How Online Tests Contribute to the Support System for People With Cognitive and Mental Disabilities

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ABSTRACT

Roughly 1 in 3 people around the world are affected by cognitive or mental disabilities at some point in their lives, yet people often face a variety of barriers when seeking support and receiving diagnosis from healthcare professionals. While prior work found that people with such disabilities assess themselves using online tests and assessments, it remains unknown whether and how effectively these tests fill gaps in healthcare and general support systems. To find out, we interviewed 17 adults with cognitive or mental disabilities about their motivation for and experience using online tests. We learned that online tests act as an important resource that address the shortcomings in support systems for people with professionally diagnosed or suspected cognitive or mental disabilities. In particular, online tests can lower barriers to a professional diagnosis, provide valuable information about the nuances of a disability, and support people in forming a disability identity – an invaluable step towards a positive acceptance of oneself. Our results also uncovered challenges and risks that prevent people with known or suspected health conditions from fully taking advantage of online tests. Based on these findings, we discuss how online tests can be better leveraged to support people with cognitive or mental disabilities before and after professional diagnosis.

CCS CONCEPTS

• **Human-centered computing → Empirical studies in collaborative and social computing**; **Empirical studies in accessibility**; **Human computer interaction (HCI)**; • **Social and professional topics → People with disabilities**.

KEYWORDS

disability, cognitive disability, psychiatric disorder, mental health, online tests, health support

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1 INTRODUCTION

Around 20% of the U.S. population, and at least 1 in 3 people around the world, have experienced a cognitive or mental disability at some time in their lives [2, 81]. Common cognitive and mental disabilities include neurodevelopmental disorders, such as autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD); mental disorders, such as borderline personality disorder (BPD) and depression; specific learning disorders, such as dyslexia and dyscalculia; and neurocognitive disorders caused by conditions like traumatic brain injury (TBI) [6]. Diagnosing these conditions is difficult due to imprecise diagnostic thresholds and high rates of comorbidity, which makes differentiating symptoms from co-existing cognitive impairments or medical conditions challenging [10, 41, 57, 87]. As a result, people often receive an insufficient explanation of their diagnoses and are frequently provided inadequate support and resources for interventions [41]. There are also several factors that impede people from seeking a professional diagnosis in the first place, including concerns about the costs or confidentiality, a lack of transportation or knowledge of where to go, and doubts about the effectiveness of a potential treatment [26, 35, 40, 58].

People who suspect or know that they have a cognitive or mental disability frequently turn to online resources to receive more information, understand how their cognitive functions may affect their lives, and meet others with the same conditions [51, 63]. Among these resources are online tests and assessments (short: online tests), which people with cognitive or mental disabilities (diagnosed or suspected) use to assess the severity of their cognitive impairment or compare their cognitive performance and behavioral functions

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to that of others [22, 32, 54]. Websites that offer such online tests (e.g., mybraintest.org, testmybrain.org, labinthewild.org, psychcentral.com) are often, but not always, based on scientific research and authored by healthcare professionals, yet are rarely suitable for diagnosing health conditions. Instead, they commonly serve the purposes of providing initial assessments and/or helping researchers study cognitive deficits, as exemplified in Figure 1. These tests assess behavioral and cognitive traits using either behavioral tasks or survey questions, followed by a results page that tells participants where they stand.

While prior work shows that online tests are perceived as useful by people with disabilities, including those with cognitive or mental disabilities [54], it is unknown whether and how effectively online tests contribute to healthcare and general support systems for people with diagnosed or suspected conditions. What benefits do online tests provide for people with cognitive or mental disabilities? When are online tests most helpful? What are the associated risks, and what may prevent people with cognitive or mental disabilities from participating in online tests? Answering these questions is the first step towards our long-term goal of designing online tests that supplement other resources provided to people with cognitive or mental disabilities.

To shed light on these questions, we conducted 17 semi-structured interviews; 13 with people who have been previously diagnosed with cognitive and/or mental disabilities, and four with people who suspect they may have a condition. Our results revealed that online tests are an important, and previously mostly unrecognized, resource both before and after diagnosis. Before a diagnosis, people use the tests to evaluate whether they may have a cognitive or mental disability, especially when they face barriers that prevent them from getting diagnosed. For them, online tests either provide sufficient confirmation, reducing the need for a professional diagnosis, or they constitute the first step towards getting a diagnosis. After diagnosis, online tests can often fill the gaps left open by people's professional diagnoses, namely the lack of explanations about the severity of their conditions, what behavioral or cognitive functions may be affected, and whether the condition may change over time. As such, one of the main benefits of online tests is that they support people in navigating the impacts of their health conditions and in establishing their disability identity. Our results also revealed a number of challenges that prevent people with suspected or known cognitive or mental disabilities from fully taking advantage of online tests. Based on these findings, we contribute design implications for online tests that could better support people with cognitive or mental disabilities while mitigating risks of misinterpretation, trust, and replacement of professional diagnoses.

Terminology

We use "mental and cognitive disabilities" as an umbrella term for common mental health conditions and cognitive disabilities, according to the Accessible Writing Guide of SIGACCESS [1]. In the medical field, these conditions are called "psychiatric disorders" [6], which was a term occasionally adopted in HCI. Therefore, following best practices for reconciling naming conventions in different fields [72], we refer these population as "people with cognitive and/or mental disabilities" when we broadly talk about how one's cognitive or behavioral functioning has been affected by cognitive or mental conditions, as well as how their lives have been impacted by the related societal barriers, throughout the paper; we refer to "psychiatric disorders" when specifically speaking within the contexts of the medical field, mostly in the *Related Work* section.

