Published in final edited form as:

J Mot Learn Dev. 2023 December; 11(3): 525-540. doi:10.1123/jmld.2023-0007.

Identity and Discourse Among #ActuallyAutistic Twitter Users With Motor Differences

Riya Chatterjee¹, Nicholas E. Fears^{1,2}, Gavin Lichtenberg¹, Priscila M. Tamplain³, Haylie L. Miller¹

¹School of Kinesiology, University of Michigan, Ann Arbor, MI, USA;

²School of Kinesiology, Louisiana State University, Baton Rouge, LA, USA;

³Department of Kinesiology, The University of Texas at Arlington, Arlington, TX, USA

Abstract

Despite a growing awareness of the prevalence of motor differences in the autistic community, their functional impact is poorly understood. Social media offers the ideal setting to observe this discourse in a less-contrived setting than lab-based structured interviews. The aims of the present study were (a) to determine the proportion of Twitter users who self-identify as autistic and dyspraxic/having developmental coordination disorder, relative to autistic alone, and (b) to identify common themes emerging from two moderated chat threads with motor-related prompts. Using the Twitter research application programming interface, we harvested data from users' public profiles and tweets containing terms related to autism and developmental coordination disorder within a 1-month time period. We also harvested data from two #AutChat threads related to motor skills, which included 151 tweets from 31 unique autistic users (two with co-occurring developmental coordination disorder). Of these tweets, 44 were explicitly about motor differences, while the remainder consisted of discussion topics more loosely associated with motor skills. The following common themes were quantified: manual dexterity, lower extremity, oral motor, gross motor, posture, balance, stimming, movement pain, and coordination. Together, these findings indicate that motor differences are highly recognized and discussed among autistic individuals but are not overtly integrated into their identities at the same rate.

Keywords

autism; social media; developmental coordination disorder; dyspraxia

Despite a growing awareness of the prevalence of motor differences in the autistic community, ¹ their functional impact is poorly understood. There is a particular dearth of literature on the experiences of autistic adults, in part due to the limited accessibility and inclusivity of autism research. It is critical to understand how autistic adults think and feel about their motor differences, and to what degree these differences impact their identity

Miller (millerhl@umich.edu) is corresponding author.

^{1.} We use identity-first language throughout the manuscript; please see the Author Note for additional information about the motivation for this choice.

and comfort with daily living skills. We need new methods to build this knowledge through natural discourse, with minimal burden on autistic individuals.

Motor Skills and Autism

Despite an uptick in recent attention, there is still a dearth of research on the specific relation between identity, motor skills, and daily living in autism. Motor competence is an important factor in the development of autistic adolescents' identity (Timler et al., 2020), and as such, it is critical to understand autistic people's perspectives on this relationship. Autistic individuals' relationships with motor competency will help to inform therapeutic and accommodative approaches so that they are identity-affirming and tailored to self-advocate needs and preferences. Conversely, motor differences are associated with poorer mental health and quality of life in related neurodevelopmental conditions (e.g., developmental coordination disorder [DCD]; Tamplain & Miller, 2021). It follows that a similar relationship may exist for autistic people, given the overlap in observed motor differences between these two populations (Caçola et al., 2017; Miller et al., 2021). Prior research indicates that poorer motor skills (e.g., gesturing, postural control, body position, and facial expression) are associated with greater difficulties in social communication among autistic children (Craig et al., 2018) and that poorer motor skills are associated with lower adaptive behavior scores after controlling for intelligence quotient (IQ) among autistic children and adolescents (Fears et al., 2022). However, the degree to which autistic people recognize their motor skill differences as part of their identity and perceive their impact on daily living remains unknown.

Given that motor skill differences are a lifespan issue (Leversen et al., 2012), autistic adults can offer valuable insight into their downstream developmental impact. Social media platforms are a useful aggregator of autistic adults' perspectives. In recent years, autistic and other neurodivergent and disabled people have formed online communities that engage in meaningful, lively discourse about their identities, their abilities and disabilities, and their daily living experiences. This rich body of data is an excellent resource by which we can gain insight into autistic people's experiences with motor differences and the degree to which they perceive motor differences as part of their identity.

Disability, Neurodivergence, and Online Identity Discourse

Online identity discourse among the neurodivergent community is thought to be an important factor that contributes to the everyday life of individuals and may shape people's perspectives on their own neurodivergence. Individuals with intellectual and developmental disabilities vary in the degree to which they view disability as part of their social identity (Beart et al., 2005). This diversity in identity may be because of disagreements with or difficulty understanding key descriptive terms applied to their community, because of a general awareness of the stigma attached to disability as an identity, or because of direct experiences with others' biases related to their identity (Beart et al., 2005). These factors may result in negative experiences that are detrimental to an individual's self-concept and may shape their discourse within and outside of the disability community (Bitman, 2021). This is particularly salient for those with concealable communicative disabilities (e.g.,

autism), whose social media experiences are directly correlated with their self-concept and perception of their identity (Bitman, 2021). Specifically, in a study of Facebook users, three factors related to whether those with concealable communicative disabilities (e.g., autism) had positive experiences with social media: whether these individuals saw themselves as disabled, the extent of their fear of stigma, and the degree of disability they experienced in daily living. Although social media platforms represent both positive activism and negative stigma, these platforms can provide a space for people with disabilities to promote their own perspectives and promote acceptance through disability activism.

