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Exploring a Later in Life Diagnosis and Its Impact on Marital Satisfaction in the Lost Generation of Autistic Adults: An Exploratory Phenomenological Qualitative Study

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Abstract

The diagnostic criteria for autism spectrum disorder (ASD) have undergone substantial modifications over the years, resulting in an increased understanding of the autism spectrum and a more inclusive approach to its diagnosis. However, there is growing concern surrounding the underdiagnosis and lack of clinician training of assessing adults on the spectrum. Adults well into marriage and family life tend to seek assessment when a child or family member is diagnosed, or they are experiencing ongoing unresolved marital challenges. This study explores the potential impact of undiagnosed autism on marital dynamics, emphasizing the need for increased awareness and support for couples who are navigating the complexities of a mixed neurology relationship, and further training for clinicians who assess adult autism and work with neurodiverse couples.

Keywords: Autism spectrum; Diagnostic changes; Late diagnosis; Neurodiverse couples

Abbreviations: ASD: Autism Spectrum Disorder; ICD: The International Classification of Diseases; DSM: Diagnostic Statistical Manuals; AQ: Autism Quotient; WHO: World Health Organization.

Introduction

Historically, ASD has been predominantly associated with childhood developmental challenges, leading to the oversight of adults who display atypical symptoms or present with unique coping skills, compensatory strategies, or masking mechanisms. However, autism is a lifelong neurodevelopmental issue with persistent challenges for those on the autism spectrum in social communication and reciprocal social interactions [1]. The expanding understanding of autism, coupled with revisions to diagnostic criteria have increased the prevalence of undiagnosed individuals within the adult population and confusion amongst providers who are tasked with diagnosis and assessing autism in adults. Research and broader understanding of ASD grew faster than the slowly evolving changes in the Diagnostic Statistical Manuals (DSM) and The International Classification of Diseases (ICD) leaving decades in the gap of Hans Asperger's findings in the 1940's to the syndrome that would bear his name in the 1994 DSM update [2].

Volkmar and Klin [2] argue that differences in diagnostic criteria, untrained clinicians and common stereotypes of autism have been barriers for many in receiving a diagnosis. There has been debate concerning incidence and prevalence rates and true increase [3], but a ground-breaking study of 2.1 million participants in a five-country cohort study in 2019 reported an estimated heritability rate in ASD to be 80% [4]. Knowing more about the hereditary factor, can we assume there are missed adults? Researchers such as Rowland [5], disagree and argue that autism is overdiagnosed.

The current autism rate reported in children by the Center for Disease Control and Prevention (CDC) is 1 in 36 (CDC, 2023), and the World Health Organization (WHO) reports a worldwide diagnosis rate of autism in children to be 1 in 100 [6]. What was known as Asperger's Syndrome (AS) in the DSM-IV (APA, 1994) has again been reclassified as ASD, Level 1 in the DSM-

5 (APA, 2013) and has been referred to by many professionals as "high functioning autism" (HFA). Lai and Baron-Cohen [7] refer to the adults who were diagnostically missing prior to 1994 as the "lost generation". Stoddart et al., [8], reported adults in their 40s and even older often remain missed.

There is a growing need for clinicians not only to better assess adult autism but to understand autism in marital relationships as more and more couples seek help for neurodiverse relationships [9,10]. Smith et al. [11], stated that individuals on the autism spectrum report challenges in initiating, developing, and maintaining their long long-term relationships. The non-autistic partner, or neurotypical (NT) partner is often the partner in distress seeking support and resources for the marriage [11], and the autistic partner, or neurodivergent (ND)partner, usually reports higher satisfaction in the marriage [12], than the nonautistic or neurotypical partner [13,14]. McDowell et al. [15] argues that the prevalence of ASD is projected to increase and so will the rise of neurodiverse couples seeking marital help. Studies concerning neurodiverse couples tend to focus on the impact of marriage on the NT spouse [16]. This study will examine barriers to adult diagnosis, co-occurring diagnosis, discrepancies in marital satisfaction, and understanding of marital issues through the lens of those on the autism spectrum.

Diagnostic changes and lack of adult autism training

Leo Kanner's [17] description of what was referred to as infantile autism was not recognized as a new diagnosis, according to Rosen et al. [18], until the DSM-III (1980) [19]. Reports of descriptions of children who most likely had autism were found dating back to the 1700s [18]. In the 1940's Hans Asperger began his study on what he felt was a "broader autism phenotype" [18,20,21]. Complicating the understanding of how to diagnose and assess ASD, Rosen et al. [18], stated the WHO's ICD took a different approach to classifying and identifying AS/ASD from the DSM which was not further addressed until the DSM-IV's (1994) revision [18]. In 2013 the DSM-5 [22] shifted the focus of ASD "from a multicategorical diagnostic system to a single diagnosis based on multiple dimensions" [18].

