

“HELLO ABLEDS, IS IT VACATION YET?”: DISABILITY, DOMESTICITY, AND DIGITAL ALCHEMY DURING COVID-19

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ABSTRACT

When the novel coronavirus began spreading globally in 2020, people within disability communities marked the term ‘social distancing’ as oxymoronic and ignorant of those for whom isolation, quarantine, and limited public life is common. For many, COVID-19 did not signal a complete upheaval of their domestic lives; instead, it created opportunities to increase disability visibility in digital spaces and to lament the ways the pandemic further erased their existences. The first few months of quarantine saw the digital rise of prominent disability advocate Imani Barbarin, known to her social media communities as @crutches_and_spice. Barbarin’s persona as a Black disabled fat queer woman became distinct subversion to non-disabled people’s frequent social media laments of boredom, loneliness, and/or living in quarantine. Drawing upon Bailey’s digital alchemy theory situating how Black women’s online identity performances combat anti-Blackness and sexism (2021), I assert Barbarin is a purveyor of ‘disabled digital alchemy’ who employs social media for the “construction, constitution, and production of self through identity play and performance” (Marshall & Barbour 2015, p. 2). Combining Bailey’s framework with disability and persona studies conceptualizations of performance, I use Brock’s critical technocultural discourse analysis to examine how Barbarin utilizes social media affordances to challenge ableist notions of disabled people’s selfhood while calling out problematic pandemic rhetoric. Critically analyzing @crutches_and_spice specifically within TikTok enables a nuanced grasp of disabled people’s digital personas, how they are often ignored, and ways they perform domesticity to mitigate erasure in an ableist body politic.

KEY WORDS

COVID-19; Critical Technocultural Discourse; Disability Advocacy; TikTok

INTRODUCTION

On March 15, 2020, disability rights advocate Imani Barbarin began her @crutches_and_spice TikTok account with a double entendre. In the video, Barbarin is seated in what looks like a leather chair; she is visible from the mid-chest up. A text-box with white lettering above her head states, “How I plan on surviving quarantine...” (Barbarin 2020a). The influencer is looking up and into the distance while her body shakes suggestively. She bites her tongue before coyly looking into the camera. It appears Barbarin is masturbating off-camera; however, she deftly pulls one of her crutches into the frame with one hand while holding up a cloth with the other. The text-box switches to the words “Clean your mobility devices babes!” (Barbarin 2020a). She wipes her crutch and sticks her tongue out in a ‘gotcha’ gesture.

This bawdy humor introduced Barbarin’s COVID-19 TikTok persona where she utilised jocularity and/or ‘spice’—ribald and/or scathing—to critique government and social responses to the pandemic. Barbarin’s already established influencer status—her blog crutchesandspice.com launched in December 2004, and she also ran @crutches_and_spice Instagram and Twitter accounts—rose to greater visibility during the COVID-19 pandemic. Beginning her TikTok account a few days into distancing mandates enabled Barbarin to reach larger audiences; news reports state TikTok received two million downloads during the first weeks of quarantine (Jankowski 2020) with two billion global downloads in 2020’s first fiscal quarter (Brown & Chmielewski 2020). As Tolentino argues, TikTok is an “enormous meme factory, compressing the world into pellets of vitality and dispensing those pellets until you get full or fall asleep” (2019). Caged rodent reference aside, Barbarin’s posts about the ways ableism shapes life for disabled people reach nearly 500,000 followers. As a self-identified Black disabled fat queer woman, Barbarin employs the platform to show how disabled people have historically been “uniquely inured to the all-encompassing state of emergency” that “gripped entire societies” during the COVID-19 pandemic, revealing her “ready insights” about a crisis that has been “overwhelming and flabbergasting to most” (Doonan 2021).

Describing how Black women, nonbinary, agender, and gender-variant people as digital content creators resist limited and limiting racist and sexist representations, Bailey states these creators are “actively reimagining the world through digital content creation” and challenging misogynoir (the hatred of Black women and femmes) in a “form of self-production that disrupts the mainstream narrative” (2021, p. 23). These Black creators are “making room for themselves on digital platforms in ways that exceed what was never intended by the engineers and corporations who designed and created these sites” through processes of digital alchemy, a Black feminist action to “transform everyday digital media into valuable social justice media” (Bailey 2021, pp. 23-24). Initially released in 2016 as a video sharing platform in China, TikTok became global in 2018 when it merged with Musical.ly, a platform mostly used to share lip sync, comedy, and dance videos. By 2020, TikTok had extended into news and politics. No longer was it a site for lip syncing divas, dance crew battles, and comedic antics; it had also become a site for activism in a “complex social media ecosystem in which earnest activists compete with mocking satirists, playful attention-seekers, and bored time-killers for visibility and clout” (Hautea et al. 2021, p. 2).

Barbarin, as a Black woman digital content creator, uses TikTok for social protest, steering a platform once known for low brow entertainment into a force for highlighting how society is oriented toward a non-disabled politic. As the pandemic forced many into unfamiliar modes of being, yielding new conceptualizations of the body, politics, and the body politic’s role in mitigating harm, Barbarin became a disabled digital alchemist who maneuvered TikTok for the “construction, constitution, and production” of a disabled self “through identity play and performance” (Marshall & Barbour 2015, p. 2). By rendering visible the historic caving of the *polis*/political into the *oikos*/domestic for disabled people, Barbarin’s digital persona ascended as she called out disabled people’s erasure from the global body politic, one that focalized the boredom, loneliness, and mental and physical challenges of non-disabled people during quarantine.