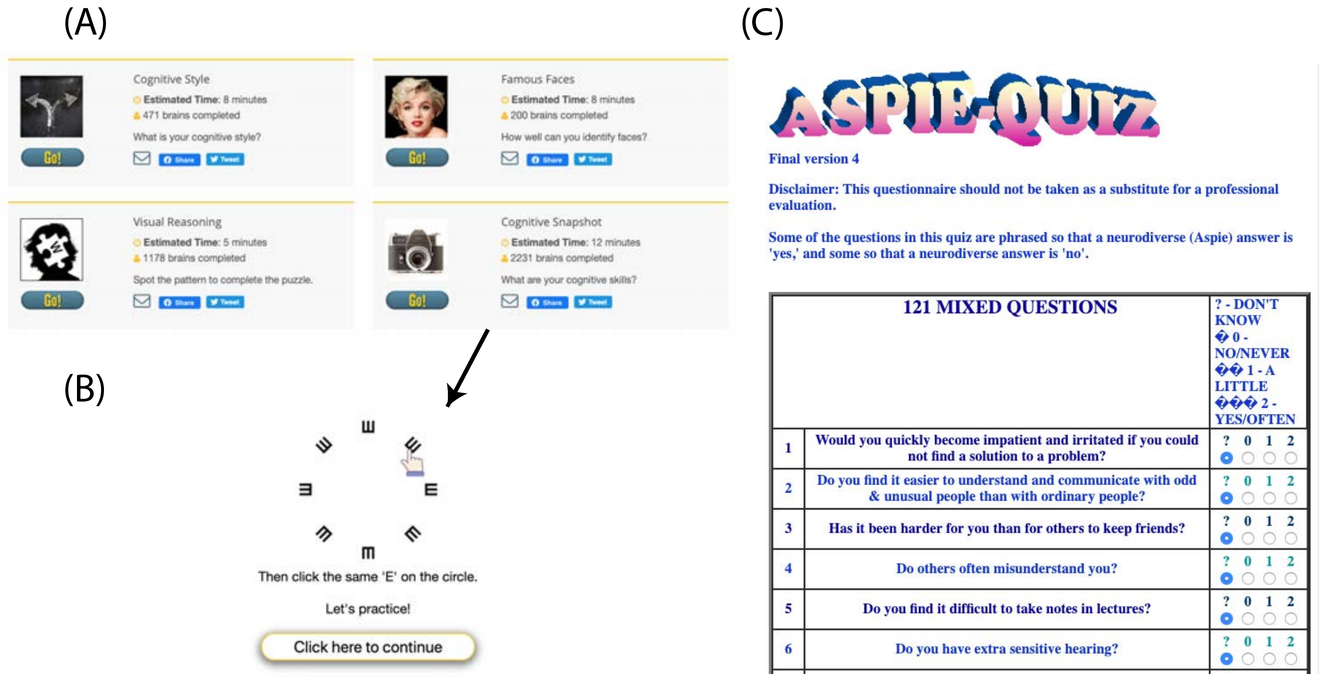
2 RELATED WORK

In most cases, receiving a professional diagnosis by a certified healthcare professional or psychiatrist is of utmost importance for any cognitive or mental health condition as it may lead to the development of treatment plans and interventions. Ideally, a professional diagnosis should be obtained as early as possible in a person's life to mitigate potential development of anxiety and depression that can also result in complications with schooling and employment [31, 42, 60]. In the following, we describe the current literature on 1) how professional diagnosis and self-diagnosis of psychiatric disorders are situated in the healthcare communities, 2) previously found barriers towards receiving a professional diagnosis, 3) the status quo of receiving a professional diagnosis and interventions, and 4) work in the field of HCI towards supporting people with psychiatric disorders, including automated diagnosis tools.

2.1 Professional Diagnosis vs. Self-Diagnosis in Psychiatry

Diagnosis has long been a dominant topic of discussion and debate in the psychiatric field. In a general framework, psychiatric disorders refer to disturbances of personal experience, social behavior, and bodily function [25]. Therefore, the concept of diagnosis is not only medically constructed, but hugely affected by the political, economic and cultural factors [5, 25]. Due to the controversial criteria for defining and diagnosing most psychiatric disorders and its complicated societal impacts [28], receiving a formal diagnosis of psychiatric disorders has its pros and cons. On one hand, a professional diagnosis can help people identify empirically supported treatments, qualify people for insurance reimbursement, facilitate self-understanding, self-legitimation and self-enhancement, and reduce anxiety [3, 64]. On the other hand, however, a psychiatric diagnosis can also have negative consequences, such as stigmatization [3]. Because the process of diagnosing psychiatric disorders is inherently subjective due to its heavily reliance on clinical interviews, a diagnosis can be invalid or unreliable if the clinicians are inexperienced, biased, or blind to the complexity of life and human nature [3, 28].

When seeking an alternative to the traditional professional diagnosis, people often turn to online communities or online self-assessment tests, as both resources provide much more easily accessible consultation for those in need [27, 61]. Online mental health communities operate as an informal medical consultancy for the undiagnosed, where members recommend online diagnostic or quasi-diagnostic instruments to each other and respond to the requests for help with described behaviors [33]. This interaction, however, remains a degree of reverence for professional expertise, as the medical consultancy of participants often include disclaimers such as "I'm not an expert." For people who face barriers that make formal mental consultation impossible or at least very unlikely, online mental health tests become a convenient tool to perform



Cognitive Style
Estimated Time: 8 minutes
471 brains completed
What is your cognitive style?

Famous Faces
Estimated Time: 8 minutes
200 brains completed
How well can you identify faces?

Visual Reasoning
Estimated Time: 5 minutes
1178 brains completed
Spot the pattern to complete the puzzle.

Cognitive Snapshot
Estimated Time: 12 minutes
2231 brains completed
What are your cognitive skills?

Then click the same 'E' on the circle.

Let's practice!

Click here to continue

ASPIE-QUIZ

Final version 4

Disclaimer: This questionnaire should not be taken as a substitute for a professional evaluation.

Some of the questions in this quiz are phrased so that a neurodiverse (Aspie) answer is 'yes,' and some so that a neurodiverse answer is 'no'.

	121 MIXED QUESTIONS	? - DON'T KNOW � 0 - NO/NEVER �� 1 - A LITTLE ��� 2 - YES/OFTEN
1	Would you quickly become impatient and irritated if you could not find a solution to a problem?	? 0 1 2 ● ○ ○ ○
2	Do you find it easier to understand and communicate with odd & unusual people than with ordinary people?	? 0 1 2 ● ○ ○ ○
3	Has it been harder for you than for others to keep friends?	? 0 1 2 ● ○ ○ ○
4	Do others often misunderstand you?	? 0 1 2 ● ○ ○ ○
5	Do you find it difficult to take notes in lectures?	? 0 1 2 ● ○ ○ ○
6	Do you have extra sensitive hearing?	? 0 1 2 ● ○ ○ ○

Figure 1: Examples of online tests that are used by people with cognitive or mental disabilities to assess themselves: (A) Examples of several cognitive assessment tests on TestMyBrain.org. (B) An example task in the "Cognitive Snapshot" test on TestMyBrain.org. (C) The Aspie-Quiz [1] , a questionnaire developed by independent researcher Leif Ekblad. Its websites states that it evaluates neurodiverse traits in adults, which "can be used to give a reliable indication of autism spectrum traits prior to eventual diagnosis."

self-diagnosis. For instance, Lewis [52] explored self-diagnosis experience of autism spectrum disorder in adults: most individuals took online self-tests for ASD when they started to doubt themselves and found a "fit" in the criteria. Online self-diagnostic resources are also favored by mental health professionals themselves. An interview study revealed that psychology students who performed self-diagnosis frequently rely on online resources, including online tests [4]. Their academic background and professional knowledge protected them from purely trusting the results of online tests and allowed them to take the tests as supplemental, educational resources.

2.2 Barriers and Stigma Associated with Receiving a Professional Diagnosis

There are various reasons for why people may not seek professional help or receive a formal diagnosis. Common concerns include costs, the lack of insurance, unavailable or inconvenient care when needed, not knowing where to go, inadequate transportation, concerns about confidentiality and the belief that the treatment will not help [26, 35, 40, 58]. Likewise, patients often feel that they can handle the symptoms themselves and do not consider their disorder as serious or recognize it as an illness [14, 26, 58]. Others refrain from acknowledging their disability due to public, perceived, and self-stigmatising attitudes towards mental conditions and cognitive disabilities. For instance, people with psychiatric disorders often feel embarrassed or uncomfortable to talk about their personal problems to others [90]. They have reservations towards talking to both strangers [89] and to people who they knew or knew they would have future dealings with [15, 90].

