

**Attention and Awareness – Women's Digital Storytelling within Instagram to Reduce
ADHD Stigma**

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Abstract

This bachelor thesis analyses how women's digital storytelling (DST) within Instagram actively reduces the stigma associated with ADHD. A reflexive thematic analysis following the six-step guidelines provided by Braun and Clarke (2019) was used to identify themes possibly correlated with stigma reduction. After the analysis, one overarching theme, empowerment, was identified. In addition, seven main themes, namely emotional experiences, consequences of inadequate executive functioning, understanding the complexity of symptoms, misconceptions about ADHD, community and peer support, pride, and personal experiences, were identified. All themes, subthemes, and corresponding codes were presented in the results section and validated after a member check interview was conducted. Even though there is support from research that some themes identified might contribute to stigma reduction, further investigation for sustained empirical validation is needed.

Keywords: social media, Instagram, mental health, ADHD, ADHD stigma, women, digital storytelling, reduce stigma, raising awareness, empowerment

Attention and Awareness – Women's Digital Storytelling within Instagram to Reduce ADHD Stigma

“Attention-deficit/hyperactivity disorder (ADHD) is one of the most common neurodevelopmental disorders, estimated to affect about 5% of children and about 2.5% of adults “(Dobrosavljevic et al., 2023, p. 883). When ADHD remains undiagnosed and untreated, it could lead to several problems, such as low self-esteem, difficulties in maintaining relationships, impairment in cognitive functions, underperformance when it comes to academic and work-related tasks, as well as an increased probability of developing mental health disorders. The development of those problems starts in childhood and remains present in adulthood (Langvik & Holthe, 2017). According to Godfrey et al. (2020), “ADHD in adults also represents an under-researched area being far less studied than its child counterpart “(p. 993)

Presentation of Symptoms

From 1952 to 1994, ADHD was considered to occur in children only (Zalsman & Shilton, 2016). The Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, published in 1994, first acknowledges that ADHD persists throughout life (Zalsman & Shilton, 2016). The Diagnostic and Statistical Manual of Mental Disorders, 5th Edition, identifies three types of ADHD (American Psychiatric Association, 2013).

The first type highlights hyperactive and impulsive behaviour and is therefore referred to as the hyperactive and impulsive type. Individuals diagnosed with this type express hyperactive and impulsive behaviours. To arrive at a diagnosis, “Six (or more) of the following symptoms have persisted for at least six months to a degree that is inconsistent with developmental level and that

negatively impacts directly on social and academic activities “(American Psychiatric Association, 2013 p. 105). The symptoms of hyperactive and impulsive behaviour are described in the following. “A) Often fidgets with or taps hands or feet or squirms in seat. B) Often leaves seat in situations when remaining seated is expected. C) Often runs about or climbs in situations where it is inappropriate. Note that in adolescents or adults may be limited to feeling restless. D) Often unable to play or engage in leisure activities quietly. E) Is often on the go, acting as if driven by a motor. F) Often talks excessively. G) Often blurts out an answer before a question has been completed. H) Often has difficulty waiting for his or her turn. I) Often interrupts or intrudes on others. Adolescents and adults may intrude into or take over what others are doing “(American Psychiatric Association, 2013, p.105).

The second type highlights the occurrence of inattentive behaviour and is referred to as the inattentive type. Individuals diagnosed with the inattentive type of ADHD display “at least six (or more) of the following symptoms for at least six months to a degree that is inconsistent with developmental level and that negatively impacts directly on social and academic activities “(American Psychiatric Association, 2013 p. 104). The symptoms are described “as follows: A) Often fails to give close attention to details or makes careless mistakes in schoolwork, at work, or during other activities. B) Often has difficulty sustaining attention in tasks or play activities. C) Often does not seem to listen when spoken to directly. D) Often does not follow through instructions and fails to finish schoolwork, chores, or duties in the workplace. E) Often has difficulty organising tasks and activities. F) Often avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort. G) Often loses things necessary for tasks or activities. H) Is often easily distracted by extraneous stimuli. I) Is often forgetful in daily activities “(American Psychiatric Association, 2013, p.104).

The third type presents a combination of the hyperactive and impulsive types as well as the inattentive type and is referred to as the ADHD combined type. To arrive at a diagnosis, “Both criterion A1 (inattention) and criterion A2 (Hyperactivity impulsivity) are met for the past six months “(American Psychiatric Association, 2013, p. 105).

ADHD in Women

In 2020, Song et al. (2021) estimated the prevalence of ADHD in adults. Current estimations assume that 139.84 million adults worldwide display ADHD symptoms, which were present in childhood and remain present in adulthood. In addition, around 366.33 million men and women worldwide display ADHD symptoms starting in adulthood without being present in childhood (Song et al., 2021). Quinn and Madhoo (2014) estimated that within the global population, 5,4 per cent of men and 3,2 per cent of women receive an ADHD diagnosis.

Women represent a minority in ADHD due to different factors that contribute to not recognising that symptoms of ADHD are present (Mowlem et al., 2018). Indications of ADHD are misunderstood by the society they are living in and fallaciously attributed to emotional difficulties instead of symptoms of ADHD (Langvik & Holthe, 2017). The public understanding of ADHD and the diagnostic criteria are mainly based on observations of symptoms occurring in boys and men (Langvik & Holthe, 2017). As a result, ADHD is considered a disorder that mainly occurs in men (Lebowitz, 2013). One factor contributing to the false conclusion that ADHD does not occur in women is that “statistics based on clinically referred samples will naturally reflect an image of ADHD as a predominantly male disorder “(Langvik & Holthe, 2017, p.2).

The gender ratio for receiving an ADHD diagnosis is approximately 3:1(Greven et al., 2018). The gender ratio indicates that males are three times more likely than women to receive

an ADHD diagnosis (Greven et al., 2018). Due to not receiving an ADHD diagnosis, women have less access to resources such as ADHD assessment, therapy sessions, medical treatment, and support (Mowlem et al., 2018). Referring to the general public perception of ADHD, there is a lack of general awareness that ADHD in women can occur in parallel (comorbidity) with other mental disorders, for instance, anxiety disorders, specific phobias, and panic disorders (Sobanski, 2006). Comorbidity describes “the co-occurrence of two or more distinct illnesses, disorders or conditions in a single individual “(Brown & Thorsteinsson, 2019, p.1).

