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ORIGINAL RESEARCH

Telling, Hearing, and Believing: A Critical Analysis of Narrative Bioethics

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Abstract Narrative ethics taps into an inherent human need to tell our own stories centred on our own moral values and to have those stories heard and acknowledged. However, not everyone's words are afforded equal power. The use of narrative ethics in bioethical decision-making is problematized by a disparity in whose stories are told, whose stories are heard, and whose stories are believed. Here, I conduct an analysis of narrative ethics through a critical theory lens to show how entrenched patterns of narrative neglect in medicine are harming not only our capacity to make use of narrative ethics but also our capacity to deliver effective healthcare. To illustrate this point, I use three examples where the patient's gender affects how their stories unfold: autism, weight, and pain management. From these, I argue that the use of narrative ethics without the application of a critical theory lens risks the exacerbation of what Miranda Fricker refers to as "testimonial injustice," the prima facie harm experienced by individuals whose credibility is undermined by others' prejudices. Finally, I suggest that narrative ethics can be a powerful tool for mitigating oppressive practices in medicine if we couple it with critical analysis that enables us to understand the power dynamics at play in storytelling.

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Introduction

From Aesop's fables to fairy tales, we are taught as children that we can derive answers to moral questions from storytelling. Narrative ethics, in harnessing this impulse, taps into an inherent human need to tell our own stories centred on our own moral values and to have our stories heard and acknowledged. However, in an unjust society, not all stories are given the same weight, and not everyone's words are afforded the same power. Marginalized groups, including those made vulnerable due to gender, race, sexual orientation, and disability, have historically been excluded from ethics and policy decision-making (Trimiew 1993, 139). Given extant disparities in healthcare outcomes that fall along these same divisions of power, the emerging use of narrative ethics in bioethical decision-making is rendered problematic by the fact that there is an entrenched imbalance in *whose stories are told, whose stories are heard, and whose stories are believed.*

Here, I will conduct an analysis of narrative bioethics using a methodology drawn from critical theory and focusing on the ways in which errors and biases affecting how sex and gender are viewed in health sciences have come to be seen as foundational by practitioners and how this has in turn diminished women's narrative power. Using three examples where the patient's gender has been shown to result in dismissal by physicians—

autism, weight, and pain management—and drawing from women's[1] personal narratives, I will show that in not *telling* the stories of autistic women, not *hearing* the stories of fat[2] women, and not *believing* the stories of women in pain, we have created an environment where the very act of telling their own stories causes women both tangible and epistemic harm. Finally, I will suggest ways in which a version of narrative bioethics that acknowledges both the physician-listener's disproportionate power and implicit biases can provide a powerful tool for rectifying injustices in the provision of healthcare.

Theoretical Approach

Narrative Ethics

The idea that who a person *is* forms a part of the moral rightness of their acts takes many forms in contemporary moral philosophy, including approaches from psychology, biology, and anthropology (Parfit 1984; DeGrazia 2005; Schechtman 2014). A narrative form of this type of identity-based ethics emerged in biomedicine in the 1980s (Brody and Clark 2014). Key to this concept is that the flow of a person's life experiences—their narrative identity—is valuable in putting ethical decisions that concern them into context. Narrative identity forms a kind of psychological unity as a moral agent gathers their life into a coherent narrative, giving meaning to single experiences within an individual's broader life; this identity can be interpreted not merely as an abstract collection of thoughts and values but as grounded in the experience of the body (Schechtman 1996; Eakin 1999). This type of interpretive technique (sometimes referred to as "anti-theory") allows the subject to become central to the moral question by taking a bottom-up approach, letting the particulars of the individual case shine (Arras 1990) and focusing less on principles than traditional moral philosophy (Montello 2014).

The ability to make ethical decisions within this kind of flexible framework without turning to specific rules represents one of the methodological strengths of narrative in bioethics (Brody and Clark 2014). At the same time, narrative ethics can also be used to develop principles for consideration further down the line. This combination of story-telling and principlism allows healthcare professionals to account for and prioritize their patient's specific context (Brody and Clark 2014) and to explore their patient's moral world (Montello 2014) while also turning to other stories (for example, past patients with similar experiences) for helpful analogies. When done conscientiously, this can serve to create a dialogue between healthcare provider and patient, allowing the healthcare provider to gain perspective both on the patient's life and the values that underpin their needs, in addition to allowing the patient to be an active participant in their own care (Frank 2014; Charon 2014).