This article situates Barbarin as a disabled digital alchemist who utilized her @crutches_and_spice TikTok account to challenge ableist notions of selfhood while exposing harmful pandemic rhetoric. By critically analyzing how Barbarin’s digital persona co-constituted “harm reduction strategies” (Bailey 2021, p. 23) during a global health crisis, this study establishes her as a purveyor of “moral, intellectual, and political guidance” (Doonan 2021) through disability performance and play. Employing Brock’s critical technocultural

discourse analysis (CTDA) methodological framework to examine Barbarin's use of TikTok's affordances to perform disability disruption, I explore the distinctions of one guiding question: how does Barbarin operationalize TikTok for disabled digital alchemy with a digital persona designed to protest pandemic ableism? I show how her persona exemplified that of a digitally savvy political storyteller who alchemized pandemic ableism into disability justice gold. Ultimately, Barbarin enables a reconceptualization of how disabled people's personas function within a non-disabled politic that routinely effaces their experiences and needs, and how disabled domesticity has always been political and never a vacation from public life.

THE DISABLED BODY POLITIC

To understand how the @crutches_and_spice TikTok account situates Barbarin as a disabled digital alchemist, explicating disability and persona studies theories is imperative. Evoking Hannah Arendt to discuss the digital doings of a Black disabled fat queer cisgender woman locates me—as someone who shares several of Barbarin's identities—on a slippery theoretical slope. I employ Arendt, acknowledging her "Reflections on Little Rock" (1959) "places public and social concerns on people's lives in a way that blatantly defends discrimination and not so subtly supports racist ideologies" (Humphrey 2021, p. 24), to impart how marginalized communities can affirm resistance to the conjectural boxes within which they are frequently confined. Arendt's ideas of the *polis* and *oikos* provide an opportunity to create an intellectual palimpsest, revealing Arendt's ideologies in still legible graphite while writing other, more liberatory theories onto the same parchment with sociocultural ink developed to mitigate conceptual violence.

Thus, I question Arendt's conceptualization of the *polis* as historical moments where public spaces were established in communities of equal citizens. She states the *polis* is the "organization of the people as it arises out of acting and speaking together, and its true space lies between people living together for this purpose, no matter where they happen to be" (1958, p. 198). Arendt's *polis* is a space of appearance where a persona or public identity is constructed for participation in the political realm. Additionally, the *polis* can be deemed a body politic or a political community with independent parts working together to achieve a common goal. Yet, as Doonan points out, the body politic has been consistently structured and idealized as non-disabled, associating illness and disability with political crisis; therefore, the disabled body must be nullified or removed from the body politic because it 'handicaps' political interdependence (2021). Inherent within this situating of the body politic are questions of who else is left out, or who has the power to include and exclude people in and from the political sphere. Who possesses the power to participate in the *polis* with a persona and body deemed capable of independent and interdependent political action?

Greek theories of the *polis* relied on equality for some, not all. Disabled bodies were considered abject, as were the bodies of non-propertied and/or non-white males. Enslaved people, women, and children—especially enslaved people of colour—performed labor within the *oikos* (household or social life beyond public political life) that freed 'citizens' to perform, act, and speak in public (Doonan, 2021). Fast forward to Arendt's era when the Civil Rights Movement began en masse exposure of the sui generis power of white supremacy in the United States. While Arendt presumed power is distinguishable from strength, force, and (physical) violence and embedded in plurality, consent, and rational cogency (1959, 1972), mass mediated diffusion of racist physical violence that had been hidden in plain view for centuries made conspicuous the terror many Black citizens had historically experienced in social and private life. One need only look at the history of lynching in the United States to understand the fear

Black people possessed of being dragged from their homes, convicted of crimes they did not commit, and murdered before a racist white mob.

During a time of contemptible ethnocentric violence (which truthfully has not ended as the fear of lynching, police killings and judicial injustice still exists), Black people as well as other people of colour, disabled folks, women, LGBTQIA+ people, immigrants and other marginalized communities, created their own political bodies to chip away at the power the overarching *polis* held. As Jackson, Bailey, and Welles note, “Much of the discourse related to U.S. progress, from the abolition of slavery to the sexual revolution, was rooted in narratives created on the margins of society” (2020, p. xxxiii). Yet, after viewing a photo of an angry white mother accosting a member of the Little Rock Nine attempting to desegregate a public school, Arendt wrote, “The question is not how to abolish discrimination, but how to keep it confined to the social sphere, where it is legitimate, and prevent it trespassing on the political and personal sphere, where it is destructive” (1959, p. 51). While I could certainly demolish Arendt’s voicing of white supremacy, instead I echo Humphrey’s acute observation that:

Arendt essentially employs the concept of the social realm as a cudgel to batter the fight for equality in all realms of American life that do not fit her definition of public...Defending the social realm as a bastion of unapologetic discrimination is to argue that the inequalities forged through history, whether it be to Black people, Indigenous people, women, or the “outsiders” in any culture, can now remain frozen. It also means the *oikos* is forever safe for power disparities to play out (pp. 25-26).