Besides not recognising the occurring comorbidity of disorders as a possible signal of ADHD, there are two main misapprehensions shaped by the public perception of ADHD. The first misapprehension is the assumption that ADHD merely occurs in childhood or adolescence and is non-existent in adulthood (Rucklidge, 2010). The second misapprehension is the assumption that women experience no significant impairment caused by ADHD (Faheem et al., 2022). According to Morgan (2023), ADHD symptoms in girls are underestimated by parents or teachers. Consequently, they are less often referred to get diagnosed. This leads to women being diagnosed later in life (Morgan, 2023). A lack of psychoeducation and misleading assumptions about ADHD can lead to the stigmatisation of women diagnosed with ADHD (Mueller et al., 2012).

Structural Stigma of Women

According to Overton and Medina (2008), individuals diagnosed with mental health conditions experience structural stigma. Structural stigma is described as a process which “involves (a) the recognition of cues that a person has a mental illness, (b) activation of stereotypes, and (c) prejudice or discrimination against that person “(p.144).

As a result of being stigmatised, women experience a reduction in self-esteem and a declining quality of life. Low self-esteem and feeling embarrassed can contribute to the aspect that women hesitate to search for peer or professional support and ADHD assessment. In addition, the inaccessibility of resources to improve quality of life and self-esteem can lead to social isolation (Langvik & Holthe, 2017). Chronis-Tuscano (2022) declares that not receiving an ADHD diagnosis can lead to severe consequences, such as possible self-stigma and external stigma due to a missing explanation for the women's "lived experiences" (p. 498). In addition, feelings of being frequently misunderstood can lead to lower self-esteem. Frequently experiencing low self-esteem could further contribute "to the development of depression" (p. 498) as well as possibly occurring "suicidal thoughts and behaviours" (p. 498).

In addition, being stigmatised externally often leads to false expectations, such as individuals living with an ADHD diagnosis being unable to keep up with responsibilities and everyday tasks (Overton & Medina, 2008). One aspect which contributes to holding stigma towards individuals diagnosed with ADHD is the lack of knowledge about the occurrence of ADHD in women as well as the symptoms present in ADHD (Mueller et al., 2012). The described lack of knowledge could occur in non-professional individuals (no education in Psychology) as well as clinical professionals (education in Psychology) (Mueller et al., 2012). To combat mental health stigma, online social media campaigns, including digital storytelling, could impact the public perception of mental health and raise awareness of mental health literacy (Alvarado-Torres et al., 2023).

Digital Storytelling on Instagram

In January 2023, Instagram had, on average, more than 2 billion active users every month. Considering the number of downloads, Instagram is the second leading social media app worldwide (Biggest Social Media Platforms 2023 | Statista, 2023). Instagram is a social media platform that is photo- and short-video-based (Instagram, n.d.). Photos shared on an Instagram account are known as Posts. Short videos posted on Instagram are referred to as Reels. After publishing a Post or a Reel, there is the opportunity for other Instagram users to comment on the posted content either with words or with emojis to express emotions, thoughts, and opinions in a verbal or nonverbal way (Instagram, n.d.).

Besides using Instagram for communication, based on sharing posts and reels, it can be used for digital storytelling (DST) (Mojtahedzadeh et al., 2021). According to Clarke and Adam (2011), “digital storytelling encompasses all narrative forms and processes produced and shared digitally, including narrative, image-only stories, internet radio stories and podcasting, and multimedia narrative integrating image, sound and perhaps text “(Clarke & Adam, 2011, p. 160). DST includes all styles of communication, for instance, talking about opinions and attitudes, sharing knowledge and experiences, sharing thoughts, and sharing skills (Mojtahedzadeh et al., 2021). Digital storytelling has become a powerful tool accessible to the public (Mojtahedzadeh et al., 2021). The trend of using digital storytelling through Instagram has risen towards sharing health-related experiences (Park et al., 2021). These experiences relate to physical or mental health (Park et al., 2021). Considering Instagram Posts with mental health-related content, women who live with ADHD have started to share ADHD-related content by using digital storytelling and hashtags such as " #adhdawareness, #adhdstigma, #adhdadvocacy, and #adhdwomen “(Instagram, n.d.-b). One step to facilitate destigmatisation for ADHD includes the

promotion of health-related information which is specially tailored to women living with ADHD. In addition, promoting health-related information and taking information preferences in terms of sources from different target groups into account would increase the likelihood of reducing stigma and raising awareness (Bussing et al., 2012).

Need of the study

Understanding how digital storytelling shapes interactions in online communities could provide valuable insight into experiences of being stigmatised due to receiving an ADHD diagnosis. According to (Eagle & Ringland, 2023), women are overlooked and rarely acknowledged in ADHD research. This study contributes to acknowledging women with an ADHD diagnosis by raising awareness and investigating possible solutions for stigma reduction while actively promoting ADHD-related information using social media, namely Instagram.

Eagle and Ringland (2023) investigated community content on Instagram, Tik Tok and Twitter focusing on the acceptance of ADHD diagnoses using the following hashtags, “#Health, #MentalHealth, #ADHD, #Neurodivergent, #ADHDWomen, #ADHDTikTok, #ADHDInWomen, #ADHDProbs, #ADHDTips #AdultADHD, #LateDiagnosisADHD, #UndiagnosedADHD, #ADHDInBlackWomen, “(p.5). Even though other researchers used similar hashtags to those described above in recent years, the selected dataset of Instagram content posted using “#adhdwomen and #adhdawarness “, as presented in this bachelor thesis, is not found in similar datasets focusing on DST.

Focusing on awareness-raising using the hashtag “#adhdawarness“ could provide valuable new insights into how women's digital storytelling within Instagram actively contributes to stigma reduction. Therefore, this bachelor thesis focuses on the following research question:

How can women's digital storytelling within Instagram actively contribute to reducing the stigma associated with ADHD?

