignity and honor of those who disagree with them, and usually are able to put together well-coordinated episodes. However, when speaking to someone from another group, the form of discourse attenuates quickly. A simplified vocabulary is used; the personalities and motives of the other are posed in a desiccated vocabulary of human purposes; taunts and condemnations replace argument and evidence; and one's own reasoning and life experiences are protected from exposure and anticipated criticism. (p. 43-44)

Because one communicative community's (biomedical researchers) resources and practices have been traditionally privileged, it is no surprise that the narratives of another community (patients) have been generally seen as unhelpful. Conversational actors constantly co-construct the meaning of communication as they communicate, and as such, particular roles have been reified. For biomedical researchers, it is the role of expert, as defined above. In the case of patients, the sick role has emerged as another dominant narrative.

The sick role

Following the July 2017 brain cancer diagnosis of American high profile political figure, Senator John McCain, public awareness spread concerning the aggressive and deadly cancer, glioblastoma, usually abbreviated as its medical moniker, "GBM." This devastating disease corners patients with no available curative treatment, left to confront a limited life expectancy

and generally poor quality of life. Living with GBM requires patients endure side effects from cytotoxic cancer therapeutics and neurological disorders stemming from tumor invasion and neurosurgical removal of the primary brain tumor--the first step in the standard of care protocol.

Adam:

I received a GBM diagnosis in June 2016, one year prior to Mr. McCain's. For this reason, beyond the sympathetic reaction shared by many, I paid close attention to media coverage surrounding the health communication tactics and information dissemination of this rare and difficult to understand disease. That month was especially hot. My family vacationed with close friends near a lake in Southern Indiana, a day's trip from our home. Seeking refuge from the heat and taking active steps to manage my seizures, I chose not to join in a planned trip to a nearby amusement park. I spent much of the morning comfortable in a rocking chair set on the shaded porch of our rented cabin, reading. I decided to retreat inside to lie down when I heard the familiar tone of a smartphone notification. News broke of Mr. McCain's diagnosis. Several friends and acquaintances reached out to notify me.

Carel (2008), a philosophy scholar living with a chronic illness, provides an extensive account of the phenomenology of illness. The author contrasts the philosophical treatment of the illness experience as a foil to the 'naturalistic' model of illness and disease paradigmatic of the biomedical research community. Carel (2008) goes to some length situating illness in a social context, describing illness as problematic in at least two ways. First, illness punctuates the ill person's inability to control how others view them, and second, all social interactions are placed in the shadow cast by illness. On Carel's view, it is not surprising that associations between McCain's diagnosis and my illness immediately presented themselves to others, prompting outreach. As I wrote in an open letter to McCain (Hayden, 2017), there is little McCain and I share in social position or common interest, yet each is now connected by a specific disease. That connection in isolation is connection enough to reshape my social position as a peer of McCain's, a position unlikely to emerge without the social implications of

becoming ill. Indeed, Carel evokes Parsons' (1951) account of this feature of illness: the sick role.

In a sociological rather than philosophical context, Parsons (1951) emphasized features of disease (later echoed by Carel (2008)). Parsons was quick to contrast biological processes of illness from sociological considerations. His novel construction of illness described the "sick role" as a "deviant role," that is, failing in some way to fulfill the institutionally defined expectations of one or more of the roles in which the individual is implicated in the society" (p. 452). In my letter to McCain, I contrast his age, storied persona as Vietnam prisoner of war, and notable history serving in the American Senate, with my youth, young fatherhood, and non-political background. McCain and I are deviant in our illness; we share a sick role, in so far as we are each rendered weak and vulnerable by disease, failing our implicated societal roles. McCain fails his implicated role as battle-tested, strong, and courageous political leader. I fail my implicated role, as a young person, nearly 50 years McCain's junior, expressing the vitality as a father with very young children.

Krista:

I remember reading Adam's letter to Senator McCain when it came out. As a publication venue, *STAT* is a "big get" for those of us in the communicating science and health world. I was proud to say I knew him. How sad is that? That I was proud to have a friend doing such amazing and high-profile work, as a result of a terrible diagnosis. In reading this again, I can see how I fall into these patterns. Communicatively, I work hard to identify Adam as a scholar and philosopher first, a "sick person" second. I often wonder if this matters discursively. Since we travel in many of the same circles, I worry (maybe I shouldn't?) about Adam being known as "the guy with the brain tumor," essentializing his identity into his diagnosis. Largely speaking, this is always a concern of mine for anyone living outside the dominant narrative. How do we honor these stories, without constantly othering? And how, as an educator of current and future biomedical researchers, do I teach people how to do (or not do) this?