In Arendt’s *polis-oikos* reading, any public institution or space—from schools to pools to government buildings to local, state, and national parks receiving taxpayer dollars—should not abide integration or agitation for desegregation. This suggests only those deemed worthy of membership within the *polis* have a natural right to challenge how political action is articulated, negotiated, and revised. She states, “All political institutions are manifestations and materializations of power” (Arendt 1972, p. 140).

Yes, the *polis* has witnessed incremental power changes thanks to activists seeking to topple hegemonic privilege. Yet, fast forward to March 2020 when governments around the world instituted COVID-19 distancing mandates. In the U.S., years of sociopolitical protest had secured the Civil Rights Act (1964), the Voting Rights Act (1965), the Americans with Disabilities Act (ADA) (1990), and other codes and Supreme Court rulings related to gender, sexuality, and bodily autonomy. People who had been historically excluded from the body politic had been given marginal entry into the U.S. *polis*; “Counter-publics, the alternative networks of debate created by marginalized members of the public, thus have always played the important role of highlighting and legitimizing the experiences of those on the margins even as they push for integration and change in mainstream spaces” (Jackson, Bailey, & Welles 2020, p. xxxiii). Though illegal in the public sphere, discrimination based on race, ethnicity, gender, sexuality, national origin, disability, faith/religion, age and so forth, remains systemically embedded in the U.S. sociocultural foundation. The nation’s overall political scheme of granting power to a few has persisted. This became more evident in the summer of 2020 as U.S. activism against the killings of several Black people by police rose along with the pandemic death toll. News reports exposed how local, state, and federal (in)action along with a plethora of misinformation contributed to a disproportionate number of COVID-19 deaths within Black and Brown communities.

Doonan notes, “During the course of the COVID-19 pandemic, the entirety of each ‘body politic’ across the globe has had to grapple with illness collectively” (2021) and face restrictions

and health measures—such as hand washing, mask wearing, distancing, and staying at home—that are standard for disabled people. As people struggled with the crumbling of their social lives, social media increasingly became a space where pandemic politics were performed. This was not new; social media platforms had become ubiquitous by March 2020. Still, the pandemic heightened the visibility of the collapse and also reinterpreted the *oikos* as a space of political expostulation. The visibility of mass crowds protesting while wearing masks alongside images of sick and dying formally non-disabled people magnified fears; non-disabled people’s cries for distancing and masking to speed up the return to ‘normalcy’ revealed what disabled people had long lamented: that they were considered abnormal. Early public health discourse situating it as a respiratory illness that would most impact the elderly and those with pre-existing conditions marked disabled people as expendable. The aforementioned hashtag #HighRiskCOVID19 became a common method for disabled people to voice their concerns with the ableism that erased their bodies, experiences, and instructive intelligence about living with and mitigating illness. This, and other hashtags such as #disabilityinclusion and #disabilityadvocacy used on platforms like Twitter, Instagram, and TikTok, became rallying cries for disabled people, those most at risk during the pandemic and who have been mostly excluded from the *polis* and relegated to the *oikos* where they largely remain invisible.

Despite thirty years of the ADA in the U.S., disabled people found themselves left out of policy considerations, their experiential knowledge ignored, and their lives deemed inessential as health precautions grew progressively political and were frequently flouted. While many non-disabled people were creating social media content—including plays on rappers Curtis Roach and Tyga’s viral TikTok quarantine anthem “Bored In The House” where people recorded themselves performing silly stunts with the song in the background—many disabled people posted photos and videos of themselves at home and/or in medical facilities. These posts often included pleas for people to stay home and wear masks in public to avoid flooding health facilities upon which they depend for basic care.

Additionally, some used social media to eviscerate misinformation that only people with pre-existing illnesses were susceptible to COVID-19 death. Disability advocate Annie Segarra wrote in an Instagram post:

It’s been over a month in lockdown and while I was indeed accustomed to staying at home most of the time...I was not ready for: increased daily exposure to real life trauma, all the eugenicism and ableism...difficulty finding certain needs due to hoarding, the impact of losing the already limited amount of outings I had (Segarra 2020).

Wheelchair user Segarra’s post with an image of walking her/their (Segarra uses she/they and her/their as pronoun descriptors.) dog while wearing a mask along with this caption and #HighRiskCOVID19 is powerful for three reasons. First, it reveals the *oikos* of a disabled person highly susceptible to COVID-19. Segarra’s use of the term ‘eugenicism’ is affecting as it refers to the possibility of ‘improving’ the human species through discouraging disabled people’s reproduction, a call to rid the body politic of those deemed unfit for membership. Second, the post highlighted how early pandemic fears placed additional burdens on those whose public and private lives are limited and largely ignored.

