

Do I Belong on TikTok? Algorithmography and Self-Making

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Abstract

Building on works in digital anthropology, belonging, and self-making, this article delves into physiological aspects of digital lifeworlds. Through collaborative ethnography the author worked with their sibling and the TikTok Ethnography Collective (TEC) to explore TikTok's utility as a site of self-discovery and learning. From the processes which unfold during the collaboration, a fledgling methodology of algorithmography emerges and is developed through the article. The use of digital ethnographic methods mediated the relationship between the author and their sibling, opening an exploration into self-making practices on TikTok. Building on recent literature around TikTok and self-making, (Bimo and Bhandari 2022), and through "Tik-Talks" with the author's sister which centre on multiple forms of diagnoses with Hypermobile Ehlers-Danlos Syndrome (HEDS), this article examines TikTok's capacity and shortcomings as a place where one can learn to belong against the grain of neoliberal and capitalist cultures.

Keywords: TikTok, belonging, self-making, algorithm, learning, social media, identity

A Slice of Semiosis in a "Tik-Talk"

Late one night in January 2022 I was scrolling TikTok – the algorithm had not yet programmed to my predilection, so I was receiving an array of seemingly random videos, from dance trends, to self-help tips, fifteen-second videos about ADHD and autism, and videos by members of the TikTok Ethnography Collective (TEC) I follow. There was nothing significant to consciously recall. Since social media was not supplying me the sociality I was craving, I called my sister. After receiving a run-down of her dogs' latest antics, the goings-ons around the house with my mom, she mentioned she had been trying to see her osteopathic doctor but was having difficulty getting an appointment. It was a fairly usual call, but something stuck out. As we were jesting about self-help my sister slipped a quote into our dialogue unannounced, I quickly recognized the phrasing she used, and stopped the conversation to ask, "wait, was that from TikTok?" She exploded in laughter, sheepishly admitting she was weaving TikTok knowledge into our conversation. That she had picked up a quote from TikTok, and repeated it verbatim in our conversation made me think about what we are learning while using the app, and how we can learn with and about each other through the shared semiotics of the application.

Introduction

This article enters into discussion with literature around algorithms and anthropology (Seaver 2017; 2018; 2019) through intimate ethnography (Waterston 2019) with my sibling. The unfolding processes of my ethnography, participant-observation, "Tik-Talks", and work with the TEC, are brought into conversation with theoretical and methodological approaches in digital anthropology. The framework is analysed through a Deleuzian lens, tracing *assemblages* and *lines of flight*, to understand and question how the socio-technical space of algorithms, and particularly TikTok as a site where people form algorithmized identities (Bhandari and Bimo 2022) entangled with neoliberal, capitalist structures. Despite this, *cracks* (Holloway 2010; Austin Locke, this volume), and fissures appear which provide us a purview of how people are reappropriating social media for their own purposes. Some of these fissures or lines of flight complexly connect (Tomlinson 1999) to one another and are theorised here as ways of learning how to belong on TikTok, and in the specific case of my sister- Alanna Cerretani and myself- learning about Ehlers Danlos Syndrome, and the communities that surround it online.

Social media platforms like TikTok are implicated in the (re)creation of power hierarchies of global capitalism and other modes of oppression (Takaragawa et. al 2019). TikTok's ability to transcend nation-state boundaries, collapsing temporal realms and (re)peripheralizing the local into the global, shows TikTok's potential as a place

for teaching and learning about central themes of anthropological inquiry like belonging. However, as Gershon (2011) points out in their article on neoliberal agency on social media, TikTok is a corporate product mired with problematic neoliberal demands on users to fashion themselves as businesses through the circuits of capital. These metrics fuel the analytic-driven algorithm towards optimum profits for the company, meaning algorithms are tuned for maximum engagement, at times leading to misinformation and a lack of oversight or policy capable of protecting users from bullying, and potential for self-harm (House 2022).

This is not to say that TikTok and other social media can be summed up solely as entities reproducing neoliberal ideologies, or their own business-centric intentions in gaining advertising revenue and data mining. Exploring self-making practices on TikTok can give us insights into how communities are forming in novel ways. Social media platforms, which share multimodal media, have been studied extensively in terms of sociality and self-making— such as self-representative practices (Thumim 2012; Tiidenberg and Whelan 2017); the harms of social media networking sites (Vogel, E. A., and Rose, J. P. 2016); and TikTok-specific *algorithmized* identity making (Bhandari and Bimo 2022). The ways people appropriate applications like TikTok for their own purposes, regardless of the corporate interests of the applications, are exemplified in the self-making processes that I explore through ethnography with my sister, my own participant observation, and in collaboration with TEC.

