



Published in final edited form as:

*SSM Qual Res Health*. 2023 June ; 3: . doi:10.1016/j.ssmqr.2023.100223.

## The experiences of adults with ADHD in interpersonal relationships and online communities: A qualitative study

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### 1. Introduction

Attention-deficit/hyperactivity disorder (ADHD) is a common neurodevelopmental condition that has an estimated prevalence as high as 7% in the global adult population (Song et al., 2021). ADHD is characterized by symptoms of inattention, impulsivity, and hyperactivity (American Psychiatric Association, 2013). Increased severity of ADHD symptoms in adults is associated with functional impairment in interpersonal relationships

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Declaration of competing interest

The authors report no conflicts of interest with the topic of this work. Marc N. Potenza has consulted for and advised Opiant Pharmaceuticals, Idorsia Pharmaceuticals, Baria-Tek, AXA, Game Day Data and the Addiction Policy Forum; has been involved in a patent application with Yale University and Novartis; has received research support from the Mohegan Sun Casino and Connecticut Council on Problem Gambling; has participated in surveys, mailings or telephone consultations related to drug addiction, impulse control disorders or other health topics; and has consulted for law offices and gambling entities on issues related to impulse control or addictive disorders. The other authors report no disclosures.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ssmqr.2023.100223>.

(Bruner et al., 2015; Cho & Park, 2016; Safren et al., 2010). Difficulties adults with ADHD face in romantic relationships have been well described, such as struggles maintaining long-term relationships and navigating conflict resolution (Wymbs et al., 2021). Qualitative studies have reported that adults with ADHD have difficulty maintaining relationships (Kwon et al., 2018; Matheson et al., 2013; Waite & Tran, 2010) and modulating behavior to be socially acceptable (Schreuer & Dorot, 2017; Schrevel et al., 2016). Although it is poorly understood why adults with ADHD often have impaired social functioning, it has been hypothesized that one possible cause of difficulties navigating relationships may be the high prevalence of emotional dysregulation in adults with ADHD (Bodalski et al., 2019; Bruner et al., 2015).

Stigma and discrimination that may be related to ableism (experienced social prejudices regarding disabilities) are other potential sources of impairment in interpersonal relationships. Adults with ADHD frequently experience stigma about their diagnoses, with 89% reporting anticipated discrimination in their daily lives (Masuch et al., 2019). Stereotypes of ADHD may include questioning the validity of the diagnosis, skepticism towards medications, and views that people with ADHD are unreliable and dangerous (Mueller et al., 2012). Previous qualitative work indicates that adults with ADHD are often not taken seriously regarding their diagnosis (Lefler et al., 2016; Schrevel et al., 2016; Watters et al., 2018), and they often do not disclose their ADHD diagnosis to others for fear of stigma (Hansson Halleröd et al., 2015; Toner et al., 2006; Waite & Tran, 2010; Young et al., 2008). Other potential impacts from stigma in this population have not been well described.

Although adults with ADHD frequently struggle with interpersonal relationships, social support has been reported to increase functioning for this population. A supportive spouse has been described as helping adults with ADHD stay organized and keep up with life tasks (Nyström et al., 2020; Toner et al., 2006). Among young adults with ADHD, having a close friend provide non-judgmental support assists with engaging in social activities in addition to helping them meet their responsibilities (Ek & Isaksson, 2013; Meaux et al., 2009). More research is needed on how to best support adults with ADHD in navigating their symptoms and their interpersonal relationships.

Adults with ADHD have reported desiring support groups, including online support groups (Schreuer & Dorot, 2017; Waite & Tran, 2010). Online groups may be helpful in building community among adults with disabilities (Miller, 2017), although there has been limited research exploring online communities for adults with ADHD. Eighty percent of adults with autism spectrum disorder (ASD) have been found to engage with social media, primarily for social connection (Mazurek, 2013). Moderate Facebook use in particular has been correlated with increased happiness in this population (Ward et al., 2018). As ASD and ADHD frequently co-occur and have overlapping symptomatology (Antshel & Russo, 2019), adults with ADHD may also benefit from engagement with online communities. People with ADHD have been found to have higher engagement with social media than the general population (Farchakh et al., 2022; Guntuku et al., 2019). Although social media use has been associated with increased anxiety among individuals with ADHD (Farchakh et al., 2022), there may be benefits for social media groups tailored for people

with ADHD that have not been previously explored. As adults with ADHD often struggle with interpersonal relationships in person, peer support has been shown to help them with functioning. As social media may be helpful for building community for adults with disabilities, social media may be uniquely situated to aid with social relations and overall symptom management for adults with ADHD.

This study aimed to use interpretive phenomenological analysis (IPA) to better understand how young adults with ADHD interpret their experiences interacting with society, managing interpersonal relationships, and building community. It also sought to understand potential benefits and drawbacks of online communities for young adults with ADHD.