Lastly, the image, caption, and hashtag show that for disabled folks, the public and private have always been political as they negotiate ableist perceptions of their bodies, intellect, and bodily agency. This is “a central tenet of disability studies: that disability is produced as much by environmental and social factors as it is by bodily conditions” (Adams, Reiss & Serlin 2015, p. 5). Disability is a social construct rendered through “sociohistorical and sociopolitical

assemblages rather than the body” (Rodas 2015, 103). Thus, the body politic associates disability with a political crisis that must be fixed. If unrepairable, the argument requires the crisis be eradicated through eugenics and/or what Imani Barbarin called sociocultural killing during the pandemic stating: “We need to stop saying ‘this was preventable’ and start saying ‘this is genocide’” (Barbarin 2020b). It is possible Arendt would have viewed historical and current ableism as legitimate social discrimination and agitation for disability rights as a public/political nuisance. It is also possible she would have performed Simone Biles level “mental acrobatics” (Humphrey 2021, p. 25) to justify the pandemic non-disabled politic continuing to exclude disabled people from conversations about preventing the virus’s spread. I imagine her viewing disabled people’s social media based social justice performances as outside her vision of the *polis*/body politic/space of appearance.

For disabled people, setting their social media accounts to public for anyone to view further connects their *oikos* and *polis*, especially when they call for policies to protect and improve their lives. Disabled people’s activism has been a concerted effort to topple public ambivalence about their lives, an ambivalence Arendt may have held (despite her father’s prolonged illness, institutionalization in psychiatric hospitals, and death from syphilis). It amuses me to think of Arendt, with cigarette in hand, rolling her eyes at all of the “Bored In The House” TikTok videos before getting hooked on the ear worm “I’m living my best life minding my business (my business)/And my anti-socials for the win-win” (Tyga 2020). However, she may not have appreciated Barbarin’s mobility device cleaning masturbation ‘gotcha’ video for its prurient association of sexual pleasure with disabled life, a lapse of the public-private boundary.

CRUTCHES_AND_SPICE

Barbarin’s social position is not optional; she does not have the ability to experience a non-disabled body. And, she does not want to. Barbarin is just fine with who she is; “It’s important that people see and affirm me as a Black disabled woman, because I have to move about in the world as such. By not recognizing those things, people are either isolating me or putting me in danger” (Brown 2021). Barbarin is a Philadelphia, Pennsylvania based communications specialist and writer born with cerebral palsy; she holds a masters in global communication from American University of Paris, a degree she uses in her job as a communications director for a Pennsylvania non-profit. Prior to the pandemic, Barbarin employed crutchesandspice.com, Instagram, and Twitter to create and advance multiple hashtags focusing on disability justice including #AbleDsAreWeird, #PatientsAreNotFaking, #TheCostOfBeingDisabled, and #ThingsDisabledPeopleKnow. However, TikTok further revealed Barbarin’s digital activism and offered prolonged views into disabled life, community formation, and advocacy.

Digital/hashtag activism has been frequently maligned over the last decade; journalists, political leaders, and ‘boots on the ground’ (an ableist phrase) activists have called it ‘slacktivism’, ‘armchair activism’, ‘clicktivism’, or ‘performative activism’ as it is considered “less valid than direct action and is mistakenly regarded as in competition with it” (Jackson, Bailey, & Welles 2020, p. xxxii). This conceptualization of digital/hashtag activism is inherently ableist as it suggests that the only valid activism takes place in person through physical action beyond a digital device, thus delegitimizing the work of those like Barbarin for whom in person or physical action is restricted or impossible. For many disability advocates, a trending hashtag on Twitter, Instagram, or TikTok is just as powerful as staging a public protest, an act that can create great harm for people with not just physical disabilities, but cognitive/intellectual disabilities and mental illnesses as well, particularly if a peaceful protest leads to outsiders intruding/usurping and instigating violence that marshals police intervention.

Despite having nearly 500,000 followers on TikTok and hundreds of thousands more on other platforms, Barbarin remains aware of social media's volatility and the ways her digital persona can be misread. In a 2021 *Vice* interview, she notes that "trolls have doxxed her, harassed her, and called her racial slurs and other sordid names" (Brown 2021); the article's author points out that "[as] a Black woman on the [Internet] with any visibility, one of the first things we learn is that there are very few safe spaces for us that include anyone who's not also a Black woman" (Brown 2021). Steele argues, "Black American women have a technological capacity built on the legacy of enslavement, rebellion, and resilience in the U.S. context. It was from this legacy that Black American women learned the skills to craft intentional discourses of resistance online" (2021, p. 10). This resistance is often developed in Black women created online spaces, or metaphorical "virtual beauty shops" where they engage in discourse in opposition to the anti-Black sexism they routinely face (Steele 2021). Generations of Black women have deemed the beauty shop as a social space for sociopolitical discourse while having our hair done. Virtual beauty shops offer similar spaces and can be sites of community building which leads to potent Black women led social justice and inclusion campaigns such as #SayHerName (to amplify Black girls, women, and femmes killed through police violence), #GirlsLikeUs (to amplify discrimination against Black trans women), and #YouOKSis (originally created to highlight street harassment Black women face before being co-opted as an 'all women' campaign).

Though Barbarin's activism is certainly rooted in the idea of the digi-political space of appearance for Black girls, women, and femmes specifically, it also moves into the spaces of multiple communities of people, including disabled and abled folks, people of colour, LGBTQIA+ individuals, fat identified folks, and women or femme identified people. Barbarin's digital disability activism recognizes that even spaces deemed safe can produce harm; for example, spaces for Black women can be ableist, queer-phobic, transphobic, or fat-phobic and spaces for disabled people can be racist, sexist, fat-phobic, queer-phobic. In other words, certain spaces deemed safe often lack the understanding of how life for people bearing several identities can lead to multiple forms of oppression.

