Master Thesis

Am I neurodivergent? The influence of social media and peer interactions on self-diagnosis.

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Disclaimer: This thesis has been written as a study assignment under the supervision of a Utrecht University teacher. Ethical permission has been granted for this thesis project by the ethics board of the Faculty of Social and Behavioural Sciences, Utrecht University, and the thesis has been assessed by two university teachers. However, the thesis has not undergone a thorough peer-review process so conclusions and findings should be read as such.

Abstract

In recent years self-diagnosis of neurodiversity has become more common among youth. One of the groups affected by this, university students. This study explores how Dutch university students go about the process of diagnosing themselves with things like ADHD and autism. Specifically looking at the influences of social media and peer connections on this process. Very little is known about this topic, so this study aims to create a deeper understanding of this process. To do this, five semi-structured interviews were conducted with students aged 24 to 25 who had diagnosed themselves with a form of neurodiversity. These interviews were then coded and analysed. Participants generally went through a process of being dismissed by a healthcare professional, after which they got more information on neurodiversity through either social media or talking with peers. In this process an important factor for most participants was getting validation for what they were experiencing and not feeling alone in what they were going through. They were able to gather practical resources to use through peers who had a similar diagnosis, or through content creators on social media that they related to. What was clear was that peer influences and social media work together and fill in for each other to create an environment in which the participants could explore their identities.

Keywords: self-diagnosis, neurodiversity, social media, peer connections, ADHD, Autism

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Introduction

Over the last decade talking about mental health problems has become significantly more normalized, going as far as people saying that having mental health problems is ‘the new normal’ (Hermann et al., 2022). This shift has had some positive effects, such as contributing to the destigmatization of mental health problems, but also comes with a few repercussions. This new view of mental health problems contributes to added pressure on often already overburdened mental health services, which are already known for their long waiting lists (Ukim, 2024).

When dealing with mental health problems getting diagnosed is seen as an important step towards getting the necessary resources that help someone manage their symptoms (David & Deeley, 2024). Yet with the aforementioned waiting lists, an increasing number of people have started turning to alternative means outside of a professional diagnosis. One of these solutions being self-diagnosis, which is when someone uses information available to them, often through the internet, to identify their own mental health problems (Corzine & Roy, 2024; Fellowes, 2024). While at first glance this phenomenon might seem like an innocent trend, mental health professionals do express their concerns (Jaramillo, 2023; McVay, 2023).

The sources people are using to base their diagnosis on has shifted over the years. From written materials to Google and internet forums, to now social media (Dewak, 2023; Robertson et al., 2014). Mental health has become a popular topic on different social media platforms such as TikTok and Instagram, where creators post short form content ranging from informational videos, to skits, personal experiences, or challenges (Jennings, 2021). These videos, designed to grab attention, are bringing information about mental health to many

people, but often without the necessary nuance and depth needed for these topics (Eaton, 2023).

The group that is most often exposed to this content are adolescents between the ages of 18 and 25 (Statista, 2024). The importance of a focus on this group is not only because of the frequency that this content reaches them, it should also be considered that this age group is in the middle of important development stages. Their identity is still being formed through many outside influences of which this mental health content has now become one. Furthermore, this is a group where mental health issues are very prevalent at this time, which is why it is very interesting to figure out if the rise of social media influence has anything to do with the heightened numbers of adolescents struggling with mental health.

Within this age group I want to even further specify to students. It is often during college or university that people who weren't diagnosed in childhood start to notice symptoms that could point to neurodiversity. Noticing these signs might cause them to look for information that could help them, with social media and peers being some of the most accessible sources. It should also be considered that for this age group the money and time it takes to get professional help could act as a barrier for choosing this option. The long waiting lists might not be considered a good option when a student is struggling at that time, and they want help not only for their mental health but to gain support in their studies.

Besides focusing on students this research will also specifically look at neurodiversity, which is a collective name for various neurological differences, including: Attention-deficit hyperactivity disorder, autism, dyslexia and dyscalculia (Miller, 2025). Specifically, ADHD and autism have historically been seen as conditions predominantly present in boys. In recent years there has been more attention to how these conditions show in girls and adolescents compared to young children. This has caused people who weren't diagnosed in childhood to

now suddenly see information that might relate to them. Making this an interesting age group and topic to research. Where before their signs that pointed to neurodiversity might have been overlooked, now they can look for information on their own and make their own conclusions.

Despite growing attention so self-diagnosis and mental health, the role of peer influence in this process remains underexplored. While social media is often used individually, opinions and decisions are rarely formed in isolation. Peer networks, both offline and online, can play a critical role in shaping adolescents' opinions and perceptions, which includes those related to mental health (Al-Jbouri et al., 2024; Reitz et al., 2014). Online communities or friend groups can offer validation and support, but it is unclear how these peer interactions influence the process of self-diagnosing (Ali et al., 2015). This study therefore aims to fill this gap by exploring the main research question: How does interaction with social media and peer networks influence Dutch university students' self-diagnosis of neurodiversity? To explore this research topic thoroughly, three sub-questions were prepared:

1. What are the motivations for Dutch students to self-diagnose neurodiversity rather than seeking a professional diagnosis?
2. What is the motivational influence of social media on the process of self-diagnosis?
3. How do peer networks contribute to or influence the self-diagnosis process?

Societal Relevance

Self-diagnosing is sometimes seen as an accessible alternative to a professional diagnosis (Monteith et al., 2024). However, it does not come without risk. Information found online and especially on social medias is not always trustworthy. This kind of information is often lacking in nuance and details, presented briefly to catch the attention of people consuming the content. Often the creators talking about mental health on social media do not have a background in psychiatry or medicine, but talk mostly about first hand experiences.

This way of information sharing can lead to oversimplification and misinformation, which in turn could lead to misdiagnosis (Starvaggi et al., 2023). If this takes place, someone who has misdiagnosed themselves may try to treat themselves based on wrong information and could also further delay seeking professional care (Monteith et al., 2024). Furthermore, the ease with which people can now access diagnostic criteria without professionals to guide them through the interpretation could also cause people to see what they want to see, instating confirmation biases (Fellowes, 2024).