In order for all components of narrative ethics to be effective, then, three things must happen: stories must be first told, then heard, and finally believed. The traditional structure of the physician–patient relationship, however, is predicated on paternalism; the physician's specialized knowledge base places them in a position of power over the patient, one that can cloud the ability and desire to listen and empathize (Venkat et al. 2013). Moreover, some testimony is privileged over others, both at the individual and systematic levels. Physicians are granted an "excess of credibility," creating a power imbalance when it is time for the physician to act as listener to the patient's story (Fricker 2007). For already vulnerable patients, the lack of capacity as a social and moral agent that is derived from a systematic undervaluing of credibility may be compounded at the individual level in the face of this imbalance. Furthermore, if physicians are trained using only certain types of stories—for instance, if they are trained to see the symptoms of certain diseases only as they appear in cisgender white men—then they will fail to adequately use their power as listeners to make necessary connections between the storyteller and the storyteller's broader context.

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[1] In discussing women throughout this paper, unless otherwise noted I am drawing primarily from the experiences of cisgender women. The experiences of transgender and non-binary individuals will likely in some ways appear very similar and in others differ drastically. However, these experiences are far less documented in academic literature to date, making it more complicated to demonstrate any overarching narrative challenges.

[2] I use the term fat, rather than obese, here as a reflection of the work that I will draw on from fat studies in this paper and with respect for the fat acceptance community's preference for this term as descriptive rather than pathologizing or medicalizing.

Critical Theory

Despite these criticisms, narrative ethics, if done with a conscious reflexivity on the part of the listener that recognizes these power dynamics, represents a methodology that holds significant potential to rectify testimonial injustices. One potential avenue for rebalancing narrative power is to view narrative bioethics through the lens of critical theories. Critical theory has carried a variety of meanings since its inception, but as it is typically employed today it is a school of thought or methodology used to situate a research question in its historical and cultural context and to recognize the position of the researcher relative to the collection and analysis of the data (Lindlof and Taylor 2002). It differs from more traditional research philosophies largely in its intent; while research is typically used to build up new ways of interpreting the world, critical theory aims instead to dismantle previously held assumptions and to unpack the power dynamics that underpin these assumptions. Critical theory in postmodernism is generally viewed as stemming heavily from the work of Michel Foucault, and critical theory as employed in bioethics owes a great deal to Foucault's *Birth of the Clinic* (Foucault 1973). Here, Foucault coined the term "medical gaze," describing the late eighteenth and early nineteenth century changes to medical knowledge that created a drastic separation in how we consider the patient's body and the patient's identity.

More recently, critical theory has branched in numerous directions, including critical feminist theory, critical race theory, queer theory, and disability theory. Rather than rely on any single branch of critical theory here, I will instead use the technique of dismantling harmful assumptions that underpin accepted medical practices and placing them within their historical and social contexts. In doing so, I will show that what has been taken to be foundational may in fact simply be a perspective that has become entrenched via unchecked power disparities (Sherwin 1999) and that these unquestioned norms cause narrative harm. As critical theory methodology asks that the researcher situate themselves within their work, I note that I approach this topic as a queer, non-binary, autistic, fat individual who was assigned female at birth (AFAB) and has struggled with reproductive pain since puberty; this perspective necessarily colours my perspective and choice of examples, while also strengthening my understanding of the personal narratives examined here. I note as well that the problem of narrative subjugation faced by women in healthcare has parallels in the treatment of and the narrative power withheld from other marginalized groups, albeit with different presentations.[3] Moreover, all of the issues discussed in this paper are compounded for people who are multiply marginalized.

With the rise of online forums where individuals are encouraged to write about their experiences, we are seeing new opportunities for previously unheard people to share their personal narratives; as such, although I draw in this paper from traditional academic journals, I also draw heavily from first person accounts of the experiences of being autistic, fat, and in pain. Combining these two types of narrative—the systemic and the individual—I will suggest ways in which a version of narrative bioethics strengthened by critical reflection can be harnessed to generate justice in healthcare.