Thus, Barbarin employs what Bailey (2021) calls digital alchemy, a Black feminist process of transforming or alchemizing digital media into social justice media, for disabled people, including those who are also people of colour, queer, or gender variant. She has further alchemized a Black feminist focused digital alchemy emphasizing Black women, nonbinary, agender, and gender-variant people of various backgrounds to focalize herself as a Black disabled fat queer woman. Barbarin's disabled digital alchemy has systematically advanced a politically engaged counter-public of disabled and non-disabled disability advocates performing digital/hashtag activism to challenge millennia old formulations of a non-disabled politic/*polis*. The COVID-19 pandemic proved to be an apt stage for this disabled digital alchemy on TikTok as "[c]reatively manipulating and transforming social media platforms [became] means of harm reduction" for Barbarin and other disabled people (Bailey 2021, p. 23). Her disabled digital alchemy became (and remains) a "praxis designed to create better representations for those most marginalized through the implementation of networks of care beyond the boundaries of the digital from which it springs" (Bailey 2021, p. 24).

Barbarin's TikTok utilization during the pandemic has recoded failed scripts to challenge the "normative standards of bodily representation and health presented in popular and medical culture" (Bailey 2021, p. 24). Though Barbarin's disabled digital alchemy existed to a large extent to educate those privileged 'bored in the house' non-disabled folks new to life on the margins of public and medical notions of good health, it maintained one foot in the Black woman's virtual beauty shop and continuously affirmed the validity of disabled lives outside the

non-disabled *polis*/political gaze. Barbarin's 'gotcha' masturbation post—mostly made for disabled community members at the beginning of the pandemic—exemplified the genesis of her COVID-19 related disabled digital alchemy, a digital persona practice/praxis that continued well into 2021.

DISABLED DIGITAL ALCHEMY: METHOD AND ETHICS

Memorial Day, May 25, 2020. Imani Barbarin took to TikTok with this message:

Hello Ableds, good evening. A lot of you like to categorize disabled people staying at home as a vacation. You've been in quarantine for over a month. Is it vacation yet? (2020c)

Barbarin appears in the video wearing a blue sweater and black satin cap, common amongst Black women seeking to protect their hair from breakage during sleep. The words she speaks are in a basic square text-box for deaf and hard-of-hearing people at the bottom of the screen. Beginning with a calm face and speaking in a deep, moderated tone she greets abled people and discusses their association of disabled people's limited or restricted life with vacation. However, her modulated timbre quickly shifts as she yells into the camera "Is it vacation yet?" The caption reads "Is it vacation yet?" with hashtags like #quarantine, #vacation, and #disability, the most potent of which is #abledsareweird (2020c).

Not unlike her 'gotcha' video, this clip reveals a side of Barbarin's digital persona. While her 'gotcha' post features her in full glamour makeup, this post shows Barbarin's everyday. The video is not glossy and does not include common TikTok affordances such as green screen effects, still or moving graphics, or background music; it is straightforward and highly affective and effective. A TikTok 'affordance' is the "multi-faceted relational structure between an object/technology and the user that enables or constrains potential behavioral outcomes in a particular context" (Evans et al. 2017, p. 36). Steele powerfully notes Black women have historically developed a "cadre of tools and technologies to resist domination" (2021, p. 38); within TikTok, these activist tools/technologies are the affordances enabling visibility/shareability, editing, and other structural actions like green screen effects, hashtags, graphics, and user tags (Zulli & Zulli 2020, p. 3-5). Yet, Black disabled women's technology practices have been under-explored in disability and media studies. Barbarin is but one example of a Black woman utilizing social networking sites' "capacity for discourse to build out a social, cultural, racial identity" (Brock 2020, 1-2). However, her disabled digital alchemy sets her apart from Black women who may emphasize the intersection of race, gender, and sexuality with her efforts to digitally discuss and combat ableism, micro and/or macro-aggressions against disabled people.

Brock contends Black folks have used social media that were not created by or for them (and embedded in whiteness) to fashion Black digital spaces "whose contours have become visible through socialite and distributed digital practice while also decentering whiteness as the default [Internet] identity" (2020, p. 5). He states, "At the intersection of the digital and Black culture, Black cyberculture offers a transformative cultural philosophy of representation, technoculture, politics, and everyday life" (2020, p. 6). For this reason, I employ Brock's methodological framework critical technocultural discourse analysis (CTDA) to explicate Barbarin's disabled digital alchemy, or transformation of existing social media tools to social justice media for disabled people routinely excluded from an ableist body politic. In this section, I expand the definition of disabled digital alchemy and outline its interconnection with CTDA starting with an overview of the data pool and including ethical considerations based upon my own identities. Brock (2020, p. 7) brilliantly asserts "Methodology arises from epistemology,

ontology, and axiology. How we know what we know, how we know what is true, and how we know what is good provide the tools for examining the world around us". Thus, I consider CTDA's methodological impetus to examine artifacts (ontology, the what of a platform including its affordances), practices (the *assemblage* of the artifact and its practices), and the beliefs users have about a platform and the culture in which the platform exists as key for studying Barbarin's disabled digital alchemy within an able-bodied *polis*.

