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gender &
embodiment

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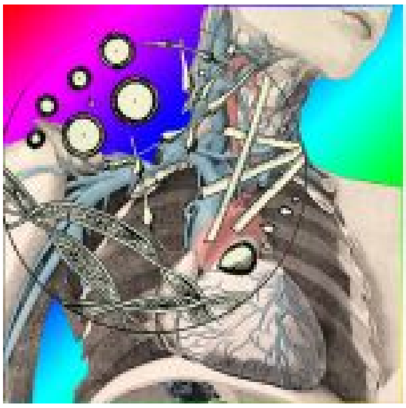

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health, gender, and
embodiment

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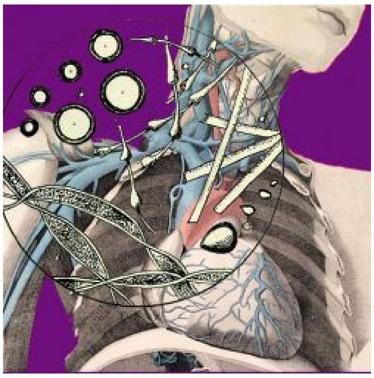

The Future of *Dósis*

Dósis will publish one final issue in Fall 2018 (1:3) before ceasing to produce new content. For the foreseeable, the website (medhumdosis.com) will remain online for readers to access the archives going back to March 2011. If you have questions please contact Brandy Schillace at bls10@case.edu.

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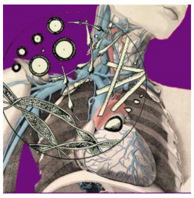
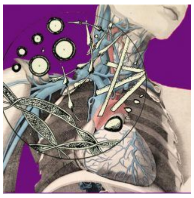


Health, Gender, and Embodiment: Part One

In this second issue of *Dósis* we are please to present part one of Health, Gender, and Embodiment. Our project at the blog, and particularly in the blogzine project (an aspect of the blog as a whole), has been to investigate—and interrogate—the way matters of health and justice combine, and not infrequently clash. We felt that the theme of gender and embodiment offered valuable insight into this contested intersection. Our readers and authors agreed, and the response justified offering the theme in two parts, Summer and Fall.

We endeavor not to be prescriptive here, but to stimulate and share conversation about what terms like *gender* and *embodiment* mean—not just in terms of medicine, but in terms of lived experience. Our authors offer a remarkable breadth of perspective here, and both the essays and the valuable book reviews can, we feel, strengthen and solidify the chorus for social justice in medical humanities. Thank you for reading.

○ *Brandy Schillace, Editor-in-Chief*



◎ "It was a parting with himself, or rather a part of himself": Tracing Severed Accounts of Disabled African American Union Veterans

○ *Alexandria Einspahr*

I.

On the screen are two articles each featuring a photograph of a shirtless man sitting upright. As disabled Union veterans grappling with the aftermaths of the Civil War, Alfred A. Stratton's and Lewis ("Louis") Martin's injuries seem to project the same narrative: Alfred displays two amputated arms while Lewis's cross-legged position exposes his amputated left foot and his right arm severed above the elbow. Their similarly fixed stares, however, are where their mirroring severs. Berry Craig's article *in O&P Business News*, a nationally distributed periodical for orthotic and prosthetic practitioners, delineates Stratton's short-lived success story in explicit detail. Despite having both arms torn off from cannon fire at the age of 19, Stratton would go on to be a minister and father of two before passing at the age of 29 (59). Martin's feature, in turn, appears in Dave Bakke's editorial in the *State Journal Register*, a daily newspaper in Springfield, IL, and generates just as many mysteries as it reveals. Bakke explains that Kathy Heyworth, an amateur historian and retired director of the Mini O'Beirne Crisis Nursery, properly identified Martin's unmarked grave in Oakridge Cemetery in Springfield. Unlike Stratton, Martin's age at the time of his death cannot be ascertained; rather, Kathy's extensive hunt through Reconstruction era publications revealed that Martin died sometime in January 1892 from, according to a source the article does not disclose, "exposure & drink."

The institutional absorption of Stratton's body and the subsequent rejection of Martin's functions as a microcosm of the lack of narratives detailing the lived experiences of disabled Civil War African American veterans. As Margaret Humphreys summarizes in her medical historiography of the United States Colored Troops (USCT), black soldiers made up roughly ten percent of the Union army by 1864: "Some 180,000 black men wore the brass buttons of the Union soldier's uniform. More than 33,000 men were buried wearing it, with 4,000 of them bearing bullet wounds and the rest defeated by disease" (6). In turn, the National Library of

Medicine's (NLM) online exhibition, *Life and Limb: The Toll of the American Civil War*, notes that amputation accounted for three quarters, or roughly 60,000, of the operations conducted during the war. Despite these overlapping statistics, the NLM does not feature or even refer to wounded black soldiers in its educational archive. Considering Donald R. Shaffer's observation that African American soldiers experienced higher mortality rates than their white comrades (206), the apparent absence of these veterans and the men who passed from their injuries is jarring.[1]

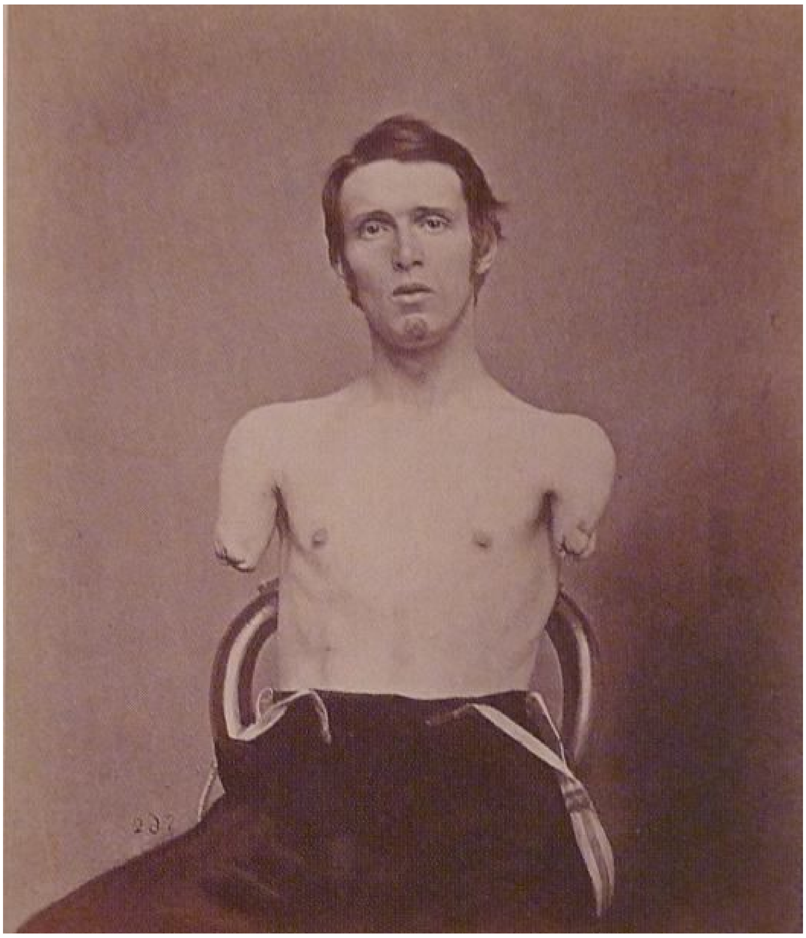


Figure 1: Alfred A. Stratton. Mütter Museum. Historic Medical Photographs, S. 23, 24 Dec. 1869. Source: *Wikimedia Commons*.

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[1] A brief note on terminology: while I advocate for person-first statements in academic discourse and disability studies' scholarship, this paper will also utilize condition-first terms, such as disabled African American soldiers. The purpose is to linguistically unify blackness and disability, which is a relationship that has been severed by historical records that cast amputation during the Civil War as an exclusively white experience. I also utilize the adjectives black and African American interchangeably in my descriptions, but it is worth noting that these two terms have their own origins and implications. In her preface notes, Humphreys directs her reader's attention to Orlando Patterson's 1998 monolith *Rituals of Blood: Consequences of Slavery in Two American Centuries* for a more in-depth discussion on the usage of these two terms (xiii, note 6).

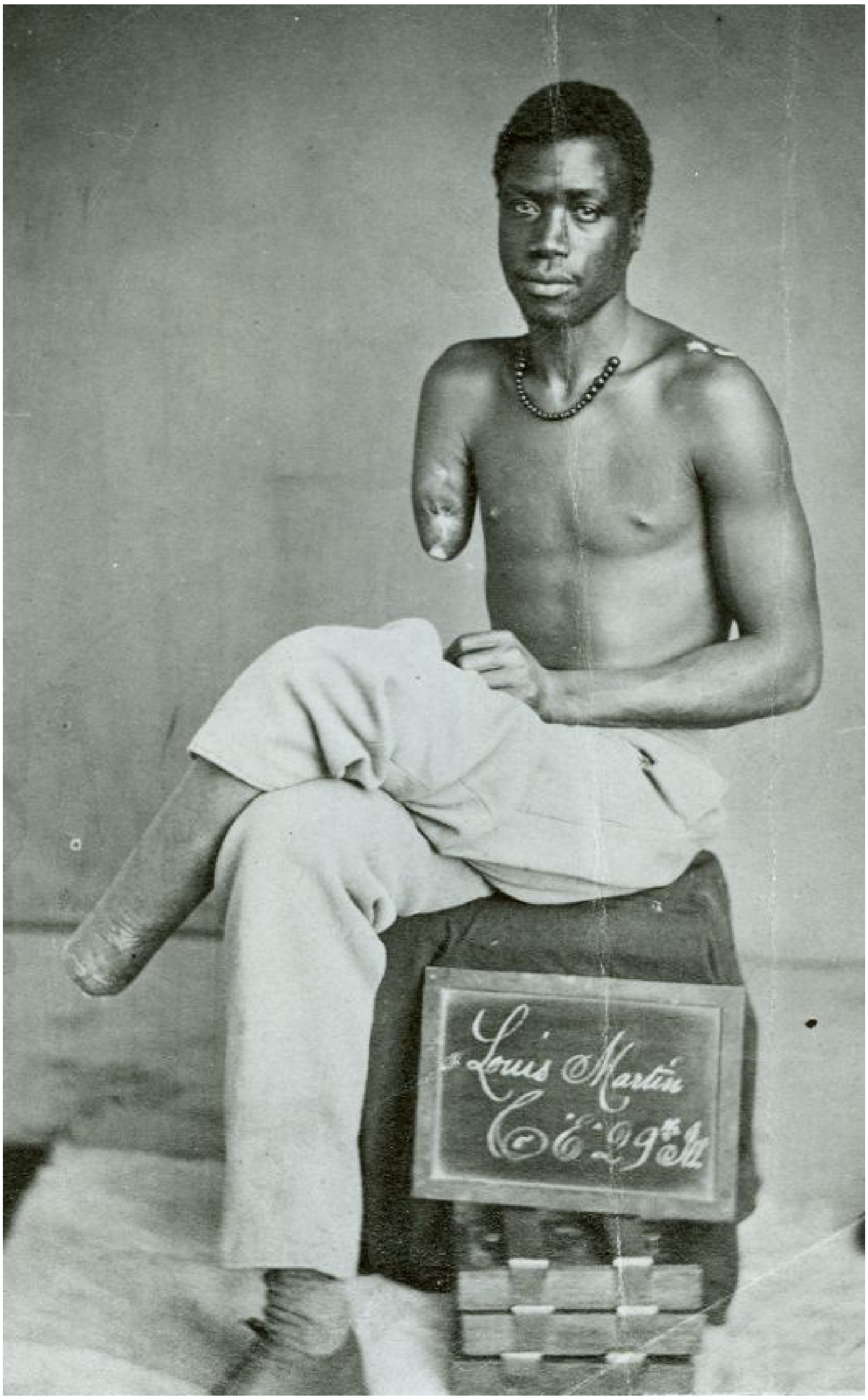

Figure 2: Lewis (“Louis”) Martin. National Archive. Photograph by Dr. Reed Bontecu.

While the high rate of illiteracy among USCT soldiers and the lack of official records (Humphreys xii) both undoubtedly play significant roles in explaining why accounts like Lewis Martin’s were left on the battlefield, they fail to justify why more critical work has not been done to restore them. In this vein, the disappearance of these narratives is arguably not just an absence but an erasure. This repositioning resonates with Ta-Nehisi Coates’ claim that white theorists, historians, and politicians have historically erased black subjects “from the written record” (3) of the Civil War in an effort to preserve a “more comforting story of tragedy, failed compromise, and individual gallantry” (2). In the face of these repressive accounts of tragic bravery, tracing representations of black veteran amputees offers a more realistic record that has been shaped by both institutional neglect and black empowerment. Graphing Coates critique to Christina Sharpe’s methodology of “wake work” (13), creating a gathering of historical documents, personal records, and contemporary media sources offers a window into the lives of disabled USCT veterans to demonstrate that Lewis Martin’s story, and those like his, still exists even when seemingly hidden from the academic gaze.

As Colleen Glenney Boggs notes, the 21,753 survivors[2] of amputation who reentered domestic life following the war recast disabilities as a fixture of the quotidian and codified a heteronormative masculinity that relied on heroic acts of sacrifice (43); within the context of these heroic narratives, however, representations of black disabled soldiers often operated as a means of inducing sympathy from white audiences. In Thomas Nast’s two-part political cartoon “Pardon/Franchise,” which appeared in *Harper’s Weekly* on August 5th, 1865, Nast depicts a fair-skinned Columbia, Nast’s personification of America, in opposing positions: perched in her Romanesque gown looking down exhaustingly upon white, richly dressed able-bodied politicians and standing aside a dismembered African American soldier still in his Union uniform. One bare arm gently grasps his shoulder while the other gestures towards him. Split between the pages, the caption reads, “shall I trust these men...and not this man?” (488-89).