2.3 Diagnosis and Interventions of Psychiatric Disorders

Despite the large number of people suffering from psychiatric disorders, diagnosing such disorders is difficult. The Diagnostic and Statistical Manual of Mental Disorders (DSM) [6] and International Statistical Classification of Diseases (ICD) [66], serves as the principal authority used by clinicians and researchers for psychiatric diagnoses and classification in the United States and internationally. In the most recent DSM-5 and ICD-10, diagnostic criteria is listed for each of the disorders, and it is often memorized by trainees in psychiatry and other fields for certification exams [41].

Because multiple changes have been made to the diagnostic criteria throughout different editions of DSM and ICD, the diagnosis

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[1] rdos.net/eng/Aspie-quiz.php

of many psychiatric disorders is at times confusing, even for specialists [73]. Moreover, the diagnostic criteria are primarily categorical rather than quantitative (or dimensional), therefore lacking concrete diagnostic thresholds or descriptions of what is typical [40, 41], clinicians are forced to make a judgement call, often based on a "clinical significance" criterion that is included with the symptom lists of many disorders. This risks adding subjectivity to the nature of assessment and denying milder symptom presentations [46, 78]. The "discontinuity" of diagnostic criteria could also affect the accuracy of the diagnosis, since symptoms may vary in severity with time and developmental and environmental factors [17, 48, 50].

In addition, evidence has found excessive and scientifically premature splitting of disorders, resulting in high comorbidity rates in clusters of related illnesses, thus, making the diagnosis for each disorder even harder [47]. In the same vein, criteria for disorders are sometimes over-specified so that patients do not precisely match any criteria and receive a diagnosis of Not Otherwise Specified (NOS) [41], leading to unpredictable implications for treatment intervention [43]. In Table 1, we provide examples of common psychiatric disorders, their definition, prevalence, and the state-of-the-art treatment and prevention strategies. Like the ambiguity in diagnosing psychiatric disorders, prior studies reveal that treatment and prevention strategies often yield equivocal efficacy, as summarized in Table 1.

2.4 Assistive Technologies for People with Psychiatric Disorders

Assistive technologies, computer-mediated systems, and design frameworks for mental health and disabilities have long been of interest to the human-computer interaction (HCI) community. For instance, Sonne et al. [80] developed an assistive technology design framework for people with ADHD. Sanches et al. [75] reviewed 10 years of HCI literature on mental disorders, showing that most innovation took place in automated diagnosis. For instance, prior work has investigated computer-mediated automated diagnosis tools, such as speech-base psychosis detection [12], emotion and disposition recognition [84], which are used to detect and identify psychiatric disorders in clinical settings [13]. Similarly, Hafiz et al. [36] showed that internet-based cognitive assessment tools (ICAT) can be used to screen for cognitive impairment in clinical settings. Researchers have also developed systems that utilize behavioral data such as mouse operations [82], search log, sensor data [44] as well as biofeedback data such as heart rate [75], to facilitate automated diagnosis. Though a wide range of computational psychiatry approaches have been studied and deployed in clinical settings, they are not accessible to the majority of the population.

Prior work has also investigated how online resources and collaborative technologies play an important role in supporting people with mental disorders and cognitive disabilities. For instance, technology has played an important role in facilitating mental health peer support [67]: people often turn to online communities and social media to self-disclose about their conditions for emotional well-being [9, 20, 62, 76, 85], and to seek information, emotional support, and advice [11, 53, 69, 70]. However, the stigma around having these disorders can often hold people back, or even become the source of more severe stress-related illnesses [39, 55, 62, 76].

Furthermore, technology has provided people with (suspected) disabilities a space to learn more about themselves through online experimentation. Li et al. found that many people with various disabilities use online tests on the volunteer-based experiment platform LabintheWild [71] to diagnose themselves, compare their abilities to others, quantify potential impairments, self-experiment, and share their own stories with researchers [54]. Li et al. additionally analyzed comments from participants and online forum entries where people discussed the tests retroactively, but did not host interviews to find out how online tests may supplement the support systems that provided through healthcare, family, and other online resources [54]. In this paper, we aim to shed light on this question by examining the role of online tests in supporting people with psychiatric disorders.

3 METHODS

Our study was guided by two primary research questions:

> **RQ1**: How do online tests support people with cognitive and mental disabilities, and how do they contribute to existing support systems?
> **RQ2**: What are the opportunities and challenges of using online tests for people with cognitive or mental disabilities?

To answer these questions, we conducted semi-structured interviews with 17 participants between February and April 2020. All participants were recruited from online forums with topics related to cognitive or mental disabilities where online tests are frequently shared: 13 from *Reddit* (r/anxiety, r/autism, r/BPD, r/dyscalculia, r/dyslexia, r/TBI) and four from *Wrong Planet.* After obtaining the permission from moderators, we posted our recruiting advertisement on these forums, asking people to sign up via a screening survey. Eligibility for the interview required participants to be at least 18 years old. Of the 17 participants, 15 interviewees were from the USA, one was from Australia, and one was from Canada. Eight interviewees identified as male, eight as female, and one as non-binary. As for their levels of education, nine of them had graduated or were attending college, five were graduate students, two completed high school, and one completed army technology school. Most (13) of the interviewees were full-time employees or students while four of them were currently unemployed. Participants' self-reported disabilities and diagnosis status are presented in Table 2.

The first and second authors conducted the remote, semi-structured interviews via Google Meet and Zoom. Interviews were audio-recorded and transcribed verbatim with permission. The length of the interviews ranged from 23 to 60 minutes and averaged around 35 minutes. Participants received $10 upon completion of the interview. The study was approved by our institution's Institutional Review Board (IRB) and was performed in accordance with the relevant guidelines and regulations.

We used the constant comparative method to identify patterns in the data and ensure theoretical saturation [18]. An initial coding pass was completed after nine interviews, in which two transcripts were coded by three authors independently in order to develop a codebook. The entire research team then met to refine the preliminary codebook, discuss and modify ambiguous codes, and discuss the data, including early themes we saw emerging. We then

Table 1: Summary of definition, prevalence, the state-of-the-art treatment and prevention of common psychiatric disorders. The prevalence statistics is cited from National Institute of Mental Health (NIMH) if not otherwise specified.