There are important remaining questions about neurodivergent people's experiences with disability as identity and about how disability manifests in daily living (Beart et al., 2005). Motor differences are common among autistic adolescents and adults, but are still poorly recognized, understood, and accommodated (Miller et al., 2021; Zablotsky et al., 2015). We still do not know the degree to which motor differences interact with autistic people's environmental and individual characteristics to produce an experience of disability. Perhaps even more specifically, to what degree do autistic people incorporate their experiences with movement problems into their social identity, and how is their social identity expressed in public discourse? Specifically, we focused our examination on the discourse of autistic Twitter users, both independently and in the context of moderated chat threads.

Autistic People's Online Discourse

Autistic people's perspectives have historically been suppressed or disregarded in public discourse and in research, and instead, caregivers' perspectives have dominated the landscape (Ward & Meyer, 1999). Studies show that the autistic self-advocacy movement is growing but still nascent compared with self-advocacy groups of physically disabled people (Dekker, 2020; Leadbitter et al., 2021). Fortunately, many (though not all) autistic individuals are able to engage in technology use and written communication (Ward & Meyer, 1999). As technology use and accessibility have increased globally, the autistic community has established a stronger presence on social media, which offers a more visible platform for expression and self-advocacy (Brownlow et al., 2006). Although neurotypical and medically dominated mainstream media discourse may distill or misrepresent autistic perspectives, social media platforms provide alternative venues for autistic people to speak for themselves, explore different perspectives and identities, build communities, and share resources (Dolphin, 2011; Sweet et al., 2020). As such, social media offers an alternative means of observing discourse and identifying commonly occurring themes in conversations among neurodivergent people in a setting that may be less contrived than lab-based structured interviews. Interactions between individuals with disabilities within online communities have often been focused on the goal of acquiring knowledge or learning new information, whether learning about similar experiences or hearing others' different perspectives on common difficulties (Sweet et al., 2020). Further, the "virtual social identities" of disabled people often parallel their actual social identities, making social media data a useful resource for understanding lived experiences (Noble, 2012).

For some (though not all) autistic individuals, face-to-face communication may feel less comfortable or accessible, particularly in relatively contrived research settings with

structured interviews. Technology-mediated discourse poses fewer sensory and social communication challenges because the individual is able to engage on their terms, exercising greater control over environmental, temporal, and interpersonal factors that could influence comfort and psychological safety (Brownlow et al., 2006). Thus, social media offers a promising forum for self-advocacy and discourse for the autistic community.

Use of Social Media Data in Autism Research

Despite the potential utility of social media as a resource in autism research, few studies have directly examined autistic perspectives in online discourse. Social media platforms are powerful tools for the autistic community to share their experiences and perceptions of the label "autism," and online communities of only autistic individuals enable a more positive, less-constrained construction of autistic identity since there are no other identities present (i.e., doctors and caregivers) that could influence interactions (Brownlow et al., 2006). Zhao et al. (2019) studied the interaction among autistic adults who were members of five Facebook support groups to identify topics that they were concerned about on a daily basis, and how group interactions addressed these needs. Content-based and patternbased analysis of group interaction yielded themes including parenting, behavior traits, and therapies. This study further highlighted the utility of social media platforms as a source of informational and social-emotional support for stakeholders in the autism community. In several instances, members received replies from others experiencing similar situations and experiences, and this social support provided emotional relief. Insights from observation of social media discourse can help researchers understand perceptions of autism and autistic identity from a wide range of perspectives, which can help to improve the ecological validity and acceptability of future research, education, and intervention/accommodation (Zhao et al., 2019).

Social media platforms are also useful for understanding characteristics or issues that are relevant to both autism and other subgroups within the neurodivergent population, and for exploring how neurodivergence manifests across contexts. Four central domains of neurodivergence are (a) language, communication, and social interaction; (b) sensory processing; (c) motor skill execution; and (d) goal-oriented and reflexive thinking, planning, and self-regulation (Robertson, 2010). Antunes and Dhoest (2021) explored the relation between social media discourse and these four domains by conducting a digital ethnographic study on three autism-related Facebook groups. The authors posit that social media can be conceptualized as an "extension of the human body" for autistic people, as it facilitates their communication and social skills. In relation to sensory processing, autistic individuals stated that they were more comfortable communicating through the use of digital media, as they were not expected to follow societal norms, such as making eye contact. The freedom and flexibility of a digital environment contribute to more controllable sensory input for autistic people and may facilitate more comfortable self-expression and communication.