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[2] This number is found in both Brian Matthew Jordan’s’ article (127) and Brian Craig Miller’s monolith *Empty Sleeves: Amputation in the Civil War South* (39). Jordan notes that this is a conservative estimate considering that there were no medical statistics during the first eighteen months of the war and subsequent records were often incomplete (127). I would also add that this number does not account for racial disparity, so it is unclear how many African American soldiers are represented in this statistic.

Figure 3: Thomas Nast's two-part illustration "Pardon [left] Franchise [right]." *Harper's Weekly*, 5 Aug. 1865, pp. 488–489. Source: Library of Congress Prints and Photographs Division

Columbia's whiteness is an embodiment of her purity, and her physical position towering above male government officials, granted a perspective that would have otherwise been inaccessible to women during this time, allows her to communicate a moralistic outrage on behalf of the wounded man. The heroic yet noticeably silent black soldier embodies the sacrifices of the war while simultaneously masking its cause.

Although *the Harper's Weekly* arguably signals a call for equality, it is nonetheless fictional; in reality, a black soldier's limb loss was often the product of medical neglect rather than a blood-stained act of valor. Lt. Col. William F. Fox's survey of regiment casualties lists that the 64th and 65th Colored Infantries respectively lost 200 and 100 soldiers due to exposure during the particularly frigid winter months of 1864-65, and many more "suffered amputation for frozen feet or hands" (592). As the medical historian Ira Rutkow notes, expedient amputation was also a common means, if not the only method, of quelling infections such as gangrene or pyemia: a puss forming blood infection that was tantamount to a death sentence (174).

Amputation, then, was undoubtedly a common practice among segregated USCT hospitals in the face of limited resources, which correlates with Humphreys' observation that "while 2.7 white soldiers died of disease for every single battle casualty, among the black soldiers the ratio was about ten to one" (11). As such, while Boggs argues that the imagery of the "empty sleeve" embodies a reconstructing of "disability's imbrications with the normative" (43), the multitude of amputations that occurred due to infection and exposure demonstrates that the empty sleeve is an exclusive construct. After all, Lewis Martin did not display his body to demonstrate his valor, or, like Stratton, sell reproductions of his likeness in order to utilize his injuries for economic gain. Rather, as Edward A. Miller points out, a surgeon, Dr. Reed Bontecu, photographs Martin for an anatomical study (95). Martin's photograph offers no sleeve to pin or war story to celebrate; what it does reveal, though, is that amputated limbs' symbolic message of bravery is often a construct predicated on an undercurrent of whiteness.

II.

Martin's exploitation by a white surgeon is a precursor of another often commonly overlooked narrative found in the medical treatment of black troops: amputation as an act of cruelty. A short article in *The Christian Recorder* on June 25th, 1864 contrasted the humane treatment of recently captured Confederate soldiers in local Union hospitals to the members of the 54th Infantry, arguably the most well-known of all USCT troops because of their depiction in the film *Glory*, who were captured at Fort Wagner: "The Charleston papers boasted that but few of the wounded who fell into their hands at the storming of Fort Wagner, got off without losing a limb by the surgeon's knife, however slight the wounds." The unnecessary amputations inflicted on the 54th Regiment's soldiers read as an act of retaliatory pleasure: a delight in the opportunity to use treatment as a professional veil to inflict violence on the black body. Yet, when reviewing an August 1st, 1863 article in *The Christian Recorder* on the medical treatment of the 54th shortly after the Second Battle of Fort Wagner, it becomes apparent that Union hospitals were not repositories for humane treatment, either:

> *On the second and fourth days after the first I passed through nearly all the wards of the hospital. On the second day a very large proportion of their wounds had not been dressed, and of course they were very painful. Some lay with shattered legs, or arms, or both; others with limbs amputated.*

Cruelty against black soldiers was not an uncommon sight in Union hospitals; Humphreys details a similar example in the court-martial case of Lyman Allens, a U.S. Colored Troops surgeon, who refused to treat a soldier under the defense that "a man with a part of his foot cut off by a piece of shell was not suffering much pain" (71). The lack of anesthesia used to treat the 54th Infantry and the men under Allens' care is a glimpse into a continued legacy of the transatlantic slave trade which Sharpe succinctly defines: "Black people in the United States receive inferior health care because they are believed to feel less pain" (50). While *Glory* dramatized the 54th

Regiment's pay inequality and their immense casualties, the film's final frame of Colonel Shaw's burial in a mass grave with other fallen soldiers (01:59:23) ignores the fact that those who did survive would continue to experience racist violence at the hands of those who were meant to heal their wounds. More importantly, missing accounts of disabled African American soldiers neatly circumnavigates the fact that medical practitioners used debilitation as a means to neutralize the armed black man.

Thus, while both the Union and Confederacy appropriated the white soldier as a hero of states' rights, the injured black combatant explicitly demonstrates not only the cost of the war but its cause: the systematic exploitation and maiming of black bodies. As such, the dismembered USCT veteran is a more accurate representation of Brian Matthew Jordan's claim that disabled veterans embodied "the politics of remembering and forgetting the war's causes and its ultimate consequences" (125). Unlike their white comrades, USCT veterans had to use their personal losses as a means to remember the lives that were lost both to slavery and to the battlefield and to remind state officials of the valiant actions that U.S. history refused, and arguably still refuses, to fully acknowledge.

In the face of this erasure, personal accounts of disabled veterans during the war function as a precursor of Sharpe's wake work as evident in W.M. Waters' letter to *The Christian Recorder* on April 15th, 1865. A member of Company K in the 26th Regiment, Waters explains that he writes on behalf of the men who the world seems intent on forgetting:

> *As nobody seems to take any interest in the 26th Regiment U.S. Colored Troops, I will endeavor to write a few lines for the benefit of all concerned, hoping our friends at the North, whom we have left behind while we went forward to fight for the defence [sic] of our Union, would be glad to hear from us.*

Waters' letter encapsulates Sharpe's proclamation that "to tend to the Black dead and dying" means maintaining a steady vigilance (10). In a war where fallen members of USCT regiments could often not share their stories, the soldier applauds the sacrifice of his colonel who lost his limb, and subsequently his life, for his men:

> *At the battle of Honey Hill we lost our Colonel, who was leading his brigade through the field of battle, when a rebel shell struck his leg. Amputation soon took place, which caused his*

> *death. The 26th admired and trusted in him, as a friend and a brave man. We greatly mourn his loss.*

Waters' account carefully curates a balance of private and public mourning. While the second-person pronoun emphasizes the camaraderie of his troop, a signifier that they have endured a loss that only their group could ever truly understand, he also invites his readers to take up their emotional work. By reading about his grief, the reader in turn counteracts Waters' opening statement that no one "seems to take any interest in the 26th Regiment U.S Colored Troops." Waters also enacts vigilance by curating his letter's relationship to history. Rather than waiting for history to acknowledge their participation, he directs its gaze: "On John's Island, in the month of July 1864, the 26th won laurels for herself worthy to be recorded on the pages of history." The question remains: have we accepted Waters' challenge to not forget his men and maintain our vigilance?

Waters' letter is a powerful reminder that the disabled men of the USCT are not gone; they are in our historical archives, in our local newspapers, and most importantly, scattered in unmarked graves throughout the country. As Shaffer notes, with a decade of difference in life expectancy in the late 19th century, African American soldiers faced higher mortality rates than white soldiers off the battlefield as well: "More than half of the white men who had joined the Union and Confederate armies and navies were still alive in the 1890...but less than 30 percent of African Americans survived" (55). Whether from their injuries or their subsequent poverty, black amputees most likely accounted for very little of this survival number. As such, Lewis Martin has not been the only disabled soldier relegated to an unmarked grave. By carefully curating which narratives appear in our history books, we do a disservice to the soldiers like Martin and W.M. Waters who could not simply ignore the information that made them uncomfortable.

Overlooking the reports and personal accounts of disabled USCT veterans is ultimately a self-masochistic amputation of our own historical body. In this sense, a *Christian Recorder* article dated from August 22nd, 1895 entitled "A Parting with a Leg" metaphorically encapsulates the United States' fractured relationship to its own past:

> *An old soldier told a reporter of the most affecting parting he ever had in his life. It was a parting with himself, or rather a part of himself. He was in an engagement before Petersburg and had the misfortune to come in contact with a piece of broken shell which exploded near him, and which succeeded in shattering his leg. Amputation was necessary, and shortly after*

> *he was lying in his tent. As he looked up he saw a cart piled up with legs and arms of others who had been unfortunate in the engagement, and right on top he recognized his own leg. "It was sad parting," he said, "to see a part of you going away never to be returned again. I can never tell you what strange feelings came over me, and to this day I can see that fine black horse hauling my leg away to its last resting place."*

In parting with a critical piece of our history, we have inadvertently parted with ourselves; yet, a black horse did not simply haul our lost narratives to an unknown resting place. Rather, the plethora of unmarked graves recasts the very soil of the United States as a site of mourning, and as such, its residents eat, drink, and breathe Sharpe's vision of an inhabitable wake work (18). Inflicting institutional violence on the black body, whether on the streets of Sanford, Fl., Staten Island, or Ferguson, Mo., then, is not only an abuse of the justice system, but an act of sacrilege to a resting place. Lewis Martin and W.M. Waters are both a part of America's cultural legacy and its biological ecosphere, and, in turn, its residents must be the prosthesis who continue their work. In this light, the reemergence of Martin's full narrative is proof that it can be done. Following his initial article, Dave Bakke released an update about Martin's gravesite in October 2013. Bob Davis, an African American Civil War reenactor, contacted Heyworth after reading about her research, and together, the two Springfield residents raised funds to memorialize the fallen soldier. The internet became a gathering space, which led to an outcry of funds from the public and donations from local businesses, including a gravestone by the Arnold Monument of Springfield. Martin's photograph is now a permanent fixture of his gravestone: both a memorial to his sacrifice and a reminder of the narratives yet to be recovered.

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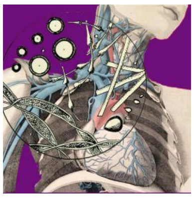


◉ The Gender Kidney Donation Gap: Where are All the Male Kidneys?

○ *Nate Hodson*

Writing for New Delhi's *The Quint* in February 2018, Kaushiky Kashyap reported on what she called "the gender gap in organ donation". Although it has been known for some time that women are more likely than men to become living kidney donors, Kashyap's critique addressed cultural factors underpinning the female propensity to donate kidneys and drew a parallel with the well-known concept of a *gender pay gap*.

As with the gender pay gap, the preponderance of female kidney donors is revealed again and again. Researchers in Birmingham, UK, studied 713 living-donor kidney transplants. They showed women donated 55% of kidneys but only received 40%. In a Norwegian study, 58% of kidney donors were female compared with 37% of recipients. A similar pattern has emerged in every age group and every racial group except for black people under 19 years old.

The extent of the gender kidney donation gap varies depending on the relationships investigated. One of the largest investigations of gender and kidney donation used the Scientific Registry of Transplant Recipients to study more than 30,000 American living kidney donations between 1990 and 1999. The majority of these donations were between related and unrelated non-spousal donors, where 56% of donors were woman. However 8% of the donations they studied, some 2,367, were spousal donations. Strikingly, women donated to their husbands in 68% of these cases and men to their wives in only 32%. A similar study of data from 1964 to 2000 at the University of Michigan Health System found that in 69% of spousal donations women were giving kidneys to men. The researchers concluded that "gender disparities in [living donor] transplantation are primarily due to a higher proportion of wife-to-husband donations".

In her report for *The Quint*, Kashyap picked up on this point, drawing particular attention to the gender kidney donation gap in heterosexual marriage and attributing the gap to cultural expectations. Before reaching the conclusion that this is a manifestation of patriarchy it is worth ruling out more benign explanations.

There are two possible medical explanations. Husbands may be physically unfit to donate to wives due to illnesses such as heart disease. Wives may be unable to receive a kidney from their husband due to immunological sensitization to him through pregnancy. In an innovative study, Deborah Zimmerman and colleagues followed 104 couples through the donation process. She showed that among those fit to donate, only 5 out of 31 husbands went ahead with immunological testing, compared with 22 out of 53 wives. Furthermore only 1 husband was excluded at the stage of immunological testing. Ultimately, 18 of the 53 medically fit wives went on to donate (that's 36%). However, out of 31 medically fit husbands, only 2 (7%) donated. Evidently, neither medical factors nor immunological incompatibility account for this vast discrepancy.

Kashyap argues that female preponderance in organ donation arises because women are socialized into sacrificial manifestations of care, with powerful descriptions of this in an Indian context. Carol Gilligan's analysis in a Western context, *In A Different V*oice, concurred: self-giving expressions of care predominate in the moral life of women whereas justice and rules are the focal points of male ethics. Denigrating the authentic values of women is a form of sexism which perpetuates both the criticism of female morality as irrational or incoherent, and male ethical hegemony. Rather than reinforcing a patriarchal individualistic worldview, we should ask why men in heterosexual marriages are, on the whole, failing to make a kidney donation within their most significant relationship. Rather than asking "why do women give away so many kidneys?" we should start asking "Where Are All The Male Kidneys?"