Scientific Relevance

The influence of social media on self-diagnosing is still a relatively new topic, with not much research being available at this time. When adding the factor of peer influence, there is even less information available. In identity formation peer validation is often seen as an important factor, but for now it is unknown if this interaction only provides support or also contributes to the act of self-diagnosing (Ali et al., 2015; Reitz et al., 2014). This study hopes to contribute to what is known on this topic by exploring the experiences of youth who have self-diagnosed and expanding our knowledge on this underexplored section of mental health.

Literature review and theoretical framework

Now that the problem has been identified, and it is clear what information is still missing. I am going to discuss self-diagnosis and identify the most relevant theory and sensitizing concepts. This will help me to make sense of the collected data, and in turn will help guide this research. Thereafter I will do the same for two other relevant concepts from this research, social media influences and peer influences. This will provide a stronger understanding of all the relevant factors included in this research.

Self-diagnosing

The first sub-question addresses the motivations behind adolescents' decisions to self-diagnose. This section therefore explores existing literature and theoretical perspectives on the factors contributing to this phenomenon. Traditionally, individuals seek a diagnosis to make sense of persistent challenges they are experiencing. A formal diagnosis can act as a framework for understanding those internal experiences, by explaining certain behaviours (Rogers & Pilgrim, 1993). Beyond just personal understanding, a diagnosis often carries functional benefits, such as facilitating educational benefits, therapeutic interventions or medication (National Alliance on Mental Illness, 2024). While a formal diagnosis can provide this support, a self-diagnosis often lacks this practical factor (Fellowes, 2023). Therefore, if a self-diagnosis is not a guaranteed way of getting the needed support, what are factors that do make it an attractive option? The first literature search provided a few different themes that could potentially construct a relevant framework. The ones that will be further explored are the influence of validation, accessibility, and the possibility of confirmation bias.

Starting with the factor of validation. Something that is seen as a very important motivator for seeking out a diagnosis, whether that is professionally or self-diagnosed, is the feeling of being understood (David & Deeley, 2024). Having a word to describe and explain

things someone is experiencing can help them accept those traits and look at them in a more positive light. Someone who first only saw their individual traits and how they are different from other people, can look at their own situation in a more positive way by having a word that explains why they might be acting that way (David & Deeley, 2024). Self-diagnosis can validate experiences by making someone think they are not alone in the problems they are facing (Monteith et al., 2024).

The second factor that could play a role is accessibility. It can be difficult to get a formal diagnosis due to long waiting lists or high costs (Trimbos Instituut, 2024). This could make self-diagnosis not just a choice made through a dislike or fear for the diagnostic process, but an accessible alternative for youth that might not have the funds or time to wait (Lewis, 2017). Self-diagnosing via online resources or by talking with peers requires no appointment and no money and can be explored anytime. This kind of accessibility makes self-diagnosis an easy place to start for understanding one's own experiences.

The third factor that might play a role in self-diagnosing is the presence of confirmation bias. This is a form of bias where individuals tend to tend to search for, interpret, and recall information in a way that confirms their preexisting beliefs or expectations (Hussaarts, 2025). This kind of bias can influence an individual's way of interacting with the content that they come across. Meaning that when youth start to suspect they may be neurodivergent can seek out information that fits within that expectation. And are less likely to look for contradictory evidence. Meaning they could selectively watch certain types of content, which could result in a wrong interpretation. So, although self-diagnosis can be a meaningful step towards youth understanding their own experiences, it is important to stay critical of content or information that crosses their paths.

Social media influence

The second sub question of this research concerns the influence of social media on youth's decision to self-diagnose. Here I will also be delving into existing literature and theoretical perspectives on how social media can serve as an inspiration and a platform for individuals searching for a diagnosis. In the current age social media has become a primary source for information, significantly shaping how people perceive themselves and their experiences. Youth increasingly turn to social media for personal insights, making this an important area of interest. But what structures are present that make social media have the influence it does? To answer this question a theoretical framework that explores the motivations and social influences is important. This study will touch upon three existing structures: Uses and gratifications theory, social cognitive theory, and availability bias.

To start, the uses and gratification theory insinuates that people actively choose and use different kinds of media to satisfy specific needs they have, rather than only being passively influenced by it (Katz, Blumler, & Gurevitch, 1973). Looking at this in the context of self-diagnosis, social media can offer an accessible and non-judgemental space for youth to search for information about their situation (Naslund et al., 2016). Making it an option that youth were already interested in finding information on neurodiversity, and having social media be an accessible way to seek out that information for themselves.

Another possible option is looking at it through the lens of Bandura's (1986) social cognitive theory. Which poses that people learn behaviours by observing them in others. Internalizing them through observation, imitation and modelling. Social media has opened a whole new world of people youth can potentially model themselves after. Seeing creators on social media discuss their experiences with neurodiversity could affect the viewers' self-perception (Moreno & D'Angelo, 2018). This theory also would encapsulate youth who did not set out looking for a diagnosis but did end up finding something they relate to. By

observing others who have gone through similar processes, individuals may feel more confident in their own self-diagnosis process.

In addition to these theories there is also a matter of bias that could be considered, in this case specifically availability bias (Tversky & Kahneman, 1973). This refers to the tendency to overestimate the relevance of information that is easily available or encountered repeatedly. Looking at this knowledge with the lens of social media, youth may be repeatedly exposed to content discussing possible forms of neurodiversity. By seeing this information multiple times, the youth might start thinking about a diagnosis, even if before seeing this content they never considered it.

Peer influence

Finishing off, the third sub question focuses on peer influences on motivations for self-diagnosis. When looking through theories that might be relevant to structure this section, a lot of the same theories that could apply to the influence of social media also seems to apply for peers. But instead of revisiting Bandura's social cognitive theory again, I will look at a similar but a little more tailored theory. According to the group socialization theory presented by Harris (1995) during the adolescence period peers are the most important environmental factor in youth's lives. Peer interactions can have influences on youth's personality and behaviours. This combined with the fact youth learn through observation and modelling, makes peers a logical choice to have an influence on self-diagnosis.