Objective of the Current Study

As social media engagement becomes more prevalent on a global scale, researchers must consider its utility as a means of gaining insight into the perspectives of stakeholders in neurodivergent communities. While prior studies have used social media to understand caregivers' or clinician/educators' perspectives, few have considered the perspectives of self-advocates. It is key to hear from self-advocates and autistic individuals themselves, as they have a deep understanding of their own, unique experiences and challenges, as well as an understanding of the cultural and societal norms that impact their lives. The rationale for the present study is grounded in two pressing needs within the field of autism research: (a) the need to hear directly from autistic individuals and (b) the need to understand motor problems in autism. To that end, our primary objective was to understand autistic people's perspectives on the relation between motor skills, identity, and daily living. The specific aims of this study were (a) to determine the proportion of Twitter users who self-identify as autistic and dyspraxic/having DCD, relative to those who identify as autistic alone, and (b) to identify common themes emerging from two moderated chat threads with motor-related prompts.

Methods

We conducted an explanatory sequential mixed-methods study to determine the frequency with which autistic Twitter users discuss motor differences and to identify common themes. In this type of mixed-methods design, qualitative analysis of data is used to explain or contextualize the results of an initial quantitative analysis (Creswell & Clark, 2018). To achieve our study objective, we first conducted quantitative analysis of the number of Twitter users who self-identified with terms related to autism or DCD. We then conducted qualitative analysis of tweets from two moderated chats specifically focused on motor skills. We collected these data using the Twitter application programming interface (API) with Academic Research access to harvest data, including user-level characteristics (e.g., the content of users' public profiles) and individual tweets (for additional information, see Fears et al., 2023, in this special section). An API is a type of computing interface that allows a user to connect to elements of a piece of software (e.g., to Twitter's data warehouse) and find and extract data using a structured request. We used the API to identify and harvest publicly available data from user profiles and tweets containing specific keywords relevant to our study objectives within a predefined period of time. All data were publicly available and warehoused by Twitter for purposes unrelated to this research study, and therefore, our retrospective secondary analysis of these data was exempt from human subject research regulations.

Data Harvesting

Using the Twitter research API, we harvested data from users' public profiles and tweets containing terms related to autism (e.g., ASD, autistic, and aspie) and DCD (e.g., DCD, dyspraxic, and dyspraxia) within a 1-month time period (October 2021–November 2021). We also harvested a targeted subset of tweets from two #AutChat threads, which are weekly moderated discussions on specific topics run by autistic people for autistic people. As a

moderator opens the session, they clearly state that the discussion is intended for autistic Twitter users, including individuals who are self-diagnosed or community recognized. Nonautistic users are welcome to retweet or share posts but discouraged from engaging directly in the discussion. Throughout the session, chat moderators address any users who appear to be neurotypical to remind them that the discussion is designed only for autistic individuals and ask neurotypical users to refrain from using the #AutChat tag.

#AutChat discussion topics range from diagnostic journeys to experiences with specific autistic characteristics in daily life. The full archive of #AutChat threads can be found at autchat.com/all-topics/. We selected two #AutChat threads from July 4 and September 19, 2021, when the discussion prompts specifically related to motor differences. Both threads used the same set of prompts posted in a series of tweets by the moderator(s), who were unaffiliated with the research team:

- "This #AutChat is about motor differences, such as: different nonverbal body language from neurotypical people; stimming; difficulty starting, carrying out, or stopping movements; echoing others' actions; moving slower or faster; differences in balance or coordination."
- "Q1: What motor differences do you experience? Do you associate them with certain diagnoses or other named traits?"
- "Q2: How do your motor differences affect your life?"
- "Q3: Are you involved in any communities relevant to motor differences? Do you know of any? If not, do you wish you were involved or knew of some?"
- "Q4: How would you describe the overlap between autism and motor differences?"
- "Q5: What is the biggest or most important thing you want people to know about motor differences?"

Data Processing

Twitter users were encouraged by #AutChat moderators to identify which question they were responding to, but not all users followed this format, which prevented us from analyzing each tweet in the context of a specific item from the prompt set. Instead, using a grounded theory framework (Charmaz, 2006; Glaser & Strauss, 1967), we read through the data set several times to familiarize ourselves with the content and begin to form ideas. We looked specifically for terms related to motor skills and problems based on our prior studies and the literature (e.g., balance, walking, clumsy, and uncoordinated) and reviewed a subset of tweets to identify additional related terms for inclusion in the final search. We then reviewed tweet contents to extract themes, assess the frequency with which certain problems were discussed (e.g., driving, dressing, working, and walking), and differentiate childhood from adulthood experiences. We then iteratively adjusted the categories and the coding of each tweet as we moved through the data set. We then used this information to develop a theoretical perspective on how autistic people's motor differences manifest in daily living, the degree to which these differences are incorporated into their social identity, and what factors may influence both of these outcomes.

We took several steps to maximize the trustworthiness of our findings, which we characterized as credibility, transferability, dependability, and confirmability following established practices in qualitative and mixed-methods research (Lincoln & Guba, 1985; Stahl & King, 2020). To ensure credibility, we used investigator triangulation to comparatively analyze the categorization and coding of each tweet, and member checking by autistic adults at the stages of study design and interpretation of results to evaluate whether our approach and conclusions seemed appropriate. Though transferability is challenging in any qualitative analysis, we have attempted to address this element of trustworthiness by describing our data extraction and analysis process in detail, both here and in Fears et al. (in this special section), so that others could apply the same steps to a new data set and evaluate the generalizability of our findings. To ensure dependability, we engaged in peer debriefing with other researchers (some of whom were neurodivergent and some of whom were neurotypical) to invite scrutiny and feedback on the data collection and analysis process and on our interpretation of the results.