## 2. Methods

### 2.1. Procedure

The following procedure was approved by a university Institutional Review Board (IRB). Participants were recruited from online communities for people with ADHD including Facebook groups, sub-Reddits, and the Children and Adults with ADD (CHADD) advocacy group website. Moderators of these spaces gave permission before study advertisements were posted. These particular sites were selected based on convenience, personal knowledge of the communities on these sites, and feasibility (e.g., TikTok was not selected based on the need for generating a video). Interested participants were first directed to a Qualtrics survey to complete an initial screening to determine eligibility. Inclusion criteria consisted of being aged 18–35 years, inclusively, reporting having been diagnosed with ADHD by a clinician, and scoring greater than or equal to 23 out of 30 on the Adult ADHD Self-Report Scale, reflecting on symptoms over the life course (Silverstein et al., 2019).

Brief individual meetings were then held with potential participants over Zoom, during which participants provided verbal consent and completed a demographic questionnaire. The full questionnaire is provided as supplementary material. There were 146 complete responses to the screening survey, and 61 of these potential participants responded to follow-up emails. Of these, 51 potential participants completed informed consent for the study, and 43 ultimately participated in focus groups. Reasons for not completing the study were largely participant non-response without further explanation, although some participants communicated that conflicts had arisen that prevented them from continuing their involvement.

All participants reported a formal diagnosis of ADHD and were asked to either provide documentation of their diagnosis or complete a release of information to confirm diagnosis with their medical providers. The State Prescription Monitoring Program, which supports 39 states, was also checked with participant permission to verify if they were currently being prescribed stimulants as a proxy for ADHD diagnosis. Twenty-seven (63%) of the participants had a confirmation of diagnosis by either method. Participants whose diagnosis was not verified were not excluded from the study. Reasons for some participants not having a confirmed diagnosis largely consisted of participants verbally agreeing to have their healthcare provider contacted but then not providing electronic release of information documentation or provider non-response. There were no instances of discrepancies between

providers' and participants' reports about ADHD diagnoses, and all participants scored above threshold on the Adult ADHD Self-Report Scale.

Focus groups took place over Zoom and were video- and audio-recorded with participant consent. There were nine focus groups over November and December 2021, with three to six participants per group, consistent with previous studies utilizing focus groups in this population (Lefler et al., 2016; Schrevel et al., 2016). Participants were assigned to groups based on dates and times that worked for them; they were not stratified based on demographics. Participants were compensated with a \$15 e-gift card after completion of the group. The focus groups lasted from sixty to 80 min with the exception of one focus group of three participants lasting approximately 40 min. Groups were led by one facilitator with an additional member of the research team present for logistical concerns. Focus groups were semi-structured and facilitated by a discussion guide that included questions on how ADHD affects interpersonal relationships and participants' experiences on online communities for those with ADHD, including benefits and concerns.

## 2.2. Participant characteristics

Among the 43 participants, the median age was 29 years and median age of ADHD diagnosis was 22 years (range 5–34 years). The median time between diagnosis and entering this study was three years. Participants were 84% female, 72% White, 14% Asian, 9% Black, and 5% Hispanic/Latino. Eighty-six percent of participants were from North America, with the remaining being from Australia, Suriname, the Czech Republic, and the United Kingdom. Fifty-three percent were employed full-time, 44% were currently students, and 88% had at least some college education. The most common ADHD subtype was inattentive (42%), followed by combined (28%), and then hyperactive/impulsive (9%). The remaining participants either did not know their subtype or had been diagnosed before subtypes were introduced. Eighty-four percent of participants had been prescribed stimulant medication, a common pharmacotherapy treatment for ADHD, with nearly two-thirds reporting current stimulant use. Seventy-four percent of participants had been diagnosed with at least one other psychiatric condition, most commonly anxiety and depression. Sixty percent of participants were currently in psychotherapy for any reason. Most participants were recruited from Facebook (72%), followed by the Children and Adults with ADD (CHADD) advocacy group website (23%), and then Reddit (5%). Ninety-three percent of participants were involved with ADHD communities on social media, most commonly Facebook (74%), followed by TikTok (40%), Instagram (33%), Reddit (28%), and Twitter (14%).

## 2.3. Data analysis

Recordings were transcribed verbatim, checked for accuracy by a member of the research team, and uploaded to NVivo 12. Transcripts were first read independently and in their entirety by both researchers who performed data analysis. Transcripts were read a second time independently to identify themes. The two researchers then met to mutually develop a preliminary code book using an IPA framework; codes were developed inductively and organized hierarchically. Half of the transcripts were independently coded by both researchers using and modifying the preliminary codebook. The researchers met to resolve

discrepancies by mutual agreement. The researchers' coding largely aligned; discrepancies were typically one researcher further teasing apart a particular subtheme than the other. The code book was iteratively updated to reflect the changes to the coding structure made by both researchers. The remaining transcripts were coded with the updated code book by the lead researcher and then discussed with the other researcher. Thematic saturation was determined to have been reached as there were no new codes developed when coding the ninth focus group. A summary of results was provided to all participants via email after completion of the data analysis.