Methodology

Study Design

This study used a qualitative and cross-sectional research design using Reflexive thematic analysis (RTA) following the six-step guidelines provided by Braun and Clarke (Braun & Clarke, 2019). The text-based analysis conducted on 93 Instagram posts contributed to gaining personal insights women diagnosed with ADHD share on Instagram.

Materials

As a starting point, Instagram (Version 42.0.21.0) was downloaded using the Google Play Store (Version 38.2.27-21 [0] [PR] 578597087). Afterwards, Microsoft® Excel® for Microsoft 365 MSO (Version 2308 Build 16.0.16731.20310) 64-bit was used to record the outcome of the pilot testing conducted on the 27th of October 2023. To ensure that the selected hashtags were actively used and, in addition, had user engagements, the analytic tool "Keyhole | Real-Time Social Media Analytics & Reporting Tool" was used to record the hashtag activity and user engagement on the 27th of October 2023, starting from 1: 00 am and ending at 6:00 pm (see Appendix B). Afterwards, Microsoft® Word for Microsoft 365 MSO (Version 2308 Build 16.0.16731.20310) 64-bit was used to manually transcribe all posts to access all information in textual form. Ultimately, the transcribed dataset was imported into ATLAS.ti 23 (version 23. 2. 3. 27778).

Procedure

In the first step, Ethical Approval was requested from the researcher to ensure that the research conducted was in line with ethical standards and guidelines provided by the University of Twente. On the 28th of September, 2023, the request (request number 231186) was approved by the BMS Ethics Committee. A pilot study was executed on the 27th of October, 2023, to access ADHD-related hashtags actively used on Instagram. The search function implemented in Instagram was used to access related hashtags. All hashtags were found by applying the search strategy of snowball sampling, starting with typing in #ADHD. After all hashtags were sampled, the most suitable hashtags, namely #adhdwomen and #adhdawareness, were selected. On the 02nd of November 2023, all data was gathered from Instagram using the hashtags #adhdwomen and #adhdawareness. All posts were downloaded from Instagram using the saving function for content, which can be accessed through the general account settings. To ensure the validity of the final dataset and correct possible misinterpretations of the findings, a member-check interview was conducted after the results section was finished.

Inclusion criteria

Three inclusion criteria were applied: the content was posted by women over 18 years old, the content is available in English and was posted between the 01st of August and the 02nd of November 2023. In addition, the post was linked to at least one hashtag, including #adhdwomen or #adhdawareness.

Exclusion criteria

All posts which were posted by men and women under the age of 18, as well as those not available in English, were excluded. Furthermore, all posts posted earlier than the 01st of August 2023 and later than the 02nd of November 2023 were omitted.

Final Data Set

After applying all inclusion and exclusion criteria, the original (N 105) post-dataset was reduced to (N 93). Therefore, the final dataset comprised 93 Instagram posts (N 93). Five posts were omitted because they presented experiences of living with autism. In addition, four posts were omitted since they were published by individuals identifying as male. Furthermore, three posts were omitted due to needing to follow at least one of the hashtags (#adhdwomen or #adhdawareness) selected.

Data Analysis

The final dataset was analysed following the approach of reflective thematic analysis invented by Braun and Clarke (Braun & Clarke, 2019). Six different steps were applied to identify themes and patterns in Instagram posts that lead to stigma reduction. In the first phase, I familiarised myself with the whole dataset by reading the transcript (Byrne, 2021). After the whole transcript was studied, codes were developed and applied in a second phase (Byrne, 2021). A sufficient code should meet two criteria, namely being as short as possible and “offer sufficient detail to be able to stand alone “(Byrne, 2021 p.1.399). In the third phase, the codes were further developed into themes. A theme emerges after similar codes are organised meaningfully to provide insight into answering the research question (Byrne, 2021). In the fourth phase, the researcher reviewed all applied codes and themes to ensure they all have an underlying meaning and provide insight into answering the research question (Byrne, 2021). The fifth step focuses on naming codes and themes as concrete as possible. “Each theme should provide a coherent and internally consistent account of the data that cannot be told by the other themes “(Byrne, 2021, p.1.407). The sixth phase focuses on writing up all decisions that have been made and deciding the order in which codes and themes will be presented (Byrne, 2021).

The whole RTA followed a semantic inductive approach. Following an inductive approach, the researcher started the analysis of secondary data and concluded the answer to the research question (Anekwe, n.d.). “The analyst is not looking for anything beyond what a participant has said or what has been written “(Braun & Clarke, 2006, p.84).

The main aim of conducting the RTA is to identify themes which could lead to reducing the stigma associated with ADHD. To incorporate the reflective aspect of conducting an RTA, I thought about my perception of ADHD in women and aspects that could lead to possible bias while interpreting the final dataset. One aspect that could lead to bias is that I identify as female. Therefore, I might sympathise with women's experiences more than having the same situation experienced by men. In addition, I know women diagnosed with ADHD myself and interact with them in my daily life. This might lead to overinterpretation in a scene of projecting my own experiences and feelings, which I had gained from personal conversations, into content posted on Instagram.

Furthermore, I might interpret the provided information from a clinical perspective due to following psychology courses at the university. Consequently, I might interpret health-related information differently according to my values and experiences as a psychologist. To limit possible overinterpretation, a semantic approach was chosen.

Following the reflexive process, the final dataset was gathered. I familiarised myself with the dataset by reading it several times. Following the process of familiarisation, the dataset was imported into the qualitative software ATLAS.ti 2023 for conducting the steps of coding and generating themes and developing codes into themes efficiently and organised. After redefining generated themes, codes were merged into groups to develop one main theme and possible

corresponding subthemes. Finally, all themes, subthemes, and corresponding codes were presented in the results section and validated after a member check interview was conducted.

Results

After coding the dataset, one overarching theme, seven main themes and eight corresponding subthemes were identified (see Table 1). The following section will explain all main themes and subthemes in detail.