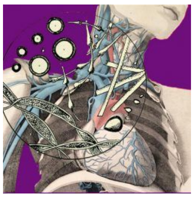
The reframing of norms seems to be central. Men who have donated kidneys are more likely to report a sense that they have done something "heroic". Women, meanwhile, seem to view it as a no-brainer. This is strange because we might expect men to be more likely to donate if they see it as a great act. In fact, evidence from behavioural economics shows that opposite is the case: people tend to do what they believe is normal, not what is exceptionally good (see *Mindspace: Influencing Behaviour Through Public Policy* for a more in-depth examination of the risks of social norms). A masculine morality seems to view donation as *supererogatory*, an act that goes beyond the call of duty. Meanwhile, from a stereotypically feminine perspective there is a normative assumption in favour of donation, so failure to donate would be to fall short. Whereas the man who donates sees himself as a hero, and the woman who considers non-donation may view it as a failure, the man who does not donate stays in neutral, his kidney stuck in an ethical no-man's land.

This difference can be understood through the two-cultures model of gender differences in language and their impact on heterosexual relationships. In *You Just Don't Understand*, linguist Deborah Tannen argues that women describe their relationships in terms that emphasise closeness and support, whereas the way that men talk about relationship tends to assert their independence. For one who views a couple as an interdependent unit, the notion of donating a kidney to a partner is natural; less of a transplant and more of a repositioning. But if the partnership comprises two individuals then the prospect of transplantation is alien and the organ graft threatens individual independence. This is borne out in the *bodytalk* of male donation which seems to assert that man is an island entire of itself whereupon we could find these missing male kidneys.

Some criticize Tannen's style, saying she "perpetuates negative stereotypes of women [and] excuses men their interactive failings" thus letting men off the hook and treating male failure as an equally valid manifestation of moral diversity. When it comes to the gender kidney donation gap, the stereotypes are there in the data. The point is that donation is a morally positive act and expectations that promote donation are, all things considered, better than those that undermine it.

Whether or not one agrees that the gender kidney donation gap can be attributed to masculine and feminine views of relationships, there remains something alarming about a gender kidney donation gap where kidneys flow overwhelmingly from wives to husbands. The evidence that 68% of spousal donations are from wives to husbands and that women who are fit to donate are over five times more likely than fit men to donate to their spouses would support the hypothesis that there is a malaise in heterosexual relationships.

It is not the sacrificial impulse that needs to be toned down, but the individualism preventing heterosexual couples actualising their potential. Men need to be socialised into generous connectedness. We must move beyond the narrative that donation is extraordinary, towards an expectation of perfect interdependence. I believe in redemption and that men are not hard-wired toward selfishness. So let's find these kidneys, plug the gap and keep track of them. Let's see if we can't transplant a new heart into this stuttering heterosexuality.



◉ The Protection Silence Does Not Offer

○ *Stephanie Quinn, Ph.D.*

When technical writers communicate, they do what most individuals will do. They attempt to anticipate their readers' needs: What information do my reader-users need to know and what is the most effective way to present the information? Technical writers apply these specific techniques learned from technical writing professors in a field heavily influenced by the science and technology industries. As computing technology exploded in the U.S. during the 1940s at the height of World War II, for example, technical writing emerged and expanded at breakneck speed.

Imagine it: rooms filled with experts (mostly men at that time) in need of other experts to communicate technical information — specialized content accessible by an increasingly narrow, and steep path for those who can climb to the top. This scene epitomizes the intellectual prowess we've come to expect of higher education and progress. As a woman teaching technical writing for 15 years, I've passed down this legacy of consolidated power in expert-centered management and design of information despite my own efforts to integrate user-centered approaches. I may explicitly instruct my students to account for the ways a diverse group of users ("abled" and "disabled") will think and act when using a technical document, but it is my silence that implicitly reinforces conformity to a tradition of ableism, exclusion, marginalization, and gender bias.

If educators analyze what they include and omit, they soon realize "the absence of something creates meaning, as does its presence" (Gabel et al., 2016, p.67). Typical technical writing textbooks reveal what Brown and Duguid (2000) in *The Social Live of Information* described as an idealized image of technical writers and the texts they create (p.85). First, a prescribed technical process outlines a plan, followed by well-established basic design features, and finally, usability testing addresses quality control (typically in a succinct subsection of a chapter or standalone chapter toward the end of the book). But usable for whom? The textbook I use, like most, contains no references to disability, accessibility, impairment, A.D.A., or WCAG 2.0 website accessibility standards.

Yet, according to the Pew Research Center, more than 56 million people in the U.S. (19% of the population) live with a disability (Anderson & Perrin, 2017). In higher education, 2 million (or 11% of) undergraduate students (U.S. Department of Education, 2016) and 4% of faculty members have disabilities according to the National Center for College Students with Disabilities (Grigely, 2017). The troubling reality is that few faculty members disclose their disability to administration, and even fewer request accommodations. Price, Salzer, O'Shea, and Kerschbaum (2017) found that 87% of faculty with a mental disability did not request an accommodation even though visible and invisible disabilities among faculty have been documented in self-disclosure publications since the 1990s. In fact, nearly 70% of faculty surveyed had no or limited knowledge of workplace accommodations.

In this case, the absence of something speaks volumes. In higher education, the culture "encourages students and teachers alike to accentuate ability, valorize perfection, and stigmatize anything that hints at intellectual (or physical) weakness" (Dolmage, 2017, p.3). Well-intentioned retrofits of physical structures and spaces (i.e. ramps, assistive technologies, and interpreters) may serve to include faculty and students with disabilities, but these do not transform institutional culture and systems that "privilege those who can easily ignore their bodies and those whose minds work the most like the minds" of able-bodied experts. As Sushill Oswal argued at the 2018 Association of Teachers of Technical Writing Conference earlier this year, "inclusion without accessibility is not diversity", and it certainly is not equitable.

For those of us — the educators living with visible and invisible disabilities — who have chosen silence, it is time we transform our silence from the periphery to activism in the center. We must commit to "language and the power of language" as Audre Lorde urged us in 1977. In technical writing, this means renegotiating the competing ethics of utility (the needs and interests of the many-majority outweigh those of the few-minority) with the ethics of care for all individuals who wish to understand and use a technical document. It means discussing the importance of usability and inclusion while simultaneously developing explicit infrastructure to create accessible texts.

I am suggesting we shift our frames of reference. In physics, a frame of reference is used to describe the motion of an object. The terms we use to describe the motion are dictated by the dominant culture, in this case higher education. In rhetoric, these terms create what Kenneth Burke called terministic screens. "Our screens become projections of ourselves, and they shape the ways in which we see the world and act in it" (Smith, 1998, p.330). When I choose to silence myself, I allow myself to be silenced by a dominant culture's prescribed identity of disability: "incapable, illiterate, dysfunctional and non-productive members of school and society" (Peters, 1999, p.104). But if I reclaim the language, my motion, my activities as a professional in higher education will require continuous renegotiating of competing, yet powerful, identifies — woman, mother, technical writer, educator, expert, person living with invisible disabilities and chronic illness, and so on.

Technical writing, much like higher education it would seem, operates like a zero-sum game*: your gain is my loss*, and *your loss is my gain*. So entrenched is this cognitive bias that it is well-documented in other fields such as psychology and economics. Inclusion and accessibility do not sacrifice design. If anything, they help us challenge values that Graham Pullin (2009) warns in *Design Meets Disability* "have become so widespread as to become assumptions" (p. 205). The current state of disability and inclusion in higher education is an unsatisfying situation. However, we cannot stop with this observation. We must acknowledge that the concept of *disability* is a diagnostic judgment of inadequacy (Jung, 2011, p.263). It is a form of social discrimination that results in negative economic, professional, and private consequences. Designing texts and organizational culture for diversity and inclusivity, rather than discrimination, will lead to fresh complications and challenges. The path is steep but not unclimbable.

Disability is not something *some* people — more than 56 million U.S. citizens — just happen to have. The failure of higher education and society stems, in part, from the failure of health-related language. When those of us living with disabilities shape the language with which to discuss our lived, material experiences, we can begin to shift from a collective lexicon of exclusion to one of inclusion while also acknowledging and honoring the equal involvement of all individuals in "the round of existence" (Santayana, 1922, p.132). Disability doesn't just happen to some of us and stop there. It impacts all of us. As an educator in the technical writing field, I am well-positioned to help shape this new literacy. All of us, Audre Lorde (1984) would argue, regardless of academic field or trade, are equipped "to establish or examine her function in that transformation and to recognize her role as vital within that transformation" (p. 43). In this essay, I have attempted to break my silence, and in doing so, I hope these actions have a wider effect on those living with disabilities and working in higher education. These experiences of oppression can only come to light when we turn our silence into visible action and language.

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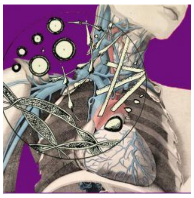

The Bio-Psycho-Social Effects of Eczema on Zelda Fitzgerald

Dr. Karen E. Tatum

Although Zelda Sayre Fitzgerald had experienced allergic symptoms (such as asthma and eczema) before in her lifetime, the most excruciating of these occurred, not coincidentally, during her first hospitalization for "nervous exhaustion," at Prangins Clinic in Switzerland, in the Spring of 1930. "By mid-June" of 1930, as biographer Nancy Milford describes, "Zelda had developed a severe eczema that covered her face, neck and shoulders . . . the eczema was virulent and painful. None of the medicines tried at Prangins were effective against it. For the rest of July, all of August, and early September, Zelda suffered its debilitating pain" (Milford 1970, 169). In September, her psychiatrist, Dr. Forel, hypnotized Zelda. When she awoke after a thirteen-hour deep sleep, the eczema had somewhat disappeared, but as Milford writes, "When she felt normal and realized the danger in her conjugal conflicts, the eczema appeared. It came, [Zelda] thought, as a sort of warning device" (Milford 177). Although this particular flare-up eventually cleared, eczema's manifestation as symptomatic of impending psychological destruction would remain with Zelda for the rest of her life, until her death in an Asheville, North Carolina asylum in 1948.

"Eczema," write Kathryn Zug and Marilynne McKay, "is derived from the Greek term ekzein, 'to boil out.' This term aptly describes the swollen, wet, oozy, bubbly appearance of acute eczema. When itchy skin has been rubbed and scratched for weeks, it lichenifies into dry, thick, scaly plaques of chronic eczema" (Zug and McKay 1996, 1243).[3] Although a variety of forms and causes exist, eczema is basically an inherited, allergic skin disease, often stemming from immune deficiencies. Not only are there environmental and genetic triggers for this allergic response, but doctors often attribute flare-ups to stress which can exacerbate the condition. Precise statistics on the numbers of people affected with eczema are difficult to come by due to the still somewhat generic use of this term to describe many types of skin irritation as well as the difficulty in determining causes (allergic or contact dermatitis).

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[3] According to Robert Youngson's *Coping With Eczema*, *lichenification* involves a "hardened and thick skin epidermis caused by abnormally persistent scratching" (Youngson 1995, 94).

However, the following factors are clear: more women than men suffer from eczema by a ratio of 2:1 (Williams and Wüthrich 2000, 43)[4] although eczema is more likely to develop in childhood than adulthood, fifty percent of infants with eczema will continue to suffer all of their lives ("Eczema/AD" 2000); and, lastly, the incidences of eczema cases reported in the last thirty years has increased by twenty percent (Youngson 1995, 5; "Environmental Hazards," World Health Organization, 2003).

All of these factors make this disease worthy of our critical attention and understanding, particularly in terms of the ways in which gender, society, psychology, neurochemistry, and eczema outbreaks are so deeply intertwined. Because eczema is so prevalent among women in contemporary society, it approaches in significance the now well-known problems that cause eating disorders in women. The psychological causes and effects of dermatological illness have largely been overlooked in medical humanities and gender studies, particularly those focusing on disability and trauma, despite the fact that issues of body image, self esteem, gender norms and male medical authority are all central to the problems that women with eczema face. By examining Zelda's works in terms of her eczema flare-ups, their accompanying psychological disorders and treatments, in addition to her feelings of entrapment and frustration with gender roles, we can better understand the labyrinth of social, psychological, and physical stressors in women with chronic eczema.

Zelda and Scott's letters demonstrate that they both had keen insights into the links between anxiety and eczema. In January 1931, before sailing to America for his father's funeral, Scott wrote Zelda's doctor, Oscar Forel, at Prangins that he believed Zelda's eczema was caused by either an increased or insufficient amount of "poisons" in Zelda's system. As he puts it:

> *Mrs. F. encourages her nervous system to absorb the continually distilled poison. Then the exterior world, represented by your personal influence, by the shock of Eglantine, by the sight of her daughter causes an effort of the will toward reality. She is able to force this poison out of her nerve cells and the process of elimination is taken over again by her skin. . . . The eczema is not relative but is the clue to the*

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[4] Original study reported in Aberg, N. and Engstrom, I. 1990. Natural history of allergic diseases in children. *Acta Paediat Scand* 79, 206-11.

> *whole business. I believe that the eczema is a definite concurrent product of every struggle back toward the normal. (Bruccoli 1993, 365).*[5]

As a writer, Scott's insights into human beings, their bodies, and their often troubled relations to the world in which they must live, allowed him to intuit the connections between chemicals (poisons), nerves, and the skin, which would take years for medical science to verify.

Esther Sternberg's recent book *The Balance Within: The Science Connecting Health and Emotions* presents convincing arguments for the definitive links between the immune system and the central nervous system. Histamines are the all-too familiar poisons released from the Mast Cells (white blood cells) during an allergy attack (Sternberg 2000, 178). Unfortunately, however, this knowledge was not available to Zelda's doctors, because it would take Daniel Bovet in Italy another six years to develop the first antihistamine substance, and another five years (1942) before the first antihistamine drug for humans would be available on the market ("Daniel Bovet" 2004).