To understand how users are working against the neoliberal grain to learn about themselves I borrow from Deleuze and Guattari, and subsequent writings around “lines of flight”, an idea developed in *A Thousand Plateaus* (1987). The concept is widely interpreted, and I make my interpretation about *assemblages*, or the diverse ways that socio-technological agency is produced and reproduced, to see a line of flight as representing the unique link within an assemblage which breaks open or adapts beyond the normalised use. Hence, for users to learn a sense of belonging and self on TikTok, against the tides of the neoliberal and capitalist cultural influences, a line of flight emerges and complexly connects (Tomlinson 1999) people in different spatio-temporalities for a purpose which cracks the strata of contemporary capitalist society. This does not evade the neoliberal influences of engagement analytics, though as Franz et. al (2022) show, it may bring users to different places on and offline to find support for their capitalist-influenced physical and mental ailments. Franz’s studies focus on medical knowledge seeking and communal support of online communities centred around self-harm, in particular “cutting” and fibromyalgia. Such ailments, in the case of my sister, Alanna, would be her lack of access to affordable healthcare and the largely unavailable medical knowledge about her disability- Hypermobile Ehlers Danlos Syndrome.

When the algorithm “teaches” us about who we are it can be fascinating, false, vague, or “hyper-specific” (Rodgers and Lloyd-Evans 2021). So, how does the application give so many a feeling that it knows them, yet it leaves some people feeling on the periphery, belonging at the edge of their “For Your Page” (FYP)¹? One member of TEC felt the need to, “break up with [their] algorithm”, after being overwhelmed by their FYP’s singular focus. While I would caution describing TikTok’s algorithm as being egalitarian, given the many potentially pernicious outcomes of essentializing groups for technocratic purposes, some of John Dewey’s principles of learning (Cross 2017; Dewey 1938), like the reciprocity necessary to learn and teach, are being utilised by TikTok users. Self-making and social media use is a highly rich field studied across disciplines (Bailey et. al 2022; Franz et. al 2022). With TikTok becoming the most used social media platform it is important to understand how what Bimo and Bhandari (2022) call “algorithmized identity” is shaping self-making and belonging.

TikTok is differentiated from other social media platforms like Instagram, Facebook or SnapChat through its highly tuned algorithm and the FYP, where it delivers, “an algorithmized version of yourself” (ibid 2022). As they write,

In addition to exhibiting a heightened awareness of this algorithm, many participants indicated a temporal element to their relationship with it; their experience on TikTok changed the longer they were on the platform. This often resulted in the use of distinctly personifying and humanising language to describe the algorithm. Interviewees repeatedly described a shift in their recommended content and this shift was described as the moment that TikTok “got them” or understood them and was able to capture their personalities and interests with pinpoint accuracy. (ibid, p. 5)

¹ The app’s landing page which feeds the user algorithmically suggested content.

So, what is the mirrored identity presented to users on TikTok? How do users have agency in creating it, and how does it teach us to belong? TikTok offers a heuristic learning experience which enables users to explore their sense of belonging or *nonbelonging* (Campt 2009; Simpson and Semaan 2021) through its advanced algorithm, and the FYP. Users scale their sociality (Miller et. al 2020) through their level of engagement, from “passive” scrolling to “active” multi-media self-representation practices through comments, tags, and creating posts or “duetting”² with other users.

TikTok Temporalities

The Covid-19 Global Pandemic created an “enforced pause” (Rodgers and Lloyd-Evans 2021), with millions of people experiencing social isolation like never before. This new era made social media more ubiquitous than ever, with more people of all ages taking up smart phones for different purposes (Bear, Simpson et. al 2021; Miller et. al 2021). With this disruption of regular temporal flows, TikTok came to prominence as the app of the pandemic. What is it about TikTok with its short-form video-centric, highly algorithmized format that made it the perfect fit for finding social connection during a period of immense isolation?