Finally, although I will frame these three examples in different ways—in stories untold, stories unheard, and stories not believed—there is obvious overlap in the harms they cause. These harms take two forms. First, the more visible of the two, is that autistic women, fat women, and women in pain share the experience of the *diagnostic odyssey*. Coming from the realm of rare disease, the phrase diagnostic odyssey refers to the years of waiting and frustration that rare-disease patients face in uncovering what is going on with their bodies. Second, these women experience an epistemic harm inherent to having one's narrative discounted. I will argue that a full and robust form of narrative ethics will need to recognize and rectify both types of harms.

Case Studies

Autistic Women and Stories Untold

The debate surrounding autistic stories and who is best suited to tell them is one that is currently at the forefront of autism research and activism. Melanie Yergeau argues that harmful narratives that emerge from contemporary autism discourse persist "because their rhetorical power derives from the figure of the autistic as unknowable" (Yergeau 2018, 3). In particular, Yergeau notes

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[3] There has been extensive work done at the intersection of epistemic injustice, healthcare, and populations of black and indigenous people of colour (BIPOC). See, for instance, Graham et al. (2011), Yancy (2008), and Ford and Airhihenbuwa (2010).

that the very ability to name oneself as autistic is often viewed as evidence that one is not autistic or not autistic enough to count (Yergeau 2018). The persistent myth that autistic individuals lack theory of mind contributes to this harm; the concept of "mindblindness" commonly attributed to autistic individuals serves as a dehumanizing trope that turns autistic people into animals or machines, separating them from collective storytelling practices (Bérubé 2016). Similarly, the sometimes nonverbal nature of autism is taken to mean a lack of ability to form or communicate a sense of self, which allows for external parties, such as clinicians, to undertake their own textual reading of the autistic body rather than to allow autistic narratives to emerge (Rodas and Yergeau 2018, 13). Recent work in this area has begun to address the need to draw on "autistic testimony" (Pellicano et al. 2019). However, this work is still mired in stereotypes, gendered and otherwise, that impact who is perceived as sufficiently autistic to participate in the discussion.

The erasure of the links between women and autism begins nearly two decades before the earliest most recognized published clinical accounts of autistic individuals. While the term "autistic" was first coined as an adjective in psychiatry in the 1910s, most historical accounts attribute our current understanding of autism to the two Austrian doctors who were the first to publish on the subject, in the 1940s, Hans Asperger and Leo Kanner. Grunya Efimovna Sukhareva, a young doctor working in Moscow in the 1920s, does not make this list, despite having published an account of six young patients in 1926 (Zeldovich 2018).

Still, even Sukhareva's analysis included only boys. Until very recently, the most prevalent public image of autism was that of a white, male child. Indeed, autism is diagnosed significantly more often in men than in women, with the most commonly cited statistic placing this difference at a ratio of four to one (Halladay et al. 2015). Many explanations for this disparity have emerged, including protective genetic mechanisms in girls and differences in how male and female children are nurtured and raised (Halladay et al. 2015). However, researchers have begun to acknowledge the possibility that this difference lies in rates of diagnosis, not in rates of actual occurrence. This too, could stem from different sources. For instance, due to differences in behaviours of gendered social groups, autistic girls may be more readily taught social norms by their peers and learn masking behaviours that allow them to pass as neurotypical (that is, non-autistic) (Russo 2018). However, one reason underpins all the others: the stories of autistic girls have not been told within medical literature and thus the symptoms are missed even by experts (Bargiela et al. 2016).

The gendering of autism that existed from its earliest clinical descriptions was more recently exacerbated with the publication of autism researcher Simon Baron-Cohen's "extreme male brain theory" (Baron-Cohen 2002). Baron-Cohen identified two thinking styles that he subsequently categorized into two rigidly gendered types—feminized "empathizing" and masculinized "systematizing"—and attributed the most systematic brains to those on the autism spectrum (Baron-Cohen 2010). This theory has been roundly rejected in recent years, with feminist scholars in particular noting that this "essentialist" version of autism reconstructs gender stereotypes while masquerading as science (Bumiller 2008). Indeed, even Baron-Cohen now acknowledges the diagnostic disparity caused by researchers ignoring the "female phenotype" of autism (although he neglects to note his role in the creation of this problem) (Lai and Baron-Cohen 2015). Nevertheless, Baron-Cohen's 2002 paper remains widely cited, carrying 2221 citations as of November 2019 (per Google Scholar).