Table 1

Main Themes, Subthemes and Codes Emerging from Instagram Posts Using #adhdawareness and #adhdwomen

Overarching Theme	Defined as	Subtheme	Primary codes included	N
Empowerment	Raising awareness by addressing the challenges of ADHD and empowering individuals to facilitate growth		Raising awareness Psychoeducation Enhancing self-worth Call for action Self-discovery	97
Main Theme				
Emotional Experiences	How women describe their emotions in terms of experiencing ADHD	Emotional Regulation Negative Feelings	Emotional regulation Emotional dysregulation Fears Forgetfulness Frustrations Other negative feelings	74
Consequences of Inadequate Executive Functioning	The impact of Inadequate executive functioning in daily life	Cognitive Challenges	Inadequate time management Inability to focus Inadequate organisation Manifestation of inadequate executive functioning	65

			Inadequate working memory	
		Neglect of Self-care	Inadequate self-care Inadequate self-control	
Understanding the Complexity of Symptoms	Developing sufficient knowledge of symptoms present in ADHD	Impulsive Actions	Impulsive behaviors Dopamine management Symptom management	63
		Hyperfocus	Hyperfocus as strength Hyperfocus explained Hyperfocus as disruption	
Misconceptions about ADHD	The process of arriving at a biased and stereotype-driven conclusion		Public perception of ADHD Misconceptions about ADHD Misconceptions of symptoms Decision making Being bored Low motivation Insufficient assessment Avoiding tasks	52
Community and Peer Support	Two or more individuals who share personal experiences and knowledge	Recommendations women with ADHD share with their Instagram followers	Tips for organisation Tips for time management Tips for improving self-care	45
		Support and Self Help	Perspective taking Setting boundaries Supporting relatives Supporting each other	
Pride	Individual character traits and talents are perceived as positive		Curiosity Creative thinking Innovative thinking Outside-the-box thinking	32
Personal experience	The sum of experiences gained through interaction with the environment		Personal experience before diagnosis Personal experience after diagnosis	29

Personal experience living
with ADHD
Interpersonal perception
Interpersonal difficulties

Note. “N” represents the occurrence of fragments coded within each theme.

Empowerment (N 97)

Note: As presented in Table 1, empowerment was identified as an overarching theme, representing linked aspects of every topic covered in the main themes. In addition, all main themes and subthemes identified belong to the overarching aspect of empowerment and awareness-raising. Empowerment is linked to and part of all primary codes and main themes developed during the analysis phase. Empowerment is defined as raising awareness by addressing the challenges of ADHD and empowering individuals to facilitate growth. Empowerment encourages individuals to raise their voices and share their experiences with ADHD. Furthermore, Individuals encourage each other to share experiences, such as tips for self-help and peer support and refer to contact details for professional support. Other aspects of empowerment include raising awareness, enhancing self-worth, and facilitating growth due to self-discovery.

One woman raises awareness by underlining the aspect that ADHD is not a disorder which occurs in children only. “October is ADHD awareness month. More than 1 in 11 children and 1 in 22 adults have ADHD “(Instagram post; posted on the 14th of October 2023; account followed by approximately 26.800 people). Another woman raises awareness by highlighting the difference between individuals living with ADHD. Whereas two different women independently refer to diverse expressions of ADHD characteristics. “ADHD looks different for everyone “(Instagram post posted on the 30th of October; account followed by approximately 26.800

people). “No two people share the same ADHD traits “(Instagram post; posted on the 27th of October 2023; account followed by approximately 140.000 people).

Furthermore, one woman expresses her knowledge regarding the likelihood of receiving an ADHD diagnosis as a girl. She highlights the aspect that ADHD can be present in all individuals independent of their gender. “While boys are twice as likely to get diagnosed with ADHD than girls, anyone can have ADHD. Boys are often diagnosed more frequently because girls are more inattentive than hyperactive, which makes ADHD harder to detect“(Instagram post; posted on the 28th of October, 2023; account followed by approximately 26.800 people). This statement implies that women are less diagnosed in adulthood due to being overlooked with ADHD assessment in childhood. Besides women trying to raise awareness, one woman tries to enhance the follower's self-worth by referring to personal experiences of struggling with completing tasks on time due to inadequate time management. “Please hear me when I say this. Your worth is not defined by your productivity. Your challenges and struggles are legitimate. You are doing enough. Who you are is enough “(Instagram post; posted on the 12th of October 2023; account followed by approximately 35.200 people).

Related to enhancing self-worth, one woman mentions that communication is the most crucial aspect of helping individuals with ADHD feel confident about themselves. “Many people with ADHD have a lot of self-doubt, so it is important that you help them feel confident and capable rather than emphasising the things they struggle with. Communicate! “(Instagram post; posted on the 30th of October 2023; account followed by approximately 26.800 people). Another woman highlights the aspect of self-discovery after receiving an ADHD diagnosis. “After years of developing the personas that fit in, you may need to figure out who you truly are inside“(Instagram post; posted on the 16th of October 2023; account followed by approximately

120.000 people). In addition, she refers to possible negative outcomes of not understanding occurring ADHD symptoms. “ADHD symptoms can have a significant impact on our lives, and when we don't understand them, they often lead to an erosion of our confidence and self-concept “(Instagram post; posted on the 16th of October 2023; account followed by approximately 120.000 people).

Statement Member Check Interview

Referring to the selected quotes that were chosen to represent the theme of empowerment, the member check partner did not have additional remarks.

There was nothing that felt weird or wrong. There was nothing that didn't fit within this theme at all. When I checked, it was clear to me.

Emotional Experiences (N 74)

Emotional experiences refer to women's experiences of emotions, mainly focusing on the aspect of how women experience their emotions in terms of living with ADHD. The emotions identified were related to emotional regulation, referring to the general ability or inability to regulate emotions or describe negative feelings. Therefore, two sub-themes, emotional regulation and negative feelings, were developed.

Emotional regulation

One woman describes the necessary skills to regulate emotions most effectively. “In a nutshell, emotional regulation is a skill set that requires three things—first, knowing what you are feeling and why—second, knowing what to do with what you are feeling. Third, knowing how to shift to an emotion that feels better “(Instagram post; posted on the 05th of October 2023;

account followed by approximately 67.000 people). In addition, she refers to the consequences of the inadequate capacity to use the above-described skills, which could lead to “Trouble regulating emotions “(Instagram post; posted on the 05th of October 2023; account followed by approximately 67.000 people).

