

Social Media-Based Community Support for People with Differing ADHD Diagnoses

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1 INTRODUCTION

Attention-Deficit Hyperactivity Disorder (ADHD), often diagnosed in childhood, is increasingly discussed on social media, leading some adults to later in life diagnoses or realizations [3]. As ADHD is most commonly recognized in young boys due to hyperactivity, this condition is often left undiagnosed for many girls due to proclivity toward the less-visible inattentive type of ADHD [7, 8]. This lack of diagnosis in girls can lead to issues later in adulthood, such as low self-esteem and rejection sensitivity dysphoria, among others [1, 5]. Due to the emergence of sub-communities within social networking sites such as Instagram, TikTok, and Twitter, many undiagnosed people are recognizing themselves in informational videos made by creators with ADHD, aiding in self-discovery of their own neurodivergence.

In this paper, we are interested in thinking through identity within ADHD communities on social media. We focus on centering people with lived experiences of ADHD, regardless of diagnosis. ADHD diagnosis is time-intensive, expensive, and historically difficult to access for women and people of color, potentially leading to traumatic medical experiences [2, 4, 6]. The ADHD community acknowledges this difficulty and provides support whether or not one wants to pursue a diagnosis. In following these community norms, by privileging neurodivergent individuals we are able to learn how people provide support in these communities without gatekeeping community membership and to explore any tensions in the community around diagnosis and belonging.

ADHD communities can differ from traditional online health communities (OHCs) in that, while ADHD is a psychosocial disability, many people with ADHD do not have the resources to obtain a formal diagnosis or the support of medication or a care team (vs. cancer or autoimmune OHCs for example). Mental health affects and cannot be disentangled from our overall view of wellbeing, but individuals may be hesitant to apply labels to themselves when it comes to mental health. However, it is important to discuss health as a holistic view of both physical and mental wellbeing and to recognize mental health conditions as psychosocial disabilities [9]. Mental health care remains inaccessible to many, and despite being a medical issue, is still treated differently than more visible disabilities. People may be forced to

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seek out self-management solutions such as mental health mobile apps, online support groups, or potentially more harmful routes of self-medication. Technology may help individuals to disclose or accept their psychosocial disabilities, allowing them to gain access or support from people in similar situations. While many people practice self-management out of necessity, digital mental health communities and technologies are a viable alternative to the traditional medical framing of mental health care.

2 MOTIVATIONS AND CONTRIBUTIONS IN ATTENDING WORKSHOP

As workshop participants, we are interested in discussing how to bring clinicians and stakeholders into this work without disrupting the fact that we are centering the opinions of ADHDers. People with ADHD are the experts of their own lived experiences and need to be recognized as such. Continuing Dr. Ringland's prior work, we hope to discuss ways in which medical communities and OHCs can collaborate and learn from each other in order to best support individuals with ADHD from a holistic viewpoint. We present preliminary work analyzing content and membership of ADHD OHCs, with the goal of proposing a larger research agenda of working with community stakeholders to discuss how best to facilitate and support individuals desiring self-management, formal diagnoses, or a combination of the two. We explore how accounts provide support and build relationships within the ADHD community to consider ways in which support can be provided to larger audiences and what specifically people need from these OHCs.

3 PRELIMINARY STUDY

To observe naturalistic interactions within the ADHD community, we utilize digital ethnography to focus on the sub-communities of TikTok and Instagram. While each of these mediums allows for media sharing (i.e., photos and videos with written or spoken commentary), they tend to differ slightly in format and audience. We, therefore, propose looking at the ADHD communities across platforms for comparison.

While TikTok allows solely video sharing, Instagram has historically been a photo and longer-form comment platform, although in recent months has introduced short video features to compete with TikTok. Instagram allows creators to post infographics and longer form textual or static photo posts to discuss various ADHD-related topics. These cover a broad spectrum of issues people with ADHD may struggle with, including why certain tasks are challenging and strategies to compensate. Other creators make use of Instagram's affordances to post comics or informational posts. Similar to hashtags, both Instagram and TikTok suggest relevant users to follow, allowing for easy identification of people with similar kinds of content.