Author Positionality

Though we took steps to maximize the trustworthiness of our results, it is important to note that it is impossible to eliminate investigators' (and indeed, community members' and peers') biases from the process of qualitative research altogether. In some instances, these biases can result in identification of important themes that may not have been evident to a neutral party, but that are clear to someone with lived experience or other positionality closely linked to the subject. In other instances, these biases can result in investigators overlooking relevant information or drawing conclusions that do not fully represent the data. For that reason, readers are encouraged to consider our positionality in drawing conclusions about this study and our interpretation of results.

At the time of data collection and analysis, the researchers were in the academic roles of undergraduate students, postdoctoral fellow, assistant professor, and associate professor. The researchers have formal training in the fields of developmental and experimental psychology, kinesiology, and/or behavioral and cognitive neuroscience. Three of the researchers had specialized graduate and/or postgraduate training in atypical motor development, with specific emphasis on autism and DCD.

Four of the researchers identify as neurodivergent, three of the researchers have a neurodivergent partner or spouse, and five have a neurodivergent family member (other than a spouse). One of the researchers identifies as disabled, none has a disabled partner or spouse, and two have a disabled family member (other than a spouse). One of the researchers identifies as Cuban American, one identifies as Indian American, and three chose not to disclose their racial/ethnic identity. One of the researchers identifies as a man, two identify as women, and two chose not to disclose their gender identity. Two of the researchers identify as members of the LGBTQIA2S+ community.

The researchers all have experience using Twitter for personal social networking and entertainment separate from the context of this study. Three of the researchers are frequently engaged (i.e., daily, or almost daily), two of the researchers are occasionally engaged (i.e., weekly, or monthly), and one of the researchers is rarely engaged (i.e., less than monthly).

The researchers also use other social media platforms frequently, including Instagram, Facebook, TikTok, YouTube, Reddit, Snapchat, Pinterest, WhatsApp, BeReal, and LinkedIn.

Results

Our initial search returned 294,336 tweets (not including retweets) containing keywords related to autism and/or DCD from 50,072 unique user profiles. Of these users, 5,503 self-identified with terms related to autism, 78 self-identified with terms related to DCD, and 51 self-identified with terms related to both autism and DCD in their profile descriptions. Thus, only 11.25% of Twitter users tweeting about autism and/or DCD openly identify as self-advocates, while the majority discourse on these topics remains driven by people who do not. In addition, <1% autistic Twitter users also identify as having DCD. This low prevalence may be due to the low awareness of DCD in the community and/or a different use of terms among autistic individuals to describe themselves.

The two #AutChat threads included 151 tweets from 31 unique autistic users (two with co-occurring DCD). Of these tweets, 44 were explicitly about motor differences, while the remainder consisted of discussion topics more loosely associated with motor skills. Our grounded theory approach resulted in the following common themes: manual dexterity, lower extremity, oral motor, gross motor, posture, balance, stimming, movement pain, and coordination (Table 1). The four most common autistic motor difference themes identified were manual dexterity, lower extremity movements, gross motor, and oral motor. For the privacy of individual users, we paraphrased examples of these themes in Table 1 rather than providing direct quotes.

Our thematic analysis revealed that their self-reported differences spanned wide range of domains, from fine motor coordination and manual dexterity to gross motor coordination and balance. Autistic Twitter users discussed the profound functional impact these motor differences have on their lives, and the adaptations they have made to compensate for these problems. Some users described choosing what regions they live in based on weather, because of fear of falling on slippery surfaces. Other users described frequent embarrassment or injury due to coordination difficulties. Others were not particularly of bothered by their motor differences but had developed specific strategies for accommodating them, such as never wearing shoes that fasten with laces, buckles, or snaps. These findings clearly illustrate the effects of motor differences in nearly every facet of autistic people's lives.

Discussion

Autistic Twitter users have self-organized into a thriving community of individuals with diverse characteristics and communication styles, including those who are speaking and nonspeaking. As such, the study sample utilized likely represented a broader range of perspectives than those traditionally included in qualitative research, which has historically relied on interview or focus group contexts for data collection (Zhao et al., 2019).

Yet, only 11.25% of Twitter users tweeting about autism and/or DCD openly self-identify as self-advocates, while the majority of discourse on these topics remains driven by people

who either do not openly identify as neurodivergent or who are neurotypical. Rather than attempting to force more autistic people to openly identify, or attempting to silence nonautistic voices, we advocate for careful evaluation of the influence this imbalance may have on public opinion, policy, and priorities in research, education, and clinical care. We also advocate for intentional platforming of openly autistic users and groups, and for centering of discourse around autistic people's priorities rather than the priorities of family members, educators, service providers, clinicians, employers, or researchers.

