

GROWING WITHOUT KNOWING: A NARRATIVE INQUIRY ON ADHD DIAGNOSED IN ADULTHOOD

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ABSTRACT

Limited studies have been conducted to look at the narratives of individuals diagnosed with Attention-Deficit Hyperactivity Disorder (ADHD) during adulthood. This study explored the life experiences of three individuals who were diagnosed with ADHD using the Narrative Inquiry approach. Thematic analysis was conducted after the interviews. The findings revealed participants' accounts of patterns of behavior typical of people with ADHD. It also delineated reasons that did not allow them to have a diagnosis early in their lives, challenges they faced from childhood to adulthood, and the coping strategies they used before and after their diagnosis. Their narrative indicated that the family behavior and perception of behavioral normality during childhood played a vital role in the delayed diagnosis. Moreover, behaviors typical of people with ADHD can be traceable to family members, who prevented them from having a diagnosis. Coping or compensatory behaviors before diagnosis included motoric activities, studying, and even procrastination. Furthermore, their narrative highlighted some insights they shared, considering their experience as adults with ADHD.

Keywords: Adult ADHD, Narrative Inquiry, Compensatory Behaviour, Good Health and Wellbeing, Reduced Inequality, Partnership for Goals

The present Diagnostic Statistical Manual 5- Text Revised (DSM-5-TR) edition describes Attention-deficit hyperactivity disorder (ADHD) as a neurodevelopmental concern affecting children's capacity to regulate attention and impulses. This results in impairment in the social, academic, and personal life of an individual. Prevalence of ADHD is estimated to be around 3.10% to 6.76% of the adult population (Ayano et al., 2023; Song et al, 2021). In higher education, on the other hand, about 15.9% of college students may have ADHD (Mak et. al. 2022).

ADHD affects their overall quality of life. Quintero et al. (2019) describe ADHD as a precursor and magnifier of other mental health issues such as Depression, Anxiety, and Suicidality. Kooij et. al (2019) proposed that the scientific community should address and take seriously the suffering of this population, stating further that it is essential to understand the clinical and developmental picture of adults with symptoms of ADHD. Recognizing further that it is difficult to diagnose, monitor, and intervene with adults who have ADHD (Di Lorenzo et al., 2021; Johnson et al., 2021; Lovett & Harrison, 2021)

Despite these relatively prevailing concerns, limited research was conducted for adults diagnosed in adulthood, and as they strive in their higher education. The focus of research mostly describes ADHD as an impairment in well-being (Di Lorenzo et al., 2021; Efron, 2019; Godoy, 2022; Hackett et al., 2020). Nevertheless, it has also given so much emphasis on childhood diagnosis and the persistence of symptoms from childhood (Godoy, 2022; Hackett et al., 2020). Moreover, Ginapp et al. (2022) indicated limited research on the topic in Asia, focusing on individual interviews and focus group discussions, not narrative inquiry. This created a gap in knowledge and methodological approaches for this population relative to what has been known about ADHD and how individuals diagnosed with ADHD in adulthood lived (Miles, 2017), compounded by limited qualitative studies (Wozniak, 2022). Thus, this is the seminal idea that this paper wishes to address.

This study articulates the narratives of individuals diagnosed with ADHD in their adulthood. This was conducted to provide an understanding of how these individuals thrive throughout their development despite their ADHD symptoms. It is also hoped that this study sheds light on factors contributing to their diagnostic delays and their implications for their daily tasks. As such, this narrative inquiry explored the narratives of people who have been diagnosed with ADHD during adulthood. Specifically, this addressed the following questions:

- (1) What were their experiences growing up?
- (2) What challenges have they encountered growing up without the knowledge that they have ADHD?
- (3) What was their coping management throughout the years in the absence of the ADHD diagnosis?
- (4) What insights can they share?