Another central driver in peer-influenced self-diagnosis is the need for belonging and validation. Theories of identity development suggest that adolescents and young adults rely heavily on peer validation to construct a stable sense of self (Erikson, 1968; Tajfel & Turner, 2004). In neurodivergent-affirming online spaces, self-diagnosis is often accepted and even celebrated as a form of autonomy and self-knowledge (Gillespie-Lynch et al., 2017). When

individuals share a self-diagnosis within a peer group and are met with affirmation and similar stories, this social feedback loop can legitimize and reinforce the self-diagnosed identity.

In this way, peer networks serve multiple functions in the self-diagnosis process: they provide experiential information, normalize non-clinical labels, offer emotional validation, and allow for social modelling. These networks can possibly reduce stigma, offer language for a better understanding of self, and can help youth feel less isolated in their experiences. Which could make peers a central factor in the change from questioning yourself to sure self-identification.

Research design

Methodological design

To fit with the explorative nature of this research, an inductive qualitative design was chosen to answer the research questions, specifically making use of semi-structured interviews. With the largely unexplored topic of the influence of social media and peer connections on self-diagnosis, qualitative research can help us get a sense of which themes play an important role in this topic. The aim of this research is to gather the insights young people with experience in the topic might have, since not much is known there are no direct relationships to be tested yet. The lack of knowledge on this topic is also the reason for taking an inductive approach. We want to gather a wide range of insights and not steer in any direction. Using the inductive approach means looking at the data with open eyes and letting it speak for itself. To not look at the data completely blind a framework based on existing literature and theory was used. The synthesizing concepts from literature were used to construct an interview guide as well as provide recognition points when analysing the data.

Participants

Originally this study was meant to include 10 participants, 5 recruited by me, and 5 recruited by a fellow master student doing research on a similar topic. In the end our target groups ended up not quite overlapping, so we decided to only include the 5 participants we each sourced. The participants included in this study were all recruited based on the following inclusion criteria: Dutch university and college students, who have diagnosed themselves with a form of neurodiversity, between the ages of 18 and 25. The participants were recruited through my own social network and through the social network of peers. The participants consisted of 2 males and 3 females, with all of them being 24 or 25 years of age.

All the participants had either diagnosed themselves with ADHD, autism, or both. Only participant 1 had a formal diagnosis for one of the disorders.

The sampling of participants was done without any randomization, as the participants that volunteered to be interviewed and fit in the study's criteria were immediately accepted into the study. This might have led to a type of selection bias called undercoverage bias (Nikolopoulou, 2023). As all of the participants that signed up ended up being in the upper part of the age range that was set for this study. This is likely due to the sampling being done through my own social circle, as I as a master student know more people towards the end of this age range.

Table 1

Main characteristics participants

Participant	**Age**	**Gender**	**Suspected diagnosis**	**Formal diagnosis**	**Education level**
Participant 1	24	Male	ADHD and Autism	ADHD	WO
Participant 2	24	Male	ADD/ADHD	No	WO
Participant 3	24	Female	ADHD or Autism	No	WO
Participant 4	25	Female	ADHD or Autism	No	WO
Participant 5	24	Female	Autism	No	HBO

Procedure

For this research 5 semi-structured interviews were conducted. The form of semi-structured interviews was chosen to facilitate flexibility within the interview while still ensuring key topics were covered. It does so by making use of an interview guide that has a predetermined thematic framework, but the questions do not have to be posed in a set order or phrasing (George, 2023). To conduct these interviews original interview guides were

constructed. These were then approved by the Utrecht University Ethics Committee, after which the recruiting of participants could start. The recruited participants were given an information letter and had to sign an informed consent form. After this, interviews were conducted either in person or online via a video call. Both the online and in person interviews were recorded with permission from the participants, after which those recordings were transcribed and anonymised in preparation for further analysis.

Instruments

An interview guide (Appendix D) was constructed based on the sub-questions of this study and the sensitizing concepts found in the literature review. The questions in the guide were designed to be open ended and non-suggestive, to leave much room for participants own experiences. In some cases, this resulted in detailed accounts of the participants life, in other cases the answers stayed only in the boundaries of the questions. While the interviews were being conducted, they were recorded and transcribed using the built-in options in Microsoft Teams.

Analysis strategies

Data analysis was done through coding of different themes present in the transcribed data. The data was analysed in NVivo, using open, axial, and selective coding. After the initial coding these were divided into loose themes by printing and cutting out all the individual codes and grouping them. Themes were grouped together using an iterative process, working from more specific codes to broader themes. While coding, the main research question and the three sub questions were kept in mind to help find distinct themes within the data. The full code tree is available in Appendix E.

Ethics

As briefly mentioned above, the participants were asked to give informed consent, based on a provided information letter (Appendix B). In this letter the participants were informed of the purpose of the research as well as their rights to withdraw from the study at any time. Furthermore, they were also informed that all their data would be anonymized and stored in compliance with Utrecht University's protocol. The research was non-invasive, even though the main topic regarded mental health, no official diagnoses are discussed. The study complies with national laws and Ethics Review Board approval from the Faculty of Social & Behavioural Sciences.

When looking into ethical considerations the positionality of the researcher should not be left out. As a 25-year-old university student with an ADHD diagnosis who started out with a self-diagnosis, there is the possibility of bringing biases into the interpretation of the data. Besides this I am aware of the social circle in which I find myself, where different forms of neurodiversity are quite prevalent and not shied away from in conversations. By being aware of this positionality, I can use caution when interpreting the data and try to stay as close to the original quotes as possible.

Empirical Chapters

The following chapters will contain the findings of this study. The chapters will follow the sub questions formulated earlier in the introduction. Starting with general motivations for self-diagnosing followed by the influences of peers and social media on this process.

Chapter 1: Motivations for self-diagnosis

As stated, this first chapter explores the motivations youth have to choose a self-diagnosis over a professional assessment. Existing identity development theory suggests that validation could play a role in this decision (Erikson, 1968). This chapter will follow the participants perspectives on this matter and compare them to existing theories. Firs, examining their experiences with professionals, followed by the barriers they faced, and finally the perceived benefits of self-diagnosis. This order reflects the order of how most participants described their process.