The impact of excluding women and girls from autism narratives is profound. Girls are much less likely to be diagnosed and to receive services, particularly if they are not on the "severe" end of the spectrum (Bumiller 2008). Many autistic women cycle through diagnoses of social anxiety, depression, bipolar disorder, and schizophrenia before ever landing on the spectrum.[4] As a result, autistic women tend to be diagnosed much later in life (Zeliadt 2018), often after they bring their own children in for an assessment (Autistic Self-Advocacy Network (ASAN) 2018). While many parents of autistic children struggle to accept their child's diagnosis, for autistic adult women a diagnosis can represent an empowering explanation for a theretofore confusing life and a "passport to an entire community" (Autistic Self-Advocacy Network (ASAN) 2018).

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[4] While social anxiety can form a part of the autistic experience, and depression is often present, particularly in undiagnosed autistic adults, without the key understanding of autism, interventions for these issues will be less effective (Halladay et al. 2015).

Autistic women's narratives have recently been on the rise in the public eye. A 2010 film about Temple Grandin, an autistic animal husbandry expert and autism advocate, brought with it a new narrative of autistic women (Jackson 2010). Meanwhile, autistic researchers and authors like Rudy Simone (*Aspergirls*), Liane Holliday Willey (*Safety Skills for Asperger Women*), and Sarah Hendrickx (*Women and Girls with Autism Spectrum Disorder*) are reshaping the narrative around the autistic experience (Simone 2010; Willey and Attwood 2012; Hendrickx 2015). Hendrickx, in fact, had written several books on the subject before her diagnosis at age forty-three; as her website notes, "Autism in women is so invisible that Sarah did not recognise it in herself!"(Hendrickx 2018). Meanwhile, online presences like the non-binary Devon Price (Price 2018) and Amethyst Schaber (Schaber 2018) have further expanded on a growing recognition of ties between autism and trans and non-binary identities and the need for research that represents a full spectrum of sexual orientations and gender identities in autism is beginning to gain footing (Lai 2018). However, it will take time for these new narratives to begin to dismantle the idea that the young white male represents a foundational aspect of autism.

In academia, critical theorists are at work dismantling these older narratives. While critical disability theory represents a starting point for autistic advocacy, the most recent critical theory on autism stems in large part from the neurodiversity movement. First coming into the public's view via Steve Silberman's 2016 text *Neurotribes*, neurodiversity recognizes autism's place in the social model of disability, where the disabling factors stem primarily from a lack of resources and acceptance rather than an inherent deficit (Silberman 2016). Neurodiversity considers autism as a distinct community and culture (Bumiller 2008; Bowker and Tuffin 2002) and has emerged as a counter-narrative to the medicalization of autism, one that does not rely on physicians to define its parameters. The emerging concept of the "neuroqueer"—a project of "disidentification" that "rejects both oppressive dominant and counterculture identities that perpetuate destructive medical model discourses of progress and cure"—brings with it an additional layer of analysis that considers the intersections of disability, gender, and sexuality (Egner 2019; Richter 2016). As such, the growing neurodiversity and neuroqueer movements have seen more space for self-diagnosis and self-identification with autism, which has in turn allowed women whose stories are inaccessible to their physicians to nevertheless find a community.

Until more substantial change occurs within medical practices, organizations like the Autistic Women's Network (AWN) have emerged to provide peer support and resources for women on the spectrum. In April 2018 Julia Bascom, president of the Autistic Self-Advocacy Network (ASAN), spoke at a United Nations event on empowering autistic women and girls.

> The stories we tell about autism may have expanded slightly in recent years, but they are still incredibly restrictive. We have to spend our whole lives speaking up, speaking out, and finding ways to cut through these overpowering, disempowering narratives and find our truth. The only way to change this is to listen to autistic people. Listen to autistic women. Stop speaking over us, stop trying to help, stop insisting that we are the voiceless in need of a voice, and just listen. (ASAN 2018)

Organizations like AWN and ASAN work to empower new narratives in autism on two tracks. First, they provide a space where autistic women can tell their stories. Second, they bring these stories to the attention of those who hold the power to validate or dismiss emerging narratives. In *telling* these stories widely and persistently, they increase their potential to be *heard*.