Disorder/ Disability	**Definition** [6]	**Prevalence in the U.S.** [2]	**Treatment & Prevention**
Attention-Deficit/ Hyperactivity Disorder (ADHD)	A persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development.	11% (4-17 years old); 8.7% (adolescents); 4.4% adults;	Medication can effectively treat ADHD symptoms [86].
Autism Spectrum Disorder (ASD)	Persistent deficits in social communication and social interaction, along with restricted, repetitive patterns of behavior, interests, or activities.	1.9% (8-year-olds)	No efficient therapeutic interventions for cor symptoms for ASD [24].
Bipolar Disorder (BD)	A group of brain disorders that cause extreme fluctuation in a person's mood, energy, and ability to function.	2.9% (adolescents); 2.8% (Adults)	Pharmacological and nonpharmacological approaches yielded mixed results [79].
(Borderline) Personality Disorder (BPD)	A group of brain disorders that cause extreme fluctuation in a person's mood, energy, and ability to function.	1.4% (adults)	Dialectical Behavioral Therapy (DBT) is effective in treating BPD [21]; effectiveness of pharmacological treatment is unknown [37].
Dyscalculia	A specific learning disability affecting the normal acquisition of arithmetic skills, a brain-based disorder.	6% [16, 77]	No effective treatment; interventions focus on specific training and instruction [59].
Dyslexia	A specific learning disability that is neurobiological in origin. It is characterized by difficulties with accurate and/or fluent word recognition and by poor spelling and decoding abilities [8].	15-20% [7]	No effective treatment; interventions are education-based, focusing on spelling, visuo-attention, visual perception, etc. [30, 68]
Generalized Anxiety Disorder (GAD)	Excessive anxiety and worry (apprehensive expectation), occurring more days than not for at least 6 months, about a number of events or activities, such as work or school performance.	2.7% (adults); 2.2% adolescents;	Cognitive-behavioral therapy (CBT) [73, 74] is found to be efficacious; medication can be used to reduce symptoms [38].
Major Depressive Disorder (MDD)	Persistent feelings of sadness and hopelessness, lose interest in activities, physical symptoms such as significant weight change, diminished ability to think or concentrate.	7.1% (adults); 13.3% (adolescents)	Commonly treated with antidepressant medications and psychological therapies [49].
Social Anxiety Disorder (SAD)	Persistent fear of one or more social or performance situations in which the person is exposed to unfamiliar people or to possible scrutiny by others.	1.9% (8-year-olds)	Same as above (GAD).

continued conducting interviews until we had reached theoretical saturation. Two authors subsequently coded all of the transcripts independently while discussing and modifying the codebook to reconcile ambiguities on an ongoing basis. All 17 interviews were coded at least twice by two or three authors individually. We discussed any discrepancies until reaching consensus. We did not, however, calculate the inter-rater reliability (IRR), as the primary goal of the coding process was not to achieve complete agreement, but to eventually yield overarching concepts and themes [56].

After coding all interviews, all authors conducted multiple sessions of thematic analysis [34] of the interviews, using affinity diagramming to uncover themes of various levels. We present our themes and results in the following section. Some of the participant quotes have been edited slightly and shortened to improve readability.

4 RESULTS

Through our interviews, we found that online tests can fill gaps left open in the support systems for people with cognitive or mental disabilities. We organized our results around four overarching themes: 1) online tests can support people who suspect they have a cognitive or mental disability by removing barriers to professional diagnosis and by fostering an acceptance of their disability; 2) online tests can supplement professional diagnoses by providing additional information and support; 3) online tests provide a basis of connection with other people, and 4) the helpfulness of current online tests is mitigated by issues with trust, difficulties with (over-)interpreting results, confirmation bias, and a lack of connection with other resources, such as online communities and healthcare professionals.

Table 2: Interviewees' demographic and diagnostic information

ID	Gender	Age	Disability/Disorder	Diagnosed
P1	M	18 - 30	Autism	Y
P2	F	40 - 50	ADHD, Autism	Y
P3	M	50 - 60	ADD, Asperger's Syndrome, schizoid personality disorder	Y
P4	F	40 - 50	Autism, learning disorder, generalized anxiety disorder	Y
P5	F	18 - 30	Borderline personality disorder	Y
P6	M	18 - 30	Borderline personality disorder	Y
P7	M	50 - 60	Bipolar disorder, generalized anxiety disorder, social phobia	Y
P8	F	18 - 30	Bipolar disorder, major depressive disorder	Y
P9	F	30 - 40	Dyslexia	Y
P10	M	18 - 30	Dyslexia	Y
P11	F	18 - 30	Dyscalculia	Y
P12	M	50 - 60	Traumatic brain injury	Y
P13	M	30 - 40	Traumatic brain injury	Y
P14	M	30 - 40	Autism	N
P15	F	30 - 40	Autism	N
P16	F	30 - 40	Dyscalculia	N
P17	Non-binary	18 - 30	Dyscalculia	N

4.1 Online Tests Provide Support Pre-Diagnosis

Our first theme revealed that online tests can be helpful for people who suspect that they may have a mental or cognitive disability. Our interviewees often used online tests as a first step to learn more about themselves, especially when a professional diagnosis was out of reach – which turned out to be a common issue.

Several interviewees mentioned struggling to discover how to receive a professional diagnosis as a key difficulty of the diagnostic process. P14, for instance, who suspects he may be on the autism spectrum, said:

> *It's not so much a question of why did you not get a diagnosis or why did you not want diagnosis. It's a question of the steps to get a diagnosis not being exactly clear. (P14)*

P14, instead, did significant research into the difficulties that a person on the autism spectrum might face, contemplated how those difficulties may relate to his own life, and took many online autism tests, all of which indicated he was *likely* on the autism spectrum. He later commented:

> *[The online tests] made me confident enough in my own knowledge to expect that, if I was to speak with a diagnostician, I probably would receive the diagnosis of autism. (P14)*

Other participants were hindered from seeking professional help due to a lack of access (e.g., clinics, transport, cost), a finding which is consistent with previous research [26, 35]. For instance, P17, who suspects she may have dyscalculia, confided in us that "*The testing is expensive. I don't have these resources, and I don't know anyone in person who can help me.*" Instead, online tests provided her with a way to "*help quantify if I even have dyscalculia on any base level, [...], so at least I feel validated enough that I might go see [a therapist].*"

Similarly, P16, who also suspects herself of having dyscalculia, mentioned that online tests and other online resources already gave her sufficient information, obfuscating the need for a costly, professional diagnosis:

> *It's not something that my insurance covers, you know, so I'm worried that it's something that's a major expense to just confirm something that I know to be true. (P16)*

Adding another barrier, P2 pointed out the lengthy time it took her to get professionally diagnosed with Autism:

> *The psychologist that I went to is really difficult to get into, because there aren't enough psychologist specializing in women and girls, especially adult women. (P2)*

During the time of waiting, she turned to online tests to assess herself:

> *I did a couple of those [online diagnostic tests], and scored fairly high. [...] Yeah, I found that quite helpful. (P2)*

Taking online tests during this period re-affirmed her curiosity and motivations to get diagnosed, leading her to ultimately accredit her diagnosis to the tests.

Online tests were also helpful for interviewees whose family members stood in the way of getting a professional diagnosis. In fact, we found that our interviewees sometimes had to rely on family members to make a professional diagnosis possible, either through providing the means to consult a professional or acting as a necessary reference for the professional. Despite this dependency, family members were not always willing to participate. P8, for example, first realized she might be different from others when she was 12, but did not seek professional help until college because her mom "*has always been someone that denied things being wrong even though she is a social worker herself.*" Instead, P8 started using online tests to understand herself better:

> *I've taken like every psychometric quiz that exists. They definitely make you self-reflect a little bit, just trying to understand yourself. (P8)*

The theme of parents denying that their children have a disability was also reflected in P14's comments, who suspected he was on the autism spectrum but never received a formal diagnosis, in part because his mother's lack of participation in the process:

> *My mom was very, very much against the idea that I might be autistic. I went through every single one of the criteria of both autism and Asperger's disorder, and she said, oh wow, those match exactly. And then I told her what they were for. And she said, no, you're definitely not autistic. And she didn't want to participate. So it's very difficult to get someone to participate in the diagnostic process, when they're so averse to diversity. That diversity to even considering the possibility [was frustrating] because she always knew that I was different than other people. But she would claim that it was just because I was smarter than other people. (P14)*

Like P8, P14 also used online tests to assess himself, but he additionally used the results to try and convince his mother that he may have ASD. Although he did not end up obtaining a professional diagnosis, online tests provided him with what he felt was sufficient information.