Furthermore, psychiatrist Peter Kramer notes that "the first modern psychotherapeutic medicine, Chlorpromazine, was an antihistamine." Also known as Thorazine, Chlorpromazine "was introduced in 1952 [and] constituted a breakthrough in the treatment of schizophrenia [because it] . . . had some efficacy in depression, calming agitated patients" (Kramer 1997, 50). Esther Sternberg relates that the Mast cells, which release histamine, gather around the nerve endings that release serotonin, one of the two main chemicals responsible for anxiety and depression. If the Mast cells release histamine around these nerve endings that release serotonin, a mis-fire can occur, causing nerve cells to activate Mast cells and vice versa (Sternberg 2000, 178-9). This suggests that allergy flare-ups and anxious and/or depressive episodes may chemically coincide. Further research has confirmed this suggestion. A 2005 study published in *The British Journal of Dermatology* found that, as the title of the article states, "Anxiety Accelerates T-Helper 2-Tilted Immune Responses in Patients with Atopic Dermatitis [eczema]" (Hashizume, H. et al. 2005, 1161). The combined efforts of allergists, immunologists, and psychiatrists (such as those cited here), provide compelling evidence in favor of the chemical communication (or miscommunication) between allergies and nerves,

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[5] Scott's letter to Dr. Forel, dated January 29, 1931, is in the F. Scott Fitzgerald manuscript collection of the Princeton University Library. The excerpt quoted here is taken from Matthew J. Bruccoli's *Some Sort of Epic Grandeur: The Life of F. Scott Fitzgerald* (1993, 365).

which Scott forecasted (unfortunately they were just about seventy years too late to help Zelda).

Zelda also insightfully attributed her eczema to psychological causes in addition to recognizing that the outbreaks caused psychological distress in her life. On February 12, 1932, upon entering the Phipps Clinic at Johns Hopkins, she told the doctors blatantly "It's this eczema and asthma that's just disrupted our home when it was running so well" (Milford 1970, 210). She complained of the strain of her father's death, of having to hold down the fort in Montgomery during this time with Scott screenwriting in Hollywood, and of being alone with her daughter. But although Zelda's doctors entertained both her and Scott's linking of these emotional stressors to her eczema, they did not pursue them much farther, apparently not taking them very seriously.

Although allergy research has assumed a more interdisciplinary approach, practitioners in both dermatology and psychology remain somewhat uninformed about the psychological effects of this debilitating skin disease. In a letter to the author dated April 6, 2005, allergy-immunology specialist Dr. John F. Dishuck writes: "Little attention has been given to the impact eczema has on the mental health of the patient or the impact of medical and non-medical treatment of psychological diseases on the treatment of eczema." Not only does eczema cause physical pain, it is also frequently accompanied by varieties of anxiety and depression. Given its chronicity, unpredictability, and traumatic impact, a negative self-image, if not a disturbance in body image, where the patient perceives her body as more grotesque than it may be, is quite likely to develop. Dr. Dishuck writes: "Eczema is increasing in prevalence and severity. Body image disorders are also quite common, especially among women." As Zelda came to terms with herself, with Scott, with her past, and with her surroundings, she depicted the nightmare of those early experiences with mental and physical disruptions in her figures, which reveal, in the words of her granddaughter, Eleanor Lanahan, "a series of painfully distorted figures" (Lanahan 1996, 14), figures that shock and defy even the Expressionist mode of art that may have influenced her.

Examining Zelda's collected writings, literary critic Mary Gordon writes: "Love and fear and horror mix themselves as well . . . . Her use of ands and commas to create a strung together, litany effect accentuates the pile up of dissimilar elements, and the reader is taken on an exhilarating ride that brings together glamour, terror, wit, and the seductive fog of the unconscious set loose" (Gordon 1996, xix). Gordon's description of the "love and fear and horror," which Zelda's work evokes, can partially be accounted for by Julia Kristeva's theory of abjection[6], a simultaneous fascination and repulsion with sick or imperfect bodies, which are ousted from the clean and proper boundaries of society, not because they threaten mortal death; rather, sick bodies, particularly those with skin lesions, threaten to dissolve the boundaries on which identity and civilization depend. As *Leviticus* states: "For whatsoever man he be that hath a blemish, he shall not approach . . . a man that is brokenfooted or brokenhanded, or crookbacked, or a dwarf, or that hath a blemish in his eye, or be scurvy, or scabbed . . . . he shall not come nigh to offer the bread of his God" (*Leviticus* 21:18-21).[7] This commandment stems from the fact that, as Kristeva explains, "The body must . . . be clean and proper in order to be fully symbolic. In order to confirm that, it should endure no gash other than that of circumcision . . . . Any other mark would be the sign of belonging to the impure, the non-separate, the non-symbolic, the non-holy" (Kristeva 1982, 102).

Certainly *Leviticus'* commandment and its underlying fears of contamination by broken skin remain with us today and are most troublesome to eczema patients who often feel like lepers. Dermatologist Robert Youngson explains:

> *Many people with atopic eczema and other obvious skin diseases have, whether they acknowledge it or not, a fear of being considered unclean or infectious and thus being socially rejected. This is not surprising. The skin is by far the most conspicuous of all organs and it is an almost instinctive tendency to react unfavorably, or even aggressively to perceived abnormality. There are plenty of instances of this throughout history. The biblical attitude to leprosy is a case in point. (Youngson 1995, 55)*

Given this religious and cultural history, which dictates that skin diseases are unclean and therefore ungodly, it is not surprising that Zelda's drawings of red, raw, disfigured, and painful bodies provoke an abject response. Zelda's grossly imperfect figures disturb us because, as Kristeva writes, they "show me what I permanently thrust aside in order to live" (Kristeva 1982, 3).

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[6] Here, in general, I draw on the chapter called "Semiotics of Biblical Abomination," in Julia Kristeva's *Powers of Horror: An Essay on Abjection*. 1982. Trans. Leon S. Roudiez. NY: Columbia, UP. 90-112.

[7] Kristeva cites these verses in *Powers of Horror*, 102. I have cited from *Leviticus* 21: 18-21 in the King James' version of the Bible (Nashville: Holman, 1989), 199.

Additionally, in her recent cultural history of the skin, Nina Jablonski points out that chronically broken skin promotes a great sense of vulnerability for an individual (Jablonski 2006, 4), and, consequently, a need for the protective covering of some sort of surrogate skin. For the more creative-minded, writing or painting, as French psychoanalyst, Didier Anzieu, puts it, “has the power to function as a skin” (Anzieu 1989, 231). A painter’s canvas can be seen as a second skin; the painting on the canvas may provide a more complete skin, and thus, a more complete sense of self. As Zelda herself said, “I don’t think I could paint anyway if it weren’t for the fact that it’s my way of communicating with someone.” Such communication is the essence of understanding, compassion, and thus, humanity, which can be the greatest healer of all.

Human beings are spiritual as well as biological entities. As long as medicine and humanity remain strangers, as long as we continue to treat physical symptoms in isolation from the psychological or spiritual realms, we continue to confuse the side effects of medications with symptoms of physical disease, and more insidiously, to perpetuate both physical and mental distress. For, as Vienna psychiatrist, Viktor Frankl wrote in his book, *The Doctor and the Soul* “Man lives in three dimensions: the somatic, the mental, and the spiritual. The spiritual dimension cannot be ignored, for it is what makes us human . . . . The proper diagnosis can be made only by someone who can see the spiritual side of man.” With this holistic approach in mind, Frankl alleviated his patients’ dis-ease by helping them find meaning in their suffering. These multi-faceted approaches to medical treatment as prescribed by Frankl and the other psychiatrists and allergists cited here are the solution to the vicious cycle of physical and psychological trauma from which eczematic women unnecessarily suffer now more than ever before.

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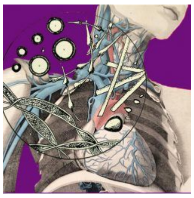

◉ Haunted Systems: The Legacies Affecting Queer Mental Healthcare

○ *Katherine Von Wald*

One of the great remaining silences within the healthcare community is mental illness, and those who live with it suffer from and in such silence. The conceptions surrounding mental health are intricately tied to cultural baggage and create challenges for those seeking quality care. This is further complicated for those in queer communities where disparities in access to adequate mental health support are exacerbated along lines of gender and sexuality. There is a severe disparity between the mental health of queer and non-queer individuals. Understanding that these glaring differences come from complex histories of structural oppression begins dismantling the negative silence surrounding queer mental health care.

The stigmatization and pathologization of non-normative bodies and behaviors continues to haunt current iterations of mental healthcare. Queer individuals face systematic discrimination that manifests in material ways to create barriers to accessing and receiving care. The implications of heterosexist patriarchy and structural inequities place queer individuals in a precarious position not often addressed by mainstream health professionals. If such disparities are to be addressed, we must first investigate the deeply entrenched formations which precede an individual and code their journey through medical institutions.

Background

I define mental illness as a mental health condition that significantly impacts quality of life and contributes to overall health problems. This includes but is not limited to depression, anxiety, affective disorders, schizophrenia, and eating and personality disorders. Mental illness affects perception and cognition; motivation and behavior;

and interpersonal relationships.[8] Mental health care refers to the treatments individuals require in order to alleviate the disruption that mental illness can cause.

Queer is used as a self-referential term for sex, gender, and sexuality minorities. This includes but is not limited to lesbian, gay, bisexual, transgender, pansexual, intersex, and asexual individuals. In a broader sense, queer can refer to any individual who is distinctly non-normative, non-binary, ambiguous, and/or fluid in their various representations or self expressions. Queer is a reclaimed slur that attempts to celebrate non-normativity rather than punish it and aims for inclusion of the multiplicity of those who do not conform to traditional social notions of gender, sex, and sexuality.[9] For the remainder of my writing, I will use queer to refer only to those who self-identify as within this category of marginalized, non-normative individuals.

Today, queer individuals report higher instances of mental illness than their heterosexual (those who desire the opposite gender), cisgender (those whose biological sex aligns with their gender identity), or otherwise normative counterparts but receive disproportionally inadequate services once in care. According to a study conducted in 2014, queer individuals "have shown rates of depressive, anxiety, and substance abuse disorders [that] are 1.5 to 3.0 times higher" than other populations.[10] These numbers are further exaggerated when intersections of race and class are considered and point to a systemic social problem. The effects of marginalization, violence, and discrimination are embodied as much as they are mentally and physically taxing. Queer individuals face stressors associated with living in a heteronormative patriarchal society that others do not.[11] This constant conflict with societal standards and oppressive institutions significantly impacts the mental health of sex/gender minority populations. The nuanced nature of lived experiences is not often taken into account by mental health care professionals, so queer individuals do not always seek medical care.

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[8] Corrigan, Patrick W., Benjamin G. Druss, and Deborah A. Perlick. "The Impact of Mental Illness Stigma on Seeking and Participating in Mental Health Care." *Psychological Science in the Public Interest 15, no. 2* (October 2014): 37–70.

[9] Lee, Amber, and Zul Kanji. "Queering the Health Care System: Expereinces of the Lesbian, Gay, Bisexual, Transgender Community." *Canadian Dental Hygienists Association*, 2017.

[10] Grant, Jon, and Et. Al. "Mental Health and Clinical Correlates in Lesbian, Gay, Bisexual, and Queer Young Adults." *Journal of American College Health* 62, no. 1 (n.d.).

[11] Puckett, Jae, Meredith Maroney, and Heidi Levitt. "Relations Between Gender Expression, Minority Stress, and Mental Health in Cisgender Sexual Minority Women and Men." *Psychology of Sexual Orientation and Gender Diversity* 3, no. 4 (2016).

Mental Illness as a Social Disease

According to the 2015 survey conducted by the National Institute of Mental Health, roughly 43.4 million individuals aged 18 or older suffered from mental health concerns in the U.S. This number represents about 18% of all adults. Despite the prevalence of mental illness, the number of individuals who receive mental health services is starkly low. Many studies show that the stigma associated with mental illness not only keeps people from seeking care but contributes to discrimination of individuals with mental health concerns. People with mental health concerns are regarded as dangerous, unpredictable, flawed, and/or weak.[12]

These types of perceptions come out of years of enculturation. Throughout Western history, there exists a tenuous relationship between stigma and social order whereby social norms surrounding behavior have at times collapsed into understanding of reasonability, normality, and even health.

In his book *Madness in Civilization: A History of Insanity in the Age of Reason*, Michel Foucault traces the often-changing criteria for and perception of mental health. According to Foucault, a drastic change occurred sometime in the early 17th century that coded mental illnesses through standards of morality. In this age of scientific advancement and intensified medical categorization, any version of unacceptability had to be uprooted. This more frequently referred to people who were viewed as outside the social imaginary and who threatened social decorum than to those suffering from health concerns.

This mingling of social anxieties and disease paradigms thus developed symptomologies inherently informed by dominating ideology. Moral obstacles could be "recast in a scientific-sounding vocabulary" and ultimately stand in as justification for the confinement of populations of the poverty-stricken, the working-class, and the oppressed. Modern Western mental health care practices rest upon a tradition that worked to uphold racial and class distinctions; the economically disadvantaged or socially cast out were imprisoned within hospitals as a means of purging cities of sex workers, the unemployed, and the homeless. Only 10% of those hospitalized during this time were considered "insane;" the rest were merely poor.[13]

This points to a deeply imprinted cultural pathway that has had resounding impacts on the stigmatization of mental health. For centuries, perceptions of the undesirable

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[12] Quinn, Diane, Michelle Williams, and Bradley Weisz. "From Discrimination to Internalized Mental Illness Stigma: The Mediating Roles of Anticipated Discrimination and Anticipated Stigma." *Psychiatric Rehabilitation Journal* 38, no. 2 (2015): 103–8.