At the onset of the pandemic, I was conducting field research in Southeast Asia, regularly based in Europe, and had the privilege to annually visit my family in the United States. By the fall of 2020, I was confined to a flat in London where I was beginning my graduate studies. Rather than taking a motorbike to the community school in rural-village Malaysia to collaborate on self-representation practices and multimodal pedagogies, or flying home for my octogenarian grandmother’s birthday, I was “travelling” online to connect with my networks via WhatsApp, FaceTime, Instagram, and Facebook. I needed to learn how to be an anthropologist in a time of extreme isolation. The onset of Covid-19 brought many anthropologists and field researchers to reckon with a long simmering tension around the tradition of long-term immersive fieldwork. The *Patchwork Ethnography* manifesto (Günel et. al 2020) argues for a movement towards a fragmented and stitched together approach to ethnography which reflects how the lives of ethnographers come with personal responsibilities and challenges which, alongside the pandemic, require new approaches to fieldwork.

London, like much of the world in Fall 2020, was locked down and there were stringent regulations on “in-person” social interactions. As an American who had been living abroad before the pandemic, my way of life was structurally disrupted by the enforced pause. Prior to the pandemic, I would describe myself as constantly in motion, trying to keep up with the culture I am part of. My identity was markedly “networked” (Knox et. al 2006; Collins and Durlington 2015), tied with many people, many places and temporalities. Yet this reflection on the notion of time and the speed of life was absent, until the pandemic slowed me down. As a newcomer to London, I found the lockdown periods especially isolating, and often turned to the internet and social media to fulfil my social needs. Scrolling, clicking, and tapping became the means by which I sought sociality.

Digital connectivity is not a replacement for physical or analogue forms of communication and meaning making. However, the digital places to which we connect constitute a culture unto their own (Pauwels 2012; Treré 2015). Spaces imbued with meaning become places where we create lifeworlds. During this period of isolation, I would connect with my sister, Alanna, through Instagram and Facebook. At the time, she was living in a small rural town in North America with my mother and my grandmother, and we were both using TikTok regularly. I wondered what we both made of this place. Did we find similar meaning in the same video memes? Did we find ourselves in the same “Toks”³? While my sister and I share overlapping cultural contexts, we also live on different continents, but with the collapsing of space and the rubber-banding of time, I was curious if and where we both felt a sense of belonging online. I wondered what she was learning about herself, as I too was experiencing a flood of new information. Within these digital communities can we build a sense of self and, in doing so, learn to belong?

As the discussions between Alanna and I progressed, the overlaps between our chats and my research became filled with anthropological potential. The intimate nature of Alanna’s engagements with TikTok, and the anthropological nature of my research meant that the ethical considerations needed took on a particularly significant charge. The ethics of working with a sibling on a sensitive research topic go far beyond a tick-box exercise and have been at the core of my research engagements with my sister.

²Duet allows you to post your video side-by-side with a video from another creator on TikTok. A Duet contains two videos in a split screen that play at the same time. source: <https://support.tiktok.com/en/using-tiktok/creating-videos/duets>

³ Spaces dedicated to a certain theme or interest within TikTok, like WitchTok, BookTok, or EDS-Tok

Anthropology has long had a presiding ethics of anonymity for interlocutors or participants. At times automatically choosing anonymity seems appropriate, but at other times, in cases like this, it seems deeply inappropriate.⁴ Taking the anonymity clause for granted and as a default practice can itself be considered a questionable ethical practice (Walford 2018; Duclos 2019; Vorhölder 2021), and my discussions of anonymity with Alanna further serves to illuminate the complexities of navigating anonymity in ethnographic research. However, to assume that all people must be anonymous is against an ethos of anthropology which is far more prescient, that we should not arrive with concrete assumptions to the field, this applies to the many worlds of digital ethnographic research as much as it does to our more physical field sites.