Theoretical Foundation

This study utilized the dynamic developmental theory of ADHD. The theory mainly focuses on the reinforcement of behavior and the impaired extinction process of previous

behaviors (Johansen et al., 2005). Sagvolden et al. (2005) further describe the theory as behavioral and biological, as it links biological reactions to the existing reinforcers or phenomena. As such, the theory provided a framework for explaining and understanding the dynamic case and experience of the participants as they grew without early diagnosis and intervention. This theory aided in examining the factors and reinforcers that might have allowed them to thrive in their academic, social, and personal lives despite the limitations of their early symptoms.

The situational self-control theory by Koi (2021) was also used to characterize and understand the thriving and coping mechanisms of the participants. For Koi, despite the neurobiological components of ADHD, individuals are still capable of recognizing their responsibilities. This becomes an essential building block for them to take action amidst their somewhat difficult impulses. Furthermore, Koi (2023) states that this sense of self-control for adults with ADHD can be characterized and analyzed through traits and environment, and restrictions of such interactions.

Research Design

This research employed the narrative inquiry approach (NIA). Creswell (2013) defined NIA as a “phenomenon” being studied or as a method of collecting different stories. As Butina (2016) suggested, NIA allows one to collect detailed information from a small group of individuals, leading to a better understanding of their story. As a method, NIA is essential in human sciences as it focuses on the person, their meaning, thriving, and stories. It bridges the artistic portrayal of biography and the scientific extraction from these narratives (Bochner & Hermann, 2020). Nevertheless, it allows an equally important premise that does not undermine the pragmatic positivistic approach. However, it complements it by centering on the human dimensions of coping and thriving (Zimmerman & Kim, 2021). Banks (2013) stated that an individual’s narrative and their perception of their experiences significantly affect their appraisal of their current situation and psychological health. Thus, the lower connection of positive life events to the present situation will more likely lead to psychological difficulties (Banks & Salmon, 2012).

Research Participants

This research utilized the snowball convenient sampling. The main author announced through social media the need for participants for this research and the desire to have participants who were diagnosed with ADHD as adults. Three participants (one male and two females) were gathered throughout the invitation. While adequate (Creswell, 2013), a smaller sample size may have implications for the data saturation to address the research objectives (Subidi, 2021). Their ages range from 23 to 25 years old. They have been diagnosed with ADHD by a psychiatrist at around the age of 24. Upon the interview, they were already diagnosed between three months and two 2 years ahead. The mothers of the participants were also interviewed as informants. Furthermore, two screening tests were also administered. Wender Utah Rating, a 25-item self-report tool to screen signs of ADHD with a reliability index of 0.94 (Kouros et. al, 2018), and validated through Principal Component Analysis (Brevik et. al, 2020). The Adult ADHD Self-report Scale v.1.1, on the other hand, is an 18-item assessment of ADHD for individuals 18 and above. It has a 0.99 reliability index and 0.84 concurrent validity (Adler et al., 2006). The table below

indicates their Wender Utah Rating Scale-25 (WURS-25) and Adult ADHD Self-report Scale v.1.1 (ASRS).

Table 1. Screening Test Results

Participant	Test	Percentile	Interpretation
Participant 1	WURS	88.8	With ADHD Symptoms
	ASRS	99.9	With ADHD Symptoms
Participant 2	WURS	5.1	No ADHD Symptoms
	ASRS	99.9	With ADHD Symptoms
Participant 3	WURS	32.3	With ADHD Symptoms
	ASRS	99.9	With ADHD Symptoms

Concerns of introspective recall may have brought about inconsistency in the result of the screening test for Participant 2. Interestingly, however, Pettersson et al. (2018) argued that neuropsychological examinations can only be used to discriminate between normal and diagnosed populations if used with Diagnostic Interviews for ADHD in Adults (DIVA). Further, DIVA alone provides better diagnostic discrimination than objective neuropsychological examinations, thus straightforwardly putting the value of neuropsychological examinations as a tool for ADHD diagnosis into question (Barkley, 2019). As such, the clinical diagnosis of an attending psychiatrist supersedes screening and even neuropsychological results.