[13] Foucault, Michel. *Madness and Civilization: A History of Insanity in the Age of Reason*. Vintage Books Ed., Nov. 1988. New York: Random House, 1988.

(both people and communities) have been viewed through the lens of of mental illness, regardless of symptomologies, care, or treatment.

The effect of such social stigmatization of mental illness has ensured the continued conflation of social fears and health concerns. Mental illness, though often unseen, has become visibly coded onto certain populations based on economic class, race, gender, and sexual orientation. Individuals with mental illness are seen as dangerously outside normal functioning because of this cultural perspective. There has developed an intense binary between those with and those without mental illness, which ensures that an individual's mental health status be concealed. Social stigma against mental illness is one of the largest obstacles to receiving care for those who could most benefit from it. This stigma does more than isolate individuals as outside of society; it functions as a means to ignore truly harmful symptomologies in favor of constructed social assumptions that uphold oppressive hierarchies.

Pathologizing Queerness

Just as stigma against individuals with mental health concerns are informed by socio-cultural anxieties, bias against queer individuals is informed by a history of pathologizing their identities, behaviors, and desires. Pathology defines the boundaries of disease; when these definitions become invested with social ideologies, they can be used to target populations for their non-normativity.

Again, Foucault's work provides an analysis of the workings of sexuality and medicine that contributed to the pathologization of sexual behaviors. Perceptions of certain sexual behaviors have always faced shifting cultural perspectives. In the 19th century, monogamous heterosexuality was determined to be the standard for healthy sexual activity. Sexuality was taken out of the bedroom, imbued with the hegemonic social standards of the time, and brought into the realm of medicine.

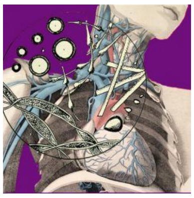
In a society structured around the privileging of man-woman reproductive coupling, this meant that any kind of non-normative, non-heterosexual, non-monogamous behavior beyond strictly defined sex/gender roles became distinctly pathological. It was considered a perversion. Thus, queerness, homosexuality, sado-masochism, intersexuality, etc. were considered to be acceptable symptoms of mental illness.

We can think of pathologization as a complex process by which social subjugation is justified by diagnosis. It transforms a social ordinance into a disease paradigm and crafts non-normative behavior as something in need of intervention and curing. In the United States, the pathologization of queerness, be it sexual orientation or gender presentation, has contributed to the violent treatment of queer individuals within mental institutions. Conversion therapy, the attempt to change individual's sexual orientation through psychological intervention, is just one example of an attempt to cure queerness by attempting to rid an individual of their homosexual desire.

Conclusion

The legacies of both stigma and pathology continue to code how individuals from the queer community interact with mental health care. Though many institutions have attempted to dismantle the stigma associated with mental illness, this history still informs internalized bias among patients and providers. Similarly, homosexuality and more recently gender identity disorder are no longer used as diagnostic tools to measure mental disorders. While this points to the continued shifts that both pathology and medicine undergo, it is also an important moment to investigate how individuals continue to be affected by structural oppression long after institutions might change.

The seething presence that haunts the mental health community is this tangled relationship between sociality and medicine. Queers face unique layering of stigma and pathologization that create material barriers, both socially and institutionally, to accessing and receiving adequate mental health care. Understanding the context of such barriers is the first step toward crumbling their foundations.



“She looked so normal”: Embodied Narratives and Promoting Awareness about Rare Disease in China

○ *Daniel Vuillermin*
○ *Li Zhuoya*

In China, embodied narratives –– the construction, performance and process of “making meaningful one’s own body” in auto/biographical forms –– are emerging as a means of promoting awareness about rare disease (Heavey 2015). As home to the world’s largest population, China has an estimated 16 million people with a rare disease (Song et al 2017). Definitions of rare disease, however, vary internationally. In the US a rare disease is one that affects less than 200,000 people, whereas in Japan the population figure is significantly lower with any condition that affects less than 50,000 people (Cui and Han 2015). At present China does not yet have an official quota. Cui and Han (2017) propose that any condition that affects 300,000-500,000 individuals could be a “reference for the lower limit of prevalence to define rare diseases for China” on the basis of pharmaceutical companies being able to make a “reasonable profit” from the development of orphan drugs. Of the 7,000 identified rare diseases only 5% are treatable and patients who have access to medicines face very high expenditure (Dong and Wang, 2016). According to a national survey conducted by the China-Dolls Center for Rare Disorders and Tencent News the costs of treatment for Chinese people with a rare disease was three times higher than their personal income or almost double that of the combined family income (Dong and Wang, 2016). In addition to the financial burden or lack of medical treatments, many people with a rare disease suffer social isolation due to unemployment and stigma, particularly those whose conditions affect their skin, stature or mobility. Rare disease in China, as elsewhere, receives significantly less research, funding, and public awareness compared to high-profile communicable diseases such as HIV/AIDS and chronic diseases such as breast cancer. As a whole rare diseases may be considered a hidden disease as they are often overlooked by medical researchers, pharmaceutical companies, and government health departments. Individuals with a rare diseases are also often overlooked as often their symptoms may be misinterpreted resulting in misdiagnosis. Due to the lack of treatments for the vast majority of rare diseases, patients have no choice but to wait in hope for the development of orphan drugs.

In response to the personal, economic, social and medical challenges of living with a rare disease, a group of Chinese NGOs are striving to provide innovative and inclusive programs that promote education and encourage social engagement. Among these organizations is the Illness Challenge Foundation (ICF). Established in 2015, the ICF is dedicated to providing resources about rare disease and improving access to services through the use of a range of narrative-based projects including *RareCompass Lab*, the *Rare Disease Science Popularization Program* and the *People Born to Challenge* short documentary series. By drawing upon embodied narratives, ICF aims to motivate and enable the rare disease community to speak out and educate the public about rare diseases, address misunderstandings, biases and prejudices, to create an inclusive and respectful social environment and bring about changes in government policies and the social welfare system.

RareCompass Lab is an innovative research and development web platform that endeavours to solve urgent health communication issues. This narrative project brings together volunteers with rare disease from the ICF, undergraduate medical students from the Institute for Medical Humanities at Peking University and rare disease specialists to create profiles about the personal, social, and medical aspects of living with a rare disease. Whether before, during or after diagnosis, patients with a rare disease often receive medical information that is difficult to comprehend or outdated. These new narrative-based profiles are being developed by medical students and verified by specialists. They deliver accurate and up-to-date information in a way that is accessible for general readers, but also addresses the personal and social aspects of living with a rare disease.

The illness profiles are intended to describe “the patient’s perception, experience, expression, and pattern of coping with symptoms” (Kleinman 1991) and are also intended to enable medical students to have an in-depth understanding of the bio-psycho-social dimensions of living with a rare disease. The project aims to make use of selected profiles to promote awareness and increase access to knowledge about aetiology, symptoms, (mis)diagnosis and (un)availability of treatments in China via online platforms and social media.

In 2017, the *RareCompass Lab* project attracted 32 volunteers (23 women and 9 men) from a wide range of backgrounds and ages; as this is a voluntary project we can not determine factors such as sex, age or socioeconomic status. The volunteers were matched with undergraduate medical students enrolled in a course –– *Illness Narratives: The Body* –– at the Institute for Medical Humanities at Peking University. Many of the profiles of women with rare disease reflected upon how their conditions affected their femininity in a Chinese context. For example, one profile describes how Aunt Xiao, who in the early 1970s started her career as a welder, was empowered by her profession yet after being diagnosed with ALS became physically inactive and "totally dependent on her husband" (Zheng). During the Cultural Revolution (1966–76), women were encouraged to break free of their traditional roles and to enter professions that were the domain of male workers. Although, on the whole women continued to suffer "extremely low status in Chinese culture" (Li 2000), women such as Aunt Xiao were able to become a "leading figure" in their professions. As one student writes:

> *Aunt Xiao told her story about ALS with a smile … At a young age, she was so energetic that she did everything with great enthusiasm, which made her a leading figure in welding. No matter how heavy work it was, Aunt Xiao was able to conquered it. It seems that her life was about hard work and diligence, until the day she was diagnosed with ALS.*

Aunt Xiao speculated that there may be a connection between her "heavy work" and ALS yet the causes of ALS are still largely unknown. ALS deprived her of the active, independent life that historically women in China were deprived of; now she was "like a bird without its wings". For women of Aunt Xiao's generation, traditional notions of femininity –– much like most other vestiges of ancient Chinese culture –– were uprooted and replaced with proletarian virtues; beauty was for the bourgeoisie. However, for young Chinese women today beauty is considered an essential ingredient not only in attracting partners but also for improving one's employment opportunities. As one woman with Neurofibromatosis 1 –– a genetic disorder that produces benign tumors on the skin –– states "I did not think my disease would hinder me from getting a job when I'm graduated from university, but I do not dare to change my current job easily, since the tumors have changed my appearance and some people may feel uncomfortable about this."

As private medical services in China are often very costly family members must perform a range of health care roles: nurse, physical therapist, counsellor. For women with a rare disease this can be very confronting, particularly when male family members must attend to their personal needs. One young woman with neuromyelitis optica — an autoimmune disease, which predominantly affects the spinal cord and optic nerves –– describes the shame and embarrassment she felt having her father assist her with enemas:

> *For the first few years, her parents would take turns to help her. Although she thought that it was really shameful for a girl for her father to assist her, she had to accept it. "Although he*

> *never complained my father was not always as patient as my mother and he would go outside sometimes. It may be that he also felt embarrassed or disgusted. That hurt me a lot.*

For some volunteers the process of raising awareness about rare disease may seem futile and, in some cases, can affect their health. One woman with scleroderma who had immersed herself in chat groups, online forums, and public events questioned the means and efficacy of randomly disseminating leaflets. She states:

> *The hospital just asked us patients to distribute leaflets to people passing by. Does it make any sense? If we let public know about our situation and they show their sympathy and understanding, then what? Will our illness be cured? After that, I never participated in those activities.*

However, upon hearing about the *Profile of an Illness* project she decided that it may be worthwhile participating as it may encourage medical students to focus their future research on rare disease. At the first meeting a volunteer asked “What is the aim of your project?” One student responded that “Although us students can not yet cure their diseases we are the next generation who are going to build the future.” In response the volunteer encouraged them to devote themselves to improving diagnosis and to find treatments for rare disease, stating, “If nobody works in this area, these kind of events will be held forever.”

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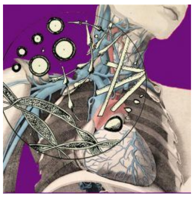
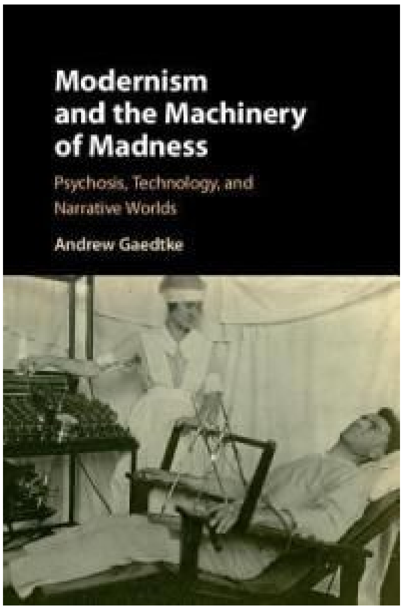


Reviews

Modernism and the Machinery of Madness by Andrew Gaedtke

○ *Burcu Alkan*



From the middle of the nineteenth century to that of the twentieth, theories of electromagnetism developed rapidly and their applications became a part of daily life in the form of telegraphs, radios, and other such devices. These developments not only revolutionised communications but also had a great impact upon the way people viewed and experienced the world around them. Moreover, they provided ample novel material for creative and aesthetic aspirations. In *Modernism and the Machinery of Madness: Psychosis, Technology, and Narrative Worlds* (Cambridge University Press, 2017) Andrew Gaetdke examines the effects of these new theories and technologies in three distinct realms: mental illness, popular technology, and literary modernism.

With examples of psychotic patients claiming to be suffering from "thought transmissions," devices that transform people's lives through tailored broadcasts, and literary texts that explore the mind-body relationship through technological metaphors, Gaetdke asks the question of how we might "understand such uncanny echoes across the discourses of psychotic delusion, technological media, and literary modernism" (2). *Modernism and Machinery of Madness* looks at several literary texts within a comparative framework that is informed by narratives of mental health patients and popular perceptions of technological developments. Additionally, the discussions sketch out the changes in the field of psychiatry from phenomenological models, such as psychoanalysis towards biological ones that focus on bodies as organic "machinery."

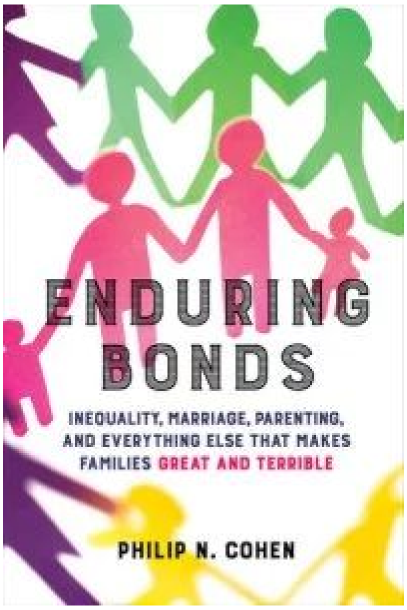
The book looks at works by Wyndham Lewis, Mina Loy, Anna Kavan, Evelyn Waugh, Muriel Spark, Flann O'Brien, and Samuel Beckett. These writers stand out both with their personal encounters with mental illness and the ways in which they employ experimental elements to portray the connection between psychosis and technology. Technological devices that transmit waves serve as astute metaphors for authors writing about alienated selves and instrumentalised bodies. For the psychotic patients, they become powerful images that help them make sense of their disconcerting delusions. In this context, Gaedtke emphasises the significance of narrativity as "world-making" that is essential to both experiences of psychosis and literary expressions. While the modernist texts are attempts at making sense of a fragmented world and achieving totality, the patients suffering from psychosis similarly use "the ordering work of narration" in an attempt to reinstall and maintain "fragile ontological distinctions" against predominantly hostile delusions.