Negative feelings

Three other women diagnosed with ADHD describe one negative feeling which is most present for them. These were the following: “Regretful decisions that hunt my conscience “(Instagram post; posted on the 27th of October 2023; account followed by approximately 145.000 people). “Feelings of failure “ (Instagram post; posted on the 19th of October 2023; account followed by approximately 145.000 people). “Feeling overwhelmed “ (Instagram post; posted on the 10th of September 2023; account followed by approximately 4.000 people).

Statement Member Check Interview

The member check partner confirms that the main theme and the subthemes are well-defined, but is *there a reason why positive feelings did not end up being a theme?* This aspect will be discussed in more detail in section 4 (see 4. Discussion).

Consequences of Inadequate Executive Functioning (N 65)

Consequences of inadequate executive functioning were defined as the observable impact of Inadequate executive functioning in daily life. Different aspects describe executive functioning, such as time management, the ability to focus, emotional control, working memory, flexibility, planning, and task initiation. The term inadequate refers to one or several executive functions which are not carried out appropriately. Two subthemes, namely cognitive challenges and neglect of self-care, were defined to capture the variety of inadequate executive functioning.

Cognitive Challenges

Three women describe which cognitive challenges they experience living with ADHD. The first woman describes one main challenge she experiences: the “inability to focus even if there are no distractions “(Instagram post; posted on the 30th of October 2023; account followed by approximately 750 people).

The second woman explains how she experiences the inability to focus: “ADHD is NOT an inability to concentrate. It is an inability to control what we concentrate on “(Instagram post, posted on the 30th of October 2023; account followed by approximately 263.000 people).

The third woman is referring to the consequences caused by an inability to focus: Finding “it difficult to concentrate on the task at hand “(Instagram post; posted on the 16th of September 2023; account followed by approximately 140.000 people). The independently described experiences all refer to one aspect of executive functioning: the inability to pay attention. Another woman described that inadequate executive functioning is typical in people with ADHD. “The deficiencies vary significantly from person to person (hence why there are so many different presentations of ADHD), but a lack of executive functions is a common denominator for people with ADHD. If you have ADHD, your executives are not functioning “(Instagram post; posted on the 12th of September 2023; account followed by approximately 67.000 people).

Neglect of Self-care

In terms of neglect of self-care, women describe that due to inadequate executive functioning, they experience neglecting themselves, which is represented in the following aspects: “Forgetting to eat, sleep and go to the bathroom “(Instagram post; posted on the 30th of

October 2023; account followed by approximately 700 people). “Brushing teeth and washing face before bed “(Instagram post; posted on the 05th of October 2023; account followed by approximately 100.000 people). “Struggling to do basic things and too little or too much sleep“(Instagram post; posted on the 03rd of October 2023; account followed by approximately 145.000 people).

Statement Member Check Interview

Asked for any additional remarks regarding the definition of the main theme and the corresponding sub-themes, no additional remarks were provided. *It was clear and straightforward, as well.*

Understanding the Complexity of Symptoms (N 63)

Understanding the complexity of symptoms refers to broadening individuals' knowledge to develop a sufficient understanding of symptoms present in ADHD. Due to the broad range of posts trying to explain ADHD symptoms from different angles, two subthemes were identified, which can be distinguished in impulsive actions and hyperfocus. Impulsive actions refer to individual actions and decisions performed without considering possible consequences. Hyperfocus is a state in which an individual is intensely focused on one specific task or action without thinking about anything else.

Impulsive Actions

Impulsive actions were described by two concrete examples of experiences by a woman diagnosed with ADHD. The first example refers to daily situations describing the engagement within a conversation. “Interrupting others when they talk and saying yes before you have the chance to think“(Instagram post; posted on the 17th of October 2023; account followed by

approximately 145.800 people). In addition, she describes the consequences followed by impulsive decision-making, namely, “frequently dropping all your plans for anyone “(Instagram post; posted on the 17th of October 2023; account followed by approximately 145.800 people).

Hyperfocus

One woman explains the experience of hyperfocus by presenting the following situation: “Hey, sorry, I cannot come out tonight. I need to research an incredibly specific random topic alone and in silence for hours on end for no reason at all“(Instagram post; posted on the 21st of October 2023; account followed by approximately 214.000 people). After sharing her experience, she refers to the possible disadvantages of experiencing hyperfocus. “Disadvantages: Lose track of time and miss deadlines. Irritated when interrupted. Life can get out of balance. Perfectionist tendencies. This often leads to burnout. 'interesting' activities often come before responsibilities “(Instagram post; posted on the 21st of October 2023; account followed by approximately 214.000 people). At the end of her post, she highlights the advantages of experiencing hyperfocus, described as follows: “Advantages: Can tune out external stimuli and get work done more efficiently. Being ‘in the zone’ can be relaxing for some people. Task performance improves. Allows people with ADHD to have a higher level of concentration “(Instagram post; posted on the 21st of October 2023; account followed by approximately 214.000 people).

Statement Member Check Interview

Ased if my member check partner thinks referring to impulsive actions and hyperfocus to capture the complexity of symptoms, the answer was the following: *I read this, and it felt pretty*

representative. There wasn't something unclear. For me, the main themes of my ADHD are impulsiveness and hyperfocus. Also, other aspects you covered later in quite good detail.

Misconceptions about ADHD (N 52)

Misconceptions arise when individuals arrive at false conclusions due to stereotyped thinking or other aspects which influence their perception of ADHD. The theme summarising the general perception of ADHD was identified after noticing posts referring to how individuals experience the public perception of ADHD, including misconceptions and stereotyped thinking. Furthermore, some posts provided insight into the challenges individuals with ADHD experience. One misconception about ADHD is connected to stereotyped thinking. One woman describes in her post that her family believed that “children would outgrow their ADHD “(Instagram post; posted on the 28th of October 2023; account followed by approximately 27.000 people). Another post refers to the misconception that individuals start self-diagnosing themselves after watching ADHD-related social media content even though “the social media content was just the first domino in the chain “(Instagram post; posted on the 27th of October 2023; account followed by approximately 50.000 people.

