

Work in Progress: Transferability of a Neurodivergent Codebook Developed from TikTok to Neurodivergent Engineers

Autumn Cuellar, Utah State University

Autumn Cuellar is a Ph.D. student in Engineering Education. Her undergraduate and master's careers were both in Computer Science. She believes that everyone can achieve their goals, regardless of physical ability. This is why Autumn strives to make engineering accessible for everyone.

Sarah Principato

Sakshi Solanki

Sakshi Solanki is a PhD student in the Engineering Education department at Utah State University. She earned a bachelor's degree in Electrical and Electronic Engineering from ITS Engineering College, India and a master's degree in Data Science from University at Albany, New York. She worked as a Data Analyst during one of her summer internships in 2020, where she learned and gained experienced in data evaluating and validating company's huge data using the techniques based on Excel, Python, and R. She is currently working with Dr. Marissa Tsugawa on Neurodiversity Research and Education. She believes that neurodiversity can help her better understand her younger brother's condition (Asphyxiation) and respond to his basic needs because his mind works differently from everybody else's due to which he unable to express his feelings and pain.

Dr. Catherine McGough Spence, Minnesota State University, Mankato

Catherine Spence is an Assistant Professor at Iron Range Engineering through Minnesota State University, Mankato in the Integrated Engineering Department. She received her PhD in Engineering and Science Education in 2019 and a BS in Electrical Engineering in 2014 at Clemson University.

Dr. Marissa A Tsugawa, Utah State University - Engineering Education

Marissa Tsugawa is an assistant professor at Utah State University focusing on neurodiversity and identity and motivation. She completed her Ph.D. in Engineering Education focusing on motivation and identity for engineering graduate students.

WIP: Transferability of a Neurodivergent Codebook Developed from TikTok – Implications for Exploring Neurodivergent Engineering Students

Abstract

The purpose of this work-in-progress research paper is to determine the transferability of a neurodivergent codebook using social media content from TikTok. The neurodiversity paradigm has started to shift public and scholarly conversations about being neurodivergent from a deficit framing to a celebration of differences in brain functioning. Engineering education researchers should join these conversations when we consider accessibility for students with hidden disabilities to integrate the emancipatory language emerging from these conversations in our research. For this WIP study, we began a directed content analysis (DCA) on publicly available TikTok content about being neurodivergent (n = 100 TikToks). We used *a priori* codes developed in a previous study during summer of 2022, which included a thematic analysis of similar TikToks about neurodivergence (n = 200 TikToks). We present our preliminary results of 20 TikToks to demonstrate the transferability of the previously developed codebook. Our current results indicate that the codebook is transferable with one code emerging from the analysis.

Keywords: Neurodiversity, Transferability, Qualitative Research, and Social Media Analysis

1. Introduction: Understanding Neurodivergent Experiences in Engineering

The purpose of this *work-in-progress* research paper is to determine the transferability of a neurodivergent codebook developed from social media content on TikTok. Neurodiversity studies and acknowledgement of neurodivergence within diversity conversations are starting to emerge within engineering education research [1]–[5]. For example, a spike of publications mentioning “neurodivergent” or “neurodiversity” in the ASEE Peer depository occurred in 2020, which marks the early COVID-19 quarantine timeframe (e.g., [6]–[9]). This quarantine was significant for the neurodiverse community as many undiagnosed adults discovered through social media (specifically TikTok) that they are, and always were, neurodivergent [10]–[14]. While neurodivergent experiences are being included, fundamental understanding of what it means to be neurodivergent is still limited to deficit-based and clinical framing [15], [16]. Recent research questions the validity of the Diagnostic and Statistical Manual of Mental Disorders and suggests that the clinical definitions for diagnoses such as autism, ADHD, bipolar, and schizophrenia are vague and inadequate [17]–[21]. Further, neurodivergent people with multiple oppressed social identities (e.g., race/ethnicity, gender, SES) experience misdiagnosis, do not have access to diagnosis, are unaware of neurodivergence, or distance themselves from neurodivergence due to stigma [22]–[27]. As such, we argue that engineering education researchers need to 1) *conceptualize what it means to be neurodivergent* and 2) *develop a neurodivergent identity theoretical framework* as we begin to include neurodivergent experiences in engineering.