Gaedtke's choice of literary works highlights the undeniable relationship among the developing theories of the mind, the existential anxieties of an era marked by speed, technology, and two world wars, and the desires of the writers to engage with them. He examines how Wyndham Lewis maintains a criticism against posthumanism's "monist reduction of the human to mechanistic and mindless disorder" (49). Works of Mina Loy and Evelyn Waugh are studied together as narratives of psychosis and psychoanalysis that explore fragile and troubled selves. The texts of Muriel Spark and Anna Kavan are discussed with a focus on their experimental formalistic mimicry of psychotic symptoms. The analyses of Flann O'Brien's works focus on the results of rapid, disorienting transformations along the lines of the instrumentalisation of the self and the concomitant anxieties. The final chapter of the book looks at Samuel Beckett's encounters with mental illness and how he is inspired by them to push the boundaries of literary texts. Gaedtke points to Beckett's turn towards the radio (plays) as a possibility of traversing such boundaries through the medium and achieving a multi-layered self-reflexivity.

Although a little convoluted and repetitive at times, *Modernism and Machinery of Madness* is a well-executed investigation of the modernist twentieth century. The works discussed are some of the most intriguing ones of their times, establishing a high point for modernism with fascinating themes, formalistic experiments, and radical modes of thinking. Gaedtke notes that the "movement in and out of delusional (and fictional) worlds comprises much of the dramatic and ontological tension that motivates late-modernist representations of mental illness" (92). The outcome of his engagement with the intersections of technological developments, mind sciences, and literature highlights the fruitfulness of interdisciplinary encounters among diverse meaning-making processes. Gaedtke's *Machinery of Madness* would prove a useful read not only to scholars who work on modernist literature but also to interdisciplinary researchers working in the field of medical humanities with an emphasis on mental health.

Enduring Bonds by Philip N. Cohen

○ *Anna J. Clutterbuck-Cook*



Readers of *Dósis* may be familiar with the *Family Inequality* blog launched by sociologist of the family Philip N. Cohen in 2009 and still active today. In the interest of full disclosure, I became aware of Cohen's work when we were both engaged in online dialogue with (and critique of) the conservative scholar-activists around the issue of same-sex marriage and queer parenting in the years around the *Windsor* and *Obergefell* decisions. I have long enjoyed his contributions to these difficult struggles around policy and family welfare, both for his unapologetically anti-oppression politics and his data-driven analysis. Cohen's latest book, *Enduring Bonds: Inequality, Marriage, Parenting, and Everything Else that Makes Families Great and Terrible* (University of California Press, 2018) pulls together pieces from Family Inequality that cluster around certain themes and presents them coherently as part of an overall assessment of "the place of families in the system of inequality, with recurring emphasis on the question of who gets what kind of family, and the consequences of that social ordering" (5).

Each chapter comes with a brief introduction to the theme followed by the blog posts — revised and updated — clustered around that theme. There are eight thematic chapters altogether: parenting, single mothers and poverty, marriage promotion, marriage equality, gender difference, gender inequality, race, and a final chapter on feminism and sexuality. It may go without saying (though I'll say it anyway) that all of these issues intersect with one another in ways that make each chapter — and subsection within each chapter — unique yet deeply interconnected.

One of Cohen's recurring concerns is the relationship between sociological research and popular discourse around the creation, reshaping, and dissolution of families and family norms. The chapter on marriage equality ("Marriage Equality in Social Science and the Courts") takes as its focus the work of University of Texas sociologist Mark Regnerus, whose research — widely discredited by his fellow sociologists — continues to circulate in legal arguments against queer parents as well as in popular culture narratives about modern sexual cultures and marriage norms. This chapter also highlights what researchers have long observed about the anti-queer religious right: that their concerns have less to do with specific same-sex desires or acts than they do with the way LGBTQ people challenge the binary, patriarchal gender norms — the theory of complementarity — that order society. "In their legal efforts," Cohen observes, "the antiequality social scientists always returned to the gender difference of parents as their main concern" (105). For Regnerus and others who accept this premise — of distinctly-gendered people who must balance one another out for society to succeed — queer and feminist families represent an existential threat to the social order.

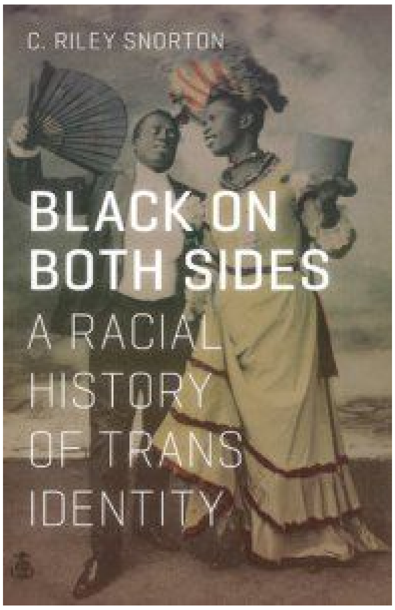
Inequality is perhaps most starkly observed along the lines of race and class in modern America. While marriage promotion continues to thrive as a proposed solution to poverty (with little empirical data to support that assertion), the most straightforward solution to poverty — redistribution of wealth to promote widespread social welfare — remains deeply unpopular. In part, this is because poverty in America has been racialized and, at the population level, white people in the U.S. are resistant to supporting social policies that they perceive as disproportionately benefiting black families particularly, and other people of color more generally. As the current widespread abuse of migrant families at the U.S. borders starkly demonstrates, only *some* families are understood as legitimate and worthy of social investment. Chapters 2 and 7 focus directly on these themes, but they recur throughout.

Cohen does not mince words when it comes to highlighting the ways in which inequality is the result of purposeful policy decisions made by those who hold structural power. When writing about the conservative argument that "money spent on means-tested programs is wasted because poor people refuse to get married (and get jobs)," Cohen straight-up calls their position "stupid and evil" (47). Deliciously for this queer reader, he calls out Regnerus' theory of gender complimentarity and the sexual marketplace for (among many other weaknesses) utterly failing to account for lesbian sex and relationships: "What about lesbians? Oh, that. …Regnerus indeed has a theory of lesbianism and — surprise — it is that women are ruining society (again), this time by destroying sexuality itself" (196).

Enduring Bonds was purposefully assembled to be read in the classroom (7-8) but is written in very accessible plain-language prose that makes the work legible to the non-specialist while also not compromising on the rigor of analysis demanded by complex population-level data and assessment of policy success (or failure). Highly recommended to those interested in how socioeconomic inequality is transmuted through and by our families; our political moment, perhaps now more than ever, demands that we interrogate the question of who "gets to" be a family (and what families we do or don't protect, as a society) from an unapologetic position of social justice advocacy. Cohen offers useful data and arguments for us to draw on in that struggle.

Black on Both Sides **by C. Riley Snorton**

○ *Laura Koch*



From the origins of American gynecology to the nineteenth-century narratives of former slaves to current political movements like Black Lives Matter, the intersections of gender and blackness have always influenced cultural understandings of femininity, masculinity, and the spaces in between. C. Riley Snorton's book *Black on Both Sides: A Racial History of Trans Identity* (University of Minnesota Press, 2017) weaves together histories of race, gender, and sexuality in the United States to examine the origins of modern black transgender identities. *Black on Both Sides* is the second book from Snorton, an associate professor of Africana studies and feminist, gender, and sexuality studies at Cornell University. He earned a Ph.D. in Communication and Culture from the University of Pennsylvania in 2010, and his work has appeared in a variety of cultural studies journals, including *Souls: A Critical Journal of Black Politics, Culture, and Society* and the *International Journal of Communication*. Snorton's previous book, *Nobody is Supposed to Know: Black Sexuality on the Down Low* (University of Minnesota Press, 2014), examined the concealment and visibility of black queerness through the lens of cultural theory, drawing on racial and sexual narratives in popular films, music, and television shows, as well as the work of feminist scholars and queer theorists. *Black on Both Sides* is, in some ways, a continuation of Snorton's previous work, offering a more historical perspective on the familiar themes of blackness, queerness, and bodily and cultural visibility.

Despite its title, Snorton is careful to note that *Black on Both Sides* is "not a history per se so much as it is a set of political propositions, theories of history, and writerly experiments" (6). Indeed, Snorton's monograph reads like a collection of related essays, each seeking to examine different cultural sources and processes through the lens of race and gender. Drawing from medical texts, journalistic narratives, and Afromodernist literature, as well as the theories of scholars like Hortense Spillers, Judith Butler, and Frantz Fanon, Snorton "focus[es] on the transitive connections between blackness and transness that emerge in moments of transition" (9). Throughout the book, Snorton deliberately separates the term "trans" from the concept of gender, employing it just as often in the broader contexts of "transitivity" and "transversality" in order to highlight his rejection of binary limitations (5). Snorton's arguments are many and varied, ranging from explorations of historical blackness as a form of "social death" to a critique of historical conceptions of time as too closely tied to narratives of progress (107).

The book's strongest and most compelling argument centers around a theory of "fungibility," or interchangeability. Snorton asserts that when the notion of "'trans' is…about a movement with no clear origin and no point of arrival" rather than limited by binary thinking, the intersections of race and gender have the potential to become spaces of mutability, freedom, and possibility (2). In his analysis of fugitive slave narratives, for instance, Snorton applies this theory to the story of Ellen Craft, a mixed-race slave who passed as a white male planter to escape to freedom, arguing that cultural productions of slaves as replaceable commodities allowed Craft to cross social boundaries and inhabit ostensibly unattainable categories of identification. Craft's slave status already served to exclude her from the cultural category of (white) femininity, because, as Snorton argues, "the ontology of gender required freedom as its prerequisite" (90). For a subject who was already unable to claim membership in the constructed category of white womanhood, a transition into another identity category (in Craft's case, white masculinity) was not a movement between two opposing identities, but rather a movement within an already-inhabited space of exclusion. Just as Craft's enslaved body was culturally produced as interchangeable or "fungible," so too could her performance of one racial, gender, or sexual identity easily replace another.

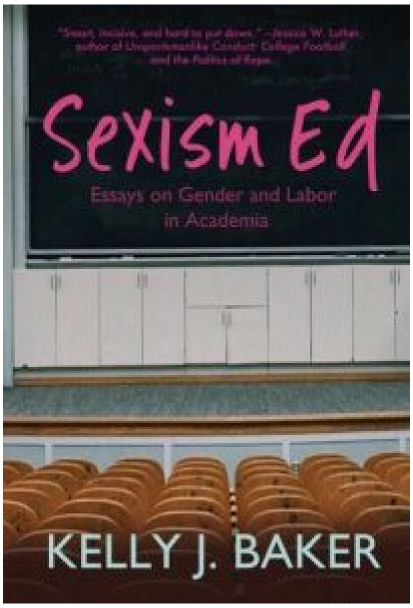
Snorton's efforts to trace common themes across topics as seemingly unrelated as early gynecological advancements, gender "passing" as a means of escape from slavery, and fictionalized representations of hate crimes are certainly ambitious. At times, the book's broad scope distracts from its project of reinterpreting racialized gender as a space of fungibility and freedom. In many places, Snorton takes on too many topics and arguments, attempting to make each of his sources act as evidence for every strand of his argument and often sacrificing clarity in the process. This tendency towards illegibility is most clearly evident in the book's first chapter, which examines the gynecological work of physician J. Marion Sims, focusing on the experiments he performed on enslaved women in the mid-nineteenth century. Snorton concludes that Sims chose enslaved women as the subjects of his experiments because the fungibility of racialized gender allowed "captive flesh [to express] an ungendered position" by producing slaves as commodities rather than human subjects (33). This characterization of enslaved women as genderless seems to disprove itself, however, as Snorton goes on to discuss the ways in which early gynecology produced anatomical criteria for womanhood; the gender of Sims's racialized subjects, far from being so obscured by captivity as to be insignificant, was, in fact, a contributing factor in Sims's decision to experiment on them without their consent.

Snorton's theory of fungibility therefore appears to be of little relevance in his first chapter, just as evidence elsewhere in the book does not always fit together logically in support of the arguments and connections Snorton attempts to make. His discussion of the 1993 Brandon Teena murder case and the subsequent erasure of black victim Phillip DeVine from the cultural narrative of the crime, for instance, presents DeVine's blackness as a source of cultural prejudice rather than freedom. In contrast to the historical and medical discourses that provide the backdrop for Snorton's analysis of the J. Marion Sims experiments, the book's final chapter considers the life of Phillip DeVine as an ahistorical "biomythography…an invention of [his] life" (183). Snorton argues that DeVine, a cisgender black man who was murdered alongside Brandon Teena, a white transgender man, has been largely forgotten as a result of his erasure from popular representations of the Teena hate crime, most notably the critically acclaimed film *Boys Don't Cry* (1999). Snorton's effort to reconstruct the story of DeVine's life by piecing together primary sources and filling in the gaps with speculation serves to reinstate DeVine as a part of the narrative– the very same narrative that Snorton criticizes for "linking blackness and death" (182). His discussion of the violent cultural intersections of blackness, transness, and death leaves readers with the sense that DeVine's blackness, far from offering him the freedom of fungibility that facilitated Ellen Craft's escape from slavery, posed a threat to his freedom by marking his death as less important than that of the white Brandon Teena. Like the enslaved subjects of Sims's experiments, Phillip DeVine fails to exemplify Snorton's theory of race, gender, and queerness as spaces of fungibility, highlighting both the complexities of Snorton's themes and his book's often unsuccessful struggle to draw connections between sources, narratives, and disciplines.