### 3. Theory

An IPA framework was used for analysis in this study as it employs the double hermeneutic (two-way system of interpretation) regarding participants' understanding of their lived experiences and the researchers' interpretation of participants' construction of their experiences (Smith & Eatough, 2006). Although IPA traditionally utilizes individual interviews (Smith & Eatough, 2007), focus groups were employed here, as being part of a group of people with similar experiences can promote participant disclosure of potentially stigmatizing topics (Sherriff et al., 2014). Additionally, focus groups have been previously used in qualitative studies of young adults with ADHD for this purpose (Lefler et al., 2016). Focus groups also allow for agreements and disagreements across topics to be readily captured.

The first author facilitated the focus groups and the first and second author conducted the data analysis. The first author is a medical student who is diagnosed with ADHD, is involved with online communities for adults with ADHD, and has conducted a review on adult ADHD qualitative research. At the time of the data analysis, the second author was a medical student with several family members with ADHD. Both authors had worked with adolescent and adult patients with ADHD in clinical settings. This insight into the ADHD community contributed to conceptualization of the project and aided in participant recruitment. Several participants asked if the lead researcher had ADHD and what their personal motivation was for the study during the individual informed consent meetings. When these questions were asked, the researcher disclosed their ADHD diagnosis, which was considered important in establishing rapport, but did not discuss their experiences further. During the focus groups, the lead researcher was familiar with the vocabulary and frameworks used by participants. This allowed for informed follow-up questions and provided context when analyzing the data. Potential biases included the researchers' preconceived perceptions of ADHD based on their personal experiences and potential projection of these experiences onto participants. To mitigate these biases, the researchers journaled to reflect on their experiences and the possible biases they created and remained cognizant of these biases while conducting data analyses.

## 4. Results

### 4.1. Interpersonal relationships

**4.1.1. Feeling different from others**—Many participants reported longstanding feelings of being different from their peers. Difficulties relating to and communicating with neurotypical people, or people without neurodevelopmental disorders, were common.

I always knew there was something wrong or different in me ... I thought that I need to try harder or learn some, do some extra steps to fit in.

They're so neurotypical, they just won't get it, because their brains just work so bloody correctly.

In response to feeling different from others, many participants masked, or hid, their ADHD symptoms. Masking prevented others from knowing the extent of their symptoms, such as not being able to keep up with coursework or having overwhelming emotions.

At school, the shame of not understanding what the teacher was talking about ... There was a lot of masking ... I was the naughty child. I was the child that would distract ... I would try to push the attention away from the classwork ... but that was just how I coped because I knew that I didn't understand the schoolwork and I didn't want anyone to find out.

I usually mask pretty much all the time except around people I'm really close to just because I feel like I'm a lot to deal with, so most of the time I just keep it in and deal with it internally ... I've always felt like I'm just putting on this façade, just pretending to be a responsible human adult.

Several participants reported masking their symptoms to the point of inverting how their symptoms presented. This over-compensation reportedly resulted in changing one's presentation from impulsivity into difficulty with decision-making, or changing from being overly emotional into aloofness. Participants reported going from struggling with one extreme of their symptoms in childhood to having to manage the opposite extreme in adulthood.

My whole life I was being told that I didn't think things through and that I would make really dumb decisions. And over time hearing that again and again kind of manifested in taking really long to make a decision ... Over time that kind of impulsive decision-making has resulted into not making decisions at all.

I know that I was really hyper as a child, but I realized that it was kind of awkward, so I internalized that, and I became really quiet in adulthood.

Participants communicated that masking around neurotypical people was difficult and often required tremendous energy to maintain. When participants were no longer able to maintain this energy, they reported that their "mask dropped," leading to extreme emotional instability.

My emotions can go from like nothing at all to all of a sudden, I'm not able to maintain that mask anymore and it's like a thousand miles an hour all hitting me at

one time which turns me into a blubbing wreck .... I had to learn the hard way that masking is not the benefit that I think it is.

Participants felt different from neurotypical people and responded to this by masking their ADHD symptoms, sometimes to the point of apparently changing their symptoms. Masking was seen as emotionally difficult to maintain.

**4.1.2. Feeling similar to other neurodivergent people**—Participants felt they could relate better to others with ADHD and therefore surrounded themselves with other neurodivergent people (those with developmental disorders like ADHD or ASD). Neurodivergent people were seen as having more direct communication styles and as being more understanding of ADHD symptoms.

Neurodivergent people, especially people with autism and ADHD, tend to communicate in a very different way. We tend to be more direct and say exactly what we mean whereas neurotypical people say things in a kind of doublespeak. That's why neurodivergent people tend to have a lot of neurodivergent friends, because we can communicate more easily if we know that person's neurodivergent.