Fat Women and Stories Unheard

Although stigmatization of the aesthetic of fatness waxed and waned in different periods of history, it is only at the turn of the twentieth century that it began to be seen as a population health issue (Nuttall 2015). Ancel Keys, author of the famous 1950 paper "The Biology of Human Starvation" and the "seven countries study" that launched a thousand low-fat cookbooks, pushed the idea of a causal relationship between heart disease and obesity caused by diets high in saturated fat (Keys 1978; Keys et al. 1984). While nutritional scientists have recently begun to rebut this claim, focusing particularly on the influence of the sugar lobby in suppressing contradictory research, Keys' claims nevertheless maintain a hold on health research bodies (Boseley 2003; Lustig et al. 2012). In 1997, the World Health Organization declared obesity an "epidemic" (Caballero 2007). This was followed almost immediately in 1998 by a lowering of the body mass index (BMI) considered "normal" from 27.8 for men and 27.3 for women to 25 for everyone, rendering millions more Americans overweight by National Institute of Health standards overnight, without a single pound gained (Nuttall 2015). Finally, after having already spent sixteen years as an epidemic, the American Medical Association declared obesity a standalone "disease" in 2013 (Stoner and Cornwall 2014; Pollack 2013).

With fatness so thoroughly pathologized, physicians are discouraged from looking past a patient's weight in the search for answers to health problems. However, as critical theorists have noted, "[t]he definition of disease is neither natural nor neutral, but is always a social construction that privileges some voices over others" (Anderson 2012, 195). While certain negative health outcomes are *correlated* with weight, many suggestions of *causation* between fat and poor health have come under scientific scrutiny in recent years. Moreover, research is increasingly showing that sustained weight loss is not possible for a majority of individuals and that the weight fluctuations that accompany weight-loss attempts contribute to unhealthier bodies (Bacon and Aphramor 2011). As a result, fat studies researchers are asking:

> What if, however, we removed the "everyone knows being fat is unhealthy" assumption and explored whether these disparities are instead a result of the systematic and structural oppression experienced by fat people? What if, for example, the impairment to health for fat people is located within the social stigmatization of fat people? (Lee and Pause 2016, 3)

Indeed, the experience of being dismissed by physicians has serious repercussions for health. In addition to diagnoses that are missed because the symptoms are attributed to weight, some fat women may stop going to their physicians at all. As @yrfatfriend, a prominent online voice in the fat acceptance movement, notes in an essay on the limitations of body positivity in generating justice for fat people: "I cannot self-confidence my way through health care that can see all of my size and none of my symptoms"(@yrfatfriend 2018a).

A recent Twitter discussion led by @yrfatfriend began with a simple question: "Fellow fats: have you ever been misdiagnosed by a doctor due to your size? What were the repercussions of your misdiagnosis?" (@yrfatfriend 2018b). Within minutes, answers poured in, mostly from women:

> Tore my meniscus playing a sport. First doc told me my knee just hurt because i was fat and I should lose weight. Tried to lose weight to alleviate the pain, made the tear worse and injured my PCL in the process. Ended up needing knee surgery. (@wynterstorm24)
>
> Told my dr about the back pain I had for years. Said it was probably due to my size. One day pain was so bad went to the ER. After a multitude of tests found out infection had killed off my kidney & was spreading. Kidney had to be removed before it attacked my other organs. (@vanillawinnie)
>
> I broke my leg when I was 17. I was told it healed fine and the pain after the initial healing period was because of my weight. Turns out my leg was still broken and I developed severe post traumatic arthritis in my ankle from it being in the wrong place. 4 years of extreme pain. (@ZiRightNow)

The stories shared a common thread: these individuals had experienced chronic health issues and repeatedly sought care, only to have their issues misdiagnosed as being the result of their weight. In the context of fat individuals, the stories are told, but the doctors are not listening (Anderson 2012). Complex narratives that centre the fat body and the trauma of navigating the world, such as Roxane Gay's 2017 bestseller *Hunger: A Memoir of (My) Body*, are only just beginning to emerge into the public consciousness (Gay 2017).

Although both men and women face size discrimination at the doctor's office, the experience for women seems to both be worse and result in more stress. Given how ideals surrounding thinness are disproportionately applied to women, many women report blaming themselves for their weight and believing that they deserve the unfair treatment received at the hands of healthcare professionals (Chrisler and Barney 2017). And this unfair treatment is commonplace: a 2006 study showed that more than half of the two thousand participants had received disparaging comments from their doctors, and women reported doctors as coming second only to family for perpetuating the stigma around their weight (Puhl and Brownell 2006).