Parsons (1951) and Carel (2008) each distinguish two paradigms of illness: one, naturalistic (positivistic, reductionist, or biological), and the other, sociological or phenomenological. Features of the illness experience fail to be captured by a purely empiricist account of disease. The issue, then, expressed recently by Wehling and colleagues (2015), is to define how best to relate patient knowledge--the “sick role,” or phenomenological--to scientific knowledge--positivistic. In violating these sick roles, both McCain and Hayden create a counterstory to the master narrative of the biomedical construction of illness, identifying them as whole people who, alongside their identity within the GBM community, still assert their identities as fathers and professionals (Japp & Japp, 2005). This introduction of additional lenses moves the reader to see the storyteller as more than just a “sick person.”

With these perspectives in mind, we offer the tactic of narrative as a tool to move biomedical researchers away from the biomedical construction of illness, viewing patient narratives as both a tool to inform research and an epistemological lens to understand the diseases they study in a new way. If we understand illness as codified through discourse, even in the context of biomedical research, introducing the illness experience into the research community could actually change the research questions.

Reimagining the Role of Narrative and Storytelling

Scholars of health communication, sociology, medicine, public health, and other disciplines have considered the role of patient narratives as a tool for conducting or informing research. Some (such as Borkan, Quirk, & Sullivan, 1991) use the gathering of patient narratives as a research methodology or narrative inquiry (Chase, 2003) in an attempt to consider the relationship between patient perceptions and health outcomes. Psychiatrist and narrative theorist Adler (2012) notes a critical role for narrative as tool for patient agency, or in Adler’s words, “autonomy, achievement, mastery, and ability to influence the course of his or her life” (p. 368). As this volume and others researchers (Charon, 2006; Epstein, 1993; Harter,

Japp, & Beck, 2005; Wehling et al., 2015) extole, narrative is a critical tool in redefinining the roles of patients and those who treat them.

However, many of these scholars acknowledge that narratives do not exist only in the context of the interpersonal relationship between the storyteller and the listener (physician, biomedical researcher, or otherwise). For example, Japp, Harter, and Beck (2005) examine the role of narrative in constructing and co-constructing the ontological meaning of health and disease. As they explain,

> Personal narratives become the building blocks of public knowledge. More and more, mediated and public dialogue, from legislative testimony to newscasts to public health promotion, rely on individual stories to embody problems, shape arguments, and engage emotions, as well as to persuade, evaluate, reward, and punish. (p. 3)

This quotation and the work of others (Epstein, 1993; Japp & Japp, 2005) illustrates the extent to which patient narratives are not only an object for researchers to analyse. Rather, the narratives, themselves, shape and are shaped by the research context in which they are collected and told.

The role of narrative in biomedical research and patient care is subject to critique. Some scholars contend that narratives in medical research can be “susceptible to the narrative fallacy (i.e., causal hypotheses are too readily constructed from sequences of events) and to the influence of constraining politically dominant narratives” (Segal, 2007, p. 290). Harter and colleagues (2005) echo this concern, reminding their readers that “[n]arratives are shaped within certain beliefs and value systems, and serve to reinforce or challenge those systems as they are constituted in social interaction” (p. 23). Thus, examining the context, as well as the narrative, is an important part of understanding its potential for influence. A further, related, concern notes that narratives are constructed with an audience in mind, and the audience, or listener, is active in meaning-making as co-creators (Pearce, 1985; Spencer, 2017). Given the importance of narrative context, here, we reconsider the role of objectivity and subjectivity in the narrative relationship between biomedical researchers and patients.

In the late 1990s, Epstein, a sociologist with a focus on science and technology, closely examined the role of AIDS activists in driving the agenda for biomedical research, specifically the testing of new pharmaceutical treatments. Epstein's (1995) work illustrates the complicated role of narrative in the relationship between biomedical researchers and patients. The author posits that, although AIDS activists were able to use their lived experience to influence the research process, they could not fully reject the biomedical model of their disease because of their need to know which treatments were most efficacious. Citing Richard's (1991) argument for more relativism in the biomedical research process, Epstein explains, "[t]he activist critique of the randomized clinical trial unseats that methodology from the pinnacle on which it is sometimes placed, but it also assumes a greater role for such trials than analysts such as Richards would recommend" (p. 425). While Epstein considers this a departure between the views of researchers and patients, we see this as a potential place of common ground.

As much as objectivity has a place in the lab and the testing of hypotheses, subjectivity is inherent to biomedical researchers decisions to choose what to study. Most researchers enter into a field of study because they are excited about the possibility of curing a disease or helping patients. This, in itself, is an emotional or subjective act. Many research societies invite patients (like Adam) to their meetings to tell the stories of their experiences. More than ever, researchers are asked to pursue funding from private foundations often started by family members or those with complex diseases themselves. Thus, patients' stories are already present in the minds of researchers when they pursue a research question.

Patient narrative can be seen as a tool to help biomedical researchers see beyond the "reductionist lens" of randomized clinical trials (Caron-Flinterman et al., 2007). The role of narrative in the biomedical research process does not have to be an either-or assumption. After all, the messiness of the narrative can potentially inform the way in which we approach researching illnesses, which are (almost by definition) also messy in their constitution. Cancer doesn't appear with the same symptoms for every patient; different cancers behave differently,

and we still don't know why; the way in which cancer affects patients lives is unique for each person and each family member.