One woman shared her experience where she was confronted with the aspect that, in other individuals' opinions, “people use ADHD as an excuse “(Instagram post; posted on the 16th of October 2023; account followed by approximately 26.800 people). When it comes to experiencing challenges, one woman reported being confronted by the assumption that she pretends to have ADHD. “I am faking ADHD, and I am just lazy “(Instagram post posted on the 13th of October 2023; account followed by approximately 145.800 people). Another woman explains that people think she is “not motivated enough and does not care“(Instagram post posted on the 19th of September 2023; account followed by approximately 43.000 people).

Statement Member Check Interview

Asked for any additional remarks regarding the definition of the main theme, no additional remarks were made.

Community and Peer Support (N 45)

Community and peer support refers to individuals who support each other by sharing personal experiences, knowledge, recommendations, and tips for time management and improving self-care. Furthermore, tips for supporting relatives and supporting each other represent aspects of peer support. Two sub-themes were identified to merge the board topic of information: support and self-help and recommendations.

Recommendations Women with ADHD Share with their Instagram followers

The recommendations identified refer to time management in daily life, such as how to overcome the feeling of being overwhelmed by “limiting, eliminating, or managing situations when too much is going on, which can help with your overall energy level and internal peace “(Instagram post; posted on the 05th of October 2023; account followed by approximately 120.000 people). All recommendations identified were provided by women diagnosed with ADHD. A different piece of advice for maintaining productivity refers to managing breaks. “Building short breaks into your days without the entire day becoming a break “(Instagram post; posted on the 31st of October 2023; account followed by approximately 115.000 people). The second piece of advice refers to starting a task again after taking a break. “Use an alarm to remind you of breaks and to bring you back to task - consider different sounds for

each“(Instagram post; posted on the 31st of October 2023; account followed by approximately 115.000 people).

Support and Self Help

One piece of advice referring to support targets individuals who do not have ADHD themselves but are in contact with a friend or relative. Highlighting the importance of gaining experience and knowledge through direct communication instead of studying knowledge provided by books and websites. “Listen and be observant. You don't just learn about ADHD from books or websites. It is most important to learn about how your loved one experiences ADHD daily. Listen to them, ask questions, and observe their behaviours “(Instagram post; posted on the 30th of October 2023; account followed by approximately 26.900 people). Another post offers support by addressing opportunities for self-help by recommending sharing the diagnosis with friends and family. Furthermore, the establishment of routines is recommended. “Share your diagnosis with your family and friends so that they can understand and support you. Establish a routine that works for you and stick to it“(Instagram post; posted on the 08th of September 2023; account followed by approximately 145.800 people).

Statement Member Check Interview

I understand the recommendations section, which makes sense to me. From my side, I have also gotten many of those recommendations in that direction.

Pride (N 32)

Pride summarises feeling proud and perceiving talents and character traits as positive. This theme was identified by recognising the pattern of individuals referring to their abilities and talents they are proud of. Women were proud of the following aspects when asked to describe

their favourite ADHD strengths. “Having a unique brain gift, us with outside-the-box thinking skills. We can often find innovative solutions and have unique perspectives in problem-solving. “Us and we refer to Individuals diagnosed with ADHD. (Instagram post; posted on the 30th of October 2023; account followed by approximately 161.000 people). Another woman stated that she is proud of her curiosity: “My curiosity and how it leads to learning lots of weird and wonderful things “(Instagram post; posted on the 30th of October 2023; account followed by approximately 161.000 people). Furthermore, one woman stated she is most proud of her ability to manage crises. “How beautifully my brain works in crisis. I am the queen in crisis “(Instagram post; posted on the 30th of October 2023; account followed by approximately 161.000 people).

In addition, one woman highlighted being proud of her creativity and empathy. “The creativity, humour and empathy. I love the buzz of hyperfocus when I am in it. “ (Instagram post; posted on the 30th of October 2023; account followed by approximately 161.000 people). Us and we refer to Individuals diagnosed with ADHD. Another post posted on the 06th of October asked women what they think is a strength in the workplace due to having ADHD. The answers given were similar to the traits perceived as general strengths. The six most common answers were reposted, namely “keeping calm in a crisis, drive to discover and reinvent, high tolerance for instability, adaptability to different tasks and positions, lifelong learning, the ability to apply logic in new ways “ (Instagram post; posted on the 06th of October 2023; account followed by approximately 145.000 people).

Statement Member Check Interview

No remarks were made.

Note: The main theme was renamed after the member check interview was conducted. The earlier name of the main theme was individual strengths.

Personal Experience (N 29)

These subjective experiences are gained through interaction with the environment. Personal experiences can be classified into two different categories. The first category describes personal experiences living with ADHD, and the second category refers to experiences after receiving a diagnosis.

One woman describes living with ADHD as follows: “In my experience, ADHD is a lot of mentally yelling at yourself to DO something to do ANYTHING while you sit with absolutely no expression on your face, scrolling through your phone or continuing to play a game or whatever as if you have no control over your body “ (Instagram post; posted on the 20th of October 2023; account followed by approximately 33.000 people). Another woman describes how she experienced receiving an ADHD diagnosis later in life feels for her. “Journey through an ADHD diagnosis later in life. RELIEF: This explains everything! ANGER: How did no one see this when I was younger? GRIEF What could my life have been if I had been treated sooner? ACCEPTANCE My successes WILL outweigh my struggles, and my brain has a lot to offer“ (Instagram post; posted on the 01st of November 2023; account followed by approximately people145.800).

Statement Member Check Interview

Referring to all aspects represented in the results section.

You hide pretty much on the dot how it is. I would not recategorise something. That was very interesting; I was reading and wondering what this theme is about, and in the next paragraph, it showed up. When I was reading the primary codes, main themes, and subthemes that you included, it covered everything. From my experience, there is everything that I have gone through, too. I feel like you grabbed the essence of how it is to live with ADHD.

Discussion

This study aims to identify themes used in digital storytelling which could contribute to reducing the stigma associated with ADHD by focusing on the following research question: How can women's digital storytelling within Instagram actively contribute to reducing the stigma associated with ADHD?

