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Commentary

Imag(in)ing the Invisible

by Elizabeth S. Cameron

Abstract: This commentary politicizes the relational-technical economy of biomedicine and the future it forecasts for feminized bodies with chronic illnesses. As digital medical imaging technologies develop, visualizations of disease are becoming more sophisticated. I begin by critically considering the implications this has for feminized bodies with chronic illnesses through the example of endometriosis, a common chronic pain disease that is not well understood within the biomedical paradigm. Enhanced imaging technologies promise to illuminate previously-unknowable aspects of disease pathophysiology, but what future is such technological progress enabling, and for whom? Through a critical intersectional lens, it becomes evident that the biomedical-technological future imag(in)es particular bodies, in particular places, and towards particular, but not unfamiliar ends. Enhancing abilities to visualize disease through digital technologies within a biomedical paradigm does not require us to look differently, which may be precisely what is needed. Thus, drawing theoretically on the work of bell hooks as well as critical feminist disability studies scholarship, I kindle the fire of a critical intersectional politic that transforms biomedical-technological ways of seeing the feminized body with chronic illness. Such a politic not only offers the possibility to imagine alternate futurities, but also contributes to their tangible realization.

Keywords: biomedicine; chronic illness; digital diagnosis; endometriosis; futurity; medical imaging technologies

Résumé : Ce commentaire politise l'économie relationnelle et technique de la biomédecine ainsi que l'avenir qu'elle réserve aux corps féminisés atteints de maladies chroniques. À mesure que les technologies d'imagerie médicale numérique évoluent, la visualisation des maladies devient de plus en plus sophistiquée. Tout d'abord, je pose un regard critique sur les conséquences de cette évolution pour les corps féminisés atteints de maladies chroniques, en prenant l'exemple de l'endométriose, une maladie douloureuse chronique courante qui n'est pas bien comprise dans le paradigme biomédical. Les technologies d'imagerie améliorées promettent d'éclairer des aspects auparavant inconnus de la physiopathologie des maladies, mais quel avenir ces progrès technologiques permettent-ils d'envisager, et pour qui? D'un point de vue critique et intersectionnel, il est clair que l'avenir biomédical et technologique imagine des corps particuliers, dans des lieux particuliers, et à des fins particulières, mais pas étrangères. L'amélioration des capacités à visualiser la maladie grâce aux technologies numériques dans un paradigme biomédical ne nous oblige pas à voir les choses différemment, alors que c'est peut-être précisément ce dont nous avons besoin. Ainsi, en m'appuyant théoriquement sur les travaux de bell hooks ainsi que sur des études féministes critiques sur le handicap, je jette les bases d'une politique intersectionnelle essentielle qui transforme les façons biomédicales et technologiques de voir le corps féminisé atteint d'une maladie chronique. Une telle politique permet non seulement d'imaginer un autre avenir, mais aussi de contribuer à ce qu'il se réalise concrètement.

Mots clés : technologies d'imagerie médicale; diagnostic numérique; biomédecine; endométriose; maladies chroniques; avenir

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The future promises great things for feminized bodies with chronic illnesses. As digital medical technologies develop, visualizations of disease are becoming more sophisticated. The previously invisible is becoming knowable. Take endometriosis as an example. This chronic inflammatory pain disease is not well understood but affects "at least 11% of women (and people assigned female at birth) worldwide" (Ellis, Munro, and Clarke 2022, 1) and unknown numbers of gender diverse people (Allaire, Bedaiwy, and Yong 2023). Endometriosis is best described as a condition where tissue similar to that of the uterine lining (the endometrium) progressively grows on organs and soft tissues within the body. This tissue responds to hormone fluctuations, particularly that of estrogen, and results in a variety of painful and disruptive symptoms (see Allaire et al. 2023).