Most patients would not advocate for biomedical researchers to fully dispose of the scientific methodology they use to test treatments (Epstein, 1993). Rather, they would prefer to see treatments tested within the context of real life. With this in mind, we envision a space where biomedical researchers invite the patient experience more fully into their thinking about scientific questions. Dahlstrom's (2014) work on the use of narrative in science communication with lay audiences offers a paradigm that, when combined with Pearce's (1989) coordinated management of meaning, could create the dialogic space we seek to create between researchers and patients.

Taking a social scientific approach, Dahlstrom's (2014) argues that narrative could be a particularly useful tool in explaining complex scientific concepts to lay audiences. The author combines extant research about narrative, science communication, and media to illustrate that narrative content about scientific topics is more likely to be remembered and shared by consumers. Dahlstrom (2014) concludes his exploration with a call for research on communicating scientific concepts that are "beyond the human scale" (p. 13618); phenomena which are beyond our perceivable reality, for example, things "as large as climate change, as small as parts per billion, or as distant as 10,000 y away" (p. 13618). However, for biomedical researchers, the lived experience of disease is, potentially, beyond their scale. If they have not lived with the illness themselves, it is a struggle for researchers to fully know or understand the experiences of patients living with the diseases they hope to cure. Empathy and inquiry are invited through story. Pearce (1989) advances the concept of narrative between groups, arguing that, if we are coordinating meeting with one another, we must seek to understand the stories that constitute our experiences. As Pearce (1989) explains, we must first recognize our communication as fundamentally part of our own group, if we are to understand the experiences of others. Then, we must strive for a form of communication that values the other; a form called

"cosmopolitan communication." The author states, "tolerance for difference liberates cosmopolitan communicators to care about and take steps to find out about worldviews other than their own" (p. 193). Combining these two perspectives, we envision a dialogic community where both biomedical researchers and patients open themselves to the resources and practices of their speech communities. Narrative is a tool that can help biomedical researchers adjust the scale of illness, seeing patients as part of the process required for knowing a disease, in all its forms.

Conclusions and Limitations

Here, we sought to identify a gap in biomedical research: namely, the absence of the patient voice, vis-a-vis patients' narratives, or their stories. In doing so, we argue that closing this gap offers a fruitful tactic to improve biomedical research by placing the researcher and the research product in dialogue with the consumer, in this case, a patient. Incorporating patients' narratives into the research process introduces an uncomfortable dialectical tension between the purported objectivity of scientific methodology, on the one hand, and the subjective, interpretive work of telling and hearing stories, on the other. We hope to diffuse this tension by pointing to the ineliminable epistemic subjectivity of scientific experimental design and observation. In other words, researchers need not fear the spectre of subjectivity; they need only to understand it.

Ultimately, this chapter offers an extended argument in support of the central thesis that inquiry is best practiced with a pluralistic attitude toward expertise; call this lay or experiential knowledge, as some authors have, or phenomenological or sociological, as expressed by others. Independent of which term of art is preferred, eliciting patients' narratives, specifically in the context of biomedical research, is an effective means of considering different ways of knowing.

Raising the patient voice in a new setting is not without controversy. The deviancy of patient narratives is punctuated by Carel (2008) and Parsons' (1951) emphasis on the sick role.

One limitation of this piece is its tacit promotion of such deviancy. The argument in this chapter, if accepted, is an critique of the dominant paradigm in biomedical research, communicated best through a meta-narrative framed by positivistic assumptions.

Wehling and colleagues (2015) raise a concern articulated by Blume (2010), which is germane: patients only gain credibility insofar as their demands are compatible with fundamental assumptions of medical science. This concern is raised within a different framework in a concise survey of objections raised by medical professionals in training against the pedagogical practice of incorporating the humanities in medical education: a discussion inextricably linked to applying the same pedagogical tactic in biomedical research. Without compatibility with dominant background assumptions, narratives may appear uninformed, if not hostile. Shapiro and colleagues (2009), report a complaint raised by a medical student, critiquing a required humanities course in his medical school curriculum. Relates Shapiro et al. (2009), “[t]his young man and students like him feel a sense of grievance: it’s unfair to be evaluated in an area they hadn’t expected to be part of their curriculum” (p. 193).

Whether addressing students, clinicians, or researchers, confronting an accepted paradigm is often met with a hostile and defensive posture, creating the us-them mentality described in Pearce’s (1989) work. In support of our deviance from the dominant paradigm and support of a new dialogic space for biomedical researchers and patients, we repeat a lesson explicated by Murphy and colleagues (2016), “patients always present an illness… this process is not disinterested but includes perspectives, values, and commitments. A presentation is always motivated and expresses an angle or disposition. Nothing can remove symptoms from these entanglements, even the most sophisticated laboratory tests” (Murphy et al., 2016, p. 104). As illustrated by these examples, biomedical research benefits from incorporating diverse angles or dispositions, learned through attention to patients’ narratives.

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