One key element identified is the overarching theme of empowerment, primarily focusing on awareness-raising for different underlying themes individuals diagnosed with ADHD experience as essential in their lives. Furthermore, seven main themes, including emotional experiences, consequences of inadequate executive functioning, information about the complexity of symptoms, experienced misconceptions about ADHD, tips for supporting each other, and feelings of pride, as well as general personal experiences, were shared by using digital storytelling. Referring to the overarching theme of empowerment, De Vecchi et al. (2016) found that digital storytelling contributes to a better understanding of how psychological disorders are experienced. Furthermore, empowerment within digital storytelling could provide a safe space to exchange knowledge, discuss and reflect. Therefore, individuals could develop better-coping strategies when experiencing stigma. Furthermore, empowerment could help individuals develop resilience, promoting better mental health (De Vecchi et al., 2016).

Lyon and Mortimer-Jones (2020) found further evidence that empowerment could promote well-being and increase self-efficacy. In addition to better mental health and increased self-efficacy, empowerment could lead to a rise in an individual's capacity to cope with challenging experiences Lyon and Mortimer-Jones (2020). Additional research conducted by Lindstrom et al. (2021) found that sharing mental health information contributes to stigma reduction by educating individuals about misconceptions and stereotypes. Even though Lindstrom et al. (2021) refer to sharing mental health information in general without explicitly mentioning ADHD, it could be an indication that digital storytelling based on empowerment could contribute to reducing the stigma associated with ADHD. As shown by the selected quotes (see results section), Instagram allows women to raise their voices and share ADHD-related information. These women can reduce stigma by breaking down stereotyped thinking (Lindstrom et al., 2021).

The first main theme identified expresses emotional experiences and refers to the subthemes of emotional regulation and negative feelings. Within this theme, women mainly described difficulties in adequately regulating occurring feelings. One essential observation is that all selected posts either refer to emotional regulation or negative feelings, but no woman described positive feelings. A possible explanation could be the selection of hashtags beneath a post. Following the inclusion criteria, all posts were selected using the hashtags #adhdawareness and #adhdwomen. Raising awareness might lead women to focus more on negative feelings experienced. In addition, focusing more on negative feelings instead of positive feelings could be explained by negativity bias (Vaish et al., 2008). This phenomenon describes that individuals value negative feelings and experiences more than positive ones (Vaish et al., 2008). One positive aspect contributing to women's empowerment is acknowledging negative feelings and

normalising their occurrence by talking about them on social media. This could help recognise negative feelings in oneself and help process them appropriately. Besides referring to negative feelings, several women described feelings of pride. The main theme, pride, highlights all the talents and character traits women diagnosed with ADHD are proud of. According to Sznycer and Cohen (2021), pride is a universally recognised emotion that contributes to satisfaction and pleasant feelings, reinforcing internal motivation to achieve goals.

The second main theme identified describes the occurring consequences of inadequate executive functioning. Therefore, it was separated into subthemes. The first subtheme describes cognitive challenges. It was noticeable that different women independently described the inability to pay attention regarding inadequate executive functioning. Referring to the neglect of self-care shows that women experience similar challenges independent of each other. Misconceptions about ADHD held by the general population contribute to experiencing challenges in daily life due to general assumptions being made (Mueller et al., 2012). This aspect indicates that there is a lack of psychoeducation and awareness about ADHD occurring in women (Morgan, 2023). Several women were confronted with one main assumption. Namely, ADHD only occurs in childhood and is not present in adulthood (Faheem et al., 2022).

Another main theme contributed to awareness raising by broadening the understanding and complexity of ADHD symptoms. Furthermore, women described experienced misconceptions about ADHD as another main theme. In line with the findings of Lindstrom et al. (2021), both themes contribute to psychoeducation and might enhance stigma reduction. While providing education might lead to stigma reduction, it is not clear if peer support and sharing general personal experiences also contribute to stigma reduction. Ginapp et al. (2023) found that receiving peer support within an online community is beneficial regarding symptom

management and acquiring new coping strategies but did not investigate if peer support and sharing general personal experiences contribute to stigma reduction. In contrast to Ginapp et al. (2023), Zhuang and Guidry (2022) found empirical support that sharing personal experiences and knowledge in the form of education might reduce stigma. Overall, all main themes identified contribute to awareness raising by empowering women to speak up and share their experiences.

Limitations

Furthermore, the findings of this thesis display possible limitations. One aspect which contributed to not adequately capturing the presented information in Instagram posts is the absence of user interactions with the post itself. Instagram turned off the function of having an insight into statistics related to the posted content, such as how many people saw, liked, and shared the post. The social media observational tool Keyhole was used to generate insight into user engagements. On the one hand, the tool provided insights into how many posts were published using one specific hashtag and further user engagements such as likes per hour; on the other hand, researchers are not the target group for this tool. Initially, this tool targeted companies to provide insights into advertising and promotional content published on their Instagram pages. One main limitation is that the tool is not available through open access. Usage needs to be paid for by different types of subscription; otherwise, the insights provided are limited to a time scope of 24 hours.

Regarding the women responsible for posting information, additional limitations were identified regarding the reliability of the information provided. There are three aspects, namely age verification, check for diagnosis and information declared scientific information. All profiles

provided pictures presenting women. Nevertheless, it was not possible to check for age or ID information. Therefore, it is impossible to identify the content creator of the information provided. In addition, a few posts referred to scientific knowledge without providing accurate source information. Overall, it is essential to note that personal information on Instagram accounts, such as age, gender, and ADHD diagnosis, cannot be verified. To prevent the spread of false information, the researcher independently checked all information declared scientific knowledge to the best of her ability.

Besides considering the reliability of the information provided, the availability of one researcher during the selection, coding and analysis process could contribute to limited insight. To enhance the validity of the findings, a member check interview with an individual diagnosed with ADHD was conducted. Nevertheless, the findings presented are based on the decisions made by one researcher without ensuring interrater reliability. Moreover, the insight into personal experiences could be limited because posts posted earlier than the 01st of August and later than the 02nd of November 2023 and content available in languages other than English were excluded. In addition, the selection of content represents insight at one moment in time due to the generation of the whole dataset within a scope of 24 hours. Therefore, the findings only capture some details due to the dynamic and frequently changing content posted on Instagram.