Experiences with professionals

The topic of the participants' experiences with professionals was brought up during the interviews when the participants were asked if they would consider going to a professional to get a formal diagnosis. From this it became clear that most of the participants had shared their struggles with a professional, either a psychologist or their general practitioner. However, their experiences with this varied. Something that caught my attention was that multiple participants felt that their concerns were dismissed. Even if they said they had their suspicions about a particular diagnosis they weren't taken seriously. For example:

> I told them I struggled with sensory issues and noise, and I feel like I get overstimulated quickly and can't function properly. I heard that these things can be

> part of autism, so I asked if that was a possibility? And then the psychologist was like 'Autism get thrown around so much, maybe you're just hypersensitive'. (Participant 5)

A similar experience was shared by other participants. Participant 3's psychologist refused to share an opinion on her possibly being neurodivergent, while participant 2's general practitioner mainly asked him for his own views. These kinds of situations left the participants feeling dismissed and hesitant to return to a professional for a diagnosis. Instead looking for their information in different places, mainly through social media and through talking with friends. From these narratives, two distinct themes emerged: barriers to professional diagnosis, and the benefits of self-diagnosis.

Barriers in approaching professionals

While invalidation was a common factor, participants also pointed to practical barriers that discouraged seeking a formal diagnosis. Several mentioned long waitlists, high costs, and the emotional labour involved in navigating mental healthcare systems. Others felt that the outcome of such a diagnosis was not worth the time or expenses. Even participant 1, who had a positive experience getting his ADHD diagnosis, chose not to further pursue an autism diagnosis, not seeing much added value. As he explained:

> I am not interested in an external party telling me if I have got autism or not. […] Because I know myself best, regardless of if an external party stick a label on me or not. That would not mean my internal experience of things suddenly changes. (Participant 1)

Others expressed similar views. Participant 5 shared that "[i]t costs money and takes time, and [that they] don't care enough about a piece of paper", while participant 2 added they

would “[o]nly [want a formal diagnosis] if it gives some financial gain, or another big gain”. Both examples suggest that a professional diagnosis is sometimes viewed as something that is transactional, that you should only get it if it results in tangible outcomes. Which isn’t guaranteed looking at the experiences the participants had. And when that can’t be guaranteed, then seemed to reach for an alternative option, which will be explored in the following section.

Benefits self-diagnosis

After gaining more information on neurodiversity when they started their self-diagnosis process, many of the participants experienced that they could already make small but meaningful changes in their daily lives. Sharing that it helped them “know what to build, and let you use existing resources” (Participant 1). Participant 2 was able to make concrete adjustments that helped him with scheduling, and participant 3 described how she got to know herself better and was able to make small adjustments accordingly. Adding to this participant 5 described how she realised “you don’t have to do things the normal way just because society says you should”. Realising she could use tricks that made her do some tasks a bit differently, so she would be able to do them consistently.

Because they all noticed these improvements, most of the participants became even less interested in seeking out a formal diagnosis. Seeing as they already provided the help they needed for themselves. These improvements also helped them gain a more positive self-image, and some felt it “very much took away some self-punishment [they] felt before”. (Participant 1)

Chapter 2: Social media and self-diagnosis

Now that we have a better understanding of why these participants chose to self-diagnose, we can further explore what resources are available and used to come to these diagnoses. Meaning we can address the second sub-question of this research: What is the motivational influence of social media on the process of self-diagnosis? Or otherwise put, how does social media assist the journey to finding a fitting self-diagnosis. The participants highlighted the unique value of different social media platforms, mainly TikTok, Instagram and YouTube. Multiple different themes came up when discussing their use of social media. Particularly, how social media creates awareness, how it acts like a constant reminder, and why they specifically relate to posts on social media. These themes will be discussed in order of broader to more specific influences.

Creating awareness

Starting with the broader theme: how social media creates awareness. For some of the participants, the first time they came across neurodiversity was via social media. For others who had prior knowledge of it, social media contributed to changing their viewpoint on these diagnoses. Content they came across on social media often painted neurodiversity in a more positive light than the participants were used to seeing. This positive framing was mostly done through creators sharing the traits that made them realise they were neurodivergent or sharing how neurodiversity influenced their day-to-day experiences. Participant 3 talked about how creators would say “this is me, this is normal for me, and it’s not a bad thing”. Being presented with these positive views, it seemed the participants were able to challenge some inherent ideas they used to have about neurodiversity, if they already knew about it, and making it more likely to identify themselves with it.

Besides showing a more positive side of neurodiversity, participants also described how social media could help them understand certain diagnostic criteria or symptoms better. Participant 5 mentioned how social media could help you gain new insights into symptoms they may have already known about. Bringing up how for “a lot of autistic tendencies, you don’t immediately notice it is autism”. One specific example she gave was taking things literally, saying how she “took that too literally, that if a questionnaire asked do you always do this, [she] would think that [she] only did that 90 percent of the time, so it didn’t count”. And social media made her realise that these could be signs of autism. Participant 4 experienced something similar, where she had already noticed some traits, and social media gave her the terms to describe it. For her it was mainly because social media depicted more subtle signs of autism and highlighted how certain diagnoses might present in women instead of men.

A constant reminder

Now we know that social media sometimes acts as a first inspiration and other times serves as a tool that reframes information the participants already had. After this I was curious how social media further influenced their journey to finding the right diagnosis, after this initial introduction. One of the questions in the interview was: ‘How would you describe the role of social media in your search for a diagnosis’. And with the possibility of the earlier mentioned availability bias in mind, one of the first things that jumped out at me was the following quote:

> Well, it’s constantly a sort of little man on your shoulder that says, ‘maybe you have that, maybe you have that’. And then you constantly sit with that question, it constantly keeps that ball in the air of ‘Oh is there something, what do you think, what do you think?’. (Participant 2)

Which to me really showed how social media doesn't just provide information, it can also act as a constant reminder and keep a possible diagnosis at the forefront of someone's mind. Participant 4 shared similar sentiments saying how social media made her "more conscious about it, so every time [she] would experience something [she] thought was out of the ordinary, [she] would think it could be a symptom". And in general, making her more aware of her own behaviours. These experiences seem to fit with the earlier mentioned availability bias (Tversky & Kahneman, 1973) that poses that seeing information more makes you think about it more, even if without seeing this information they never would have considered it as an option.