I feel like the only friends I have, the majority of them are very understanding of it or have ADHD themselves to be able to resonate with the symptoms.

Although feeling different from most of their peers, participants often felt more able to build meaningful connections with those who were also neurodivergent. With other neurodivergent individuals, participants felt they could more frequently share a more authentic version of themselves.

**4.1.3. Social impairment**—Participants' ADHD symptoms were reported to have frequently caused logistical difficulties within interpersonal relationships. Difficulties in keeping living spaces organized or being on time were reported to have created conflicts with friends and family as they perceived these to be a reflection on how much the participant cared about their relationship as opposed to being symptoms of ADHD.

I've never been able to keep a space not messy ... My relationships with people are stunted because I feel like if no one can ever visit me I'm not going to have as deep of relationships as I would have.

Even friendships as well, people aren't realizing that me being late isn't a reflection on how much I care about them.

Many participants struggled to keep contact with others which led to relationships fading. They would forget to contact others, and several reported finding written or virtual communication more difficult to manage than in person.

I feel like when it comes to relationships I don't pay as much attention to them as I should. I kind of get stuck in my own head ... So, I kind of forget to contact people.

I really struggle with written communication. It moves so slowly for me. I do really well face to face, I enjoy the company of people .... But I cannot write emails or text messages. It's just too slow and it's really frustrating .... Because of that, I

don't really have friends because anyone I find as a potential friend as an adult, it seems like that's everyone's preferred way of communication nowadays.

Participants reported struggling with communication in their relationships. They found that others were annoyed by them, and they often struggled to get across what they meant, resulting in misunderstandings.

When I meet people, you can kind of see the wheels turning in their head. They're thinking about what you said, and it seems like they didn't take it like how you meant it, so you go back and but actually, this is what I mean. And then they think you're weird because you're over explaining everything.

Several participants focused on novelty in relationships and impulsively moving on to new people. This created difficulty in maintaining long-term relationships.

In terms of relationships, because of the impulsivity, I jumped around very quickly. I would end things very fast and move onto the new person.

Perceptions of being "too much" for other people were common, whether that be thinking they were too emotional or too talkative and excitable.

I worry that my emotions are too intense for other people ... I perceive myself as being exhausting to others. But maybe I'm just exhausted with myself because it's exhausting being in my brain.

Participants' ADHD symptoms, difficulties maintaining relationships, and struggles with articulating their thoughts often resulted in social impairment. As a result, participants frequently believed they were too much for others to handle, and some would prioritize new relationships over maintaining existing ones.

## 4.2. Others' perceptions of ADHD

**4.2.1. Misunderstanding of symptoms**—Participants felt that others did not understand their ADHD symptoms and viewed their symptoms as them not caring about other people. Difficulties with listening came off as not caring enough to pay attention; forgetting things came across as a lack of prioritization.

A lot of the things they held against me have to do with my ADHD symptoms. Always forgetting everything, and that I didn't care, and that I'd lose things or all types of stuff that all came back to my ADHD so that's been hard to maintain relationships over time.

He [their husband] gave me a verbal list of things the other day. And I was like I can't keep everything straight, let me just see what you're reading. And he got so mad at me because he thought I wasn't paying attention. And I was like, "I'm listening to you, it's not that I don't care." I just can't keep all of these options straight in my head; I have to see it ... I feel like that's where the disconnect is; people on the outside think you don't care and, on the inside, you're going no, I do, but I need to learn tools and you need to learn tools to help both of us succeed.



Participants reported that neurotypical people in their lives often would take their struggles with communication or keeping up with life tasks personally instead of attributing them to ADHD, frequently resulting in conflicts.

**4.2.2. Stigma of diagnosis**—Disclosing their diagnosis of ADHD resulted in participants reporting not being taken seriously. Many reported others invalidating their experiences based on preconceived notions that ADHD is not a serious medical issue. Some felt the stigma around ADHD was more disabling than the symptoms themselves.

People will brush it off, like that's just being lazy, you're just using it as an excuse ... Beyond just how ADHD affects you, it's people's perceptions of ADHD because they don't think it's real, because they don't think it's hard. It can really make it worse than just the ADHD itself, it's how society reacts to it.

Because of the stigma they reported facing when they disclosed their diagnosis, many participants purposefully withheld telling others they had ADHD. Several provided examples of breaking down how ADHD affects them without naming it and found they were taken more seriously.

People do treat me differently when I tell them that I have a neurodevelopmental disorder rather than saying ADHD. Because if I say I have a neurodevelopmental disorder that affects my memory and executive functioning people are oh, what's that, have I ever heard of it? Well, it's like you have, but now that I tell you what it is you're not going to believe me how serious it is and how it affects me.

Preconceived notions about ADHD not being a “real” or clinically significant medical condition made participants feel devalued in their experiences and often resulted in them concealing their diagnosis from people in their lives.