Strengths

Despite some limitations that possibly influenced the findings, the study provides a unique perspective describing how women use Instagram to speak up, share knowledge and experiences, and, most importantly, build an ADHD community to empower each other. Even though it was not possible to consider all factors which might facilitate stigma reduction through digital storytelling within Instagram, this research provides indications that sharing mental

health-related information, especially focusing on sharing personal experiences, knowledge, and peer support, could contribute to stigma reduction (Lindstrom et al., 2021). Furthermore, positive consequences of empowerment were identified. They are developing resilience, self-efficacy, and better coping strategies (Lyon & Mortimer-Jones, 2020). Empowerment promotes well-being and mental health (Lyon & Mortimer-Jones, 2020). Another contribution made by this thesis is acknowledging women in ADHD research, while other studies neglected women with ADHD in the past decades (Langvik & Holthe, 2017).

Future Implications

Even though this research provides some indications which might contribute to the reduction of ADHD stigma, more empirical evidence is needed. One future implication would be to conduct a longitudinal study to investigate and track changes regarding the stigma perception of ADHD on Instagram. It would be beneficial to expand the data collection on other social media platforms to generate a deeper understanding of digital storytelling factors contributing to stigma reduction. In addition, an expansion through other social media platforms could facilitate a more diverse perspective on related themes, facilitating stigma reduction. Besides expanding the research through additional social media platforms, it is advisable to expand the research team to enhance the capacity of sampling a broader dataset, increasing the likelihood of identifying themes contributing to stigma reduction. Expanding the research team's focus on including diverse individual experiences, such as living with ADHD and without, might contribute to a less biased interpretation of the final dataset due to having diverse backgrounds and diverse angles of interpreting the information presented.

Conclusion

This thesis can be seen as a starting point for investigating factors in women's digital storytelling on Instagram to reduce the stigma associated with ADHD, especially highlighting the active participation in digital storytelling regarding empowerment and awareness raising and contributing to providing indications of themes valuable to stigma reduction. These are empowerment, sharing personal experiences, providing knowledge and education, and offering peer support. All these themes might reduce the experienced ADHD stigma.

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Appendix A

Study Information and Consent Member Check Interview

Study Information Sheet

Title:

Member Check Interview for Bachelor Thesis

Date and Time:

Monday, December 4, 2023

Location:

On campus at the University of Twente Enschede, Netherlands

Dear Participant,

You are invited to participate in a research study titled Member Check Interview for Bachelor Thesis. This study is conducted by Maria Steinbeck from the Faculty of Behavioural, Management and Social Sciences at the University of Twente.

The purpose of this research study includes the presentation of the results section conducted by Maria Steinbeck. The Bachelor thesis aims to investigate the following research question: How can women's digital storytelling within Instagram actively contribute to reducing the stigma associated with ADHD?

The Interview will be used for gathering feedback, critical thoughts, and additional remarks from the participants with the main aim of ensuring an accurate and detailed presentation of the research findings.

Your participation in this study is entirely voluntary and you can withdraw at any time. Feel free to omit any questions, discomfort, or concerns at any time.

The session is estimated to take around 45 to 60 minutes to complete and will be recorded as well as transcribed afterwards by the researcher Maria Steinbeck.

There are no known risks associated with conducting the Member Check Interview.

To the best of my ability, your answers provided will remain confidential. I will minimize any risks by ensuring confidentiality by providing pseudonyms to participants' answers to maintain anonymity for reporting the insights in the Bachelor thesis afterwards.

Note: The Bachelor Thesis (once completed) will be part of a public domain published by the University library. The domain can be accessed using the following link: [Repository home - University of Twente Student Theses \(utwente.nl\)](https://repository.utwente.nl/)

Consent:

Participants will be provided with an informed consent form before the interview, outlining the purpose, of the study. They will have the opportunity to ask questions and provide written consent before the start of the interview.

Thank you for joining the Member Check interview today!

Contact Information:

For any questions or concerns related to the Member Check Interview, participants can contact the researcher or Bachelor Thesis Supervisor.

Researcher:

Name: Maria Steinbeck

Email: m.k.steinbeck@student.utwente.nl

Bachelor Thesis Supervisor:

Name: Yudit Namer

Email: y.namer@utwente.nl

Form: Member Check Interview Bachelor Thesis Maria Steinbeck
YOU WILL BE GIVEN A COPY OF THIS INFORMED CONSENT FORM

Please tick the appropriate boxes

Yes N

Taking part in the study

I have read and understood the study information dated 04/12/2023, I have been able to ask questions about the study and my questions have been answered satisfactorily.

I consent voluntarily to be a participant in this study and understand that I can refuse to answer questions and I can withdraw from the study at any time, without having to give a reason.

I understand that taking part in the study involves an audio-recorded interview, namely a Member Check Interview. I understand that in addition to the audio recording the researcher will take written notes.

Risks associated with participating in the study

I understand that taking part in the study involves the following risks: No known risks.

Use of the information in the study

I understand that the information I provide will be used for a student's Bachelor Thesis. More concretely the outcome of the Member Check Interview will be integrated within the results section of the bachelor thesis written by Maria Steinbeck.

I understand that personal information collected about me that can identify me, such as [e.g. my name or where I live], will not be shared beyond the study team.

I agree to be audio recorded.

Signatures

Name of the participant

Signature

Date

I have accurately read out the information sheet to the potential participant and, to the best of my ability, ensured that the participant understands to what they are freely consenting.

Researcher name [printed]_____
Signature_____
Date**Study contact details for further information:****Maria Steinbeck****m.k.steinbeck@student.utwente.nl****Bachelor Thesis Supervisor:****Yudit Namer****y.namer@utwente.nl****Contact Information for Questions about Your Rights as a Research Participant**

If you have questions about your rights as a research participant or wish to obtain information, ask questions, or discuss any concerns about this study with someone other than the researcher(s), please contact the Secretary of the Ethics Committee/domain Humanities & Social Sciences of the Faculty of Behavioural, Management and Social Sciences at the University of Twente by ethicscommittee-hss@utwente.nl

Appendix B

Keyhole analytic tool