Data Collection

This research was a qualitative research project at the University of the Immaculate Conception, Davao City, Philippines. As such, approval from the research faculty was verified before conducting the research. The research protocol and ethical guidelines were also counter-checked and verified by the senior researcher and the adviser of this research. Their inputs were embedded in the whole research protocol. Each participant was scheduled for an hour of interview. The interview was conducted virtually for two participants and face-to-face for one. The interviews were recorded using the researcher’s laptop and cellphone. The data analyst thematically analyzed the recordings.

Table 2. Data Collection Method

Participant	Sex	Data Collection Method
Participant 1	Female	Face-to-face
Participant 2	Male	Google Meet
Participant 3	Female	Google Meet

Data Analysis

Thematic analysis was employed to analyze the data. Reissman (2008), as cited by Creswell (2013), noted that this was the most common analysis in NIA. This analysis was considered applicable to various theoretical lenses to bring about patterns of meaning and themes in the qualitative data (Clark & Braun, 2017). Terry et al. (2017) suggested the following phases in thematic analysis: (1) familiarizing the data, starting during data collection and transcription. (2) Generating codes can be achieved by reading and immersing in the data. (3) Constructing themes, (4) Reviewing potential themes, (5)

defining and naming the themes, and lastly (6) producing the narrative report. The study required an external data analyst to conduct the said data analysis procedure. This gave the researchers a more objective lens of the data.

Trustworthiness of the Study

Stahl and King (2020) describe trustworthiness in four layers. Trustworthiness is considered the credibility of the result as to its extent of presenting the explored reality. As they have noted, it can be achieved using triangulation. It is also about transferability or how it relates to other contexts beyond the environment of the current study. They also see it as the dependability that can be achieved by submitting the research protocol for peer-reviewing. Lastly, the confirmability of the findings and the research to objective reality can be achieved through the lens of noninvolvement and scrutiny from other researchers.

Considering these notions of trustworthiness, the following protocols were followed in this research: (1) An external senior researcher was invited to validate and scrutinize the research protocols. The senior researcher's perspective was critical in executing the research. While she was written as a co-author in the research, no monetary or other benefits were promised to her that may compromise her objectivity. As the research mentor, the second author also checked the whole research process. (2) Triangulation was employed by interviewing the mothers of the participants and by administering screening tools for adult ADHD to them. (3) The researcher's noninvolvement was ensured by using an open-ended interview to allow participants to expand their narratives without being limited by the questions prepared by the researcher. Moreover, their narrative was presented to them to countercheck the data.

Ethical Considerations

This research adhered to different ethical considerations throughout the research process as explained in the guidelines described in the National Ethical Guidelines (2022) by the Philippine Ethics Board.

- (1) *Social Values* - Mulgan (2010) defined social value as a relatively immeasurable soft outcome of an intervention, organization, or, in this case, research. As such, the social value of this research provides a better understanding for individuals who have been diagnosed with ADHD as an adult. This will foster social and individual understanding and permit individuals with ADHD to learn and get inspired by the narratives described in this research.
- (2) *Informed Consent* - The consent of the participants is an essential part of the whole research process. Before proceeding with the interview, the participants provided with an informed consent form. The first author read it to them aloud. He informed them of their rights and responsibilities as participants. They were not forced to participate if they did not intend to. They were also informed that they could withdraw from the research anytime.
- (3) *Documentation of the Interview* – A part of the informed consent to tell the participants that their interview will be to be recorded via the researcher's phone. This was not accessible to anyone except the researcher, the subject mentor, and the external senior researcher. The recording shall be deleted after a year of the research publication.

- (4) *Privacy and Confidentiality of Information* - The basic information of the participants and their affirmants will not be put in public. Code names were used to describe the participants and their informants throughout the research.

Themes in the Narratives

Challenges Encountered

1. Social Stigma and Relational Concern

“In relationships, I tend to be all out at first. Then eventually I become passive in the relationship. I do not like dealing or talking with my partner about our problem” (Participant 1).

“One the struggles is that, someone becomes out of sight out of mind for me. So if I do not see you, you do not exist. It is not that I do not care about you, it is simply that you do not exist for me. I am often scolded by my family because of this. Since we don’t see each other often, I don’t communicate with them” (Participant 3).