### 4.3. Benefits of online communities

**4.3.1. Changing perceptions of diagnosis**—For some participants, online communities for people with ADHD were the impetus to either seek out a diagnosis or come to terms with an existing diagnosis. Relating to information distributed in these communities helped some participants realize their previous perceptions of ADHD were inaccurate and based on stereotypes. The TikTok algorithm in particular seemed to target ADHD content to participants, both to those who had preexisting formal diagnoses and to those who had not been previously diagnosed.

I'm a medical student ... but the way that I realized I had ADHD was through TikTok and memes. And I was relating, and I was like this is absolutely crazy when I have studied ADHD before.

I've always been curious about my symptoms ... so, I start lurking around, just Googling them up ... a lot of it just kept showing ADHD. I think growing up with the stigma of it just being an attention problem, I just never resonated with that, there's no way. I can focus, I can play video games for seven hours ... I'm just unmotivated ... One day I opened up the subreddit for ADHD. I resonated very

deeply with some of these stories, and they get really personal ... And it wasn't until really recently did I finally get an official diagnosis.

I was originally diagnosed in my early twenties and then was like. "No, I don't really think that's right." ... I just rejected it for so long ... Years later I download TikTok in the middle of the pandemic and you fall into the different hashtags like #ADHD TikTok, for example. And you start hearing other people describe things, and you think, "Okay I thought that was just the way that everybody was." And you start to realize that some of the things you experience aren't actually neurotypical things.

By engaging with content about ADHD in online communities, participants embraced their identities as people living with ADHD. This content was seen as more relatable and accurate in describing the condition than their previous understandings of ADHD.

**4.3.2. Awareness of symptoms and features of ADHD**—Many found that the resources available in online communities were more accessible than traditional clinical resources as they were presented from the perspective of people who also have ADHD. Information focused on how symptoms affected daily life in concrete ways in contrast with clinical resources.

A lot of the ADHD creators have been making informational videos and putting up more resources and saying, "Here's where to learn more, here's a study about this." It's really kind of broadened my understanding of what ADHD affects in my life so much more than before because a lot of the resources that are available, at least that I've seen outside of TikTok, are from a neurotypical perspective.

Nearly all participants reported learning about new ADHD symptoms from online communities, although many struggled with identifying specific symptoms during the focus group. Participants reported the value of learning new vocabulary for symptoms they knew they experienced, but were now able to attribute them to ADHD. Such terms included rejection sensitivity dysphoria describing hypersensitivity to social exclusion, executive dysfunction, and neurodivergent, meaning differing neurological function from the "norm", typically in reference to those with neurodevelopmental conditions.

It's been really beneficial because it gives you more of a technical name to a lot of symptoms that you know you're doing but you aren't exactly aware of what they are. When I first learned executive dysfunction, it's one of those things that I didn't have a name for it until I started looking at papers and communities. People would poke fun at hey, you know how you really wanted to move and do that thing but you just can't? This is what that is.

It has been seeing emotional dysregulation and seeing these terms, and just seeing the word neurodivergent, and I thought, "Oh what a beautiful word!" I think I only heard that this year, it's existed before 2021, but I think it only came into my brain this year and I'm like I don't have to say weird, I don't have to say unique, I don't have to say different, I can just say neurodivergent, and I feel really proud of that statement.

Upon learning that their experiences were attributable to symptoms of ADHD, many participants felt validated. Participants reported that validation and normalization of symptoms helped them improve their self-image.

Finding that community really helped me to see that even the things that I've always felt super badly about within myself were just part of the diagnosis. And so, once I recognized that, I was able to implement things to help me improve those things and not just accept it as like this horrible personality flaw or whatever.

Having content created by and for people with ADHD was often seen as more beneficial than the clinical information and resources to which participants previously had been introduced. Learning about ADHD from online communities was validating to participants, especially being able to name previously inexplicable symptoms and attribute them to ADHD.

**4.3.3. Finding similar people**—In addition to reporting having felt validated by learning their tendencies were attributable to a diagnosis, many individuals also reported finding online communities helpful for identifying people with whom to interact and who understood them. These communities were reported to have generated a feeling of belonging, especially since some participants had not interacted with other adults with ADHD before finding these online spaces.

I think that the online community is very important for my own personal experiences. All of us trying to understand what it's all about... that's the only place where you feel understood. I feel like when you have ADHD that's the only place you can relate to, you're almost in tears sometimes. So, the online community is very important to me, that's where I feel normal, that's where I feel like I belong.

Hearing others' stories helped many participants feel less alone in their experiences, and the anonymity of online spaces facilitated personal disclosure.

It helped me realize that I'm not crazy with all this stuff going on in my head. It helped me realize I'm not alone because these things are hard to explain in person to someone close. Online you have some kind of anonymity.

Online spaces were seen as vital for building community with those who had similar experiences and helped participants find a sense of belonging.