Relating to content

Even when social media had similar influences on most of the participants, they still had their own preferences for what content inspired them the most. With so many different content creators available to watch, it isn't surprising that different people get pulled to different kinds of content. The content the participants talked about ranged from purely informational content made by professionals to content just showing daily life, to memes about neurodiversity. Participant 4 enjoyed memes because these were funny and easy to relate to. Participant 3 preferred watching content creators who had a lot in common with her, because she could really recognise herself in their videos. Also talking about how "[i]t gives you a deeper connection, and makes you feel like they get what you're going through".

To me this really illustrated the different ways people are inspired by social media content. Most of the participants just watched what was presented to them through algorithms and didn't specifically go looking for it. Though participants 1 and 5 did look up different types of content about neurodiversity themselves. And in these cases, they mainly looked for informative content or concrete tips that could help them.

Chapter 3: Peer networks and self-diagnosis

Now that we're more aware of how social media can inspire and influence the participants to self-diagnose neurodiversity, the next step for me was to see if interacting with peers played a similar kind of role. Also answering the third and last sub question: How do peer networks contribute to or influence the self-diagnosis process? According to my participants' peer groups play an important role in motivating, validating, and guiding them through key moments in their process of self-diagnosis. While they were talking about the influence from their peers a few themes emerged from the data: How peers provide recognition and validation, and how they can provide additional support in practical ways. In the rest of this chapter I will further explore what was said about these topics.

Recognition and validation

Back in chapter 1 it was noted how professionals often dismissed the participants, and didn't provide recognition for the things they were struggling with. But when further talking about their process it came up how peers were able to fill in this role. In the interviews it became clear that a lot of the participants had peers around them that had a form of neurodiversity and had already gone through the process of a formal diagnosis or were planning to. Multiple participants indicated that conversations with these peers played an important role in recognising neurodiversity in themselves. Similar to what social media did for some of the participants, these interactions helped frame certain traits or behaviours in a different light. One quote where this was clearly worded is the following:

> Yes, just things people do who do have a formal diagnosis, and then oftentimes they are like 'Oh you do that as well, for me that is caused by my autism'. Which made me think, ahh that could be it'. (Participant 5)

This experience was shared by others, making clear in different ways that peers were used to bounce ideas off one another, and that peers were in some cases the first to recognize that the participants might have a form of neurodiversity. The conversations the participants had with their peers about traits, struggles, and experiences they had surrounding neurodiversity really helped them regain confidence in themselves. This was mainly because they now had someone around that understood them and validated their struggles. Participant 3 mainly relied on peers for her self-diagnosing process and had many positive things to say about how contact with peers helped her. Talking about how "[she] think[s] it has been really good for [her] own self-image" and how "[s]ometimes you need to complain, and then these people understand what you're talking about".

Many of the participants' experiences match up with the earlier mentioned theories of identity development by Erikson (1968). Seeing how affirmation and interacting with people similar to them can legitimize and reinforce their self-diagnosed identity. Mainly making them feel like they weren't alone in their struggles.

Peers offering support

In addition to helping recognize neurodivergent traits, it turns out peers oftentimes play an important role in providing both the practical and emotional tools to cope with symptoms the participants might have been struggling with. Particularly participant 3 brought up how having peers that do have a formal diagnosis had an added benefit. Saying how if she had a problem one of her friends "within no time would say [he had also] experienced that, and to try this technique or listen to this podcast". As this friend with a diagnosis had gotten tips and tricks to deal with certain symptoms through a professional. Participant 5 shared a similar sentiment saying how for her it was "mainly the knowing what it is and how have other people dealt with it, knowing which tricks people have for dealing with it" that was important to her. They both really benefited from having peers that had gone through similar

processes. The possibility of this transfer of knowledge created a supportive environment where others could benefit from resources they otherwise might not have had access to.

Beyond the direct sharing of tips, just the presence of neurodivergent peers in the participants' social circle had a normalizing effect. Being around others who face similar struggles reduced feelings of isolation and contributed to being more accepting of themselves. For participant 3 this had a big impact, just "knowing you're not the only one who experiences or struggles with something" brought a sense of relief and belonging.

When youth is surrounded by peers who openly identify as autistic or as having ADHD, then that label becomes less threatening and more empowering. Instead of stigmatized ideas that some participants had seen in media, these labels now had a new meaning to them. When seeing these labels in people they connected with instead of just hearing about a clinical version of them, they were able to connect to these labels much stronger.

Conclusion

In this study I set out to explore how Dutch university students navigate the process of self-diagnosing different forms of neurodiversity, with particular attention to the influence of social media and peer networks. Through exploring existing theory and interviews with five participants this study aimed to gain insights into this. The findings show that self-diagnosis is not just seen as a last option but is also seen as an accessible alternative to a professional assessment. Particularly when trying to get a formal diagnosis results in being left feeling dismissed.

Across the participants, a recurring theme was a lack of validation they received from healthcare professionals. There was a lot of reluctance amongst the participants to further pursue a formal diagnosis. This is when self-diagnosis became a fitting alternative. Providing a sense of agency and allowing the participants to interpret their own experiences. Participants' main objective was gaining a better understanding of themselves and finding some tips that could help them with their struggles. Most of the participants did not explicitly go looking for information but found it anyway through a combination of social media and peer connections. Both had an important influence, but it differed per participant which shaped their journey the most. Looking at the whole picture, it seems that the decision to self-diagnose is shaped by a combination of limited access to a formal diagnosis, the search for validation and the accessibility of information through digital platforms and social circles.

Strengths and limitations

The strength of this research is the in-depth approach, allowing for nuances in the participants experiences which at this stage of research has been very valuable as not much was known about these processes. As with any qualitative research, this study has its limitations. The sample size was small, and participants may not reflect the full diversity of

student experiences. This study also ended up covering a very limited age range instead of the wider one that spanned adolescence.

Recommendations

My recommendations for future research are that it should include a larger range of ages. I also think it would be interesting to conduct similar research amongst students who do not have peers who are neurodivergent in their environment, to find out if it is just the presence of peers that facilitates validation of self-diagnosis, or if its specifically neurodiverse peers that have this effect.

Furthermore, this study started out calling for caution surrounding self-diagnosis, and naming the ways it could have adverse effects. After analysing the experiences that people have with this process, I think most people who start this process do use caution and don't just accept anything they see or hear as truth. Seeing the way self-diagnosis can help youth feel validated and accepted and how it can improve their lives, I think is a perspective that should be considered besides only warning for the dangers.