Since the nineteenth century, endometriosis has been definitively diagnosed through surgery which enables histopathological interpretation of diseased tissue. Histopathology is the medical practice of looking at tissue through various techniques (under a microscope, for example) to determine which particular pathology (disease) is present (Brown n.d.). The introduction of video-assisted laparoscopic surgery[1] in the late twentieth century replaced its more invasive predecessor, abdominal laparotomy (making a surgical incision in the abdomen as a way to see inside the body) (Nezhat, Nezhat, and Nezhat 2012). Videolaparoscopic technology invited "a completely new understanding of the anatomy" because tissue that appeared normal to the surgeon's eye could be magnified to "visualize atypical lesions" that would have otherwise been missed (Nezhat, Nezhat and Nezhat 2012, 53).

Despite these technological advances, presently, getting diagnosed with endometriosis usually takes several years. As will be further discussed below, depending on who you are and where you seek treatment, it can sometimes take more than a decade (if it ever happens at all). This delay arises for a number of reasons, including a limited number of practitioners with surgical expertise to perform diagnostic procedures (which are often accompanied by excision, or removal, of the problematic tissue) (Ellis, Munro and Clarke 2022; also see Seabrook and Cattapan 2023 for further explanation of the diagnostic delay associated with endometriosis).

Because diagnostic delays result in immense consequence for people with endometriosis as well as health care systems (see Levy et al. 2011), non-surgical interventions are quickly replacing surgical extraction as the preferred method for diagnosing and treating endometriosis. This clinical turn[2] has been supported by the development of more sophisticated medical imaging technologies. Transvaginal ultrasonography and pelvic magnetic resonance imaging (MRI) are recommended for use in clinically diagnosing endometriosis (Allaire et al. 2023; Becker et al. 2022), with other options rapidly transforming the future possibilities for diagnosis. For example, recent developments in electron microscopy are deepening understandings of "both anatomical and pathological conditions at ever smaller, constitutive levels, in turn providing more terms of reference for precise targeting and functional imaging" (Burfoot n.d., citing Nahirney and Tremblay 2021). Neural interactivity has been mapped in humans since 2010 through MRI technology, and an entire neural network was mapped in tissue extracted from a fruit fly for the first time in 2023 (see Elam et al. 2021; Naddaf 2023). As Annette Burfoot (n.d.) has also described, photoacoustic tomography is increasingly used with ultrasound to produce a three-dimensional moving image that visualizes "in real time the uptake of pharmaceutical treatment … or how a body reacts to pharmaceuticals, including nano technologies, *during* exposure" [emphasis in original]. This technology "promises to enhance early cancer assessment especially in deep and dense tissue like the breast and to monitor activity in the heart" (Burfoot n.d., citing Zhang et al. 2022).

These developments suggest how more sophisticated imaging technologies may help illuminate previously-unknowable aspects of endometriosis pathophysiology (referring to the physiological disorder caused by and/or resulting in disease, see Witthöft 2013). For example, photoacoustic tomography could be explored as a means to visualize endometriosis more precisely through non-surgical methods. If cancer, "as a distinctive cellular material, can be identified and located at the initial stage of molecular change as can heart dysfunction" through "this way of looking" (Burfoot n.d.)—and surgery can be guided in real time—what might be the implications for endometriosis?

Additionally, in the drive to confer more accurate diagnosis and treatment, and do this faster than ever before, artificial intelligence-assisted diagnosis has already become part of the endometriosis treatment paradigm (Dungate, Tucker, Goodwin, and Yong 2024). Soon, clinical diagnoses may not be determined by a human. As Burfoot (n.d.) has argued,

> we have been marching steadily towards [the application of artificial intelligence software within medical imaging and diagnostic processes] by reducing what is being scanned to its constitutive parts and creating ways of distinguishing such from surrounding "noise." What appears to be ever more realistic to the human eye, and a more informative non-destructive gaze inside a living being, is the result of layers of digitization and computer manipulation.… What is to stop more sophisticated automated scan/read systems from making diagnoses based on the raw digital data gathered more accurately and far more quickly than the human eye/brain, which requires considerable enhancement to make the data readable?