Wozniak (2022) pointed out that various research has shown negative implications of ADHD in intimacy and relationships. However, he argued further that the literature has provided limited data and that a more thorough and qualitative exploration must be needed. Moreover, Asherson (2013) pointed out that ADHD has been a compounding concern for adults. The disorder is highly comorbid with personality concerns and other disorders that may have unknowingly affected their relationship with other people.

Nevertheless, individuals with ADHD have constantly been subjected to bullying (binti Marcus et. al, 2022). This somehow affected their capacity to make and create interpersonal connections. The bullying that they have experienced would somehow undeniably mark a traumatic experience for this individual, which would eventually lead to closing themselves from any intimate relationship. This has been supported by Godoy (2022), indicating that adults with ADHD may have difficulties with their social, personal, occupational, and family life. These realities have pushed them forward in consulting with a mental professional. ADHD is a common comorbidity among mental health disorders. As such, individuals with ADHD are more likely to have concerns with substance regulation, job stability, and overall poorer quality of life (Hackett et al., 2020).

Considering the narrative of the participants in this research. The interpersonal and intimate concerns arising from ADHD can be both an Executive and Emotional dysfunction. While they may be able to hold individuals as peers or friends, it would be difficult for them to maintain such perception if an individual with ADHD receives no stimulation. Thus, the more they do not meet or feel like they belong to someone in their lives, the more their cognitive and executive conception of that person fades.

2. Cognitive and Functional Challenges

“At home, I have such a lot of pending tasks and hobbies, I also buy impulsively. I would buy something, yet I would not open or will not finish it at all” (Participant 1).

“Whenever I hang out with my friends, I talk with them standing up while they sit. My feet feel so fidgety during then, I tap my hands on the table, or play with my pen” (Participant 2).

“it will take me a whole day just to finish a letter. I tend to overthink whether it is corporate enough or grammatically correct” (Participant 3).

Kosheleff et al. (2023) and Salomone et al. (2020) argued that adults with ADHD experience functional concerns. However, compared to pediatric counterparts, theirs can be unique, affecting overall life satisfaction. As such, the current research reflected in their narrative, affecting their capacity to perform various activities such as letter-making, socialization, and even finishing tasks. Thus, this supported Kosheleff et al.’s (2023) claim that ADHD could not provide any advantage for an adult with expected work performance. Rubia (2018) argued that the brain complexity of adult ADHD made them more susceptible to concerns with working memory, inhibitions, timing functions, and even motivation. This has been supportive of the current research narrative.

Coping Mechanism Before their Diagnosis

1. Studying and Academic

“In class, I self-study because I do not listen or have difficulty listening to lectures. So, if I do not study, I will have more difficulty answering my exams. I Study by myself. Then I teach my classmates to understand the concepts better” (Participant 2).

“During elementary, I find refuge in books so that I would not be scolded. In High School, I have a lot of distractions, if not books, then TV series or anything else” (Participant 3).

Surprisingly, this narrative contradicts the research findings by Colgan (2015). While their research revealed that the Coping mechanisms usually utilized by individuals with and at risk of ADHD are more likely emotional-oriented, the narrative presented by the participants shows the contrary. They have been utilizing cognitive response and studying to cope with their concerns of inattention and impulsiveness. However, the same coping allowed them to mask early signs of dysfunction typical to children with ADHD as described by the Diagnostic Statistical Manual 5-TR.

2. Procrastination

“I tend to make myself lost on streets. I go to unfamiliar places to compensate for my excitement about something new. I also procrastinate when finishing my tasks and assignments. Whenever I finish it ahead of schedule, I tend to be down and gloomy”. (Participant 1)

“If I am tasked to make a letter for the directors, I would put it off because I am bored. I would start doing it after two days. It is not because I am lazy; I do not feel interested in the tasks. The motivation is usually outward”. (Participant 2)

Barra (2021) warned that individuals with ADHD are more likely susceptible to using maladaptive coping mechanisms in dealing with their life circumstances. In return, this created an increase in life impairment concerns. Canela et al. (2017) argued that individuals with ADHD do have self-learned mechanisms to compensate and deal with their behavior. They have classified it into five: Organizational, Motoric, Attentional, Social, and Psychopharmacological. The participants likely utilize some organizational and attentional mechanisms through procrastination and hyper-focus on their studying.