P14's experience also shows at what stage online tests may be most useful to people who suspect they may have a cognitive impairment or mental disability. Similar to others, he sought out online tests primarily when he first started to realize he might be different, as he was having a particularly difficult time with job interviews:

> *I did [online tests] much more frequently when it was closer to that time than I have over the past few years because it was when something is new, you're kind of focusing on it, you're wanting to learn about it. (P14)*

P2, who took online tests about autism prior to seeing a healthcare professional, also emphasized that online tests became less interesting for her after her diagnosis:

> *I don't really do them anymore. It was sort of pre-diagnosis when I was wondering and up in the air a little bit, but now I don't really take them. (P2)*

Our analysis also revealed that online tests can act as a meaningful resource, providing ways of understanding and coping with their potential cognitive or mental disabilities without having to experience the perceived risks associated with professional diagnosis, such as for privacy concerns, fear of confirming what may be perceived as negative news, or fear of being labeled. P15, for example, feared a professional diagnosis because she did not want to receive an official label, which may result in being treated differently than others. By taking multiple online tests, such as the face blindness test and the autism spectrum quotient test, and discussing the results with others on Wrong Planet, she was able to learn more about how autism affects her life. The test results confirmed her suspicions that she may be on the autism spectrum and allowed her ways of managing how autism may affect her life, without having to receive an official diagnosis:

> *Just being an adult where I can go and see, you know, professionals and have a therapist and things, I've come to more understand myself in these nuances [of ASD]. Now I'm less concerned about looking for a diagnosis or labels so much as just learning skills to deal with things. (P15)*

In summary, the path to obtaining a professional diagnosis is paved with obstacles that prevent people from getting diagnosed early or even at all, ranging from a resistance in the family, fear of costs and being labeled, or privacy concerns. Participants therefore took online tests as a first step towards understanding their suspected cognitive impairments or mental health conditions and seeking professional help.

4.2 Online Tests Provide Support after a Professional Diagnosis

Our second theme exposed that online tests can fill some of the gaps left by a lack of support after people receive a professional diagnosis and could even help forming a new identity. Those participants who had previously been diagnosed with a mental or cognitive condition commonly felt that they did not receive enough information or support to understand how the condition might affect their lives and how they can mitigate the negative impact. For example, P11, who was diagnosed with dyscalculia, said: "*I was actually given by the diagnosis, honestly, not much*". Likewise, P8, who was diagnosed with major depressive disorder and bipolar disorder, said "*I was given literally nothing.*"

In particular, interviewees repeatedly raised frustrations over not receiving information about improving their conditions. Their diagnoses were often conveyed as a static condition that cannot be changed. This created a sense of hopeless and felt like "*a lifetime sentence of failure*", as P7 described it. P5, who was diagnosed with borderline personality disorder, revealed to us:

> *It would have been nice to be told that this is the treatment for it. With BPD it took a long time for me to realize that I wasn't destined to live like this forever. And I don't think that was communicated to me very well. They are just like, this is what you have. (P5)*

The lack of information at the time of diagnosis was also apparent in P3's conversation with us, who had been diagnosed with schizoid personality disorder when he was a child, and with ADD and Asperger's Syndrome in his adulthood. Referring to his therapist, he said:

> *[...] they didn't really talk to me about it [schizoid personality disorder] at all. And later in life, like much later, I had to research that on my own. And as for the shrink, his words to me were like, well, I'm sorry, sir, but there's nothing much that I can do to help you. (P3)*

Interviewees were also disappointed about receiving no or only little information about the nuances of their disability, such as how it might express itself in particular situations or what other cognitive functions it may affect. One participant noted:

> *There are so many symptoms of BPD, it can be really difficult to figure out which one is the most urgent to address. (P5)*

To reduce this complexity and better understand specific aspects of their diagnosis, some of our interviewees turned to online tests. P1, for example, communicated to us his doubts about his professional diagnosis of autism and that he did not believe many of the symptoms applied to him. Talking about the time after his diagnosis, he said:

> *I took tests just because of curiosity, procrastination, and just wondering what happened. Also there is a tendency among a lot of autistic people to doubt their diagnosis: "Am I like that? Is it correct? I can totally handle this." (P1)*

As such, online tests helped P1 develop an acceptance of his disability over time by discovering how it expresses itself and delineating which parts of his cognitive and behavioral functions are typical.

Similarly, other participants described their motivation for taking tests as being "*part of the awareness of knowing myself.*" (P4) and "*to find out more about myself and my capacities.*" (P3). Online tests helped them know themselves better and form a disability identity – an important step in adapting to a disability [23].

Like other participants, P3 also perceived online tests as something that helped him get a sense that there was something he could do about his diagnosis. For example, he described using online tests to mitigate some of his symptoms:

> *[Taking online tests] is the chance to quickly and easily learn something. [...] I guess it's a form of brain exercise for me. (P3)*

Using online tests as a form of intervention, such as to exercise the brain, was rare among our interviewees (likely due to the type of tests our interviewees reported taking), but has been found to be a common theme in participants' comments on online testing platforms, such as LabintheWild [54].

What was more common in our interviews was to employ online tests for keeping track of changes in their mental state and ability. This form of longitudinal self-experimentation appeared to be especially valuable for people who experience long-term effects, such as memory loss. For instance, P12 who was diagnosed with traumatic brain injury 20 years ago, took online tests to test how his memory has been affected:

> *I wanted to know what's changed in the last 20 years and even taking a quiz on things that I thought I knew was troubling. (P12)*

Similarly, P8, who was first diagnosed with major depressive disorder (MDD) in 2015, and then bipolar II disorder in 2017, told us that she has been taking the same online tests every one to two weeks over the course of the past two years:

> *[I keep taking] the Myers-Briggs Type Indicator or more popular standardized ones, seeing like, I took it two years ago, what did I get? versus now? Have I changed? I like thinking about these questions and how my experiences have changed who I am, especially now, you know, I graduated high school five years ago, and now I'm graduating with my masters. My life has changed so much in a short period of time, so I've obviously changed a lot in a short period of time. (P8)*

Testing the malleability of their cognitive abilities with the help of online tests was described as a way to gain insights into their disabilities and overcome the feeling of helplessness. Interviewees especially emphasized the importance of this support for adults, as professional interventions are usually focused on children.

To summarize our second theme, participants often felt insufficiently supported by their diagnosis alone and found that online tests could help fill this gap by furthering confidence in a previous diagnosis, explaining nuances that a binary diagnosis could not, and by providing a tool for the self-tracking of health conditions.