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Appendix A

Reflection on Interdisciplinarity

Understanding why youth choose self-diagnosis over a formal diagnosis cannot be done through just one disciplinary lens. It would be very hard to properly answer how interaction with social media and peer networks influence self-diagnosis of neurodiversity without making use of at least psychology and sociology. Although psychology offers insights into how individuals seek validation through labelling, and theories on identity formation or confirmation biases help explain why youth might reach for self-diagnosis, this alone cannot provide a satisfactory answer. Leaving out the angle sociology brings would mean you only look at the youths' motivations to understand themselves. And leaving out the psychology angle would assume that self-diagnosis is only done for or through interactions with peers. Both of which leave an incomplete picture of the real situation.

Monodisciplinary approach

Interdisciplinarity would always be the preferred approach for this kind of study, in fear of losing interesting perspectives and lived experiences. To effectively use a monodisciplinary approach the research would have to be less broad than it is now, really focussing on just one aspect of self-diagnosis such as only looking at it through the lens of healthcare professionals or only looking at how self-diagnosis is depicted on social media. Leaving out how individuals would interact with it, or how interactions with their environment also influences decisions. But even when specifying the research to just one aspect of self-diagnosis it would still be difficult to keep it entirely monodisciplinary, since this process does not happen in a vacuum and you'll probably always see influences from different disciplines.

Methodological and analytical methods

This study primarily made use of a qualitative research form, like the semi structured interviews, and looking through existing literature to create a theoretical framework. Semi-structured interviews were the preferred way to research this topic at this stage, when not much is yet known about how social media or peers influence self-diagnosis. Using this I could collect a broad range of experiences, through open questions that left room for participants to elaborate on anything that is relevant to their process. This did mean that data collection was time intensive and that the results will not be generalisable. To get better insights into if the experiences that were recorded in this study also apply to the rest of the population, there would have to be an added element of quantitative methods. The insights gained from this study could be used to develop a questionnaire that can be widely spread to find out if the results are generalisable.

As for different analytical approaches, the use of multiple analytical levels can enhance depth and relevance in research. By approaching a problem from multiple levels, you get a more complete understanding of the actual situation. I already approached the problem from multiple levels. Addressing micro level through looking at individual motivations, meso-level by looking at the influence of social media and peer interactions, and macro level through looking into the barriers present for getting a professional diagnosis. While for this specific research I don't think it is necessary to expand this, for other research within this topic it would be interesting to also get an even broader perspective on this issue and look into the broader societal opinion on the matter of self-diagnosis.

Appendix B

Information letter

Informatie over deelname aan

Ben ik neurodivergent? De invloed van sociale media en peer connecties.

Hallo!

Voor mijn master scriptie doe ik onderzoek naar de invloed van sociale media en peer contact op het stellen van een diagnose van neurodiversiteit, denk hierbij aan ADHD, of autisme. Het onderwerp van dit onderzoek is de rol van sociale media en contact met vrienden in motivaties om zelf te diagnosticeren. Sinds een diagnose stellen soms nog best lastig kan zijn, en niet alles op sociale media even goed onderzocht is, is het zeer waardevol om er verder achter te komen hoe mensen interacteren met de content die beschikbaar is en hoe dit gebruikt kan worden om tot een diagnose te komen. Er is momenteel nog weinig bekend over wat sociale media bijdraagt als informatie bron rondom neurodiversiteit. Daarom zijn nieuwe inzichten hier in hard nodig.

Voor dit onderzoek ben ik opzoek naar studenten die vermoeden dat ze neurodivers zijn en die actief zijn op sociale media. Om mee te doen aan dit onderzoek hoef je geen professionele diagnose te hebben, wel is het belangrijk dat je minstens een stap hebt ondernomen om meer over de diagnose uit te zoeken bij een professional. Je bent dus via informatie van sociale media of door het er over te hebben met vrienden tot de realisatie gekomen dat je een van deze stoornissen hebt.

Je kan dus mee doen aan dit onderzoek als je: Tussen de 18 en 25 jaar bent en momenteel studeert, actief sociale media zoals TikTok, Instagram of Youtube gebruikt, vermoed dat je neurodivers bent, en hier ook een stap in hebt genomen om dit professioneel te laten uitzoeken.

Hoe wordt het onderzoek uitgevoerd?

De onderwerpen van het onderzoek zullen worden uitgevraagd in een semigestructureerd interview, wat ongeveer 30 tot 45 minuten zal duren. Tijdens dit interview zal er dus gevraagd worden naar jouw interactie met sociale media, hoe jij jouw proces van een diagnose vinden ervaren hebt, en de uitdagingen die je tegen komt op dit onderwerp.

Wie ben ik?

Ik ben Jonna, een masterstudent aan Universiteit Utrecht. Ik heb de bachelor Pedagogische Wetenschappen twee jaar geleden afgerond en volg nu de master Youth Development and Social Change. Waarvoor ik nu dus bezig ben met mijn scriptie en daarnaast een stage.

Data verwerking

Het interview zal tijdens het afnemen worden opgenomen, en na afloop wordt deze opname getranscribeerd. Jouw data zal anoniem zijn, de persoonsgegevens zullen gecodeerd worden

zodat ze niet terug te leiden zijn naar jouw naam. Na het afronden van het transcriberen zal de opname van alle opnameapparaten en universiteit databases verwijderd worden, wat betekend dat alleen de anonieme transcripten bewaard zullen worden tot de afronding van de thesis. Verder zal deze anonieme data alleen beschikbaar zijn voor analyse voor de onderzoeker, een mede-onderzoeker en de supervisor. De thesis zelf zal voor 5 jaar gearchiveerd worden.

Dit onderzoek is onder supervisie van Dr. Jaco Smit, en in het geval van vragen kan je hem contacteren via w.j.smit@uu.nl.

Dit onderzoek heeft ethische goedkeuring gekregen van de Facultaire Ethische Toetsingscommissie – Faculteit Sociale Wetenschappen. Alle data zal bewaard worden via UU-protocol. Wat betekend dat data alleen bewaard zal worden op servers van de faculteit, en dat de data niet langer bewaard zal worden dan nodig is.