CTDA centers a marginalized consumer's technology use (TikTok here) within her "own understanding of [herself] rather than unmarked racial and socioeconomic standards of 'modern' technology use" (Brock 2020, p. 8). The method is designed to bolster any critical cultural theory, such as disabled digital alchemy, as long as it can be used to explain "the semiotics of the information and computer technology (ICT) hardware and software under examination as well as the discourses of its users" (Brock 2020, p. 8). Combining Bailey's concept of digital alchemy with CTDA facilitates an understanding of how Barbarin employs TikTok to bolster a persona for disability activism. Digital alchemy can be either defensive or generative. Defensive digital alchemy responds to and recalibrates against misogynoir, the hatred and marginalization of Black women and femmes; generative digital alchemy works for new types of representation (Bailey 2021, p. 24). I expand these articulations of digital alchemy to assert disabled digital alchemy that is defensive as responses to and recalibrations against ableism and one that is generative offers new renderings of disabled life beyond social and medical associations with abjection and/or lack. Thus, my guiding question for the study was: how does Barbarin operationalize TikTok for both defensive and generative disabled digital alchemy with a digital persona designed to protest pandemic ableism?

TIKTOK DATA POOL

I specifically analyzed Barbarin's @crutches_and_spice TikTok videos from the account's genesis on March 15, 2020 to March 15, 2021, one full year into the pandemic, which amounted to over 200 videos related to disability and ableism, the pandemic, racism, and/or the 2020 presidential election. I was less concerned with breaking down the quantities of each type of post as well as the numbers of defensive and generative posts and more concerned with how the posts *perform*, aid Barbarin's digital persona, and explicate the interconnection between her persona and disabled digital alchemy. I looked for the ways in which TikTok's affordances like graphics, hashtags, and text boxes facilitated cultural beliefs that empowered Barbarin's digital persona and her challenging of the able-bodied politic, the *polis-oikos* symbiosis, and her right to exist as a Black disabled woman online.

For example, Barbarin's mobility device masturbation 'gotcha' video can be deemed generative disabled digital alchemy as it provides a portrait of a disabled Black woman's sexuality and double entendre personality play. The video subtly mocks societal representations of disabled people as asexual despite research showing that most disabled adult women, including those with physical disabilities, have engaged in sexual relationships and frequently possess the same levels of sexual desire as non-disabled women (Payne et al. 2016). Barbarin combined her sexuality with humor, 'spice' not typically associated with disabled women, to send a light-hearted message to her disabled community. Conversely, her "Is it vacation yet?" video is decidedly defensive, a weapon to chastise abled people for their aberrant association of staying at or being confined to the home as leisure.

CTDA's techno and socio-cultural imperatives to represent underrepresented or marginalized people's lived experiences, ways of being, and methods of knowing fits this study. The methodological framework was developed to counter epistemological assumptions about

the Internet and information technology as white, non-disabled, and hetero-androcentric. Brock (2020, p. 10) states “People follow the interactions and practices mapped out by the designers and engineers who code the technology, but they also find ways to create additional pathways and practices to represent themselves within that technology”. Employing CTDA to examine Barbarin’s disabled digital alchemy essentially works to reveal the ways a disabled person employs social media to craft and maintain digital personas for those ignorant of disabled life. Her personality play did not then and does not now exist within a digital environment representative of inclusive public/political practice.

ETHICS

As a Black queer disabled larger-bodied woman, I keenly understand the potential ethical quagmires that come with studying the digital persona of a Black disabled fat queer woman. Not only do I draw upon my institution’s Institutional Review Board template for humanistic qualitative studies, but also the Association of Internet Researchers’ guidelines for ethical pluralism and cross-cultural awareness to mitigate the possible harm that may come from analyzing the persona and work of a person with several intersecting marginalized identities (franzke et al. 2020). Data analyzed here were not collected or examined through contact/interaction with Barbarin.

Big data research often muddies the processes of informed consent when a person’s account is public. Because the @crutches_and_spice TikTok posts are easily found, have garnered news stories, blog posts, and social media posts from others, and the account is devoid of any personal information beyond which Barbarin has explicitly shared, I restrict my work to what has been publicly available since 2020. I do not triangulate TikTok with Barbarin’s other social media accounts or crutchesandspice.com to paint a portrait of the advocate as a Black disabled fat queer woman. Instead, I rely upon what is present in her TikTok account with biographical information from one news profile because they are good tools for understanding the relationship between her digital persona and life during the pandemic. While I do claim the identities Barbarin asserts, I *do not* consider myself an arbiter of knowledge about her. Instead, I utilize my understandings of what it means to be Black, disabled, queer, large/fat, and a woman to articulate a scholarly rendering of Barbarin’s @crutches_and_spice persona and disabled digital alchemy. Is my articulation entirely correct? Likely not. Yet, it is a reference for those within a range of disciplines interested in the intersections of disability, race, gender, sexuality, body type, and technology use within a limited and limiting body politic/*polis* AND *oikos*.