Coping After the Diagnosis

1. Willingness to seek Professional Help

“Every time I feel something, I consult my Doctor” (Participant 2)

2. Task Prioritization

“At school, I tend to be more organized. I do prioritize things. I study first the lessons that I am not familiar with (Participant 1)

“I do note-taking activities; scheduling was the most life-changing activity for me (Participant 2)

Canela et al. (2017) argued that organizational compensation is one of the most efficient ways of handling the inattentiveness and impulsiveness characterized by ADHD individuals. However, this has been seen as compensatory behavior before treatment and was never clearly seen as a treatment or part of the treatment and behavioral interventions.

This narrative supports the Theory of Situational Self-control by Koi (2023). While their symptoms of ADHD were not fully eradicated, their capacity to manage it became more evident. The need to perform and understand how their body reacts in terms of performance provided them with the capacity to regulate their behaviours better. Nevertheless, this is relatively apparent and linked to how they understand their symptoms and the extent to which they are expected to perform.

Insights Shared

1. Self-advocate

“Be the one to lobby on the things that you need. If you have special needs, you know better what you need and ask for it (Participant 3)

“If we do not know where to go, you can self-check first” (Participant 1)

2. Do Self-help Activities

“If we have certain techniques that can help us, like me, I use loud music to cover up the noise in my head. No matter how simple it is, we must do it ourselves” (Participant 1).

“If I cannot do it anymore, I will be forced to change my environment. Like I would turn of my phones”. (Participant 2)

Iwona (2020) considered self-advocacy as a mechanism for individuals to gain the support they need. This is especially important for people with different or somewhat special needs. By doing self-advocacy, the direct community can be communicated as to what they can do to assist them.

Manos and Short (2023) argued that task prioritization is essential for ADHD. This will assist them to have control of their unique tendencies. The aim of task prioritization is not so much on symptom reduction but more on performance expansion. This relates quite well with Situational Self-control, arguing that it is possible for ADHD to have a sense of fulfillment by focusing on what they can do rather than what they are limited to do.

Discussion

The chronological narrative of the participants described typical signs of ADHD: divided attention, impulsivity, changing of seats, uncontrolled tendency to talk, and hyperactivity. Nevertheless, contrary to the DSM-5 TR described, it did not affect their social, educational, and personal lives. While they may have encountered challenges growing up, it did not prevent them from performing better than their peers. Furthermore, difficulties in functioning, which relatively occurred during early childhood, escalated during their early adulthood. In the case of the participants, during their college years. While academically achieving during their elementary and high school years, they have narrated difficulties in executive functioning during their college years. This affected their academic performance, confidence, and overall quality of life in the educational setting.

The difficulty they have had in college contributed quite significantly to their experience of mental health issues. As suggested, Quintero et al. (2019) describe ADHD as a precursor and magnifier of other mental health issues. This results in psycho-emotional turmoil and the development of Depression, Anxiety, and other behavioral concerns. This makes childhood diagnosis and intervention essential. However, as reflected in the narrative, individuals with ADHD were likely underdiagnosed or were not diagnosed during childhood, brought about by financial constraints, familial perception, and the normalizing tendencies of adults with regard to the behaviors of the children. This somehow explains the disparity in terms of accounted prevalence by Ayano et. al (2023) and Song et al (2021).

Some of the challenges they faced were social stigma, relational concerns, and cognitive and functional concerns. Wozniak (2022) and Asherson (2013) believe that ADHD is a precursor to relational disturbances and problems. However, what was not clear was that the concerns really stemmed from ADHD's cognitive maladjustments, personality traits, or the effects of comorbidity.