Alanna's willingness to be involved in this research was discussed during our first Tik-Talk, and was a repeated topic throughout the research process, during which we clarified the topics and content she and I felt comfortable discussing in a public forum. She is under no pretence about the potential consequences of sharing one's intimate life details. Alanna has read and approved of every draft of this article, making sure her words and story were well conveyed, and nothing was out of the scope of what she wanted to share. To be clear, I am not arguing that anonymity is a practice which should be altered across the board, it is imperative to do no harm, and avoid any social, personal, psychological, or other impacts with those who we build our relationships with through our work as ethnographers. In engaging in ethical practices, such as deciding whether to anonymise, our participant's own agency and considerations of the matter must be taken into account. For example, Alanna's own acute understanding of anonymity, as evidenced in her asking me to not name specific persons she was interacting with in writing, shows that she is under no pretence about the potential consequences of sharing one's intimate life details. Alanna has read and approved of every draft of this article, making sure her words and story were well conveyed, and nothing was out of the scope of what she wanted to share. She is acutely aware of having sensitive information on the internet and the risks that come with it, both from our direct discussions on the topic, as well as her own experience of all-things-online. In simplest terms, Alanna Cerretani, wants to be named, for this is her story to tell, and it is a matter of ownership. The risks of taking Alanna's story from her by coding her into an anonymous character far outweigh any benefits, and in fact, Alanna is squarely opposed to the idea and I agree with her wholly.

The remainder of this paper is going to explore the ideas and theories which have emerged from Alanna's experiences on TikTok, and from the fruitful exchanges of our Tik-Talks. It will offer insights into the TikTok algorithm and the self, and the increasing role of algorithmically controlled social media platforms in how many learn about themselves in intimate and exploratory ways.

Algorithmography

Studying anthropology during the pandemic was challenging with limited social connection, so the TEC became a place to teach each other how to cope with the quickly shifting fields around us. TEC meetings made it possible to have space to reflect on our individual and shared explorations into digital lifeworlds, including the methods we were creating through experimentation on a relatively new platform. Learning to use TikTok ethnographically was born out of my aim to keep strong connections with those who are dear to me and who I was unable to visit during the pandemic.

In my engagements with TikTok I veered between a more active attempt at curating or controlling my FYP by closely considering the decisions around the time spent on a video, liking, following, commenting, and a more passive engagement with the app, typically of late-night scrolling, unconscious decision making, and seeking entertainment as compared to interest or knowledge seeking that came with the more active side of the scrolling cycle. This active engagement with and attempt at changing my FYP was an incidental stepping towards a method of what I will later refer to as *algorithmography*. I was trying to reverse engineer who the algorithm thought I was, and explore how I could shape that by trying to define or defy that through my engagement. Keeping in mind literature on algorithms and their cultural embeddedness (Seaver 2017), and holding a wariness of recreating anthropological dialectics between analogue and digital, human and machine (Seaver 2018), I set out to better understand myself and my sister through the use of TikTok, and the many cultural forces that inform its

⁴ In cases like this paper, in which the story at hand is that of my sister, I argue it would in fact be completely out of line with anthropological, Hegelian (Stark 2014), Kantian (Pinzan 2022), and kin-ship responsibilities (this article), not to mention something of an appropriation of one's story which has been told by them through our relationship.

algorithm. With the algorithm mediating my fledgling methodological interrogations I undulated in my modes of engagement.

When I was more focused and critical about each and every action on the application, I could quickly see a change in the videos towards something more engaging, or more attuned to my momentary interest, as compared to when I casually scroll and linger on videos of little interest, or when I don't take time to like, comment or intentionally linger on a video to receive more of that content. I felt I could see ripples in the algorithm, like a liquid reflective surface of a pond. With diligent engagement one may see the image to be quite closely resembling themselves echoing like an infinity mirror, but with a carefree scroll the peripheral winds chop up the water, revealing the wrinkles in the ripples of the digital twin, and such an image may be reduced to entertainment in its textures and contours, but not a very accurate portrayal of the self, leaving me unfulfilled.

In her breakthrough book, *Algorithms of Oppression* (2018), Safiya Umoja Noble discusses how algorithms reflect and are inscribed with the negative biases that exist in wider society, and can therefore reinforce and perpetuate racism. Nick Seaver (2018) adds to this discussion expressing the human-side of algorithms, stating that programmers are attuned to culture as they write code, and that the demands of users come into dialogue with programmers who attempt to adapt an algorithm based on an issue which is brought to them. Whilst Programming teams do make some attempts to overcome the problematics of misinformation on algorithm based social media apps like TikTok, and recalibrate algorithms to be more discerning or offer some warnings about medical information, they can often remain caught in the perspectives of the broader cultural and political-economic systems of which they are part. Meaningful interventions concerning misinformation on the part of the platform are yet to be seen in the case of Ehlers-Danlos Syndrome Tok or EDS-Tok. In such situations the aim of maximum engagement shows how dominant cultural constructs come to shape the content users are most likely to see. Understanding of the cultural representations circulating on and embedded in the application concerning a community like EDS-Tok could be expanded through improved dialogue with such communities about their experience and use of the app.