This stigma affects multiply marginalized women with particular intensity. For queer women who fall into the BMI categories of overweight or obese, fat stigma compounds the stress of navigating healthcare as a sexual minority (Johns et al. 2017). In fact, physicians may double down on their stereotyping in these cases. McPhail and Bombak, in a critical discourse analysis of public health research on obesity that references lesbians as a "risk population," argue that the longstanding conflation of lesbians with medicalized fatness may stem from medicine's history of pathologizing both fatness and queerness, setting queer women up to be viewed as multiply "deviant" (McPhail and Bombak 2015, 540). Anna Mollow notes how fat black bodies are viewed as holding responsibility for violence perpetrated against them, as "antifat misconceptions uphold constructions of fat black bodies as being impervious to victimhood" (Mollow 2017, 108). This continues despite growing evidence that causal presumptions about fatness and health have been largely overstated and that the stigma associated with being fat contributes to discrimination that can shorten life expectancy (Mollow 2017, 110).

Recognizing the harms of pathologization and stigmatization of fatness, fat studies scholars and some nutritionists and dieticians have begun to embrace Bacon and Aphramor's Health at Every Size (HAES) paradigm (Bacon and Aphramor 2011), which aims to provide people with the best possible quality of life without focusing on weight or weight loss (Lee and Pause 2016). This shift represents an opportunity for healthcare professionals to adopt a much broader understanding of their fat patients' stories and to incorporate this into their practice. For instance, as narrative ethicist Larry Churchill notes, a patient's medical record can form a compelling part of their narrative; this narrative, however, is necessarily skewed by biases in what past physicians have chosen to report and in what manner (Churchill 2014). Seemingly minor changes, like opting not to record a patient's weight in their medical file unless strictly necessary for disease management, could allow physicians to remove an unhelpful lens and listen more closely to the story that their patient is trying to tell. Teaching simple approaches like these to physicians while they are still developing their practices, alongside work that seeks to undo prejudicial approaches to listening, could allow them to learn to hear fat women's stories more clearly, increasing the chances that they will be believed.

Women in Pain and Stories Not Believed

Modern stereotypical narratives around women and pain date back to the turn of the nineteenth century. Hysteria, attributed primarily to women's bodies, was a diagnosis of a woman as "sickly, weak, and delicate" (Werner et al. 2004, 1037). The word hysteria, however, has a much earlier connotation. Coined in the fifth century by Hippocrates, the term (from which we also derive the word hysterectomy) referred to a wandering womb and the idea that the womb might move around a woman's body, releasing toxins and causing illness (Scheurich 2000). Although this notion and the surrounding language have fallen away, the accompanying narrative of women in pain as malingering has persisted quietly and insidiously into modern medicine.

Women's pain is consistently underestimated by healthcare professionals when compared with men's (Schafer et al. 2016). As far back as 1996, it was recognized that men and women presenting to emergency rooms with chest pain showing similar symptoms, risk factors, and exam results received different treatment, with fewer women receiving electrocardiograms and cardiac monitoring (Lehmann et al. 1996). These differences in treatments persist across sources of pain; in a study of male and female post-operative appendectomy patients without complications, males received significantly more narcotic analgesics than females (Hoffmann and Tarzian 2001). A study by Weir et al. of chronic pain patients who were referred to specialty pain clinics found that men were more likely to have arrived after a referral from their general practitioner, whereas women arrived only after having seen a specialist (Weir et al. 1996). This suggests that the disparity in belief of men and women at the hands of their physicians begins with the first appointment (Hoffmann and Tarzian 2001).

Disbelief in women's pain from healthcare providers begins as early as adolescence. In a study of the types of dismissal reported by adolescent girls in contrast with adolescent boys, girls reported experiencing express disbelief, minimization of their pain, and being told that they were faking their pain at higher rates than those reported by their male counterparts (Igler et al. 2017). As adults, women reported expending significant energy at doctors' visits on the task of behaving like a credible patient, attempting to alter their appearance and demeanour in order to be believed by their doctors (Werner and Malterud 2003). Women are forced to work harder to prove that they are sick and are not treated equitably until they are "perceived to be as ill as similarly situated males" (Hoffmann and Tarzian 2001, 17). Physician, cardiologist, and academic Dr. Bernadine Healy referred to as this as "Yentl Syndrome" (based on the short-story and film of the same name), arguing broadly that "being 'just like a man' has historically been a price women have had to pay for equality" (Healy 1991, 274).