Doe je mee?

Deelname is geheel vrijwillig. Als je niet mee wil doen, dan hoeft je verder niets te doen. Ook tijdens het onderzoek kan je op elk gewenst moment stoppen. Je hoeft nooit te zeggen waarom je niet mee wilt doen, of waarom je wilt stoppen. In het geval dat je deelname op enig moment wil stoppen zal al jouw verzamelde data verwijderd worden

Als je mee wilt doen kan je dit bij mij doorgeven via: j.e.vandeventer@uu.nl of 06-87120886

Met vriendelijke groet,

Jonna van Deventer

Appendix C

Informed consent form

Ben ik neurodivergent? De invloed van sociale media en peer connecties.

16-04-2025, Utrecht

Deelname

Deelname aan dit onderzoek is geheel vrijwillig. Je bent vrij om op ieder moment met het onderzoek te stoppen. Ook ben je vrij om geen antwoord te geven op vragen waarmee je oncomfortabel bent. Ook achteraf aan het interview kan dit nog aangegeven worden.

Consent

Wanneer je jouw handtekening zet ga je akkoord met:

- Participeren in dit onderzoek
- Verzameling van jouw contact gegevens
- Verzameling van persoonsgegevens, waaronder
    - Leeftijd
    - Gender
    - Opleidingsniveau
    - Vorm van verwachte neurodiversiteit

Mocht je nog vragen hebben over het onderzoek kan je contact opnemen met Jonna van Deventer, te bereiken op 0687120886 of j.e.vandeventer@uu.nl

Naam Participant:	Naam Onderzoeker: Jonna van Deventer
Datum:	Datum:
Handtekening:	Handtekening:

Appendix D

Interview guide

Opwarming

- Small talk
- Zoals je waarschijnlijk al weet, gaan we het vandaag hebben over zelf-diagnose. En om het in de latere stadia van interpreteren ook duidelijk te maken dat het hier over gaat en niet en officiële diagnose, zal ik soms ernaar refereren als de ‘verwachte diagnose’.
- Heb je nog vragen voor we beginnen?

Persoonsgegevens

Leeftijd, gender, opleidingsniveau. Heb je jezelf gediagnosticeerd? Verwachte diagnose?

Sociale media

- Hoe vaak gebruik je social media?
- Op welke social media ben je actief?
- Welke social media gebruik je het meest?
- Wat voor content kom je tegen?
    - Is er content wat je interessanter vindt?
    - Zie je content die te maken heeft met mentale gezondheid of neurodiversiteit?
- Wat is je voornaamste reden voor sociale media gebruiken?
    - Wat vind je het leukst aan sociale media
- Zijn er specifieke creators die over mentale gezondheid of neurodiversiteit praten die je leuk vindt om te kijken?
    - Waar praten zij over?
    - Wat voor advies geven ze?
    - Want vind je leuk/interessant aan ze?

Diagnose en invloeden

- Welk moment dacht je voor het eerst dat je misschien [verwachte diagnose] had?
    - Wat was de inspiratie?
- Kan je me vertellen over jouw pad, hoe ben je er achter gekomen dat je waarschijnlijk neurodivers bent?
- Wat waren voor jouw indicators dat dit misschien aan de hand was?
    - Was er een specifiek moment dat er voor zorgde dat je er meer over ging denken?
    - Merkte je voor dat moment ook al bepaalde uitdagingen?
    - Wat dacht je dat deze uitdagingen betekende?
    - Hoe heb je ze geïnterpreteerd?
    - Heb je de mogelijke oorzaken van deze uitdagingen onderzocht?
    - Waren er oorzaken die je wel overwogen hebt maar later toch verworpen hebt?
        - Waarom?
- Wanneer geloofde je dat je inderdaad in het label van [verwachte diagnose] paste?

    - Wat overtuigde je ervan dat dit is waardoor je uitdagingen ervaarde?
- Wat heeft je gemotiveerd om zelf op zoek te gaan naar deze informatie?
- Hoe zou je de rol van social media beschrijven in het uitzoeken van deze informatie?
- Was er een moment waar social media je liet reflecteren op uitdagingen die je daarvoor had ervaren?
    - Kan je een voorbeeld geven?
- Wat voor soort content droeg hier aan bij?
    - Was er content die meer indruk maakte dan andere?
- Heb je buiten social media content nog verder informatie opgezocht?
    - Heb je gekeken naar online beschikbare criteria?
- Ben je blij met de soort informatie die voor jou voorbij komt op sociale media?
- Hoelang heeft het ongeveer geduurd voordat je tot deze conclusie bent gekomen?
- Ben je van plan ook langs een professionele zorginstelling te gaan om de diagnose verder uit te laten zoeken?
    - Zo ja, heb je al stappen gemaakt?
    - En waarom wil je het wel/niet professioneel laten uitzoeken?
    - Maakt de zelf-diagnose het waarschijnlijker of onwaarschijnlijker dat je ook professionele hulp opzoekt?

Invloed van peers

- Heb je het met mensen in je omgeving gehad over dit proces?
    - Wat bespreek je dan met hen?
    - Hebben deze gesprekken invloed gehad op het proces van een diagnose vinden?
    - Hebben deze gesprekken invloed gehad op hoe je nu naar je diagnose kijkt?
        - Op welke manier
- Heb je vrienden die door een soortgelijk proces aan het gaan zijn?
    - Waar hebben jullie het samen over?
- Ben je ook actief in online gemeenschappen?
    - Hoe is een online gesprek anders dan een face-to-face gesprek?
    - Heb je het vooral over dit proces online of face-to-face?
        - Is er een rede voor dat verschil?
    - Is er verschil in wat je bespreekt met verschillende groepen?

Invloed van diagnose

- Op welke manier heeft deze diagnose invloed gehad op jouw leven?
- Hoe is jouw leven veranderd sinds het zelf stellen van de diagnose?
    - Heeft dit invloed gehad op je mentale gezondheid?
- Hoe open ben je er in je dagelijks leven over?

Afronding

- Wat zou je advies zijn voor iemand die in een vergelijkbare situatie zit?
- Zijn er nog dingen die je graag kwijt wil, waar ik niet naar gevraagd heb?
- Heb je nog vragen voor mij?