Black on Both Sides will likely appeal primarily to scholars, as Snorton's work assumes a familiarity with a variety of historians, theorists, and bodies of sources. The language is decidedly academic, making the book largely inaccessible to readers without a background in reading academic texts. For those studying the intersections of race and gender in the United States, *Black on Both Sides* will surely be an instructive read insofar as it represents a valuable interdisciplinary effort to bring together a rich variety of sources. Still, Snorton's book would function better as a collection of separate but related essays than as a narrative made up of numerous tenuously connected strands.

Sexism Ed by Kelly J. Baker

○ *Hannah Lowe*



Sexism Ed: Essays on Gender and Labor in Academia (Raven Books, 2018) begins with a very clear statement of purpose. "I started writing about sexism in higher education to figure out what the hell happened to me," writes Kelly J. Baker (xvii). Baker, who holds a PhD in American religious history, spent years in academia as an adjunct professor and lecturer before leaving to work as a freelance writer. *Sexism Ed* is Baker's fourth book, a collection of pieces written for *Chronicle Vitae* and *Women in Higher Education*. In thirty-seven essays, Baker relives the dead ends she faced in her career. She writes eloquently about systemic inequality, misogyny in American culture, and her personal encounters with scholastic sexism.

Part one of *Sexism Ed*, titled "Academic Sexism," draws on a number of sources relating to gender in higher education, including studies conducted by other academics, social media campaigns, and Baker's own experience. In each essay, Baker approaches the topic at hand like a professor in class. She presents questions — such as "Is there a gender gap in academic publishing?" and "Why is academia so inhospitable to mothers?" — and guides the reader through explanation to a conclusion (9, 14). The statistics are damning, but Baker is careful not to leave her reader disheartened. For the most part, each essay ends with a concrete way to effect change.

Part two, "Academic Labors and Their Discontents," delves into the thorny issue of academic labor. Baker addresses concerning trends including the corporatization of universities, the growing contingency of the academic workforce, and the perils of poor work-life balance. From this section, contingency emerges an equal villain to sexism and racism. In the chapter "The Perils of 'Do What You Love,'" Baker sits down for a conversational Q & A with Miya Tokumitsu, Ph.D., author of *Do What You Love: And Other Lies About Success & Happiness*. They discuss toxic work culture and agree that solidarity is the key to fixing the problem — a common conclusion in the essays of part two.

Sexism Ed concludes with a series of personal narratives broadly discussing sexism in America. Part three, titled "Sexism, Up Close and Personal," opens with an extraordinary account of Baker's struggle with sound and silence titled "Listen to the

Sound of My Voice.” Another standout is “Being Visible”: in this 3,000-word piece, Baker uses the story of an August 2017 interview she gave about white supremacy to discuss the current political climate, abuse of women online, and public performance of self.

At its best, *Sexism Ed* intertwines personal narrative and concrete research. Even when Baker is optimistic, there is profound sadness in reading her essays; it’s clear that Baker herself is one of the many women wronged by systemic inequality in academia. She says it best on page fourteen: “Here’s my life, reduced to an unfortunate statistic.” However, Baker gives her reader hope with calls to action and dialogue with other academic women. She references and relates to the work of bell hooks, Rebecca Solnit, and Miya Tokumitsu, among others. In the essay “Teaching As Liberation,” Baker envisions an ideal classroom through bell hooks’ concept of engaged pedagogy. Her description of the classroom as a liberated space of “shared vulnerability, mutual respect, and collegial efforts to learn” gives the reader hope that it is possible to make academia more inclusive (131).

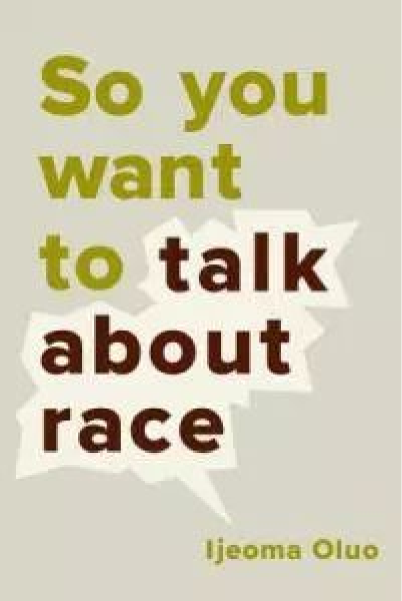
Though Baker recognizes her own privilege early in the book — “Academia remains a very white space,” she writes, as a white woman — there are some issues which she does not address in full (xx). Baker handily exposes the structural racism within academia, but does little to address ableism and says nothing at all about anti-LGBTQ+ discrimination. Likewise, she begins to discuss classism writ large in higher education, but ends the conversation with “Academia will only exist for those who can afford it” without further elucidation (137).

Despite its specific topic, *Sexism Ed* has universal appeal. Baker’s use of industry-specific terms — “MOOCs” and “total-institution model” among others — indicates an intended audience of academics, but her conversational, witty prose appeals equally to undergraduates and those outside the ivory tower. Her breakdown of scholastic sexism equips the reader with the language necessary to participate in the conversation Baker has started. In simple, concrete ways, Baker encourages her readers — regardless of gender and level of education — to join her in the fight against sexism.

***So You Want to Talk About Race* by Ijeoma Oulo**

○ *Danielle Nielsen*

In *So You Want to Talk About Race* (Seal Press, 2018), writer Ijeoma Oluo approaches the difficult discussions about race that Americans, especially, are engaging in right now. Styled as a self-help book, Oluo aims to her white audience and others who might be hesitant to address race become better equipped to participate in these discussions.



In the first five chapters of *So You Want to Talk*, Oluo defines the terms necessary to both engage in ,and understand, discussions of race and racism in America. Oluo explains concepts like *racism* and *intersectionality* and provides techniques for how to approach conversations about race. For instance, Oluo explains that if her white readers want to participate in discussions about race, they should make sure their intention is clear, perform their own research, and refuse to tone-police people of color. These introductory chapters set the stage for the remainder of the book, which cover more specific topics such as police brutality, affirmative action, model minorities, and microaggressions. Oluo organizes most chapters, especially in the second part of the book, around the same structure: an anecdote, historical context, assumptions about the topic, and ways to combat those assumptions. For instance, if readers want to know about the school-to-prison pipeline, it is their obligation to research that topic on their own before engaging with the subject in conversation. The topics are wide-ranging and appropriate for a book entitled *So You Want to Talk About Race*, and they cover many of the most prominent talking points of race in contemporary America.

While reading the book, two things consistently gnawed at me: the dependence on anecdotes and the lack of intersectionality. Nearly all of the chapters start with anecdotes. Many of these anecdotes are from Oluo's own experiences or the experience of people that she knows. For instance, at the beginning of a chapter on the school-to-prison pipeline, Oluo opens with the story of a five-year-old boy who was accused of assaulting his kindergarten teacher and the repercussions of that accusation. For this reader, more statistics would be helpful, and I know they're available. The research on the school-to-prison pipeline, the use of suspension and expulsion as a tool used disproportionately against children of color, and research on implicit bias in teachers is all out there and convincing. If the book is intended to help her reader stalk about race, it is helpful to have a combination of anecdotes – to encourage empathy and deploy pathos – and statistics – to get at the heart of one's more logical or logos-driven brain. At times, Oluo does use statistics to support these anecdotes, and these statistics are particularly helpful in the chapter about police brutality and in the discussion of affirmative action, where she discusses wage disparities on both gendered and racial levels. I do acknowledge, though, that Oluo may also be asking us as readers – as she explicitly does in the opening chapters – to go and do our own research. She does not, however, provide examples of research beyond the few sources in her bibliographic notes. And I must acknowledge that it is not her job to do it for me.

My second concern is the lack of intersectional analysis in the text. The affirmative action chapter, understandably, is one of the places where Oluo most clearly discusses intersectionality and the importance of ensuring people from all marginalized groups, women, LGBT people, and people with disabilities, in addition to racial minorities, are acknowledged. I recognize that, in a book called *Let's Talk about Race,* the focus of the text will be race. Oluo's reliance on, often personal, anecdotes also moves the text towards a discussion of being black in America. Race in America is a complex and certainly intersectional concern, and all of Oluo's recommendations can further the discussions for all groups mentioned above. Beyond research, Oluo recommends political action – such as protests and visiting city council meetings – and action on social media to educate others about race. These same actions can also take into account the concerns of other marginalized groups.

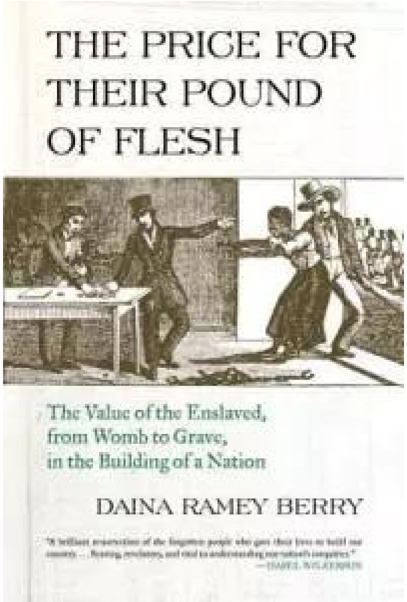
All in all, Oluo's *Let's Talk about Race* encourages readers to think about how to engage conversations about race in the current political atmosphere with poise and dignity. It acknowledges that these discussions will never be easy, but that they should happen. The biggest strengths of Oluo's work are the diversity of topics that she covers, the assumptions that she debunks, and the insistence that participants in these discussions take ownership of their own education about racial issues. This book is set to help anyone who wants to be a well-informed ally.

The Price for Their Pound of Flesh by Daina Ramey Berry

○ *Sarah E. Parker*

> *Historically, black bodies in the United States have represented two competing values: one ascribed to the internal self and the other to the external body. (ix)*

In *The Price for Their Pound of Flesh: The Value of the Enslaved, from Womb to Grave, in the Building of a Nation* (Beacon Press, 2017), Daina Ramey Berry (Associate Professor of History, UT-Austin), offers an account of the various ways that enslaved people were valued, even before they were born and after they died. Berry is an established historian of slavery who has published numerous books and articles focusing on gender and slave value, and she continues that work in this book. *The Price for Their Pound of Flesh* considers three kinds of valuation: "soul, appraisal, and market" (7). It is not by chance that Berry lists soul value first here, for the book's clear mission is to demand recognition of the value that enslaved people placed on their own souls. Indeed, one of the things that makes this book so absorbing is the relentless and sickening shock that comes from reading about an economic system that placed a monetary value on human life combined with the constant reminder that we are reading about *people*. And yet, enslaved peoples' accounts of their own experiences are notoriously difficult to find in the archives. Many historians have discussed the ways that archival records fail to represent disenfranchised voices, and Berry continues the important work of recovering the traces of those effaced experiences. As she points out, scholarship on the economics of slavery has focused on the value of male enslaved field hands, and so has tended to overlook the early years and the afterlife of slave value as well as the experiences of women, children, and the elderly. Her focus on women's value is especially compelling, and her discussion of the history of medical education in American universities, specifically their use of enslaved bodies for anatomical instruction, makes this book a must-read for medical historians.



The Price for Their Pound of Flesh is structured so that each chapter follows the life of an enslaved person, from "womb to grave" as the title indicates. Using archival material from property appraisals, auction sales, advertisements about slaves, and life insurance that slave owners purchased on their slaves, Berry considers the many different ways that slaves were assessed and valued over the course of their lives and beyond. Berry's discussion of the postmortem values of enslaved bodies will be especially interesting for *Dosis* readers because Berry connects the history of medicine so clearly to social (in)justice. Berry labels the post-mortem value of enslaved bodies *ghost value*, and she describes the history of an illicit cadaver trade that played a foundational role in the beginnings of medical education in this country. For example, she follows the fates of Nat Turner and other slaves who participated in the Nat Turner rebellion and were punished beyond death by dismemberment and dissection. Though historians rarely discuss the fact, "When Nat Turner and his followers went to the gallows, Virginia medical students were nearby to claim the bodies for their research" (99). Turner's body was dissected, and parts of his body "were commodified and traded" as part of an appalling trade in "souvenirs" (101, 128).

