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NOTHING WITHOUT US: AGENTIC POWER IN #MYDISABLEDLIFEISWORTHY

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Introduction

On January 7, 2022 Dr. Rochelle Walensky, Director of the CDC, went on Good Morning America to discuss the state of Omicron. While explaining that more than 75% of those who died after receiving the full series of Covid-19 vaccines were people who had at least “four comorbidities” Walensky concluded, “So really, these are people who were unwell to begin with. And yes; really encouraging news in the context of Omicron” (Good Morning America 2022). This statement inspired the viral hashtag #MyDisabledLifelsWorthy, started by Imani Barbarin. The goal of the hashtag, like #MeToo and #BlackLivesMatter before it, was to push back against the rhetoric that it is ok if chronically-ill and disabled people are dying or discriminated against. The hashtag raises awareness toward the high prevalence of chronic illness and disability in the United States while also critiquing discourse which dismisses these lives as expendable. While abled people were quick to argue that this was not Walensky’s intention, the hashtag brings to light how an inattention to disabled life perpetuates a system of harm. In this presentation, I analyze how the hashtag was strategically utilized by chronically ill and disabled people to push back on rhetoric which implies their lives are acceptable losses in a pandemic. This moves beyond the common declaration of the disabled community, “nothing about us without us,” to a new demand of “nothing without us.”

Literature Review and Research Questions

This project pulls on two distinct areas of inquiry: disability studies and digital studies, the latter focused on the sub-area of hashtag activism. Modern conceptions of disability are tied to the 19th century, when the Platonic Ideal was replaced with the modern concept of normal as the goal (Baynton 2013). With the Platonic Ideal, it was understood one can strive for the ideal but never reach it. With the concept of normal, however, there is an unattainable goal that now appears reachable. Worse yet, all those who do not reach normal are seen as deviant (Davis 1995; Goffman 2003). This is the world in which disabled people were largely unable to hold typical jobs (because they

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would not be hired) and the successfully disabled were found in the freak and side shows of the likes of P.T. Barnum (Craton 2009; Hughes 2012). This idea of disabled people as unable to be part of society because they deviate from the norm and are, therefore, not worth more than entertainment, has carried into the 21st century. To receive disability benefits in the United States, disabled people cannot work, have more than \$2,000 in their bank account, and typically only receive \$800-\$1800 on average. In addition, if a disabled person marries, they lose some or all of their disability benefits (SSA.gov 2022). This perpetuates a system in which disabled people are not able to be independent while simultaneously seen as disabled, continuing a cycle that infantilizes and makes deviant the disabled (Dolmage 2014). This is the environment in which we find ourselves when Dr. Walensky makes her ill-considered comment that allows disabled people to be seen as acceptable losses. And this is the environment disabled people are trying to change through #MyDisabledLifelsWorthy.

Hashtags are a common source for digital activism, known as hashtag activism (Dadas 2017). #MyDisabledLifelsWorthy follows in the steps of #MeToo and #BlackLivesMatter in that its focus is on bringing attention to an inequitable aspect of society that leads to severe harm. In both of these previous hashtags, agency is a key issue— the people being impacted (women and Black people) were the primary users of the hashtag (Wolfe 2018; Yang 2016). Importantly, these hashtags function as both a way to label and organize tweets as well as a rhetorical call (Denomme 2019). By using hashtags, members of a specific community can quickly find each other, share their stories, and perpetuate a discussion under a specific banner (the hashtag) with intent to increase the reach of the message (Wilkins et al 2019). Given the power of hashtags to circulate discourse and make meaning, hashtags can be a key feature of digital citizenship, drawing on Rob Asen's discourse theory of citizenship (2004). Therefore, I am considering the rhetorical power of #MyDisabledLifelsWorthy as an agentic attempt for equitable citizenship.

Methods

Since a key component of this project is the discursive strategy of #MyDisabledLifelsWorthy, this project uses the rhetorical methodology of discourse analysis. The project looks at the first 200 tweets using #MyDisabledLifelsWorthy to better understand how the disabled community is mobilizing this hashtag as a response to Walensky's words for the purpose of raising awareness and making change. By focusing on the first 200 tweets, I am better able to capture the initial meaning and intent behind the hashtag. Over time, the meaning and reach of a hashtag can shift or diminish. By focusing on hashtag use from the start of the digital response to Walensky, I am better able to understand patterns of intent that are central to the discursive power of #MyDisabledLifelsWorthy.

Preliminary Findings and Discussion

Notably, the pushback carried out through #MyDisabledLifelsWorthy led to an apology by Walensky to various disability advocacy groups for her "hurtful, yet unintentional"

comments. However, the disabled community continued to push for a public apology and acknowledgment that their lives are worthy. Through their hashtag, Disability Twitter questioned societal standards of normalcy and the dismissal of disabled life as expendable. Through this hashtag, the disabled community shared their conditions, stories, poems, critique of ableist language, and, perhaps most importantly, built a viral movement that could not be ignored by the CDC. While before the concern was nothing about us without us, #MyDisabledLifeIsWorthy illustrates a moment in which the disabled community banded together and moved for more inclusive equitable practice for disability in daily life. Because disabled life is worthy. My disabled life is worthy. We are not expendable.

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