Appendix E

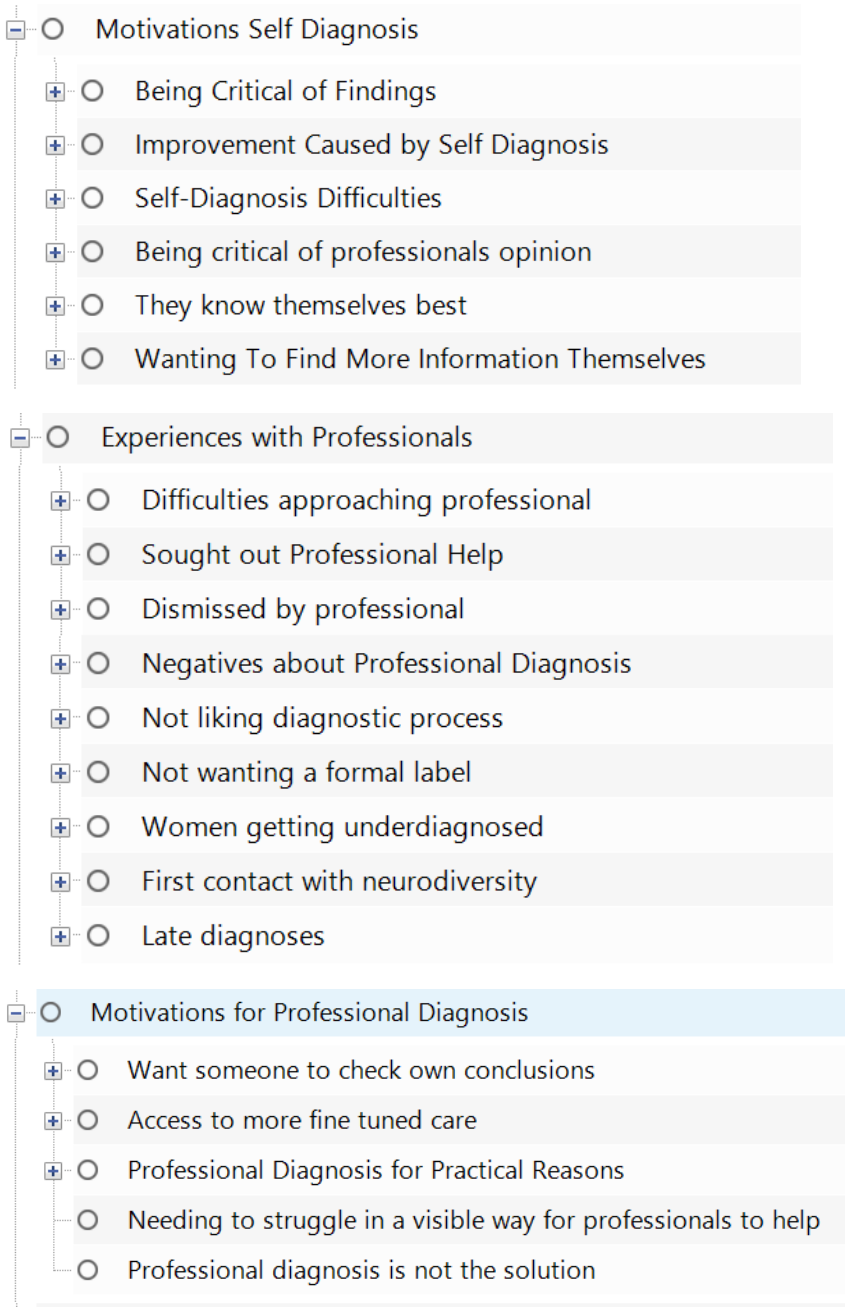
Code tree

Overarching codes

- Social media influence
- Peer Influence
- Motivations Self Diagnosis
- Experiences with Professionals
- Motivations for Professional Diagnosis

Sub codes

- Social media influence
  - Why Social Media as Source
    - Social media reframing information they already had
    - Creators normalising neurodiversity
    - Recognizing Yourself In The Content
    - Easy to connect to creators
    - Social media providing new information
  - Background Information
  - Content Preferences
  - Used social media
  - Social media is a constant reminder
  - First interaction with neurodiversity
  - Negatives social media
- Peer Influence
  - Peers understanding struggles
  - Peers Helping with Uncertainty
  - Some peers not understanding
  - Talking about neurodiversity with peers
  - Talking With Peers Makes Approaching Professional Easier
  - First sign they might be neurodivergent
  - Practical tips for struggles
  - Family Influence
  - Using label to explain to others why they do certain things


Motivations Self Diagnosis
Being Critical of Findings
Improvement Caused by Self Diagnosis
Self-Diagnosis Difficulties
Being critical of professionals opinion
They know themselves best
Wanting To Find More Information Themselves
Experiences with Professionals
Difficulties approaching professional
Sought out Professional Help
Dismissed by professional
Negatives about Professional Diagnosis
Not liking diagnostic process
Not wanting a formal label
Women getting underdiagnosed
First contact with neurodiversity
Late diagnoses
Motivations for Professional Diagnosis
Want someone to check own conclusions
Access to more fine tuned care
Professional Diagnosis for Practical Reasons
Needing to struggle in a visible way for professionals to help
Professional diagnosis is not the solution

Appendix F

Definitions and operationalisation

Definitions of central concepts

Concept	Definition
Neurodiversity	A range of differences in individual brain function and behavioural traits, by some seen as a normal variation in the human population, by others classified as disorders.
Self-Diagnosis	Giving yourself a label that you think fits your symptoms based on information gotten from the internet or people around you.
Formal/professional diagnosis	Diagnosis received going through professional channels, and going through a diagnostic trajectory with a health care professional
Social media	Interactive technologies that facilitate the creation, sharing and aggregation of content, such as ideas, interests, and other forms of expression, among virtual communities and networks.
Peers	A person in the same age group or with the same social position as you, or someone at your own level.
Social media content	Variety of text, images and videos shared on social media platforms. These can have different themes and topics to them, including mental health and neurodiversity.
Social media creators	Individual people on social media who create content and share it on their social media platforms. Creators can make content about a specific topic or a variety of things.