According to Lai and Baron-Cohen [7], where the biggest gap exists in locating this "lost generation" of autistic adults exists are the decades of change in research and criteria from DSM-III [19], to DSM-IV [23]. Referred to as "little professors" the children Hans Asperger studied intellectualized emotions and thus displayed challenges articulating and processing feelings, had lower ability to give empathetic responses, and struggled with social cues and use of social pragmatic language [2]. These "little professors" could talk at great length on topics of interest but struggled with facial expression, gestures, modulating their voice, responding to social context, and understanding nonverbal cues in social communication [2].

Klin and Volkmar [24], compared the six sets of clinical criteria defining this "higher functioning" autism, which compared the work of Asperger himself, Wing, Gilberg and Gillberg, Tantam, Sazatmari et al., and the DSM-IV (1994) [23,25-28]. The six sets of criteria agree upon the clinical features of social impairment which include poor nonverbal communication, lower empathy responses, and challenges developing and maintaining relationships [29]. On the criteria of language and communication challenges, 5 of the 6 researchers agreed on aspects of the criteria and this was not clearly stated in the DSM-IV [23]. The researchers noted that Asperger, Wing and Szatmari et al. [25,28,30] agreed on challenges in idiosyncratic language and the other criteria sets did not state this domain. Only Asperger [30] and Wing [25] noted impoverished imaginative play.

Volkmar and Klin [29] contrasted 5 of the 6 criteria sets noted an all-absorbing interest and Szatmari et al. [28], did not note this as a necessary criterion. Four of the 6 noted motor clumsiness as a diagnostic criterion, but this is not found in the DSM-IV [23] criteria. As you compare the six sets concerning onset of symptoms, developmental delays and if this syndrome was part of the autism spectrum itself, there are mixed comments. Asperger himself [30] felt what he was finding was part of the autism spectrum, as indicated in the DSM-IV [23], but not all researchers agreed [29].

With changing diagnostic books and disagreements among researchers, the inclusion of Asperger's Syndrome in 1994 diagnostic language began to broaden perceptions of the autism spectrum, but again confusion among clinicians in diagnosing and assessing adults with the 2013 criteria. This confusion and differing opinions of how to interpret the criteria continues to be part of the issue in locating the "lost generation". Stereotypes, stigma, biases, and lack of training on adult autism still exist; providers and professionals tasked in diagnosing ASD may not have adequate understanding of autism and may only have limited experience with adults on the autism spectrum in their practice [9,31-32]. In addition to this lack of understanding of adult autism, there are few studies that examine ASD and romantic relationships [13].

Autism and marital satisfaction

Most of the research on marital satisfaction examines the marital satisfaction of those who are married to someone on the autism spectrum (Arad et al., Aston, Bostick-Ling et al., Rench) [13,14]. One study was found that examined marital satisfaction from the perspective of the partner on the spectrum. Strunz et al. [12] recruited 229 individuals who were on the spectrum for their study on relationship satisfaction. Strunz et al. [12] reported only 17 individuals in their study indicated no desire to be in a romantic relationship, and those who were in relationship with someone else who was also on the spectrum reported being

significantly more satisfied than those who were in a relationship with an NT or non-autistic partner.

Satisfaction measures indicated having similar profiles and social needs and having similar shared interests and expectations with low stress in the relationship. Themes of concern in the Strunz et al. [12] study found 65% of the autistic adults were afraid of not being able to fulfill a partner's expectations; 50% expressed not knowing how romantic relationships work or how to maintain the relationship; 30% indicated sexual activity was unpleasant for them, and 28% indicated the physical nature or contact that comes with a romantic relationship can be unpleasant (p. 8). What is unknown in the study is how many adults entered their romantic relationships with the knowledge that they were on the spectrum or did their partner also know they were on the autism spectrum. Through this researcher's clinical work and dialogue with other professionals in the neurodiverse marriage field, higher dissatisfaction in the marital relationship is reported when the autism is unknown or diagnosed later in life and the couple has been married quite some time before realizing their challenges are impacted by unknown ASD traits or diagnosis.

Methodology: Exploratory, Phenomenological Qualitative

Research on adults on the spectrum is emerging through the neurodiversity movement; however, there are few studies that examine romantic relationships through the lens of those on the autism spectrum. An exploratory study is used when something is not yet thoroughly understood [33,34]. Researching a phenomenon from the perspective of those living in the experience is phenomenological research [35,36]. The lens of phenomenological research views the participants as more than subjects but partners in the endeavor to describe a unique experience [33,34].

Research questions

The purpose of this study was to examine the experience of those on the spectrum in romantic relationships and to compare marital satisfaction of those on the spectrum with neurotypical individuals married to autistic partners. A broad survey of 34 questions examined various aspects of neurodiverse relationships, questions relevant to this study include:

- Q. 10 Were there any other diagnoses you received prior to diagnoses or identification of the spectrum?
- Q. 12 At what age was the autism spectrum identification made in your life?
- Q. 16 How would you rate your satisfaction with your relationship?
- Q. 30 Did anyone that worked with you as a marriage helper, or anyone you mentioned the autism/Neurodiversity to say anything dismissive or disregarding the autism?