**4.3.4. Learning coping skills**—Collectively strategizing ways to manage their ADHD symptoms was frequently endorsed as a benefit of online communities. Participants learned new coping skills and felt rewarded when they were able to share skills they had developed with others.

I think it's really helpful in communities where you say these are symptoms that I'm having and people can be first of all yes or no that is related to ADHD, and second of all here's a solution to that problem that you're having which I think is one of the really big benefits of having community.

Here's my little hack or trick or life hack or trick. It's to be able to give back to people if you can and also realize you've made some growth, you've made some

progress. Because that was a problem for you six months ago or a year and now, you're on the other side of it helping somebody else out.

Specific coping skills shared in online communities included organizational tips and suggestions for how to start tasks. Body doubling, or completing tasks alongside others to impose structure, was utilized by some participants. Many felt that strategies developed by people with ADHD were uniquely helpful.

Lately I've become really obsessed with people who reorganize their fridges. I don't know who else buys groceries and they disappear into the void of the fridge and two weeks later everything's rotten ... I'm watching all these TikTokers who took all of their sauces and things that don't expire quickly and put them at the back of the fridge and put all the fresh produce at the front in the door, so it's visible and it's there so you see it. And how to kind of modify your life to be more helpful for you instead of trying to exist in a neurotypical world.

How do you get off of your phone? Well close your eyes, turn your phone off, and throw it across the room. And what are you going to do now? You're going to stand up and now that you're up you might as well do other things, right?

I was part of ClubHouse ... I joined this ADHD group ... there was a mod who would check in after 45 minutes, call you by your name and ask did you get what you needed to get done ... Just by hearing different people what their to do list was or the nuances of their day, their life, it helped me .... It was nice to find that and to actually have a group where you understand because you have the same struggles. I don't know if I could go into another random room and work with people [without ADHD].

Sharing coping skills for managing ADHD symptoms, such as organizational and time management strategies, not only helped participants navigate their symptoms, but also mutually helped each other facilitate community building.

#### 4.4. Concerns with online communities

**4.4.1. Misinformation**—The most common apprehension with online communities for people with ADHD was the spread of inaccurate information. Participants noted that many people posting content do not have any medical or psychological training and may be more concerned with going viral than with providing accurate and nuanced perspectives.

I think TikTok was good but it kind of got out of hand ... They're spreading misinformation ... Just saying certain symptoms are this disease, but they're not a provider, they're not doing a differential diagnosis, I don't know what they're doing on there.

There's an oversimplification ... Especially with the fact that TikTok, Instagram, Facebook, Twitter, the goal is to become viral. So once that viral information goes out you can't take that back. And you can't add onto it and say hey, I was misinformed, this is what I really mean. It's an easy way for misinformation to get out there, and the information that is put out there is very oversimplified for something that's very complex and different for each person.

There was concern that people on social media attributed common human experiences to their ADHD, thereby “creating” new symptoms that are nonspecific if not wholly inaccurate. Some were cautious that hearing other’s symptoms could reshape how they conceptualize their own experiences and result in altered self-perception.

Sometimes it’s like this is the common experience for a bunch of people with ADHD but not necessarily because of ADHD. It might be something that humans do. I’ve seen that talking to yourself be a meme recently on ADHD Reddit and Facebook ... That’s just a way that people process things. But everyone’s like, “Yes, OMG, I thought that I was weird, and this is clearly just ADHD-related.” ... So sometimes it can have a false positive on symptoms.

Trying to make sure I keep everything with a grain of salt and not to just agree because it feels validating, it might not necessarily be accurate.

Although participants regarded the information they found on these online spaces helpful, there were many concerns with spread of inaccurate information. This was seen as in part due to people describing common experiences and attributing them to ADHD, thus increasing relatability in order to further spread content. Participants reported self-reflection and additional research to attempt to discern which information was accurate.

**4.4.2. Difficulty with online communication**—Many participants struggled with communication online more so than in person. Several preemptively worried they would be ignored or rejected so they would refrain from engaging with others online. This rejection sensitivity dysphoria was also triggered if they did post content which did not receive responses. Others struggled with written communication generally and preferred face-to-face interactions.

There’ve been so many times when I’ve typed out a comment or a response to something online, typed the entire thing out and thought, “No, if I write this, they’re going to think I’m stupid, they’re going to think I’m mean, they’re going to hate me.” So I delete it and then move on. I don’t end up responding to anything because I anticipate that it will be taken poorly.

Some participants had apprehensions about disclosing personal information to people they had not met in person.

I’m not involved personally because I kind of have a problem with meeting strangers and trying to do community things. It just is difficult for me; I have to get to know somebody first and then that’s how the community forms for me personally.

Fears of rejection and disinterest in disclosing personal information online created barriers to participants engaging in online communities.