In addition, <1% of autistic Twitter users also identify as having DCD. We identified a sizeable community of autistic Twitter users, a small subset of whom also identified as having DCD (<1%). This number is considerably lower than the possible co-occurrence rate observed in research studies where autistic people's motor skills are directly measured (~85%–97%; Green et al., 2009; Licari et al., 2020; Miller et al., 2021). It is also lower than the rate of diagnosed DCD co-occurrence in a large cohort of children in the United States (14%; Ketcheson et al., 2021). Instead, it approaches the much lower rate of selfreported dyspraxia co-occurrence in an international sample of adults (6.9%; Cassidy et al., 2016). It is possible that many autistic Twitter users were diagnosed with autism prior to Diagnostic and Statistical Manual of Mental Health Disorders, 5th edition (DSM-5) or International Classification of Diseases, 9th edition (ICD-9), in which co-diagnosis of autism and DCD became permissible. It is also possible that clinicians who assessed latediagnosed adolescents and adults did not assess for DCD because of the individual's age, instead focusing on the core diagnostic features of autism. As such, there is a high likelihood that many autistic people may not have been introduced to the terms DCD or dyspraxia as a diagnostic term for the motor differences they experience, even if they meet clinical criteria. Although only a small number of autistic Twitter users self-identified as having DCD, many of those identifying solely as autistic still described profound motor differences that affected their daily lives. The low prevalence of autistic Twitter users in our sample who self-identified using the terms DCD or dyspraxia may reflect limited clinical and community awareness of what DCD is and the degree to which it co-occurs with autism.

An alternative explanation may be that some autistic individuals with significant motor differences do experience negative effects in daily living due to self-generated or caregiver-provided scaffolding in their environments and tasks. For example, they may live in single-story residences that do not require navigating stairs or may have furniture placed in locations where it can be used to aid balance. They may have self-selected into recreational or vocational activities that are not heavily dependent on motor skills. They may also leverage relationships (e.g., roommate, spouse, and caregiver) with others who are more comfortable completing daily living tasks that require a high degree of motor control or coordination (e.g., chopping foods and ironing). Each of these compensatory strategies could have influenced the number of autistic adults in our sample who self-identified as having motor problems and/or the types of motor problems they discussed in their tweets.

Autistic Twitter users who did report motor differences discussed the many domains in which they played a role, and the substantial downstream effects on their recreational and vocational activities, geography and housing choices, social engagement, self-care, safety, and mental health. Prior studies reported lower participation in recreational activities and

physical activity among autistic adults in part due to lower perceived ease (Hillier et al., 2020). Others have identified a relationship between motor problems and low participation at home, in school, and in the community among autistic children and adults (Oliveira et al., 2023). The discourse observed in our study about the relationship between motor differences and activity participation corroborates these findings. Prior work also indicates a higher rate of emergency department use related to falls and injuries in autism (Vohra et al., 2016). The lived experiences of injuries related to motor differences reported by Twitter users in our study provide some insight into the types of situations that may underlie those clinical data. Researchers have yet to directly study autistic people's awareness of their motor differences and the effect of that awareness on their social-emotional outcomes. However, the DCD literature clearly shows that awareness of one's motor differences can lead to reduced social engagement and poorer mental health outcomes (Tamplain & Miller, 2021). In alignment with this perspective, some Autistic Twitter users in our study expressed embarrassment about their motor differences. But, in contrast, others were not distressed by their motor differences. This dichotomy suggests that in autism, but not DCD, a hidden variable or variables may moderate the relationship between motor difficulties and socialemotional outcomes. Autistic Twitter users discussed the profound functional impact these motor differences have on their lives and the adaptations they have made to compensate for these problems. Some users described choosing what regions they live in based on weather, because of fear of falling on slippery surfaces. Other users described frequent embarrassment or injury due to coordination difficulties. This result is in alignment with the qualitative results reported by Gowen et al. (2022), who found that some participants experienced negative emotions like frustration or confusion as a result of motor differences. Others were not particularly bothered by their motor differences but had developed specific strategies for accommodating them, such as never wearing shoes that fasten with laces, buckles, or snaps. This result from our data set also corroborates Gowen et al. (2022), who reported data from multiple participants who were unaware of their motor differences despite describing significant difficulties with specific motor tasks. What is clear is that motor differences are a relevant current issue in the autistic community, and more work is needed to determine their impact on daily living, quality of life, and identity. For a deeper discussion of motor differences in individuals with DCD, please see Tamplain et al. (2023) in this special section.

Together, these findings indicate that motor differences are highly recognized and discussed among autistic individuals but are not overtly integrated into their identities at the same rate. Specifically, when autistic individuals are discussing their motor differences with others in the autistic community, they describe difficulties with a wide range of motor skills, but many fewer autistic individuals self-identify as dyspraxic or having DCD. This gap between their experiences with motor differences and their self-identity may be due to either perspectives of motor differences as a characteristic of autism itself (i.e., identifying as autistic encompasses having motor differences) or a lack of exposure to identity-related terminology (i.e., dyspraxic). Future research should examine how autistic individuals incorporate their motor differences into their identities as well as the impact that diagnoses and support for motor differences influences these identities.