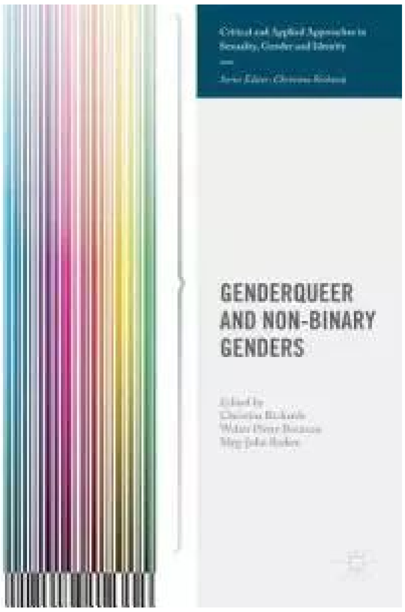
Refreshingly for a work of historical scholarship, Ramey Berry does not shy away from talking about the importance of spirituality and the sense that having an immortal soul could supersede an oppressive system's attempt to commodify human life. She calls the spiritual value that enslaved people placed on their own lives *soul value* and gives voice to the bonds of love and family that connected the enslaved. Berry argues that slaves also expressed *soul value* when they ran away or subverted the system in other ways (such as crop destruction, learning to read and write, etc.). One of the things that makes *The Price for Their Pound of Flesh* such an engaging read is that Berry weaves these stories of resistance throughout the book, for example in the story of a certain Celia, a fourteen-year-old girl who murdered her owner and serial rapist (80-81). In finding stories like Celia's, Berry recuperates the traces of *soul value* that can be difficult to find in the plantation ledgers and auction reports that serve as the typical source material for historians and economists who study slavery.

Anyone interested in United States history, the history of medical education, and the history of slavery should read this book. Furthermore, the commodification of black lives is certainly not relegated to the past. Berry calls attention to the connection between placing a value on black bodies, the devaluation of black souls and more contemporary, twenty- and twenty-first century events , such as the way Henrietta Lacks' cells were used for genetic research while she and her family had little access to medical care, and the urgent demands of the Black Lives Matter movement. Thanks to Berry's vivid writing, quotes from abolitionist poetry, and first person accounts drawn from slave narratives and oral histories, this book is more accessible than the typical scholarly monograph, and non-specialists will also find her vivid writing and important subject matter well worth reading.

***Genderqueer and Non-Binary Genders* by Christina Richards, Walter Pierre Bouman, and Meg-John Barker, eds.**

○ *Heather Stewart*

Genderqueer and Non-Binary Genders (Palgrave MacMillan 2016) offers the first sustained, comprehensive academic and clinical resource specifically focused on non-binary gender. As such, the book is a massive undertaking. It aims to explore non-binary gender experience in a variety of realms: social life and activism, mental health and related institutions, and clinical medicine. The editors of the collection themselves span an impressive array of backgrounds: Christina Richards is a psychology associate and clinical researcher at the National Health Service (NHS), as well as an activist and educator around trans and non-binary issues; Walter Pierre Bouman is a medical doctor, psychiatrist, and psychotherapist specializing in gender and sexuality; and finally, Meg-John Barker is a writer, therapist, and activist-academic, specializing in gender and sexuality. Their diverse educational and professional backgrounds have contributed to the creation of a text that is equally diverse and expansive, and which is strengthened by the incorporation of voices from various specialists and experts on non-binary gender (each chapter is authored by different people who specialize in the particular subject of that chapter).



The text is broken down into three main sections: *Societies, Minds,* and *Bodies*. Part I: *Societies,* is broken down into chapters on History and Cultural Diversity, Non-Binary Activism, Academic Theory, and Law. Part II: *Minds,* is broken down into chapters on Psychotherapy, Psychiatry, and Psychology. Finally, Part III: *Bodies,* is broken down into the most technically complex chapters, Child and Adolescent Endocrinology, Adult Endocrinology, Chest Surgeries, Surgery for Bodies Commonly Gendered Male, Surgeries for Bodies Commonly Gendered Female, and finally, a chapter on Future Directions. I personally found the first part of the book on *Societies* to be the most accessible to a general reader who is not professionally trained in a mental health field or clinical medicine, though I gleaned important insight from all of the book's parts and individual chapters. For the sake of brevity, I will point out a few (of many) key insights from each chapter.

In chapter 2, "History and Cultural Diversity" (the first chapter following the Introduction), authors Ben Vincent and Ana Manzano use various historical examples to show how fluid and diverse articulations of gender are, and how particular contexts generate highly varied expressions of gender (25). In chapter 3, "Non-binary Activism"—my personal favorite chapter—authors S. Bear Bergman and Meg John Barker discuss the important role of non-binary activism in shaping understandings of non-binary experience. Barker gives a historical overview of the progression of activism in this area, while Bergman talks specifically about the development of language, and the power that appropriate and affirming language has on constructions of identity, personal senses of belonging, and social acceptance (39-43). To the contrary, dominant (read: binaristic) language can be used to oppress or harm non-binary people, by making their experiences seem illegitimate or incomprehensible (41). Chapter 4, "Academic Theory," traces the theoretical lineage of thinking about non-binary gender within the academy, and especially how recent developments in queer and trans theory are challenging the dominant medical and scientific understandings of sex and gender (58-9). Chapter 5, "Law," discusses the various ways in which non-binary folks interact with the law, as well as ways in which the law (which still insists that gender is binary in nearly all cases!) could adapt to be friendlier and more accommodating to non-binary folks: name changes, relationship recognition, equal access to bathrooms and other public spaces, equality acts, and so on (73, 77).

Chapter 6, “Psychotherapy,” offers the transition into the section on *Minds*. In the chapter, authors Meg-John Baker and Alex Iantaffi survey the dominant approaches to psychotherapy (namely, psychodynamic, cognitive-behavioral, and humanistic) and show how they are all steeped in the assumption that gender is binary (109). They then offer the possibility of two alternative approaches, namely existential and systemic therapeutic approaches, to be more non-binary affirming (111). In chapter 7, “Psychiatry,” authors Sarah Murjan and Walter Pierre Bouman discuss the ways in which non-binary people interact with the institution of psychiatry. Specifically, they focus on changes in diagnostic criteria in the ICD and DSM, and offer hope that the language used in these clinical diagnostic criteria are moving in the direction of non-binary inclusion (125). Finally, in chapter 8, “Psychology,” Christina Richards offers a detailed and incredibly useful assessment tool for mental health practitioners (150-164). In it, she provides justification for why she includes certain questions in the assessment plan, and how they can help mental health practitioners better understand their non-binary patients. All of the chapters in the *Minds* section did an excellent job of reinforcing the extremely important point that while non-binary folks do often have worse mental health outcomes (and thus need to utilize mental health services, perhaps at disproportionate rates), this is typically *not* the result of mental pathology, but is often culturally-contingent—the product of systemic and pervasive bias and discrimination leveled against them, as well as being repeatedly put into distressing situations as a result of their non-normative gender expression (108, 132-133). I think this is an incredibly important reminder for readers, as to not suggest that the mental health needs of non-binary folks are the result of their non-binary genders.

The final section, *Bodies,* begins with “Child and Adolescent Endocrinology.” In this chapter, Gary E. Butler focuses on the effects of hormonal exposure on sexual and gender identity at various stages of development, as well as the role of therapeutic hormonal interventions for non-binary youth (171). Leighton Seal continues that conversation in chapter 10, only focusing on the effects of hormonal exposure and therapeutic treatments in non-binary adults (183). Seal is clear to point out that non-binary adult hormonal interventions are vastly understudied, and thus not currently fully understood. At present, endocrinologists have to rely on binary-based data, to the detriment of precise and patient-specific care. The following 3 chapters give detailed analyses of surgical options for non-binary folks, focusing on chest surgeries, surgeries for those commonly gendered male, and those commonly gendered female, respectively. All of these chapters, together, paint the picture that when it comes to clinical interventions (and especially surgical ones) there is no one set plan of action for non-binary folks—non-binary people don’t all desire the same level of medical intervention, if any at all, and need to be treated and have their needs assessed on a very individualized basis.

With respect to the intended audience of this text, the editors are clear that they intend for this text to appeal at once to a wide variety of readers, some with an extensive background in the fields being addressed. For this reason, while they hope a general readership will find the text helpful, the authors of the various chapters do not take time to define and explain the professional jargon they are using. This can, of course, be a stumbling block for readers who are not themselves health care providers or academics. And while the editors are upfront about this in their introduction (4), I do think the text would have been more widely accessible and useful had the authors provided brief overviews of the chapters in more accessible language and/or provided a glossary of terms, which a more general audience could refer to, to feel better equipped to engage with the arguments of the more technical chapters.

One conceptual issue that resurfaced, repeatedly throughout the text, was the relation between non-binary gender identities and trans identities. Some of the authors seemed to suggest that non-binary gender identity does fall under the larger "trans umbrella," though of course is importantly different from binary-trans identity (i.e., mtf or ftm trans identified people, to use language used in the text) (5). Other authors, however, seem more critical of the tendency to lump non-binary gender identification in with other trans identifications, and resist the idea that the label of trans is all-encompassing of any non-cis gender identity or expression (41, 74). The matter, of course, is not purely theoretical—some non-binary folks experience themselves and/or identify themselves as trans, while others do not (131). Still yet, some non-binary folks who would not otherwise identify themselves as trans do so for purely pragmatic reasons. For example, they may use the language of transgender identity to access medical resources or treatments that they believe (and likely are, in fact) more likely to receive if they use the language more familiar to most health care professionals (131, 285. See also McKinnon 2013). Overall, I think the most clear and concise definition we get of "non-binary" comes in chapter 5 of the text, where authors R. Clucas and S. Whittle define non-binary as "an all-encompassing name for those people whose gender identities fall outside the dominant societal gender binary" (74).

One important takeaway from the text is how genuinely difficult it is to make any sort of generalizations about non-binary experience, especially when empirical research is in such preliminary stages (105). There is an incredibly wide range of non-binary experiences (5), and institutions (legal, medical, psychiatric, and otherwise) do a great disservice to non-binary people when they attempt to over-generalize and/or draw broad conclusions on the basis of very limited interactions with non-binary people. The reality is that we know (at least in an empirical sense) very little about the lives, outcomes, and general wellbeing of non-binary folks, and this is due in large part to how difficult it is to collect accurate data (a product of most forms and surveys still only providing binary-gendered options). In fact, we still have little idea of precisely how many non-binary people there actually are (5).

My most significant concern with the text is the general lack of non-binary identified voices (or, at least people who position themselves openly as such), with few exceptions. In the clinical chapters in particular, clinicians wrote *about* non-binary folks, not *as* non-binary folks. This is an important distinction, especially in the nascent stages of what will hopefully become a larger literature on non-binary identity, but which is currently incredibly limited. At this crucial time, when so many people are being exposed to non-binary gender identity for the first time, it is absolutely imperative that non-binary people have the opportunity to speak for themselves and tell their stories in their own voices. This is essential if non-binary people are to understand what it is like to be non-binary, from the perspective of people who themselves experience themselves in that way. This concern maps onto a larger critique that I have with the text about the politics of citation – again, it matters whose voices are being included and excluded. With the exception of S. Bear Bergman and Meg-John Barker's chapter (chapter 3 of the text), very few trans or non-binary theorists, philosophers, or other scholars are cited or engaged with in any substantial way. Similarly, in the medically-oriented chapters, there are no substantive patient testimonies or presentations of first-hand experiences with gender-affirming surgery. To the contrary, there are voices *included* that arguably should not be cited in a text that is supposed to be inclusive and affirming, but yet are cited as authoritative on these issues. One glaring example is the citing of controversial psychologist Kenneth Zucker (see 267, 282) who, despite an extensive research and publication record on child and youth gender dysphoria lost his job at his Gender Identity Clinic for failing to update his practices to be in line with the most up to date research and gender-affirming best practices for trans and gender nonconforming youth. His clinic has been accused of engaging in "reparative" or "conversion" therapy, which has been incredibly harmful to trans youth, leaving many feeling traumatized and ashamed (Allen 2018, Anderson 2016, Ellis-Peterson 2017). It should go without saying that in the early stages of non-binary scholarship, folks like Kenneth Zucker should no longer be regarded as the authority on trans and non-binary experience, and we need instead to be listening to those who themselves live and identify as non-binary.

This worry—about who is speaking and what language is being used—is echoed (or, at least acknowledge or gestured at) at various points in the text. An important thread running throughout the book has to do with the power of language to shape our understandings of non-binary gender. For instance, in the Introduction, the editors acknowledge the difficulty in finding the proper language to use, when so much of the language and so many of the concepts available to them are rooted in (or are themselves) dominant constructions which are medicalized, pathologizing, stigmatizing, oppressive, and even harmful. Specifically, the editors expressed the concerns they had about naming the chapters that pertained to genital surgery, which they found difficult to do in a way that was at once explanatory, but also free of binaristic medical hermeneutics that do not accurately map onto non-binary experiences (3). They note that the ideal situation would be one in which they were able to create new and imaginative concepts and terms which more accurately capture the variety of gendered experiences, and which are not always already packed with *a priori* assumptions, but of course this is difficult, given the ability of powerful institutions (medicine, law, psychiatry) to shape the dominant discourses (3, 12, 19, 41, 147. Also see Fricker 2007). And given that non-binary folks are forced to operate in contexts where they might lack the language or otherwise be unable to render their experiences socially intelligible, non-binary people often suffer a lack of understanding, and an inability to get proper uptake from the dominant institutions that do have the power to control concept formation and language use (147).

Overall, I think the editors have put together in important text, which I hope will prompt scholarly engagement and popular response alike. Ideally, more people (and non-binary folks in particular) will begin to think critically about gender, about the way binary-thinking pervades our institutions, and the power that language has to construct our realities and perceptions of others. This text has offered an important entry point for dialogues about non-binary experience in a variety of areas, and I applaud the authors for their significant and novel contribution to the literature.

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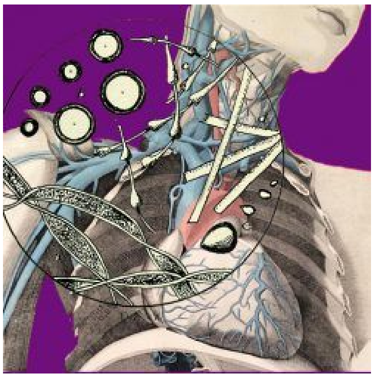

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