PLAYING DEFENSE ONLINE

Defense can be viewed as actions for resisting or countering an attack and can solidify in multiple political environments, including the digi-sphere. Social networking platforms are often effective for defensive maneuvers, especially for marginalized people seeking to upend their subjugation. While negative portrayals of Black women have existed time immemorial, the Internet has allowed many of them to proliferate thanks to algorithms situating our bodies as abject, hyper-sexual, and/or pornographic. Black women, agender, nonbinary, and gender variant folks have employed defensive digital alchemy to redress misogynoir, or the hatred of Black women and femmes, as a reactionary position that can take the form of one-to-one responses through hashtags, memes, and viral videos (Bailey 2021). For example, when a group of Black men created the Twitter campaign #RuinABlackGirlsMonday where they posted photos of women of other races they considered more attractive than Black women, Black women responded with #RuinAnInsecureBlackMansTuesday, a Twitter photo campaign where they

posted photos showcasing their individual and collective beauty. The results of this campaign are debatable. However, Bailey (2021, p. 25) states, “This tit for tat does not engender the kinds of transformation of misogyny that leads to long-lasting change, but it does let the offensive content be called out as such”.

When Barbarin takes to TikTok for defensive disabled digital alchemy, she does not always appear to be concerned with tit-for-tat battles with specific people, but instead debunks stereotypes or false information. In an August 9, 2020 post, Barbarin responds to a question from a follower who asks if her asthma counts as a disability. She states, while appearing to hold up screenshots of website information and graphs from news reports on screen with one hand, “...this is the official definition of disability. Now, notice one thing; there is no list of disabilities that qualify you or disqualify you” (2020d). The screenshot is from the ADA National Network training guide website stating a disabled person is one “who has a physical or mental impairment that substantially limits one or more major life activity. This includes people who have a record of such an impairment, even if they do not currently have a disability” (ADANA, 2022). Barbarin goes on to share a screenshot from the U.S. Centers for Disease Control (CDC) articulating that approximately 26 percent (or 1 in 4 of 61 million) of Americans have a disability and another from Gallup noting that 43 percent of Americans have a pre-existing health condition that might not be acknowledged as a disability because of ableism (2020d). She continues with the stark assessment that many more people could consider themselves disabled but capitalism prevents it because of the ableist belief that if one can work one is not disabled (a blatant disregard of employed disabled people). Lastly, she states “Forty million people are unemployed because of a pandemic they can’t control – like a diagnosis” (2020d). She looks into the camera and says “How is that working?” (2020d).

Barbarin’s point about COVID-19 resulting in 40 million people becoming unemployed is a sharp reminder that the virus systematically disabled millions of people, leaving them unemployed when businesses shut down or unemployable during and potentially after the run of the virus in their bodies. Especially effective is her use of the green screen affordance in the video to strengthen this point. TikTok’s platform affordances enable users to incorporate a number of green screens in videos. Here, Barbarin uses the affordance for photo stickers, one that makes it appear as if she is using her hand to stick and remove photos directly onto and from the camera lens. With these gestures, the viewer sees information they may have dismissed or ignored if solely Barbarin appeared talking on screen. The images from the ADA National Network and CDC websites and the Gallup report are seemingly unimpeachable and enhance her ultimate message; claiming or not claiming disability is not a matter of identity politics or playing the disabled card. It is something inherently rooted in the fear of being denied employment and/or financial stability because of a mental or physical impairment, a major concern for many during the pandemic. Nowhere in this defensive response does she chastise the person who asked the question; instead, she caustically reprimands the systems forcing the person to ask during a respiratory virus pandemic if their pre-existing respiratory illness is a disability.

Barbarin’s disabled digital alchemy is keen; TikTok’s affordances aid her defensive play or attempt to challenge the public interrogation of certain conditions as disabilities. This is one of many examples of Barbarin skillfully employing TikTok to challenge the ableist body politic/*polis*. While not all of her posts incorporate graphic affordances, those that do commonly include text-boxes with titles and captions for the deaf or hard-of-hearing, GIFS, emojis, different green screens, and including other videos next to her own using the platform’s duet affordance.

In an October 2, 2020 post, Barbarin appears to be sitting inside a dark vehicle wearing a blue hoodie and black satin cap. Above her head is a text-box with a shape commonly seen in comics or print cartoons. As she speaks, her words fill the box; she states that then U.S. President Trump had just tested positive for COVID-19, but had attended a photo opportunity in protection of people with pre-existing conditions “where he was unmasked around a bunch of medically vulnerable children” (2020e). She ends with a sigh of frustration. Here, the cartoon style text-box is a moment of digital sarcasm aligning the video with a political cartoon or a comic that should be funny or unreal but is not. Instead, it is a defensive indictment of a moment that potentially placed vulnerable children at risk for contracting the coronavirus, further establishing the public political indifference and ableist response to disabled people during the pandemic. What makes Barbarin’s sigh and the comic text-box all the more poignant is what is beneath the message, what is unspoken; the children Trump appeared with could become sick and die. Though it is a simple post, it is a powerful example of defensive disabled digital alchemy from a politically astute activist desiring to highlight ableist ambivalence within the U.S. *polis*.