Moreover, their Organizational and Attentional (Canela et. al., 2017) compensatory behaviours allowed them to thrive from childhood to adult life despite their seemingly noticeable cognitive and behavioural dysfunctions. Compensatory behaviours such as procrastination and hyper-fixation on academic activities provided them both a

mask and an advantage compared to their peers. However, their dysfunctions during adulthood have provided them with reasons to seek help. Their performance and ability to care for themselves and their tasks created much distress to the point that it has already affected their self-esteem.

Surprisingly, the research findings by Colgan (2015) contradict the participants' narratives. While their research revealed that the Coping mechanisms usually utilized by individuals with and at risk of ADHD are more likely to be emotion-oriented, the narrative presented by the participants shows the contrary. They have been utilizing cognitive response and studying to cope with their concerns of inattention and impulsiveness. However, the same coping allowed them to mask early signs of dysfunction typical of children with ADHD as described by the Diagnostic and Statistical Manual 5-TR.

The theory of Situational Self-control and the research findings by Manos and Short (2023) coincide with the participants' insights. Task prioritization provided them with leverage in performing their tasks. However, the results did not fully explore how much task prioritization helps. Furthermore, as much as it provides an advantage for work performance, further studies are still needed to explore the extent to which it assists individuals with ADHD. Task prioritization can also be further explored to mitigate and assist students in higher education who may have signs of ADHD or be underdiagnosed with it.

Implications for Future Educational Practice

The research findings revealed that adults diagnosed with ADHD already manifested typical signs of this developmental concern during their childhood. However, early diagnosis was not merited due to the adult's perceived normalcy and the capacity of individuals experiencing the symptoms to still thrive in almost all aspects of their lives. Thus, it is imperative to strengthen early detection and assessment, especially in school, and to study further the developmental pathology of ADHD among high-functioning individuals. If possible, screening should be provided to all students regardless of their academic ranking and performance. Strengthened special education programs should also be implemented, most especially in schools that have high tendencies of students with neurodevelopmental needs, such as ADHD.

Empower schools to provide awareness campaigns and programs, especially for parents. This includes workshops and seminars at a grassroots level addressing misinformation about ADHD. This should also include talks regarding coping and other skill sets to help them deal with their tendencies. Such coping skills should include addressing procrastination, appropriately using to-do lists, and regulating motoric concerns.

The research further revealed possibilities of underdiagnosis and misdiagnosis due to financial concerns, family values, and understanding of ADHD. This creates issues for individuals manifesting signs of ADHD as they enter higher education. It is important for universities and colleges to retrofit and adjust educational strategies. School counseling offices and mental health units should also be working hand-in-hand with faculty and school administrators. Their role is essential for the assisted educational experience of these individuals.

Recommendation for Future Research

This research revealed that there had been a connection between the interpersonal and romantic relationships of ADHD and the possible maladaptive handling of such relationships. However, what was not clear in the research was whether this maladaptive behavior was a product of seemingly disoriented Executive Functioning, personality traits, or comorbidity with other disorders. This suggests future research in both qualitative and quantitative mechanisms to explore this further. This will also provide an avenue to discuss ways to prevent and intervene with this concern.

The narrative of the participants revealed interesting facts about their coping before and after their diagnosis. Surprisingly, the narrative pointed towards cognitive-type, organizational, and attentional types of coping. However, it was not clear as to which coping was effective for them before and after their diagnosis. This information might provide additional merit in addressing the concerns of individuals with and at risk of ADHD.

Concluding Remarks

Attention-Deficit Hyperactivity Disorder is a developmental disorder commonly associated with children. However, financial factors, adult perception, and other circumstances may restrain individuals from being screened and diagnosed during childhood. This research revealed that adults with ADHD are somehow academically inclined and use their academic abilities to mask and compensate for their ADHD symptoms. Nevertheless, challenges with relationships and functional concerns were noticeable as they grew older. Thus, leading them to seek professional help during their adulthood. It is, therefore, imperative to provide screening to all children regardless of their academic status. Moreover, coping strategies for both at-risk and diagnosed ADHD should be explored better with consideration of their personality trait and type of ADHD. The relationship is challenging as well for individuals with ADHD as they go through their adulthood. It is part of the need to address and clarify this through further research.

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