4.3 Online Tests Facilitate Communal Attachment

Another theme that emerged from our analysis is that online tests often provide people with the opportunity to connect and share their experiences with each other, thereby facilitating the process of communal attachment in which people start feeling part of a community [23]. One of our participants who was diagnosed with bipolar disorder described how she used a combination of a Facebook group and online tests to help her process her diagnosis and get to know herself better:

> *I have a [Facebook] group that we have like 15 people in it, and we do personality tests and stuff all the time, and we always share things and talk about it. (P8)*

By discussing the results of online tests on disability-specific online forums, such as Reddit, Wrong Planet, or Facebook, online tests were valued as a starting point to generate conversations. Our interviewees described they often received confirmation and encouragement by posting tests themselves and/or engaging in these discussions, which made them feel more positive about their disability. Having taken and shared the Wisconsin Card Sorting Test (WCST) on Reddit, a neuropsychological test that assesses perseveration (i.e., the ability to switch ideas or responses) and abstract thinking, P12 commented:

> *I was glad to post the study on Reddit. I was glad to be validated in that somebody read it, somebody understood it, somebody thought it was something. (P12)*

Sharing the studies created a sense of community – participants appreciated that they could support others by inviting them to take the same test and by discussing the results. For example, P17 said:

> *I feel like [sharing the studies on Reddit] does create a sense of community, just because you get to talk about something that you all have access to and can only interpret within the same context. (P17)*

What is noteworthy here is that our interviewees frequently pointed out that online tests gave them a reason to start a conversation in an online community and that these conversations often led to a comparison of people within that community. This is important because current online tests only rarely provide comparisons to others, and if they do, it is often reduced to a comparison with a general population, including neurotypical participants. For P13, this is a shortcoming of current online tests. When talking about his online test results, he expressed that it would be valuable to know "*if it was an extremely similar result based on the severity of their TBI.*"(P13). Online communities allowed participants to receive this more precise comparison to a group of people that mattered to them. For example, P14 described to us how he discussed his results of an online test with people on the Wrong Planet Autism Community Forum:

> *So what I was able to gain was that my results were very, very much in line with the majority of other people's results within those discussions [on Wrong Planet]. It was as close to a confirmation that I could find. Basically the test listed multiple different dimensions where you seem to be a match for all the criteria. It seemed that given all of these different groups, I matched in the majority of those groups, so, there was a lot of confirmation within the discussion. (P14)*

While some participants were wary of fully trusting the words of others on online forums, especially those without active moderation, this participant found the combination of online tests and online community served as a way to self-diagnose and forgo a professional diagnosis. Consistent with the findings of Giles and Newbold [33], this outlines how the combination of these two resources enable people to come to terms with their disabilities by facilitating a way of communal attachment.

4.4 The Challenges of Online Tests

While our previous three themes emphasized how online tests can support both people with suspected and diagnosed cognitive or mental disabilities and provide the basis for them to connect with others, we, additionally, saw a fourth high-level theme emerging: online tests are far from perfect. A few of our interviewees even mentioned actively avoiding such tests for a variety of reasons. Here we lay out three key pitfalls of current online tests that emerged from our analysis.

Trust in online tests. One common issue raised by our interviewees was the difficulty of finding trustworthy and helpful tests. Not knowing whether to trust a test was sometimes a deterrent for participants who feared for their privacy. P8, for instance, talked about ramifications of taking potentially dubious online tests:

> *Having [...] certain information on the internet that can technically be accessed by anybody can be dangerous for you when it comes to insurance. (P8)*

After seeing an abundance of online resources that "*explain the borderline personality disorder thing in such an archaic way*", P5 concluded that she refrained from taking any online tests that are related to BPD altogether:

> *I usually try and avoid [online tests] because like, I never found one that I thought was credible, and I was just like very trying to be careful with the kind of the internet content [that I pay attention to]. (P5)*

Those interviewees that used online tests were often wary of "*recreational type of tests, such as buzzfeed-like quizzes*", and instead tried to find tests that they could trust using various heuristics. Looking for tests of dyscalculia, P17, for example, heavily relied on the URL to determine the tests' credibility:

> *That having a trustworthy URL may be linked to a society or something like a university or like a trustworthy source. You know, I'm not going to take a quiz from a link that says "dyscalculia is dumb.com". (P17)*

Our conversation with another interviewee, P2, underlined the subjectivity of determining whether a test is trustworthy. Asked how she determines a test's credibility, she answered:

> *[I'm] more attracted to the ones that looked more professional and looked more like they were designed by professionals.*

Interestingly, these conversations highlighted the struggle for finding appropriate and trustworthy online tests, but also showed how people are on their own in identifying what makes tests trustworthy.

(Over-)interpretation of the results. In addition to worrying about the difficulties in determining which test to trust, participants also sometimes struggled to interpret the results, and consolidate the results with their assumptions. For example, P15 suspected that her inability to recognize people was due to having autism, and therefore, took a face recognition test to find out:

> *Hilariously, I scored in the 98th percentile in terms of being good at recognizing faces. So my inability to recognize my family members outside of context, I still don't understand. I don't know if it's because that test only scores your short term memory or more because of other reasons, like they only use a certain number of faces or something. (P15)*

P15 felt that the result did not align with her assumptions about the symptoms of autism and struggled to find a reason for her high score. She was also surprised that the test did not confirm her struggles with recognizing faces, showing how participants can over-estimate how generalizable tests are to a variety of situations.

Very similarly, we found that confirmation bias played a role in whether someone trusted and accepted test results. For instance, P10 told us that he only occasionally took online tests related to dyslexia — but that he would only trust the results if they confirmed his prior dyslexia diagnosis and what he already knew about dyslexia or himself:

> *This is coming from someone who knows they have it, has known they've lived for it forever. I feel like I would trust the result if it told me what I already knew. (P10)*

Other participants confirmed having issues with trusting results of online tests and explained when they were more likely to believe the results. For example, P7, who has been living with bipolar disorder, generalized anxiety disorder, and social phobia for more than 20 years, told us:

> *I probably would have to see results from other people and get a large study, to be confident of the veracity of any particular test. (P7)*

Similar to P7, P12, who was diagnosed with traumatic brain injury (TBI), also emphasized the importance of seeing his online test results in the context of others to aid his interpretation:

> *I think it's very important that somehow people really ought to get a baseline for just general capabilities, because trying to figure out where you were without being able to qualify where you were, is really difficult. (P12)*

Presenting the results in the context of neurotypical participants was also mentioned as important to ensure that people do not overreact, as a quote from P7, who is on the autism spectrum, exemplified:

> *I think that [comparing to others] would be very interesting. It would let me know if I'm overreacting if I compare myself to a control. I'll know then where I was, where I stand in any particular situation. (P7)*

Taken together, these findings emphasize the difficulties of interpreting results and the important role of surrounding information, such as comparisons to others. The following subtheme further underlines that online tests cannot be seen as a stand-alone solution.