The issue of not believing women in pain has already been widely studied. Women with chronic pain have reported being mistrusted (Ahlsen et al. 2014; Hayes et al. 2010; Werner et al. 2003; Werner and Malterud 2003; Gustafsson et al. 2004) and psychologized (Werner et al. 2004) by their healthcare providers (Samulowitz et al. 2018). They also reported being perceived as hysterical (Katz et al. 2008; Barker 2011) and emotional, (Cote and Coutu 2010) and of complaining (Werner et al. 2004), not wanting to get better (Werner et al. 2003), and fabricating their pain (Dao and LeResche 2000). Outside of these types of self-reported studies, other research shows that woman with chronic pain are often assigned psychological rather than physical causes (Hoffmann and Tarzian 2001). Some women reported having to beg their physicians for treatment, sick leave, or painkillers (Werner and Malterud 2003). Overall, not being believed had a significant impact on women's health and well-being (Lillrank 2003), ranging from deep feelings of shame around their health to vital missed diagnoses (Gustafsson et al. 2004).

While the consensus of these studies is that women in pain are often not believed, the specific reasons for this disbelief are less clear. In one study on the interplay of pain, gender, and culture, researchers found that the ability of a woman's body to withstand reproductive labour often resulted in an assumption that women possess a "natural capacity to endure pain" (Bendelow 1993). Another study, this one on nurses, found that the model of pain taught to nurses trained them to look for elevated vital signs or behavioural expressions of pain, overemphasizing biological indicators and underacknowledging women's self-reporting (Mehmood et al. 2015). Regardless of the reason, the impacts are clear. In one study on chronic pelvic pain, women had received seventy-three different diagnoses to explain the cause of their pain and reported that their physician implied that there was nothing wrong if no cause was identified (Hoffmann and Tarzian 2001).

It is not only that women's pain is taken less seriously than men's, but also that the types of pain experienced only by women are minimized and ignored. Of those suffering from autoimmune diseases, 78 per cent are women (Fairweather et al. 2008); autoimmune diseases are also under-researched and, when symptoms present in women, dismissed as being stress-based (Rosenfeld 2017). Pain relating to the reproductive system is particularly egregiously disbelieved. Take, for example, the birth control device Essure. On the market since 2002, women spent years warning one another of horrific side effects, including chronic abdominal pain. The FDA has now begun to restrict its sale and usage, but only after more than 26,000 complaints and eight deaths (Doyle 2018). As journalist Sady Doyle notes, this scepticism is explicitly tied to women's pain:

> Experiences as universal as menstrual cramps and PMS were thought to be imaginary until recently (and PMS still has its skeptics). In 2018, doctors determined the pain of cramping could be "almost as bad as a heart attack," yet physicians were still being taught that over-the-counter drugs like ibuprofen "should be good enough" (Doyle 2018).

Indeed, women are often dismissed on the subject of their own reproductive health and pain to the point where they are forced to develop their own medical expertise. Kate Seear refers to this process, in the context of endometriosis, as a "third shift" of labour (in addition to women's other paid and unpaid work) (Seear 2009). In 2018, author and graphic artist Kate Beaton wrote about her sister Becky's lengthy diagnostic odyssey and eventual death from cervical cancer. After her initial lesions were missed despite heavy and irregular bleeding, she underwent seemingly successful treatment, only to have another set of doctors dismiss her when pain and swelling emerged in her legs. A note in her chart from this visit reads: "Rebecca continues to be paranoid." The cancer had, in fact, re-emerged. Twenty months later, she was dead (Beaton 2018).

These examples show that sometimes sheer volume of stories is insufficient to bring about change. Of the three examples examined in this paper, the case for the undertreatment of women in pain has the strongest examples in the academic literature, yet the issues with women being disbelieved persist, with sometimes fatal consequences. Below, we will consider how this might be rectified.