Without a doubt, "the internal human body and its functions has [sic] never been so illuminated, and the images never so widely disseminated" (Burfoot n.d.). But Burfoot (n.d.) raises a critical question: If, with the enhanced ability to "visualize the body in ever more minute and easily digitizable forms, and … compute increasing arrays of function all through mediations that do not require eyeballs, do we trust things without them to read on our behalf?" Indeed, social discrimination is "baked-in" to these technologies and, without addressing this, discrimination will be digitized (Burfoot n.d.; also see Tuzcu 2021). What is to stop the promised diagnostic future from reproducing inequities already existing within medicine? Why would digital white supremacy/patriarchy/cisheteronormativity/ableism be any different from their analog analogues?

We might ask ourselves, then, what future such technological progress is enabling, and for whom. Machines produce a mechanical reading of the molecular structures of endometriosis tissue, unlike a human, who, for example, might interpret results variably based on their mood, education, and biases towards racial, gender, and sexual identity categories ascribed to the body being visualized. But which bodies are even funnelled towards diagnosis? Who gets to have their disease visualized and diagnosed at all? This is also of concern. Further, machines are taught, programmed, and designed with the knowledge possessed by their human creators; (diagnostic) algorithms and technologies are not created in a social vacuum (see Tuzcu 2021). These matters become even more pressing as endometriosis diagnosis and treatment rapidly shifts towards new methods that do not require technologically-assisted surgical incisions which follow a suspected diagnosis but, rather, rely on biomedical-technological interventions that capture layers of corporeal material without breaking skin to direct diagnosis and subsequent treatment.

In her book *Killing Rage*, bell hooks (1995) describes "white supremacist capitalist patriarchal ways of seeing black womanhood" (85). I want to briefly consider how such a regime sees the feminized body with chronic illness. Critical menstruation and critical feminist disabilities scholarship has argued the feminized body is rendered through compulsory systems of able-bodiedness and cisheteronormativity within white supremacist capitalist patriarchal culture (Przybylo and Fahs 2018; Jones 2021; also see hooks 1995). Using this critical intersectional perspective, biomedicine can be understood as a system which organizes the body, including its fertility and disease, in line with white supremacist cisheteronormative and ableist social structures. This means that bodies are compelled to fit within a very particular acceptable form. The biomedical paradigm of endometriosis care works to control the body with this feminized, gendered disability (Jones 2021) as a substitution for a cure. For example, clinical treatment for endometriosis, projected to be a $3+ billion pharmaceutical market by 2030 (see Lindeman 2023, 187), is an increasingly encouraged practice as this may reduce painful symptoms – but it does not cure the disease or prevent its progression (see Allaire et al. 2023).

Further, a racialized cisheteronormative ableist economy confers endometriosis diagnosis and treatment for some while excluding others. The biomedical-technological future imag(in)es very particular bodies: those who are white, cisheterosexual, of reproductive age, with economic resources, living in a city in the global North and with access to the best diagnostic technologies (see Jones 2021). For instance, advanced transvaginal ultrasonography, as performed by sonographers, radiologists, or gynecologists with special interest and training, "has been shown to reliably detect deep endometriosis in systematic reviews" (Allaire et al. 2023, 367). But in practice, as with surgical endometriosis interventions, this advanced imaging is not routinely available to most Canadians, which may contribute to less-than-timely referral to specialized surgeons or centres of expertise (Allaire et al. 2023, 369; see Wahl, Yong, Bridge-Cook, and Allaire 2021). Ways of seeing also produce ways of not-seeing: in knowing who is imag(in)ed, we should ask, who is not imag(in)ed?