We begin to explore what it means to be neurodivergent and work toward developing a neurodivergent identity theoretical framework in our on-going research. Last year (2022), two of the authors, Cuellar and Webster, shared their own narratives with disability and

neurodivergence in engineering [6]. Their narratives revealed differences in access to accommodations and understanding their needs based on the (in)visibility of their disability and neurodivergence. Particularly, Webster engaged in the video-based social media platform, TikTok, which served as an information hub and helped reduce stigma when learning about their recently discovered invisible disability and neurodivergence. Social media platforms uniquely give voices to marginalized social groups [28], [29] and provide a plethora of lived-experiences and socially constructed knowledge within those communities [30]–[34]. Particularly, neurodivergent people formed their own niche communities on TikTok [11], [35], [36] and Twitter [31], [37] where lived experiences are shared to connect with other neurodivergent people. Through these online communities, neurodivergence is being reconceptualized as a positive characteristic of identity [31], [38] by generating their own emancipatory language to describe their experiences.

We chose to explore content created by and for neurodivergent people on TikTok to learn the emancipatory language needed to understand and represent what it means to be neurodivergent. We downloaded, transcribed, and qualitatively coded 200 TikToks over the summer of 2022 and developed a neurodivergent codebook containing 56 codes that broadly characterize neurodivergence (manuscript under preparation). Before determining the transferability of our neurodivergent codebook in engineering contexts, we need to establish quality and rigor of our codebook [39]. As such, in this WIP paper, we begin to establish the transferability of the neurodivergent codebook by analyzing 100 new TikToks from the fall of 2022 because the neurodivergent language may evolve over time and social context as the community grows. We can establish quality and rigor by determining the transferability of our codebook in the same social context but different temporal context. By establishing quality and rigor in our codebook that characterizes neurodivergence, we will have a strong tool that characterizes neurodivergence when applying it to engineering contexts.

2. Positionality and Neurodiversity Research Paradigm

Before delving into this study, we provide our positionality statement here as our positions influence how we conceptualize the theory and methodological choices [40], [41]. Although the research team is diverse in many ways, we share a common goal of highlighting the voices of neurodivergent and other marginalized peoples in our research. All but one has backgrounds in engineering whereas the other author has a background in math and math education. A majority of the research team are neurodivergent or disabled and leveraged their lived expertise in this research. The team is also diverse in race/ethnicity, gender, and international status which also provided diverse perspectives in approaching this research. Autumn Cuellar, who led the analysis, is a White woman from the Western United States. She identifies as Neurodivergent with her disability being physically visible due to the brain's cerebellum. Cuellar has a background in Computer Science and is currently pursuing an Engineering Education doctorate. Her experience in computer science, and STEM in general, influenced her desire to make engineering education more accessible for everyone.

The *neurodiversity paradigm* shifts the thought of disability and mental illness away from pathological (e.g., medical conditions) toward a diversity perspective that values and celebrates differences or diversity in brains [16], [42]–[44]. As a relatively “new” psychological state [16],

published knowledge about neurodivergence is limited to pathological models of disability (e.g., [17], [45]–[47]). Pathological models limit understanding of neurodivergent experiences because it reduces neurodivergence to curable disorders and diseases [48], [49] (e.g., the case of autism [50]). Instead, neurodiversity advocates for a social model of disability where disability is a result of bodies and minds interacting with the social and physical environment [51]. The *neurodiversity research paradigm* centers neurodivergent voices and accepts their autonomy and self-determination [16] and reject “fixing” disabled people [52] in order to understand, support, and create access for neurodivergent people [44]. The main tenants of the neurodiversity research paradigm include accepting neurodivergence/disability as a part of one’s identity, self-determination, and including neurodivergent/disabled people in the research process.