Algorithmography situates itself in relation to literature on algorithms which dissuade a simple reading of algorithms as solely technical, and considers algorithms as socially informed, culturally constructed, complex, sociotechnical systems. This methodology, through autoethnographic reverse engineering of the algorithmized self, offers a partial window onto dominant cultural contexts of which algorithms are a part of, through attention to the self-making practices unfolding on such platforms. The same socio-economic systems anthropologists have interrogated for decades can be seen in the algorithmized self, which shows these systems to be creations steeped in culture as reflected through an algorithm-engaged autoethnography or *algorithmography*.

The differentiation of this methodology is the *line of flight* it takes; algorithmography asks how do our sensorial experiences within an application reflect the lifeworlds that these socio-technical systems are engulfed in? What does an algorithm's influence on our sense of self and our shaping of those algorithms tell us about the problematics of our neoliberal infused societies, as read through the creative (re)appropriations of TikTok to heal capitalist oppressions? How close do algorithms bring us towards a sense of belonging and can algorithm-engaged ethnography, or algorithmography say anything about filling this perceived-gap?

Tik-Talks

In speaking with Alanna about her exploration of her bodily experience through TikTok, I was able to delineate to a further extent the somatization between her physical and emotional affects. We discussed the videos and users she related to and those she strayed from. The discussions or "Tik-Talks", pushed my understanding of her experience past a surface-level association with the videos I saw about EDS, without which I may have been left with an essentialized understanding of the community which lacked nuance or the proper tools to empathise. This mediation of my relationship with, and understanding of, my sister and her experience speaks to the ways in which TikTok can bring us to teaching one another about our experiences.

When I was talking to my sister and she quoted a TikTok video, I realised how, despite my many misgivings with the application and social media in general, there was potentially something interesting to explore in understanding how my sister and I were learning about ourselves through the app. This opened a point of departure from simple recapitulation of the capitalist modes of the application towards an entry point to insight into our relationship – TikTok mediating a dimension of Alanna and I's empathy for one another.

Our first concerted effort at having a recorded Tik-Talk was a video call which focused on catching up on what we have been seeing and learning from TikTok, discussing the videos we have recently sent each other and sharing related content while co-analyzing the videos. The following is some of what we learned from and about each other.

We start out with a laugh as we both say, nearly in unison: “I am still figuring it out every time I use it”. I ask, “does your FYP get you?” Alanna replies, “well that’s how you start” with the FYP.

She went on to explain that for her, the FYP served the purpose of finding some interesting accounts to follow when she first came onto TikTok and that now she uses the following page primarily to follow exactly 100 accounts. As the conversation moves onto exploring the offerings of the FYP, I am caught when she says she likes to, “keep it clean, stay away from the darker depths, I try to stay away from the scary shit”. This she says is in reference to things she finds “depressing”.

She is also making videos, and says, “the kinds of videos I make are like the ones I look for in other content makers. Did you see my new video?” I had not seen it. Normally, I check her account each time I log in to see if she has posted anything new. Among her videos are some of her “pranking” our mom, and most are of her doing karaoke with her favourite songs. This new video though is different she tells me, “I posted one of my own songs”. We talked for a while about music, and her innate talent for singing. I mentioned that the song she posted would fit well with piano music, and maybe she can find someone on TikTok who would duet it.

Music scenes have been a place of community for my sister since we were teenagers. We were especially drawn to the punk and DIY scenes of our small towns, and frequently made trips to surrounding cities for shows from our favourite bands. These scenes were important parts of our self-making processes as youths and continue to shape our ethos and outlooks today. So, it comes as no surprise that part of my sister’s online community is centred around music. As it has become more difficult for her to attend music shows due to her chronic-pain related to Hypermobility Ehlers-Danlos Syndrome (HEDS), she has increasingly gone to the internet to find her scene.