Pinar Tuzcu (2021) has theorized how knowledge in the digital age is produced[3] through *cybercolonial* dynamics. As with postcolonial[4] hierarchies in non-cyber realms, such dynamics concentrate epistemic power in the hands of "Western companies, usually owned by wealthy white men, that are increasingly monopolizing their control over the information sector" while silencing the *cybaltern*, or those "whose voices are muted and rendered unheard, paradoxically despite and because of the digital tools available" (Tuzcu 2021, 516, 520). This works to deepen "geopolitical hierarchies between the Global North and South" (Tuzcu 2021, 515). It is "not only the technology per se" which produces this dynamic, but the elite's "discursive and methodological power over the technology" (Tuzcu 2021, 515). In this way, "tools that theoretically should make [cybaltern] voices heard become the very means for suppressing their voices" (Tuzcu 2021, 520). Imaging technologies, then, which can make the previously unknowable visible, become tools of domination and subordination when wielded within a cybercolonial present: a mode of digital medical knowledge production that gazes through a predictably narrow scope, towards predictably narrow ends.

The surveillance of the body made possible through medical imaging technologies can be further seen as a form of data colonialism (Couldry and Mejias 2019). This suggests that the "abstract quantification methods of computing" assist the extending of "predatory extractive practices of historical capitalism" to new dimensions of social life (Couldry and Mejias 2019, 337). Who benefits from the ability to visualize the body like never before? If the emergence of Big Data provides any indication of what happens to a sea of digital information generated about human activity, we might assume the primary benefactors of increasingly agile imaging technologies are probably not the bodies being visualized.

This highlights the tensions inherent in the process of becoming knowable, particularly given the primacy afforded to visualizing pathology within medicine (Burfoot n.d.). As technology makes the previously unknowable, and uncontrollable, legible, bodies with feminized chronic illnesses such as endometriosis risk being brought further under biomedical-technological regimes of control. Enhancing our ability to visualize disease through digital technologies within this paradigm does not require us to look differently, which may be precisely what is needed. What if we consider what we fail to see because of what Burfoot (n.d.) describes as a culture of the visualized body? How might the image of endometriosis change if knowledge was no longer premised on what is possible to visually observe? It's a familiar question among critical feminist disability scholarship: What can be gained in the absence of perceived "ability" and what do we learn from our impairment (Jones 2021)? What becomes possible by redirecting our gaze?

You might be expecting me to call for a rejection of medicine's visual culture and declare my refusal to engage with it outside written critique. And while this is certainly a valid refusal for any person to make—very much in alignment with feminist refusals to engage with oppressive structures which promise to amplify harm—doing so here would risk negating the also-valid desires of people with invisible chronic illnesses to be relieved, even cured, of their impairments, including pain (Kafer 2013; Jones 2016; Wendell 2014). These are desires I share. If there is a digital technology that can visualize the disease inside me and, say, guide more accurate or targeted treatment, or a non-invasive test to confirm without a doubt that yes, it *is* endometriosis and not "something else" (Whelan 2007) that might necessitate different treatment, sign me up. Hence, the need for a critical intersectional politic in assessing the medical endometriosis paradigm, including diagnostic imaging. A critical, feminist, queer, and crip politic names white supremacist capitalist patriarchy as the primary organizing logic of biomedicine, separates impairment from disability, and refuses biomedical/individual models which position the disabled body as something that needs to be cured. Rather, a political-relational model of disability (Kafer 2013) is adopted. This positions impairment as something medicine may be a helpful in reducing and positions disability as an embodied location that is disadvantaged by a social world, including biomedical-technological relational structures, which constantly demand performances that comply with able-bodied and cisheteronormative imagined ideals (Kafer 2013).