**4.4.3. Feeling overwhelmed**—Participants largely regarded smartphones and social media in general to be distractions from accomplishing tasks that they wanted to do. Engaging in too many online communities worsened already present struggles with keeping

up with responsibilities. Joining multiple communities was difficult to maintain over time as participants already found remembering things difficult.

My friend, she signed me up for a Facebook group and I couldn't, there were too many messages. It's a lot when you have other stuff to do.

I joined a lot of communities and a lot of them don't stick because I forget that they're there.

Spending too much time on social media in general was detrimental to participants fulfilling tasks in daily life. Social media groups could overload participants with content to the point where they felt a need to disengage.

**4.4.4. Not fitting in—**A few participants did not relate to others in online communities for various reasons such as not knowing anyone in a group, not wanting to engage in debates, or not having a “normal” experience to stimulants. This resulted in feelings of exclusion from the ADHD community.

There's these pre-established groups, and everyone already knows each other, so I don't know if I fit in here. Or it can be political, like don't say disabled, say disabled, say neurotypical, don't say that. I just want to figure out if getting a textbook reader software is going to help me stay up on my class readings. I'm not that far ahead to be debating terminology and stuff like that.

When I started medication, I was kind of bouncing off of the posts on people also being on meds for the first time ... It actually kind of made me feel left out. I'm not like other people who have ADHD and are on medication because it's not working for me.

Although most participants experienced online communities to be helpful for community building and relating to others, some questioned how well they fit into the ADHD community based off interactions on social media.

## 5. Discussion

This qualitative study explores how young adults with ADHD navigate the world around them both in person and in online ADHD communities. In our sample of mostly white women, we found that those with ADHD struggle with maintaining relationships with those without ADHD, mask to conceal their symptoms to people without ADHD, and experience stigma about their diagnosis and their symptoms. Online communities were overall regarded as positive as they helped participants come to terms with their diagnosis, provided vocabulary for their symptoms, and built community to validate their experiences. Concerns with online communities included spread of misinformation, such as inaccurate symptoms of ADHD, and general difficulties using online platforms.

These findings build upon previous qualitative work on the lived experiences of adults with ADHD. Longstanding feelings of being different from individuals without ADHD have been well described (Brod et al., 2012; Lefler et al., 2016; Nyström et al., 2020; Schrevel et al., 2016; Sedgwick et al., 2019; Toner et al., 2006; Waite & Tran, 2010; Young et al., 2008).

These feelings of difference throughout the lifespan, which often result in low self-esteem (Nyström et al., 2020), may contribute to the degree of social impairment that has been observed. Adults with ADHD have reported to struggle with maintaining relationships over their lifespan (Kwon et al., 2018; Matheson et al., 2013; Waite & Tran, 2010), have difficulty modulating their behavior to be socially acceptable (Schreuer & Dorot, 2017; Schrevel et al., 2016), and strain to communicate their thoughts and feelings to others (Matheson et al., 2013; Nyström et al., 2020). Stigma about the diagnosis of ADHD has been previously described as participants not being taken seriously (Lefler et al., 2016; Schrevel et al., 2016; Watters et al., 2018) and ultimately preventing their disclosure of the condition to others (Hansson Halleröd et al., 2015; Toner et al., 2006; Waite & Tran, 2010; Young et al., 2008). The findings presented here of people with ADHD relating to and communicating easier with other neurodivergent people have not been previously described, to our knowledge.

The term masking was used in 1969 to mean concealing disgust (Ekman & Friesen, 1969) and has since come to be used within the autistic community to mean hiding one's symptoms (Milton & Sims, 2016; Willey & Attwood, 2015). Masking among autistic people has been hypothesized to originate as a response to the stigma people with autism face in their daily lives, in part related to the medical model of disability, and may lead to delays in diagnosis and burnout (Pearson & Rose, 2021). To our knowledge, this study is the first to explicitly describe masking in the context of adult ADHD, although previous research has detailed that women and girls with ADHD may be more likely to utilize compensatory strategies to conceal their symptoms which may factor into underdiagnosis in this population (Hinshaw et al., 2022). More research is needed on how masking may affect ADHD symptom presentation and to develop strategies to mitigate the harms masking may create.

The findings that adults with ADHD relate well to other neurodivergent people and mask their symptoms around neurotypical people indicate that some of the social impairment they face may be due to ableism and stigma as opposed to inherit difficulties with interpersonal relationships. Viewing the struggles that individuals with ADHD face as resulting from discrimination and not inferiority is in line with the social model of disability (Oliver, 1990) and the neurodiversity movement (Singer, 1998). ADHD may have beneficial features. For example, anxiety related to interpersonal conflict or executive dysfunction may act as a trigger for disintegration in the context of Dabrowski's theory of positive disintegration (Dabrowski, 1964). The positive challenge of reintegration may lead to further growth, development, and increased awareness of oneself.