Videos marked with ADHD-related hashtags have billions of views on TikTok (#adhd: 6 billion+ views, #adhdttok: 1.5 billion+).¹ The content of these videos varies greatly, but often includes people's everyday experiences with different ADHD symptoms, tips for managing ADHD, and informational content around the psychology of ADHD or how to start the diagnostic process. ADHD content specific to women is also popular (#adhdinwomen has 580 million+ views). There are also hashtags for further sub-communities such as #adhdinadultwomen and #adhdinlackwomen, making it easier to find the most relevant content. Creators that identify as women make video and text posts addressing common symptoms that may go unnoticed (e.g., rejection sensitivity, low self-esteem), leading many undiagnosed women to recognize themselves in ADHD-related content.

Community content is created not only by people with ADHD but also by doctors and clinicians attempting to inject scientific knowledge into the community.² They give concrete advice including non-medicinal routes of care such

¹#mentalhealth has 16B views for comparison and #beyonce has 5.3B

²For example, @domesticblisters, a licensed professional therapist with 1.2M followers and @thepsychdoctorMD, a psychiatrist with 200k followers

as how to get accommodations, therapeutic techniques, behavior modifications, etc. These creators make use of the video response to comment feature to answer people who have very specific queries. These creators are not telling people whether or not to take medication, but providing resources for those who are unable to or do not want to take medication to manage their ADHD, sharing many ways to self-manage or relieve symptoms.

Many commenters note their hesitation in seeing doctors after discovering they could have ADHD through TikTok videos. Others note that they have attempted to seek diagnosis or treatment, only to not be taken seriously by family members or clinicians, which has led them to hide their symptoms or not seek a diagnosis. Hiding or masking symptoms due to lack of acceptance from people in the user's life leads many to seek support online, where others discuss their negative diagnostic experiences. Some creators make videos specific to these situations, including how to get a diagnosis and scripts for what to say to a doctor if you discovered potential ADHD through social media. Providing concrete steps helps relieve some of the anxiety of uncertain situations, as people have a better idea of what to expect. Comments left by users across platforms express the validation felt through creators sharing similar experiences. This content has helped people not only find coping skills but also a supportive community where they are able to accept and work with their neurodivergence. These comment sections make up a large part of the community, as other users can respond to people's comments and provide emotional support, relational experiences, and advice that pertains directly to the commenters' needs.

4 DISCUSSION AND FUTURE WORK

Overall, users joining ADHD social media communities experience benefits such as knowing they aren't alone through videos of shared experiences, information dissemination, advice for specific questions, and a space where they can give and receive support and find validation and acceptance. Social medias communities expand users' networks and allow them to make friends with a variety of people. This preliminary research shows the viability of OHCs for supporting individuals with diagnosed or suspected ADHD. There are numerous examples of adults discovering their undiagnosed ADHD through social media, leading them to self-actualization and explanations for their past behavior and struggles. While we provide a brief overview of the type of content and users within the ADHD OHCs, we have barely scratched the surface in terms of kinds of content. Clinicians may cast doubt on patients self-diagnosing through social media. Future work will engage directly with these communities to document their experiences within the medical system and how best to work together to support the ADHD community and build trust between these groups. It will also be important to further explore community structure and if feelings of belonging are dependent upon diagnostic status.

My graduate research has focused on alternative mental health treatments for individuals that are unable to afford therapy or medication, but I also have a background in clinical research, thus I bring a diverse perspective on mental health care and management to the workshop. I am hoping to gain a broader understanding of pain points between the medical community and OHCs as well as to discuss ways to reduce harm and find ways for the two to work together to support community members. The first author has been immersing herself in this community for the past few months to learn the bounds of the space and peoples' experiences.

5 ABOUT US

Dr. Kathryn E. Ringland (she/her) is an Assistant Professor at the University of California, Santa Cruz. She received her Ph.D. in Informatics from the University of California Irvine. Her areas of interest include human computer interaction, games studies, and critical disability studies. She is interested in understanding how disabled individuals leverage social media and game spaces as access in their online and offline interactions.

Tessa Eagle (she/her) is a third-year Ph.D. student in Computational Media at the University of California, Santa Cruz. She conducts research within human computer interaction and digital mental health. Her work focuses on alternative solutions to traditional mental health care and community-based avenues for supporting individuals with mental health conditions.

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