4. Method

For this study, we replicated a small-scale, qualitative study conducted over the Summer of 2022 during an NSF Research Experiences for Undergraduates (REU) program (manuscript under preparation). During the REU program, neurodivergent undergraduate researchers collected content from the video-based, social media platform TikTok (n = 200 video posts), transcribed the videos, and generated a neurodivergent codebook through inductive coding and thematic analysis [53]–[56]. In this WIP paper, we begin to determine the transferability of our neurodivergent codebook using directed content analysis [57], [58]. Transferability helps determine how well results from one qualitative study apply to another similar qualitative study. While qualitative research cannot be generalized like quantitative research, readers of qualitative should be able to identify elements that can be applied to other situations [59]. We chose to analyze TikTok again as the neurodivergent community and its language are still evolving. Our aim was to determine the temporal rigor of the codebook (e.g., the codebook captures the content despite conversation shifts about the content). By determining whether the codebook is transferable in the same context, we can provide evidence for its robustness and application in engineering educational contexts. Figure 1 shows an overview of the research process including the summer study.

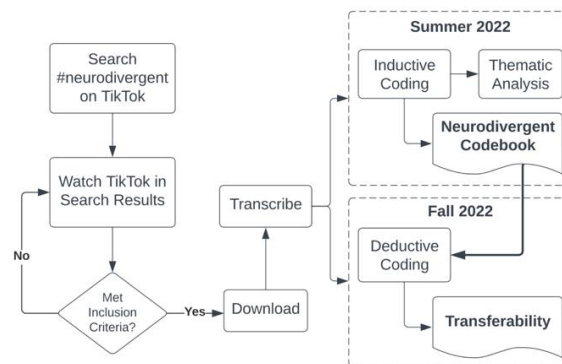


Figure 1. Overview of the research design.

4.1. Research Context – TikTok

TikTok is a popular, video-based social media platform where users create short video clips that describe or show their experiences as a form of expression and has unique community interaction [60], [61]. TikTok, gained popularity during the COVID-19 pandemic [60] and continues to be

one of the top apps on both the Apple App Store and Google Play (as of February 2023). Unlike other social media platforms (e.g., Instagram, Twitter, Reddit), the TikTok algorithm personalizes users' For You Page (the "homepage") which generates niche TikTok communities [61], [62]. TikTok content can also be searched and content from followed Content Creators are populated in a separate page. Content Creators, also known as TikTokers, can quickly and easily create video content (TikToks) using smartphones to share lived experiences, communicate with and respond to other users, and build community. Each TikTok can be as short as a few seconds or up to three minutes and may fit into a number of different genres including acting, animated infographic, documentary, news, oral speech, pictorial slideshow, and TikTok dance [63]. Finally, TikTok offers community engagement (e.g., likes) and interaction features (e.g., "stitch") unique to this platform [29].

To protect autonomy and equality of individuals, we designed our research following the Internet Research: Ethical Guidelines 3.0 [64] when centering neurodivergent voices on the internet using person-centered research methods. We collected publicly available content only (not private) and stored the data in a secure Box folder. To protect the identity of the creators, we also used pseudonyms for each content creator and blurred out faces and usernames on shared screenshots. We will delete all content on Box at the end of the analysis providing a deidentified dataset to the institution's digital commons for study replication.