It is necessary to politicize the relational-technical economy of biomedicine and disidentify (Muñoz, in Jones 2021) feminized chronically ill bodies with the projected biomedical-technological future. Disidentification implies "neither completely identifying with nor completely rejecting dominant culture – but rather transforming it" (Jones 2021, 204). The imagined biomedical-technological future is not a future that these bodies necessarily desire, accept, or endeavour to be made visible to. Instead, it is important to recognize our digitally colonized selves and the ongoing practices of dispossession from our bodies and the images (and other digital data) made of them. This is a readily available means to resist this projected future that allows queered and cripped possibilities to emerge in place of present hegemony. For example, a critical intersectional politic takes seriously questions such as: What happens when uncertainty and the unknowable are embraced? What does inability to visualize the chronically ill body make possible? More concretely, how might endometriosis be understood through other ways of seeing bodies with feminized chronic illnesses, beyond the white supremacist capitalist patriarchal microscope? What would we learn from examining the disease's relation to what isn't so easy to see, such as the immune, endocrine, and nervous systems? Instead of being put on medical ice while biding our time for surgery, are other possibilities possible?

To conclude, I begin to articulate, without claiming definition, an alternative future that people with feminized chronic illnesses might desire. What do we accept and what do we resist? What do we reclaim? To what and to whom do we endeavour to be made visible?

First, we desire a queer, cripped futurity that disidentifies with the compulsory white supremacist capitalist patriarchal regime of biomedicine and, in particular, disidentifies with the technological future this regime compels us towards. Many of us desire cures for impairments alongside our desire to rupture white supremacist capitalist patriarchal culture, and this doesn't make us traitorous to our shared cause (Kafer 2013; Wendell 2014). Second, we accept the limits of biomedical authority over the body. In doing so, we invite solidarities with an expectation of difference. This politic has been well articulated by Audre Lorde (1984) and Sins Invalid (2015).

Bodies with feminized chronic illnesses also resist certainty and control – both tenets of biomedical authority, which demands agency be ceded for legibility. The creation of critical intersectional discourse undermines biomedical-technological knowledge production processes and challenges the authority being claimed over our bodies. And finally, we endeavour to be made visible to ourselves and each other. Through this work, we begin to reclaim power. We reclaim agency of our bodies and embodied knowledge through recognizing and naming the colonizer and reinhabiting our bodies as embodied agents rather than biomedical discursive constructions. We are already coming to know ourselves as bodies with desires, agency, and capacities that resist the imagined biomedical-technological future. Through such effort, we are not only imagining something else in its place but actually building an alternative feminist/queer/crip futurity (see Kafer 2013). This is an invitation for others to take up a critical intersectional politic to transform the biomedical-technological regime and white supremacist capitalist patriarchal ways of seeing (hooks 1995) the feminized body with chronic illness.

Endnotes

1. Video-assisted laparoscopy refers to a surgical procedure where a magnifying lens on the end of a scope displays an image of the tissues in real time. This technique has resulted in "lower morbidity, better visualization of areas difficult to access … [and allowed] for more precise dissection" as well as allowed faster recovery time compared to abdominal laparotomies (Nezhat, Nezhat and Nezhat 2012, 53).

2. The European Society for Human Reproduction and Embryology and the Canadian Medical Association Journal have recently encouraged the clinical diagnosis of endometriosis to reduce delays in starting treatment (Becker et al. 2022; Allaire, Bedaiwy, and Yong 2023). This means that if someone has a symptom history consistent with endometriosis, responds positively to clinical treatment (currently, this involves taking hormonal medication to suppress menstruation as a way to reduce pain, see Allaire et al. 2023), and medical imaging does not rule out endometriosis or suggest other diagnoses, the person can be clinically diagnosed with endometriosis by a medical practitioner (see Becker et al. 2022).

3. Knowledge production is not only accelerated but also takes new forms; for example, artificially intelligent computers can not only store and display information but actually generate it (Tuzcu 2021, 515).

4. Indicating an absence of ongoing imperialist colonization of land but the remaining presence of power hierarchies that continue to produce colonial relations of domination; see Tuzcu (2021) and Couldry and Meijas (2019) for more discussion.

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