Current online tests do not provide a way forward. Another challenge that our analysis revealed was that online studies often fell into the same trap as professional diagnoses: People often felt left alone with the results and did not know what to do with them. Our interviewees emphasized the need for providing additional resources and follow-up advice. When asked about how online tests could be improved, P17, who suspects they have dyscalculia, answered:

> *It'd be kind of crappy to get a result that says you have to struggle and then leave you stranded, you know, on a lifeboat all alone. You have spent your whole life [suspecting something is wrong] which is probably why you're taking the quiz in the first place. (P17)*

Other interviewees confirmed that the results of online tests seemed to often confirm and reinforce that they were struggling, rather than provide a way forward to deal with the struggle. This is in line with suggestions by one of our participants, P11, to provide pointers on how to connect with a psychologist and/or how to get a professional diagnosis:

> *I don't know how practical it is that maybe somebody kind of popped up, [...] like a psychologist nearby that could help you, or just give a location on a map [...]. But then it kind of comes off like sponsored [...] I feel like just giving more options for resources [would be helpful]. (P11)*

This further emphasizes the shortcomings of current online tests, which are seen as disconnected from the professional healthcare system and do not provide a straightforward path towards finding other resources or obtaining a professional diagnosis. However, P11 also pinpointed one of the difficulties of connecting tests and providers, describing it as a risk for the test being perceived as sponsored. In the following, we will discuss our overall results in the context of such challenges and provide potential solutions for online tests to better support people with cognitive or mental disabilities.

5 DISCUSSION AND DESIGN IMPLICATIONS

In this paper, we showed that online tests provide an opportunity to supplement, and to some extent replace, resources that are otherwise out of reach for people with suspected or known cognitive or mental disabilities. Our interviews have revealed that online tests are already contributing to the support system for people with cognitive and mental disabilities.

In particular, we found that our participants predominantly use online tests before (and sometimes instead of) a professional diagnosis. Getting professionally diagnosed was often described as out of reach, due to cost and access issues or because of resistance within their own families. To work around such barriers, our interviewees use online tests to validate their own suspicions and justify the need for a professional diagnosis to both themselves and their family members. With our interviewees often turning to online tests as a first step towards professional diagnoses, we can see that these often relatively informal and anonymous tests play a unique role in the support systems of people with disabilities: a way of slowly and informally introducing people to their disability without the potential risks perceived by an official, inescapable professional diagnosis. People can choose to believe the results of an online test, but, as our interviews have shown, there is a way out by disputing a test's validity. As such, online tests suffer from confirmation bias, but at the same time, our data shows that this might be their strength given that it allows people to slowly develop an acceptance of their disability. A professional diagnosis should of course provide final confirmation, but it should also come with enough resources to help a person accept a potential positive diagnosis of a cognitive or mental disability and move forward with a treatment plan.

The above also underlines the important role of online tests towards forming a disability identity, which includes an acceptance of one's disability, developing a positive view of oneself, and feeling connected to others with similar experiences [23]. Establishing a disability identity has been shown to support individuals in coming to terms with their disability, and to lower stress levels and the risk of mental health effects [45]. Our interviewees report that online tests slowly help them accept their disability, while also providing a reason for connecting with others. For example, participants frequently post their results of online tests in online communities (as shown in [54] and confirmed in our work), facilitating *communal attachment* [23]. This allows for a valuable additional pathway towards forming a disability identity.

It needs to be emphasized that online tests should not be seen as superior to, or a replacement of, a professional diagnosis. Instead, we hope to showcase that, with all the barriers to receiving professional healthcare and the stigma associated with being labeled as having cognitive or mental disabilities, getting a formal diagnosis is not always possible and desirable; in those situations, taking online tests provides great benefits and can be a first step for people to better understand themselves and prepare them to seek support from professionals.

We also hope to push towards a norm of including and providing more attention to individuals who self-diagnose disabilities, than it is now. On one hand, our community can think about including people who self-diagnosed disabilities in studies, which could help achieve sufficient N to detect medium and small effects, but we would always encourage researchers to treat self-diagnosis and professional diagnosis as two levels in the analysis. On the other hand, there is insufficient work to know whether and in which cases online tests could fail and how the self-diagnosis results compare to professional diagnoses. Therefore, future work of rigorous clinical trials would be needed to assess this.

Our results also show the value of online tests post-diagnosis. This is similar to the findings in Li et al. [54] and Oliveira et al. [65], who showed that participants in online tests provided on LabintheWild frequently try to better understand their disability. We extend this prior work by showing that the tests are also used for the purpose of validating a professional diagnosis and for exploring what other behavioral or cognitive functions may be affected. Participants in our interviews commonly described this as finding out what their capacities are and what the symptoms of their disability are in comparison to others. Similarly, they were often given no information as to the malleability of their disability over time, instead perceiving it like an unchangeable "lifetime sentence of failure", as one of our interviewees put it. Online tests support them in establishing a personal disability profile by participating in a range of tests and comparing their personalized results to others. Interviewees also use online tests to track how their disability expresses itself over time, which confirms the finding in previous work that such tests are sometimes used for self-experimentation [54]. Both of these activities are likely supporting the process of establishing a person's disability identity, which, according to our results, is a gap that conventional resources available to people with disabilities often leave open.

While these findings are very encouraging, our interviews also lay open a number of challenges that online tests will need to overcome to improve their utility for people with cognitive and mental disabilities. In the following, we will discuss these challenges in the context of their implications for the design of future tests. For each design implication, we first state the implication that the finding brings, and then explain the finding from our interview.

Design Implication 1: By integrating high-quality online tests that assess cognitive and mental disabilities into professional healthcare systems, more people could benefit from taking these tests.

Our findings are encouraging in that they indicate online tests often provide a pathway to obtaining a professional diagnosis. While such tests cannot replace a professional diagnosis, they can point out who may be at risk and additionally raise awareness of specific disabilities, which may also help advocate normalization of disabilities more generally [91]. It is important to note that such tests would need to be rigorously and carefully developed to avoid pitfalls, such as over-interpretation of the results. Therefore, one possible solution is to partner with the medical community.

By better integrating online tests into professional healthcare systems, online tests can assist in reducing barriers to obtaining a professional diagnosis and serving as a first step towards it. Tests developed by researchers and doctors could include pointers to resources such as how to find an adequate healthcare professional for a formal diagnosis. Such resources could increase access to professional diagnosis and empower online experimenters to continue taking steps towards understanding their (suspected) health conditions through credible means. However, one of our interviewees raised the issue of perceiving tests as sponsored if connected to specific healthcare resources. Therefore, providing a choice and more general pointers to professional healthcare resources, such as to a database of psychiatrists, may be a solution. Partnering with hotlines and other services available for people with cognitive or mental disabilities may also be a way of providing online test participants with immediate, in-person support if needed.

Design Implication 2: Standardized guidelines should be developed for the design of tests and for communicating the test results, before verified tests could be promoted publicly and confidently.