GENERATING DISABILITY VISIBILITY

Speaking about the disabling impact of racism, sexism, and sexual trauma on Black women’s mental health, Schalk notes “[Black] women are challenging the historical and cultural pressure to remain silent and to internalize oppression and trauma...[and healing] requires both stopping the harm from continuing and addressing the harm that has been done” (2020, p. 539). While Barbarin’s defensive disabled digital alchemy can be viewed as “addressing the harm that has been done”, her generative disabled digital alchemy can be perceived as attempts to stop harm against disabled people from continuing. By posting creative content with messages that play offense rather than defense, she scores major points for disability visibility within a platform designed for viral content.

Bailey states generative digital alchemy “moves independently, innovated because it speaks to a desire or want for new types of representation...[It] is born of an interest in creating new media that appeals to the community from which they come” (2021, p. 24-25). Barbarin’s generative disability digital alchemy also moves independently and focuses on not only appealing to different disability communities, but to non-disabled people who are allies, interested in unlearning ableism, or wishing to gain knowledge about disabled life. Her generative TikTok posts utilize the platform’s video producing affordances to help share accurate information with her audience. These generative videos often show her as scornful in her description of ableism’s impact on disabled and abled people; her digital persona’s ‘spice’ seeks to draw attention to past and ongoing harm.

A February 17, 2021 post begins, “We need to talk about what’s happening in Texas because a part of it is a direct result of the ableist stereotypes you tell disabled people not to worry about” (Barbarin 2021). The video goes on to incorporate TikTok’s green screen affordance to show images of Texas Governor Greg Abbott juxtaposed with screenshots of news reports about him. Barbarin explains that the Republican Party uses the fact Abbott is a wheelchair user as an example of a person who ‘overcame’ their disability to undermine marginalized communities’ cries for acknowledgment and protection. She explains that Abbott’s policy of keeping businesses open exacerbated the COVID-19 death toll in Texas. At the time, Texas was experiencing a winter storm that left many without electricity. Barbarin explains that just as Abbott’s failed leadership led to thousands of pandemic deaths, him blaming the storms on wind turbines and the Green New Deal also exemplifies incompetence. She ends, “Ableism affects everyone because your health and your life itself is very much so predicated on the stereotypes we tell each other” (Barbarin 2021).

While many in Barbarin's audience likely knew about the storm, some may not have known much about the state's elected disabled leader. Clever use of the platform's affordances allows Barbarin to show images of the governor in a wheelchair and news reports about his policies' impact on Texans. The post is a scathing assessment of how criticism of Abbott's leadership is attacked as ableist. Referring to the Republican Party's exploitation of disabled politicians like Abbott, the post's caption says "once their [sic] in power they are almost never held accountable because any criticism is blamed on ableism" (2021). The video and its use of platform affordances including hashtags (#texas, #texasblizzard2021, #gregabbott) combine to educate audiences about compounding devastation in Texas and how ableist beliefs allow a disabled person to be used to marginalize constituents.

Powerful politicians deemed Abbott worthy of membership in the *polis* and bolster his leadership. Seemingly 'overcoming' his disability enables Abbott to show his constituents and the wider public that his disability is not one that should be treated as 'special' nor should he or other disabled people agitate for potentially life protecting rights. Barbarin's generative disabled digital alchemy in this post ultimately reveals the nature of ableism within public life. The symbiosis of Abbott's disability, routinely deemed unnecessary for public concern, and his political career function to erase the struggles of those without his privilege or access to power. He is often considered an inspirational figure, one Arendt would have likely championed. The space of appearance in which Abbott exists marks what other disabled people should desire to be, something Barbarin argues further complicates the lives of disabled people who do not have the same backing or resources. Here, her TikTok persona functions as generative disabled digital alchemy designed to show that her life as a Black disabled fat queer woman can never be compared to Abbott's life as a white disabled man who does not champion for disability rights, something Arendt likely would have respected.

CONCLUSION

As I imagine Arendt bopping along to "Bored In The House" videos, I also imagine her being disgusted with disabled people inserting their struggles into public COVID-19 conversations. Would Arendt have viewed disabled people (or those with pre-existing conditions who may not identify as disabled) as the pandemic's unfortunate casualties? Would she have respected disabled people's public political engagement as they encouraged people to wear a mask? It is likely Arendt would have appreciated non-disabled people's pleas for basic precautions to hasten a return to pre-pandemic public and social life, while not addressing the underlying ableism in protests over mask wearing.

As millions declared that 'Black Lives Matter' during Summer 2020, Barbarin used TikTok to assert that disabled lives matter also. Barbarin's identity performance and play went beyond that of an angry disabled woman seeking personal attention during a global health crisis. Her defensive and generative disabled digital alchemy sought to address the institutional harming of disabled people and the further disabling of millions of people who contracted COVID and remain ill. Though illnesses and deaths have subsided, the pandemic's impact will be felt for years to come. Barbarin recognizes this; the digital persona she built during the height of the pandemic continues. Her 'spice' remains. What would a conversation between Arendt and Barbarin look and sound like? I imagine Barbarin, after likely seeing her discussions of public and social systemic ableism falling flat with Arendt, would soon thereafter post a TikTok video eviscerating Arendt's ableism.

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