Most importantly, the data show the presence of motor differences in autistic individuals, as well as a great level of awareness of the problem and its wide-reaching consequences. These findings can have several implications for several different levels of assessment, intervention, and policy change. As indicated by the results, motor problems present a significant barrier to the performance of daily living activities, as well as for social, and cognitive development. In fact, research has shown that motor problems are as prevalent and functionally impactful as problems with other domains recognized as specifiers to an autism diagnosis (e.g., language; Licari et al., 2020). However, the fact remains that motor problems are a commonly overlooked feature of autism. Self-advocates' experiences and perspectives like those documented in this study support the need for a clear clinical pipeline for the assessment and management of motor problems. The focus of this study is not to debate whether motor problems should be documented as a specifier within the autism diagnostic criteria or as a co-occurring diagnosis of DCD, but interested readers are encouraged to refer to Miller et al. (2023) for a thorough discussion of this issue.

Limitations and Future Directions

One major challenge of analyzing social media discourse is the volume and complexity of the available data. Despite the qualitative results being well within the sample size norms of many qualitative studies, a limitation of the current analysis is the scale of the qualitative results is relatively small compared with the scale of the quantitative results. Future directions may include the use of machine learning techniques such as natural language processing and computer vision to aid in data reduction and automation of analysis for text-based and image-or video-based data, respectively. Image- and video-based data analytic tools would be particularly useful for platforms such as Instagram, TikTok, Snapchat, YouTube, and BeReal, where computer vision could be used to directly quantify motor differences from users' video-based content, and qualitative analysis of memes, photos, and gifs could provide additional context for interpretation of individuals' posts and subsequent engagement from other users. However, while machine learning can be an effective technique for feature classification and identification of patterns within a complex data set, these tools are still susceptible to bias introduced in the process of training the underlying algorithms. Therefore, we advise caution in the use of any fully automated approach to drawing meaningful conclusions from large data sets. Although it is tempting to assume that the large number of tweets harvested will all yield meaningful information, machine learning models may lead to inaccurate conclusions and misguided insights from training on unrepresentative data. These potential inaccuracies and biases highlight the need for careful oversight in the curation and filtering of data inputs for machine learning approaches as well as smaller scale, more detailed human processing of data to ensure accuracy and relevance of social media discourse analysis.

Conclusions

From this body of data, we conclude that motor differences are common within the autistic community and create varying levels of problems with safety, comfort, and convenience. The degree of difficulty autistic people experience seems to depend on the individual and the demands of their environment or chosen activities. These remaining questions could

be addressed via follow-back surveys to Twitter users about the various accommodative or compensatory strategies they use to mitigate the impact of motor differences on daily living. Further studies in this area should also examine the influence of intersectionality and the role of other social determinants of health, including access to care, transportation, and community support. Use of data from other social media platforms including those that rely more on image- and video-based content may also be valuable sources of information for future research on motor differences and identity in autism.

Acknowledgments

We paraphrase and refer to themes throughout the manuscript rather than using direct quotes, so that users' tweets are not subject to greater publicity than they may have reasonably expected, in keeping with best-practice guidelines for use of Twitter data in research (Williams et al., 2017). For this reason, content referenced in this manuscript is not attributed to individual users. Instead, we offer our gratitude to the entire #ActuallyAutistic community on Twitter for the opportunity to learn from their perspectives.

Out of respect for preferences expressed by many autistic self-advocates in our studies, in the literature (Bottema-Beutel et al., 2020; Botha et al., 2021), and in the community, we have chosen to use identity-first (rather than person-first) language throughout this manuscript when referring to autistic people. The developmental coordination disorder/dyspraxia community has not yet established best practices for language in the literature or expressed strong preferences in our studies, and so for consistency throughout the manuscript, we have chosen to use identity-first language when referring to this group as well. In doing so, it is not our intention to diminish or invalidate the preferences or perspectives of those who prefer person-first language. We recognize that identity is deeply personal and affirm that all individual preferences regarding the language used to express identity are valid and should be respected. We also use the term "motor differences" to describe features that may or may not cause problems or disability, depending on a person's goals, context, and access to appropriate supports or accommodations. We continue to welcome feedback on ways that we can effectively partner with the autistic community to advocate for respect, acceptance, inclusion, and representation in research.

Funding:

This research was supported in part by the National Institute of Mental Health (K01-MH107774) and the University of Michigan.

References

- Antunes D, & Dhoest A (2021). The digital as prosthesis: The role of social media in autistic people's lives. The Journal of Social Media in Society, 10(2), 202–220.
- Beart S, Hardy G, & Buchan L (2005). How people with intellectual disabilities view their social identity: A review of the literature. Journal of Applied Research in Intellectual Disabilities, 18, Article 4756. 10.1111/j.1468-3148.2004.00218.x
- Bitman N (2021). 'Which part of my group do I represent?': Disability activism and social media users with concealable communicative disabilities. Information, Communication & Society, 26(3), 619–636. 10.1080/1369118X.2021.1963463
- Botha M, Hanlon J, & Williams GL (2021). Does language matter? Identity-first versus person-first language use in autism research: A response to Vivanti. Journal of autism and developmental disorders, 1–9.
- Bottema-Beutel K, Kapp SK, Lester JN, Sasson NJ, & Hand BN (2021). Avoiding ableist language: Suggestions for autism researchers. Autism in adulthood, 3(1), 18–29. [PubMed: 36601265]
- Brownlow C, O'Dell L, & Taylor S (2006). Constructing an autistic identity: AS voices online. Mental Retardation, 44(5), 315–321. [PubMed: 16970515]
- Caçola P, Miller HL, & Ossom-Williamson P (2017). Motor symptom similarities between individuals with developmental coordination disorder and autism spectrum disorder. Research in Autism Spectrum Disorders, 38, 6–18. 10.1016/j.rasd.2017.03.004 [PubMed: 29057009]