Of course such ubiquitously available tests carry a number of risks. Our interviewees confirmed a perhaps unsurprising fact that current online tests are frequently untrustworthy. Indeed, a quick web search for "online test" surfaces a number of scientifically questionable tests. Exacerbating this problem, people also commonly overestimate the diagnostic abilities of such tests, or they relate a specific test to their disability despite no indication that it is designed to assess or diagnose related behavioral or cognitive functions [54]. Because of these risks, it could be helpful to develop efficient ways to verify online tests for potential participants, such as by developing a set of heuristics that indicate scientific validity. Verified tests could be made available on a single platform that could be promoted in schools and in online communities commonly accessed by people who suspect they have a cognitive or mental disability. Such platform could also employ user ratings that convey perceived helpfulness. In addition, it will be beneficial to develop a set of guidelines that tell participants what to expect, who developed the test, what the test can and cannot do, and how to interpret the results. A key to the guidelines will be to research and develop language that prevents participants from over-interpreting the results, such as by communicating uncertainties and offering additional resources. Note that there may not be a one-fits-all rule, but that these guidelines can be broken down by types of the disabilities or other criteria. Providing test designers (both researchers and others) with guidelines and best practices for the development of these tests and for communicating results is perhaps the most important first step before we can confidently promote such tests.

Design Implication 3: Online tests should ideally rely on representative baseline data to provide participants with nuances of their conditions and with comparison to a specific group of people.

An additional disadvantage of current online tests that our work uncovered is that they often insufficiently support people's desire to understand the nuances of their conditions and how their symptoms compare to others. Just like professional tests for assessing or diagnosing disabilities, online tests lack (normative) baseline data to provide an individual with comparison to a specific group of people, such as those without a disability, or people of the same age group with the same diagnosis. Creating tests that can provide such comparisons and provide information about the nuances of the conditions (e.g. the severity of various symptoms) would require testing a large number of people, which is difficult, but not impossible. In Gajos et al. [29], for example, the experiment platform LabintheWild [71] was used to collect normative data from 250k healthy individuals and develop classifiers for accurate detection of Ataxia and Parkinsonism. The resulting system can compare individuals' performance to the baseline data of a specific age between 5 and 80 years old. Similar data collection efforts to develop predictions of severity levels and to provide comparisons to other people with similar demographics could be employed for cognitive or mental disabilities too.

Design Implication 4: Online tests should align with the affirmative model of disability by highlighting a test participant's strengths and providing additional resources that describe positive examples.

We found that one of the challenges of online tests is that they are frequently perceived as "downers", i.e., as a way of confirming what many already suspected without providing a positive path forward. This is counterproductive to the affirmative model of disability [83], which promotes a more positive view of disability and has the goal of people focusing on their strengths rather than on personal tragedies. A good example for refocusing the discussion of a disability on its strengths are books, such as "*The Gift of Dyslexia: Why Some of the Brightest People Can't Read and How They Can Learn*" [19], which describes success stories of people living with dyslexia. To align online tests with the affirmative model of disability, online tests would need to diversify and test several behavioral and cognitive functions in order to emphasize those in which a person may excel. In addition, support to see their own strengths may be provided by including additional resources that outline a path forward which does not exclusively focus on low-performance functions.

Design Implication 5: Online tests should support participants in sharing and discussing their results with others by providing links to appropriate online communities and to specific threads discussing a certain online test whenever available.

Helpful for working towards an affirmative model of disability and supporting people's creation of a disability identity is connecting them with others in a similar situation. Our participants suggested that online tests gave them a reason to discuss their disability in online communities and made them feel more connected to others. However, to do so, they had to find an appropriate online community and introduce the test there. An obvious solution to this problem may be to create online testing websites that offer a forum for an immediate discussion of results, similar to what has been proposed in [54]. If the forum allowed anonymous posts to preserve privacy, we believe this could indeed better support participants in sharing and discussing their results with others. But there is something to be said about keeping online tests and online communities separate: Online communities are already established and many of them that are specific to certain disabilities, e.g., the subreddit r/ADHD or WrongPlanet.com, to have lively discussions with many long-term members. Instead of offering yet another forum or online community, a more fruitful approach for online testing websites could be to partner with, or to simply point participants to appropriate online communities. Ideally, a link would not simply lead participants to the online community's homepage, but rather to the specific thread that discusses a test.

6 LIMITATIONS AND FUTURE WORK

While our work contributes exciting insights into the role of online tests for identity formation, it is only a first step towards our larger goal of better supporting people with cognitive or mental disabilities. Because we recruited participants for our interview study from online communities on a variety of cognitive and mental disabilities, the findings presented here are specific to people who currently use these online communities and thus, either suspect or know that they have a health condition. As such, our findings cannot shed light on the opportunities and challenges of online tests for people who do not suspect that they have a disability or for those who refrain from using online communities, for example because they may not yet have started the process of accepting their disability. Our choice to recruit from online communities was made because prior work had reported that online test participants often share their results in online communities; however, future work could broaden our findings by studying a broader sample of people with cognitive or mental disabilities, including those who do not necessarily use online communities.

Another limitation is that the majority of our participants came from the U.S., with one from Australia and Canada, respectively. Although the two non-U.S. participants found the benefits and the limitations of online tests to be the same in our analysis, our findings may largely reflect gaps in the American health care system for supporting people with cognitive or mental disabilities. We do believe cultural differences exist; for example, stigmatization differs across cultures and so does the acceptability of seeking out professional diagnoses. Culture has also been shown to be a leading diagnostic factor in cognitive and mental disabilities in previous work [5]. Therefore, online tests may play different roles within different cultures, societies or mental health care systems. An interesting direction of future work could be a larger survey study that sheds light on the variations across countries and reveals a potential relationship between mental health care systems and the usefulness of online tests for people with cognitive or mental disabilities.

Likewise, self-selection bias may also impact the generalizability of our findings. People with mental disorders, for example, might have been reluctant to respond to our call because of potential prior experiences with stigma, marginalization, and oppression [88]. Those people may also refrain from using online tests because of similar fears, especially if online tests do not make it 100% clear that they do not collect identifiable data.

The work we presented here shows that online tests are often perceived as helpful by people with cognitive or mental disabilities and that they provide opportunities for forming a disability identity which a professional diagnosis and resources provided by the healthcare system often do not. However, there is a risk that online tests could be *perceived* as helpful while they are actually not, or worse, that they could be worsening a participants' state. An urgent next step therefore needs to investigate which online tests are truly helpful for people with cognitive or mental disabilities from the perspective of healthcare providers AND from the perspective of test takers. Studying this question with a large sample of online tests (with various degrees of scientific quality) may also reveal heuristics for developing best-practice guidelines for tests that are truly useful.

7 CONCLUSION

This paper contributes insights into the use of online tests by people with cognitive and mental disabilities as a first step towards better supporting them pre- and post-diagnosis. Our findings from 17 interviews with people with a variety of cognitive and mental health conditions (both suspected but undiagnosed and professionally diagnosed) showed that one of the main values of online tests is that they address shortcomings in the support of people with cognitive and mental disabilities, such as difficulties obtaining and justifying a professional diagnosis, a lack of information about the nuances of a disability, and a lack of continuous support provided by healthcare providers. Most importantly, our findings revealed that online tests are an important resource for developing a disability identity for people with suspected or known conditions. By contributing a discussion of challenges that current online tests pose, we hope to lay the foundation for future research efforts that leverage the advantages of online tests and maximize their benefit to people with cognitive and mental disabilities.

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