Epistemic Justice

So far, I have argued that in order for narrative bioethics to work, we need to critically examine and understand whose stories are *told*, *heard*, and *believed*, as well as why, with the goal of improving physicians' ability to employ narrative tools effectively. However, the harms that stem from poorly executed use of narrative in medicine extend beyond the surface health implications. In her work on epistemic injustice, Miranda Fricker addresses the idea that a person can be wronged specifically in their capacity as a knower via negative identity-prejudicial stereotypes. She defines this kind of stereotype as: "A widely held disparaging association between a social group and one or more attributes, where this association embodies a generalization that displays some (typically, epistemically culpable) resistance to counter-evidence owing to an ethically bad affective investment" (Fricker 2007, 36). In essence, she argues that certain kinds of prejudices contain an intrinsic quality of disbelief, where the stereotype negatively colours the listener's judgement of the storyteller's credibility. She distinguishes this kind of epistemic injustice from the practical injustice that occurs because of the disbelief (Fricker 2007, 45). Practical implications of denying credibility in healthcare, as we saw above, include lack of ability to access resources, misdiagnoses, impaired quality of life, and impaired trust in the medical system. What Fricker is discussing here, however, is the first-order harm that an individual experiences when her credibility is questioned based on prejudice. In this conception of epistemic justice, being allowed to tell one's story and having that story heard and believed are goods unto themselves.

Although this first-order harm of having one's credibility questioned as a result of prejudice encompasses only one part of the injustices described above, Fricker's work carries interesting implications for how we might begin to tackle the challenges to narrative bioethics raised in this paper. In a study on the influence of patient sex, provider sex, and sexist attitudes on pain treatment decisions, the researchers were surprised to discover that while both patient sex and provider sex impacted pain management approaches, controlling for providers' sexism scores did not substantially alter results (Hirsh et al. 2014). This suggests that even in physicians who do not carry or display significant sex or gender prejudice in general, prejudices surrounding their assessment of women's credibility may run deep. Approaches that tackle these issues only by educating physicians on the prevalence of autistic women, the needless pathologization of fat women, or the under-treatment of women in pain may be insufficient to fully address the flaws in their capacity as listeners.

As part of the solution to this type of prejudice, Fricker argues for the development of critical reflexivity in the listener that will enable them to more easily notice their biases at work. She notes that:

> our experience of unreflectively taking in what we are told is not, after all, best characterized by an account that represents our critical faculties as entirely inoperative, but by an account that represents our critical faculties as ongoingly operative in a lower-level, more automatic manner. (Fricker 2007, 66)

Becoming a good listener, then, means taking these critical faculties from automatic to conscious. Although one's ethical sensibility—one's innate sense of rightness and wrongness—is first formed through our absorption of the attitudes and cultural mores of our particular context, training in critical thinking can enable us to reflect on and criticize these attitudes (Fricker 2007). As such, Fricker argues that our "testimonial sensibility"—our ability to notice and reflect on the prejudices in our own listening capacity—can be similarly strengthened in order to bring "critical thought to bear on […] internalized habits of hearer response in order to shake them up sufficiently" (Fricker 2007, 84). The prejudice represents a "source of bad training" (Fricker 2007, 82) for the listener in the development of their testimonial capacity, one which can be counterbalanced by "ongoing correction and adjustment in the light of experience and critical reflection" (Fricker 2007, 85). In addition to education around gender bias that will be necessary to shift dominant biomedical narratives on a grand scale, teaching this kind of critical reflexivity could improve physicians' capacity to conscientiously receive individual testimony in a way that empowers the patient.

Conclusions: Interrupting the Echo Chamber

> *"I am the expert in medicine, but you are the expert in you."*

I rocked back in my chair the first time these words were spoken to me by my physician. I had struggled for years with myriad health problems that appeared to have no end and the constant exhaustion of not being heard or believed was staggering. To have this experience validated seemed as unlikely at that point as finding out what was wrong. And while I wouldn't receive any new answers at the doctor's office that day, the very act of being heard and believed made me willing to continue searching.

Patient-centred care, based on fostering trust and communication with patients and providing higher patient satisfaction, has emerged in the late twentieth century as an attempt to reform what was viewed as an increasing disconnect between patients' health and their broader context (Starfield 2011). Narrative ethics, in focusing on the individual's story, appears to be a perfect mechanism for the kind of patient empowerment envisioned in patient-centred care. Yet the number of unconscious individual and systemic biases embedded in the provision of healthcare makes many physicians, as currently trained, unreliable listeners. Storytelling holds incredible force, but any version of narrative ethics that does not reflect on biases both in individual medical practitioners and the practice of biomedicine as a whole risks simply becoming an echo chamber for the stories of those in power. As such, narrative ethics can be a powerful tool for mitigating oppressive practices in medicine *if* and *only if* we couple it with critical analysis that enables us to understand the power dynamics at play in storytelling.

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