4.2. Data Collection and Transcription

One hundred neurodivergent TikToks were collected between November 15, 2022 and November 21, 2022 using the mobile app (iPhone). To ensure process reliability [39], [65], [66], TikTok settings related to access other phone features (e.g., camera) were disabled to prevent any external influence on the algorithm. Inclusion criteria included content must be available to the public (public TikToks are downloadable while private TikToks are not); informational, narrative genre (excludes TikTok dances and jokes); and educational such that they describe lived experiences, discuss scenarios or hypotheticals, or spread awareness of social interactions. The first 50 TikToks that met the inclusion criteria were downloaded from the Search page by searching "neurodivergent." Content populated from the search page tends to be old and based on popularity rather than recently uploaded. The last 50 TikToks were downloaded from the For You Page using the same inclusion criteria as we were previously not able to initiate the TikTok algorithm to collect random and novel TikToks. Finally, all 100 videos were transferred to Box for storage then transcribed using Microsoft Word's Dictate feature. Any text that appeared in the video (e.g., captions or pop-up text) or visual cues essential to the videos were also transcribed. Transcripts were then uploaded to MAXQDA for analysis.

4.3. Data Analysis

Cuellar led a directed content analysis (DCA) which is a deductive coding method using *a priori* codes and allows for codes to emerge from uncoded data [57], [58]. We used the neurodivergent codebook generated during the Summer 2022 REU program as *a priori* code. The REU researchers (Sarah Principato and Brady Webster) developed the neurodivergent codebook which contains 56 unique codes through inductive coding methods from the 200 neurodivergent TikToks collected in May 2022. These codes describe both lived experiences and characteristics of neurodivergent people on TikTok (code samples shown in Appendix Table A1). The codebook also includes example quotes that support the code definition. To ensure validity [39],

[65], [66], Cuellar co-coded the first few transcripts with the other authors for procedural and communicative validation and process reliability then focused only on the transcripts being coded [87]. She also discussed any coding uncertainties with Tsugawa for pragmatic validation.

5. Preliminary Results

For this study, Cuellar transcribed and coded 20 of the 100 downloaded TikToks. As the previous study was not able to initiate the TikTok algorithm to populate neurodivergent content on the For You Page, we prioritized analyzing TikToks from the For You Page. We prioritized these TikToks because we wanted to see if the neurodivergent codebook generated from searched content would transfer to novel TikTok content. Figure A1 (left) in the Appendix shows the frequency of codes across TikToks (documents) where codes are counted as one per document containing that code (e.g., a code appears in 14 documents has a frequency of 14). Figure A1 (right) in the Appendix shows the frequencies of the codes from the previous Summer 2022 study. Currently, the top two most frequent codes in this analysis are ASD (Autism Spectrum Disorder, $n = 14$) and Neurological Differences ($n = 14$) compared to ADHD ($n = 115$) followed by ASD ($n = 91$) in the previous study. So far in this analysis, one new code emerged (Hyper-Empathy) in one. As the research team continues to analyze the TikTok content, this new code may be used in other TikToks and other emergent codes may emerge.

6. Discussion

The preliminary results for this WIP study gave us insight on the evolution of neurodivergent conversations and the transferability trends. ADHD and ASD (autism) tend to dominate the conversation on neurodivergent TikTok. Our previous results indicated that ADHD and ASD were the most common topics discussed on neurodivergent TikTok. However, the neurodivergent community is aware of this disproportionate representation which may be captured in the conversation shift to *neurological differences*. The neurodivergent codebook generated in Summer 2022 is trending as transferable to a different but similar context. The context was similar because we investigated TikTok and different because we were able to view recommended TikToks from the For You Page. All codes were used at least once and in their original meanings.

7. Summary

In this WIP, we presented our initial findings to determine the transferability of a neurodivergent codebook developed from TikTok. By determining whether the codebook is transferable, we will be able to use this codebook in engineering contexts. We analyzed 20 neurodivergent TikTok videos using directed content analysis which requires *a priori* codes when analyzing the data. The preliminary results indicate that the codebook is transferable with only one emergent code. The research team has 80 more TikToks to analyze for a finalized neurodivergent codebook. Engineering education researchers can use this codebook in their neurodiversity research to understand neurodivergent student experiences in engineering education and make engineering more accessible.