Cassidy S, Hannant P, Tavassoli T, Allison C, Smith P, & Baron-Cohen S (2016). Dyspraxia and autistic traits in adults with and without autism spectrum conditions. Molecular Autism, 7(1), Article 48. 10.1186/s13229-016-0112-x

- Charmaz K (2006). Constructing grounded theory: A practical guide through qualitative analysis. Sage.
- Craig F, Lorenzo A, Lucarelli E, Russo L, Fanizza I, & Trabacca A (2018). Motor competency and social communication skills in preschool children with autism spectrum disorder. Autism Research, 11(6), 893–902. 10.1002/aur.1939 [PubMed: 29493892]
- Creswell JW, & Clark VLP (2018). Designing and conducting mixed methods research (3rd ed.). Sage.
- Dekker M (2020). From exclusion to acceptance: Independent living on the autistic spectrum. In Kapp S (Ed.), Autistic community and the neurodiversity movement (pp. 41–49). Palgrave Macmillan.
- Dolphin D (2011). Digital disability discourses: User-generated content, identity, and resistance [Master's thesis]. Retrieved from ProQuest Dissertations and Theses database (UMI No. 1491454).
- Fears NE, Chatterjee R, Tamplain PM, & Miller HL (2023). Harvesting Twitter data for studying motor behavior in disabled populations: An introduction and tutorial in Python. Journal of Motor Learning and Development. Advance online publication. 10.1123/jmld.2023-0006
- Fears NE, Palmer S, & Miller HL (2022). Motor skills explain adaptive behavior in autistic children and adolescents. Autism Research, 15(6), 1083–1089. 10.1002/aur.2708 [PubMed: 35322578]
- Glaser B, & Strauss A (1967). The discovery of grounded theory: Strategies for qualitative research. Aldine.
- Gowen E, Earley L, Waheed A, & Poliakoff E (2022). From "one big clumsy mess" to "a fundamental part of my character." Autistic adults' experiences of motor coordination. PLoS One, 18(6), Article 286753. 10.1371/journal.pone.0286753
- Green D, Charman T, Pickles A, Chandler S, Loucas T, Simonoff E, & Baird G(2009). Impairment in movement skills of children with autistic spectrum disorders. Developmental Medicine & Child Neurology, 51(4), 311–316. 10.1111/j.1469-8749.2008.03242.x [PubMed: 19207298]
- Hillier A, Buckingham A, & Schena D (2020). Physical activity among adults with autism: Participation, attitudes, and barriers. Perceptual and Motor Skills, 127(5), 874–890. 10.1177/0031512520927560 [PubMed: 32443953]
- Ketcheson LR, Pitchford EA, & Wentz CF (2021). The relationship between developmental coordination disorder and concurrent deficits in social communication and repetitive behaviors among children with autism spectrum disorder. Autism Research, 14(4), 804–816. 10.1002/aur.2469 [PubMed: 33421296]
- Leadbitter K, Buckle KL, Ellis C, & Dekker M (2021). Autistic self-advocacy and the neurodiversity movement: Implications for autism early intervention research and practice. Frontiers in Psychology, 12, Article 690. 10.3389/fpsyg.2021.635690
- Leversen JS, Haga M, & Sigmundsson H (2012). From children to adults: Motor performance across the life-span. PLoS One, 7(6), Article 38830. 10.1371/journal.pone.0038830
- Licari MK, Alvares GA, Varcin K, Evans KL, Cleary D, Reid SL, et al. (2020). Prevalence of motor difficulties in autism spectrum disorder: Analysis of a population-based cohort. Autism Research, 13(2), 298–306. 10.1002/aur.2230 [PubMed: 31625694]
- Lincoln Y, & Guba EG (1985). Naturalistic inquiry. Sage.
- Miller HL, Licari MK, Bhat A, Aziz-Zadeh L, Van Damme T, Fears NE, Cermak S, & Tamplain P (2023). Motor problems in autism: Co-occurrence or feature? Developmental Medicine & Child Neurology. Advance online publication. 10.1111/dmcn.15674
- Miller HL, Sherrod GM, Mauk JE, Fears NE, Hynan LS, & Tamplain PM(2021). Shared features or co-occurrence? Evaluating symptoms of developmental coordination disorder in children and adolescents with autism spectrum disorder. Journal of Autism and Developmental Disorders, 51(10), 3443–3455. 10.1007/s10803-020-04766-z [PubMed: 33387238]
- Noble CD (2012). Cyberspace as equalizer: Opening up life worlds and empowering persons with disabilities in the Philippines [Doctoral dissertation]. Retrieved from ProQuest Dissertations and Theses database. (UMI No. 3520657)