There has been little research about how online communities may relate to ADHD diagnoses. People with ADHD on Twitter have been found to post more often than those without ADHD and post about themes of emotional-dysregulation, self-criticism, substance use, and exhaustion (Guntuku et al., 2019). Social media use in community building has been studied among parents of children with ADHD; these communities have been found to promote emotional support, disseminate helpful educational resources, and help decrease feelings of guilt among parents (Dauman et al., 2019; Margalit & Raskind, 2009). Although not directly focusing on ADHD, social media groups for adults with disabilities have been

reported to help build community, validate experiences, and assist with forming a disability identity (Gallagher, 2021; Miller, 2017). These findings support the current study's findings that online communities could form a critical role in developing identity formation of adults with ADHD, assist with spreading information about the condition, and lead to community building.

Although participants in the current study regarded online ADHD communities to be positive overall, some expressed concerns about spread of misinformation and difficulty navigating online platforms. TikTok in particular, whose algorithm shows more related content the more individuals interact with the topic, was described as "figuring out" participants had ADHD before they realized it themselves. TikTok often portrays mental illness in a positive light (Gallagher, 2021), which is described as empowering, but participants in the current study wondered if videos describing ADHD symptoms were made to be generally relatable or desirable to foster more views. Branding normal experiences as symptoms of ADHD may lead to people falsely believing they have the condition. Participants in the present study reported official diagnoses of ADHD; the experience of those who have self-diagnosed with ADHD have not been previously studied. This population may include people with true underlying ADHD in need of diagnosis and treatment, people living with other psychiatric symptoms, that although they attribute symptoms to ADHD, the symptoms may be better explained by another diagnosis, as well as people without any psychiatric pathology who are looking for community. Regardless, healthcare providers should be aware of this population and be willing to explore potential diagnoses. Additionally, some participants in the current study struggled with online communication as they felt overwhelmed or that they did not fit in. Among adults with disabilities, online communities were found by some participants to focus too highly on negative experiences, and when participants did not receive attention from these communities, they often responded by disengaging (Miller, 2017).

Online communities may be a beneficial supplement to in-person social support for adults with ADHD, although more research is needed to further establish which sites are beneficial and for which populations. As this study highlights both benefits and drawbacks of ADHD social media groups, further investigation is needed to understand the specific characteristics of the distinct online communities to help people make decisions about which communities may be most beneficial for them to join. Development of a resource guide describing the different websites may be advantageous to help people with ADHD make informed decisions about which groups are right for them.

This study may inform how ADHD symptoms present in adulthood. Difficulties with interpersonal relationships such as feeling different from neurotypical people, masking, and struggling with communication are not currently part of the diagnostic criteria for ADHD (American Psychiatric Association, 2013). Given the relatively homogenous and predominantly female study population, further focus groups could be conducted with increased representation of men, people of color, individuals with the hyperactive sub-type of ADHD, and those diagnosed as children to further elucidate whether these findings are generalize across groups. Further investigation is needed to test the psychometric



properties of these potential symptoms to see if there are reliable differences from the general population, and if so, to what extent these differences are specific to ADHD.

This study has limitations. There was a high level of non-response among people who initially completed the screening survey, therefore making this a self-selecting group of people. There are likely perspectives not represented in this study as the sample was predominantly White women from North America who were diagnosed with the inattentive ADHD subtype in adulthood. It is possible that people of these demographics comprise the majority of members of the online communities from which participants were recruited as the demographics of these communities are currently unknown. It is also possible that people with these demographics were more likely to participate in this study or that some other factors were in operation. We hypothesize that because women and those with the inattentive sub-type may be more likely to go undiagnosed until adulthood, they may be more likely to seek out previously missing resources when they ultimately receive a diagnosis. As women are underrepresented in studies of those with ADHD (Hinshaw et al., 2022), online communities could serve as a mechanism for participant recruitment to further study how the condition presents in women. Further, the study was qualitative in nature, thus having both strengths and limitations. With the information gained, it may be possible to develop and test quantitative measures that assess additional aspects of adult ADHD. There is also the possibility to generate additional qualitative studies that focus on aspects not fully covered in these focus groups (e.g., ableism, how concerns related to anxiety and depression may manifest in people with ADHD, and how people with ADHD make decisions about joining online communities).

## 6. Conclusions

This study explored how young adults with ADHD navigate relationships in person and their experiences with online ADHD communities. Findings from this study suggest that adults with ADHD struggle with maintaining relationships with neurotypical people in part due to stigma and difficulty communicating which may promote the use of masking to conceal their symptoms. Online communities were viewed as helpful to understanding their symptoms and developing coping skills but came with the drawbacks of potential spread of misinformation and difficulty managing online communication. The medical community should be aware of the social difficulties faced by adults with ADHD as to better tailor therapies. Online communities that spread reliable information may be helpful for adults with ADHD in navigating their symptoms.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## Funding

This work was supported by the Yale School of Medicine Office of Student Research One Year Fellowship, NIDA K12DA000167.

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