We discuss what brought her onto TikTok in the first place, which was a musician she followed on Instagram reposting TikTok’s and encouraging people to use TikTok as they described it as “a place for self-expression”. She returns to a theme of fear when using the application, saying that this musician’s positive reflection on the creative outlet is what convinced her to get on even though she was wary of getting “addicted” to the application. The first thing she did was to follow five musicians, she recalled the one who got her to migrate from Instagram to TikTok, and two others.

As we are talking, I am cruising around TikTok and start to receive videos that say Russia has invaded Ukraine. This is prior to the invasion being reported on mainstream news. My sister says, “that’s what happens, the news is on there as news, before the news”. She uses the Travis Scott concert tragedy at AstroWorld as an example, “that’s what happened with the Travis Scott thing, with the AstroWorld festival, where people were helping, sending videos out on their phone...so, maybe right now Ukraine is being invaded ... if it’s accurate we will probably be flooded with it either way.” We both look around for something Ukraine related through the search function and scrolling with intent, moving quickly through videos that don’t match our inquest, but neither of us see anything more about it. TikTok can feel random like that as well, not always fulfilling the algorithm feed. Our Tik-Talk begins to wind down and we recap about her original song and where she might take it. My mom comes into her room, and we veer off from Tik-Talks to a family catch-up and then my mom leaves the room, and we start to talk about the prank videos of my mom that my sister made. She said she only kept one on her page because she felt bad. “I did keep the mouse one up because it was good”. I ask what she did with the other ones, she’s archived them she says.

We continue to talk about music accounts and reminisce on another show we saw. She mentions how next time we need to talk about “lives”⁵ and how “there are a ton of good lives”, she says, especially from the musicians she follows. She is excited to tell me about a musician who I had not heard of. She said this artist talks a lot about mental health and music, saying that is what she gravitates towards, because she relates to what she has

⁵ TikTok Live, is a way of broadcasting a video in real-time on the application source: <https://support.tiktok.com/en/live-gifts-wallet/tiktok-live/what-is-tiktok-live>

gone through in her life. We talk about how people showing vulnerability makes us feel comfortable, it builds trust, and gives a sense that you can open up as well.

You aren't going to want to follow these content creators unless they share a piece of their life, like did you really go through something? Why do you care about this? ...there's this other musician on TikTok, (he) has a lot of kids who follow him. He's sober now, but he also went through it, he had a very wild life...he's sober now though, and didn't die from trying to commit suicide, he's not in some huge band, but he's got a band that he's proud of, these little guys are the ones I like to follow, because they are excited about something small, but big to them. They get on live, and the chit-chat in the comments people they don't know at all, and talk to them about their days, and how they are doing, like "oh man that rent didn't go through, something is going to work out, it's going to work out for you", they are talking to them [fans as she describes the other users] like that with them. I am seeing these creators doing that kind of stuff, and I get down with following you, that's the kind of people I like to follow.
(Alanna)

We wrap up our talk, and I am left thinking of TikTok's (re)production of the self as seen in others, our criticism, and analysis of others' videos for their authenticity, and how this makes us feel a sense of belonging among these peers.

On August 2nd 2022, I went on TikTok and searched for "EDS syndrome" and began scrolling through the videos in the order they appeared. After beginning with some analysis around the accuracy with which some users are describing certain symptoms as they seem vague or inconclusive like, "being able to touch one's thumb to wrist", or some other signs of general hypermobility, I continue to scroll because I want to understand what videos my sister has been seeing, and to learn more about HEDS in one of the places where she has learned about it.

Thinking of my sister and her deep dive into such videos I sought a sense of how this process works, identifying with content and proceeding to self-diagnose, the relation to clinical diagnoses, and the impact for HEDS. As I scroll, a video showing finger bending comes up. Again, this reminds me of childhood and how kids would show 'weird bodily things' to get a reaction. I would bend my thumb behind my hand to show I was "different", and recall being disappointed when people would be surprised, shocked, or concerned, and could do the same. We used to say I am flexible or "double-jointed" using the term without medical knowledge. Some would imply it's normal, and that many people can do this thumb bend. But what about the chronic pain, my sister feels that she links to these signs in her body, connecting to others through social media? How does one discern the links between cause and symptom, or avoid concern regarding relations between hypermobility and chronic pain? After a few more videos I find myself reaching for my hand to see if I can stretch in that way. This raises questions: who tests their body for these things? For who is this abject, and for who is it visceral or cathartic through connection to others? I notice myself in the act of participant-observation, sharing in the question "does your body bend this way?" I feel myself pulled in, and wanting to step back, so I write down some notes around this process:

I click on a TikTok about HEDS:

A song called "sippy cup acapella version" by Melanie Martinez is being used in the first two videos. And the "symptoms" that people are self-describing as attributed to HEDS become more diffuse. "Personality disappears" "buys clothes bigger than your size", "standing in grocery stores and not buying anything" "all or nothing"- the last one solicits a comment, *all or nothing- omg*, a seeming revelation of connection between similar experiences. There seems to be a conflation between depression, (a lyric in the song also says- "kids are still depressed when you dress them up") and EDS, as to whether EDS is causing depression, or depression causing EDS, or how much they fuel each other in somatization cycle, makes for a further inundating web to untangle not unlike the physical description of the muscular fascia of someone with hypermobile eds being stuck together, implacable. The song and lip-syncing video style along with top-text which is listing the "things about Ehlers-Danlos they don't tell you.

The affect of thinking of my sister as being overwhelmed by this and having described many similar problems to me as those in the videos, is palpable. I imagine that the empathy I am feeling here translates some of the feelings she has with feeling stuck, and overloaded, and I question how the algorithm feeds and closes down further one's feeling of having a way out. The way in however, is something I can try to understand. It makes some sense that if you are dealing with these things, you will eventually try to understand them, and that social media is a direct and gratifying way to start to grasp what is going on with oneself when you are isolated from

others sharing similar traits. So, what happens when we see ourselves in others who are similarly suffering on social media, and particularly through what the algorithm feeds us on TikTok? How do we relate, apply, contrast, and build community and sense of self through these spaces?

August 3rd. I call my sister to catch up and we have a careening chat. The conversation is mostly light-hearted, but I mentioned that I had been watching EDS videos on TikTok and found them to be very intense, and asked her to catch up for another Tik-Talk later that week.

Conclusion

The ethnographic explorations of EDS worlds on TikTok or ED-Tok brought me to the juncture of anthropology and psychology gender and youth studies and towards an algorithmography of self-making. Ethnography can be an effective way of building empathy, as I have come to realise through participant observations of EDS-Tok and how it has helped me to understand the semiotics of affect in which my sister has been coming to understand her chronic-illness. Through a shared multimodal language (Alvarez et. al 2021; Dattatreyan and Marrero-Guillamon 2021), one which came directly out of TikTok videos, I am better able to perceive the thicketed world of (mis)information which someone with chronic-pain seeks to diagnose themselves. This speaks to the importance of taking seriously TikTok and newly emerging social media as sites with distinct knowledge making practices where anthropology's methodological approaches are well suited to investigate new cultural expressions. Places, loosely construed, which progress beyond antiquated notions of traditional field sites with a lone researcher towards networked understanding of identity which is not bounded or essentialized, but perhaps as Bimo and Bhandari (2022) have described TikTok lifeworlds – *algorithmized*. The culture of capitalist (re)production which these applications are built on is also reappropriated by users for their self-making practices, representing a line of flight, on which these neoliberal assemblages are adapting.

While anthropology and affect has been a main focus of my intellectual pursuits I am not trained in the fields of medicine or psychology. As I discuss these topics with my sister I am coming to her as her sibling and not as someone prescribing or equipped to help with the physiological realms of what she is going through. However, as her sibling, my care for her drives my desire to understand her on her own terms, which is also part of my practice as an ethnographer (Waterston, 2019). Through my use of TikTok and experiencing the rapid onset of clusters of content, I understood better how one can find and lose themselves in a funnelling cone of (mis)information spinning round, up and down, adhering to and recoiling from identities in a process of self-making as they try to understand something significant about who they are, like identifying a disability. This brought me to have a better sense of my sister Alanna, and what she was going through. TikTok mediated our relationship in a positive way, striking my attention to the benefits of our uses of TikTok that attempt to go beyond the limitations of neoliberal driven value-assessments of us as social media users.