Oliveira KSC, Fontes DE, Longo E, Leite HR, & Camargos ACR (2023). Motor skills are associated with participation of children with autism spectrum disorder. Journal of Autism and Developmental Disorders, 53(4), 1403–1412. 10.1007/s10803-021-05318-9 [PubMed: 34669103]

- Robertson SM (2010). Neurodiversity, quality of life, and autistic adults: Shifting research and professional focuses onto real-life challenges. Disability Studies Quarterly, 30(1), Article 1069. 10.18061/dsq.v30i1.1069
- Stahl NA, & King JR (2020). Expanding approaches for research: Understanding and using trustworthiness in qualitative research. Journal of Developmental Education, 44(1), 26–29.
- Sweet KS, LeBlanc JK, Stough LM, & Sweany N (2020). Community building and knowledge sharing by individuals with disabilities using social media. Journal of Computer Assisted Learning, 36(1), Article 2377. 10.1111/jcal.12377
- Tamplain P, & Miller HL (2021). What can we do about mental health in individuals with developmental coordination disorder? Current Developmental Disabilities Reports, 8(1), 24–31. 10.1007/s40474-020-00209-7
- Tamplain PM, Fears NE, Robinson P, Chatterjee R, Lichtenberg G, & Miller HL(2023). #DCD/ Dyspraxia in real life: Twitter users' unprompted expression of experiences with motor differences. Journal of Motor Learning & Development. Advance online publication. 10.1123/ JMLD.2023-0008
- Timler A, Mcintyre F, Bulsara C, Rose E, & Hands B (2020). The influence of motor competence on adolescent identity health: A mixed method study. Research Quarterly for Exercise and Sport, 91(1), Article 3821. 10.1080/02701367.2019.1643821
- Vohra R, Madhavan S, & Sambamoorthi U (2016). Emergency department use among adults with autism spectrum disorders (ASD). Journal of Autism and Developmental Disorders, 46(4), 1441–1454. 10.1007/s10803-015-2692-2 [PubMed: 26762115]
- Ward MJ, & Meyer RN (1999). Self-determination for people with developmental disabilities and autism: Two self-advocates' perspectives. Focus on Autism and Other Developmental Disabilities, 14(3), 133–139. 10.1177/108835769901400302
- Williams ML, Burnap P, & Sloan L (2017). Towards an ethical framework for publishing Twitter data in social research: Taking into account users' views, online context and algorithmic estimation. Sociology, 51(6), 1149–1168. [PubMed: 29276313]
- Zablotsky B, Pringle BA, Colpe LJ, Kogan MD, Rice C, & Blumberg SJ (2015). Service and treatment use among children diagnosed with autism spectrum disorders. Journal of Developmental and Behavioral Pediatrics, 36(2), 98–105. 10.1097/DBP.000000000000127 [PubMed: 25650952]
- Zhao Y, Zhang J, & Wu M (2019). Finding users' voice on social media: An investigation of online support groups for autism-affected users on Facebook. International Journal of Environmental Research and Public Health, 16(23), Article 4804. 10.3390/ijerph16234804

Chatterjee et al. Page 15

 Table 1

 Paraphrased Examples of Motor Difference Themes Identified in #AutChat Tweets

Theme	N tweets	Paraphrased example
Manual dexterity	19	I have to concentrate really hard on typing because I can't get my finger to press the right button, or to stop pressing a particular button. I couldn't advance farther working in kitchens because of the coordination needed for knife skills, no matter how hard I tried. I have difficulty tying laces. I can't cut or fold paper neatly, so crafts are hard.
Lower extremity movements	8	I trip even when there isn't anything to trip on. Going down stairs is hard. The main problem seems to be my feet doing what they need to. My feet get tripped up when the sidewalk isn't smooth.
Oral motor	6	I bite my lips or tongue when I eat, and I choke on spit or food. Choking scares me so I might not ever live alone. My speech communication is affected by my motor differences.
Gross motor	7	I have to think really hard about movements. It's difficult to decide how to move, plan it, and do it. I often make lots of funny errors, or I'm slow to respond.
Posture	4	When I was younger, I was almost completely slumped over when I ran. I never sit straight up. I like to stretch out or sit asymmetrically.
Balance	4	It is dangerous for me to go down stairs, walk on slippery surfaces, or walk where there is ice on the ground. High heels are not an option, I feel like I'll fall. I don't have any balance.
Stimming	4	I have several motor stims with my whole body or arms. I sometimes mimic people's stims, or movements. I have to hold back on stims so that I can stand or sit like people expect me to.
Movement pain/ fatigue	2	Exercise is exhausting. Walking in a very straight-line hurts. It always hurts some amount to do any kind of movement, but it's better in water.
Coordination	5	My life is very affected by not being able to drive. I frequently drop or spill things, trip over things, or injure myself in unexpected ways. I really wanted to play an instrument, but my hands and feet wouldn't move together the right way. It takes time to process stairs. All kinds of things feel clumsy. Frustration and fatigue make it worse. I have to think really hard to do something precisely.