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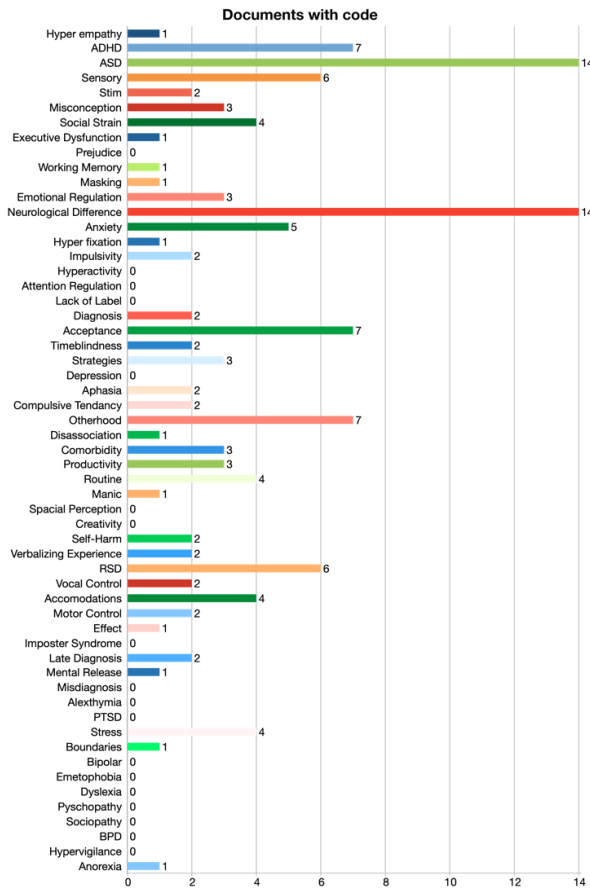
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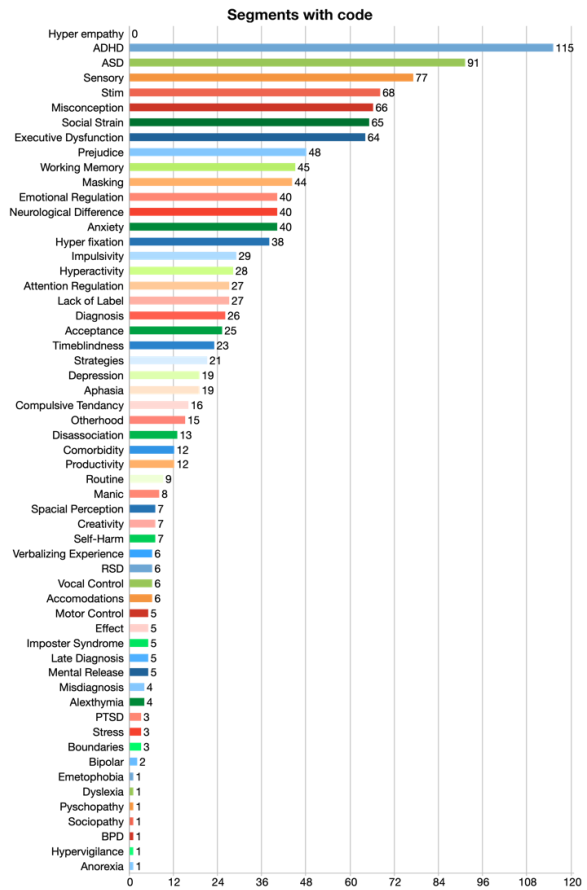
Appendix

Table A1. Example codes from the neurodivergent codebook developed over the summer of 2022.

Codes	Descriptions
ADHD	Attention deficit Hyperactivity disorder
ASD	Autism Spectrum Disorder
Neurological Difference	Deviation in brain chemistry/function/or overall makeup (Includes difference in mental structures, systems of memory information storage)
RSD	Rejection dysphoria
Stim	Repetitive self-stimulation



a) Current Study Code Frequencies



b) Summer 2022 Study Code Frequencies

Figure A1. Code frequencies across TikToks (documents) where a) displays code frequencies for the current study while b) displays code frequencies from the Summer 2022 study.