During the last Tik-Talk with my sister before drafting this she says she's almost completely stopped using the app. She says it is mostly because her health has declined so much and making TikToks takes a lot of effort compared to using 'traditional' social media like Instagram or Facebook, where she can "just throw up a picture of my dogs and get some quick responses from friends and family". She says she cannot actually hold the phone long enough to use TikTok and that for her the point of TikTok is not only to consume but also to create. She went there for the music community. A few days after we speak, I open my TikTok and the first video I see is a new one from my sister. There is top text saying in large letters Hope, and the below caption reads, "I have decided to document my journey from here on out, in finding any freedom from pain – I feel alone in this so much, so I know talking about it will at least bring some relief." In the video she goes on to discuss her multiple diagnoses, and her challenges in working with doctors, and says that today she has seen a new doctor and been given an additional diagnoses, new meds, and that "there is still hope, even when there is so much pain". Since our last talk she has posted a dozen TikToks following her 'journey', including a road trip with my mother to see a metal concert in the next state over.

The onset of the Covid-19 pandemic created a large rupture which brought with it the need for anthropologists to think differently about the spatio-temporal realms. This brought me to learn about anthropology by thinking through how our social relations and how the digital mediates kinship structures. For my sister, TikTok was a place of learning and teaching others about her experiences with HEDS, and learning what communities she wanted to seek out online. While we were stuck inside there were many aspects of finding community that recalled our pursuits in local DIY music scenes, in finding others with similar passions and seeking alternative pathways to figuring ourselves out. TikTok and social media in general feel more fraught with unsuspecting

misinformation to me than the music scenes or back of classroom chats where we learned and traded ideas, and undoubtedly the internet does not substitute for these spaces of meaning, and yet there are new conversations, one's which would not be facilitated in brick and mortar, "real-world" scenarios which can make us feel more connected and learn a sense of how to belong since in my sister's case she had not come across others with HEDS other than online.

My venture into understanding Alanna's pursuits in self-making opened new fora for our relationship to grow regardless of geographic separation through Tik-Talks. To get a sense of how TikTok's algorithm generates an image of the self while at the same time gauging how that self perceives how *they* are being assessed by the application, allows for an algorithm-engaged autoethnography. Such a process opens possibilities to understand the ways in which users are educating themselves on the algorithm and using the application to serve their needs of belonging offers the potential development of new modes *algorithmography*. This proved to be a useful approach which mediated a deeper understanding of self and relationality to others online as I observed through the Tik-Talks with my sibling.

TikTok's algorithm and its reading of users through engagement analytics leaves me feeling a sense of ambivalence as described by Alvarez et. al (2021) about the ethical implications of this form of multimodal research and by Takaragawa et. al (2019), and generates concerns about reproduction of power hierarchies through techno praxis. Algorithmography is understanding how a person is viewing, interpreting and interacting with the sensory input of an algorithm and how an algorithm is designed to see a person 'the user', being a part of a culture which is entangled with capitalism can also be highly influenced to see themselves in the value constructs of neoliberalism- that is someone whose value is tied to their ability to consume and produce capital. The way in which individuals, based on their culture and identity, have various cracks of interest based on their need for belonging, can be seen as a lines of flight, which move them outside and beyond the shells and contours of engagement analytics, enabling them to have a sense of the construction of this digital self, and perhaps the future places of socio-techno space are being made through these processes.

Through an intimate ethnographic exploration with Alanna, into her challenges with Hypermobility Ehlers-Danlos Syndrome, I have come to see the importance of using TikTok as a way of understanding how we construct self-identity through finding community and belonging. In my sister's case trying to comprehend her symptoms alongside an online community. Without my use of TikTok I do not feel I would be able to see and perceive the nuanced experiences of my sister's work towards understanding herself, her body and her sense of belonging in these online communities. Through participant observation of EDS-Tok, and Tik-Talks with Alanna about her heuristic forms of self-discovery, a larger pattern of how TikTok is creating vectors for algorithmized identity has emerged. Following this *line of flight* – which is part of, yet paradoxically cracks through–capitalist modes of knowledge production, can contribute to digital anthropology's potential for mitigating the effects of techno-capitalist dominance by placing emphasis on the intimate and empathy-building capacities of social media like TikTok, while pointing towards the need for further research into what my sister described as the "darker depths" of which she tries to avoid while constructing a sense of self and belonging on the application that the world turned to for comfort during the Covid-19 pandemic.

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