Research design

The design of the study was to a targeted population of adults on the autism spectrum and individuals who are or have been in a romantic relationship with someone on the autism spectrum. The survey questions were selected and crafted by a small team comprised of NT and AS individuals. A former Speech Language Pathologist reviewed the survey for clarity of questions. A small sample of participants took the survey to review ease of use and made recommendations for ordering of questions and clarity of questions. A survey was created through Survey Monkey and in the survey, participants were asked if they would participate if chosen in a 30-minute semi-structured interview.

Twenty couples were chosen from survey participants for the second part of the research design for further interview which comprised 23 adults on the spectrum and 17 neurotypical partners. Three of the couples indicated both were on the autism spectrum. All interviews were done through Zoom and audio recorded then transcribed through a transcription service using clean verbatim word for word transcription. Quotes and themes were identified specifically for this study from the voice of those partners on the autism spectrum.

Sample

A minimum of 100 participants was sought for the broader survey. The survey was created on Survey Monkey and sent on social media sites that cater to neurodiverse relationships. A Google search for providers who work in the field of neurodiverse relationships was conducted and a research link sent to providers asking them to circulate the survey to their clients who were in or have been in a neurodiverse relationship. Purposive sampling and snowball sampling allowed for further recruiting of participants [33]. A total of 322 respondents filled out the entire survey. From that population 20 couples were chosen for semistructured interviews.

Participants

Three hundred and twenty-two individuals completed the 34-question survey. Of those surveyed 108 individuals reported they were on the autism spectrum, and 214 reported they were non-autistic. Of those reporting autism only 10 were female. Over 80% of the participants were Caucasian/white and 100% reported heterosexual. Ninety-five males and 226 females participated in the survey. From this larger sample, 20 couples were chosen to complete a semi-structured interview. interview. Of those interviewed, 23 participants identified or had been diagnosed as on the autism spectrum. For this study, only the voice of the autistic partner will be mentioned concerning a later in life diagnosis, relationship satisfaction, and advice or concerns they would like non-autistic partners to understand about autism in relationships.

Data analysis/explication of data

Simple percentages were used to analyze participants' responses to survey questions and displayed on tables. For the second level of the research design, the exact words of the participants were used for in-vivo coding and thematic coding. Thematic and in-vivo coding were used for descriptive content to describe the lived experience from the participants from the voices of those on the autism spectrum from clean verbatim transcribed manuscripts of audio recordings [33].

Researcher's role

While seeking truth and open discussion, this researcher identifies as an NT wife in a ND relationship and a former licensed professional counselor. This exploratory research is based on the realization that my own clinical training did not adequately prepare me to assess adult autism or therapeutic training to provide marriage help to neurodiverse couples. Yin [37], stated it is permissible for the researcher to disclose their position and analyze what is familiar and unfamiliar in the process of gathering data. This researcher seeks to reach beyond clinical and personal experience to gather data from as many neurodiverse couples (NDCs) and adults on the autism spectrum as possible to describe their lived experience for the purpose of informing better diagnostic processes and working with NDCs.

Ethical Considerations

Before collecting data from participants who are on the spectrum and those who are not, a clinical social worker who identifies as on the spectrum reviewed the 34-question survey for bias and possible harm. When the survey was finalized and reviewed with the statement of without bias or potential to cause harm, this researcher followed AASPIRE guidelines [38], for the inclusion of autistic adults in research as study participants. Participants gave informed consent for the survey and a second informed consent for the semi-structured interview. Those participants on the autism spectrum were adults in romantic

relationships who were not cognitively impaired.

Limitations and Assumptions

The survey and semi-structured interview relied on self-report data concerning the process of diagnosis or identification of those on the autism spectrum and did not require proof of diagnosis. Thirty-one of those who were identified on the spectrum were identified through an online measure such as the Autism Quotient (AQ). While the survey was open to all types of couples of varying race, culture, and variety, 88% of respondents were white/Caucasian and 100% were heterosexual couples. The length of the survey may have prohibited more respondents from finishing the survey. Because questions asked about personal faith may have led to those without a faith tradition not to participate. While autism is diagnosed 4:1 male to female, there were only 10 females on the autism spectrum that completed the survey. The research sample was adequate for the survey responses but small for the interviewed portion.

Results

After examining the results of the survey, this researcher sought a sample of 20 couples for a semi-structured qualitative interview. The data was downloaded and identifying information redacted and AS individuals were chosen based on how they answered the "marital satisfaction" question. A range was sought from happily married and satisfied to very dissatisfied with the marital relationship. In addition, this researcher specifically located participants who identified as female on the autism spectrum to make sure the sample included AS/ND males with NT females, AS/ND females with NT males, and couples where both partners identified as on the spectrum. Tables below indicate age of diagnosis, a diagnosis the individual received before getting an adult autism identification later in life, statements professionals made as to why the individual did not appear to be on the spectrum, and marital satisfaction differences between the AS partner and the NT partner (Table 1).

Table 1: Age of Individual at *Diagnosis/Identification of the Autism Spectrum.

Age	N: 108	% (rounded)
40-49	47	42
30-39	17	16
60-69	17	16
50-59	13	12
19-29	9	9
6-10	2	2
11-18	2	2
1-5	1	1
70-79	0	0
80+	0	0

^{*31} of 108 self-identified through online assessment or criteria

As the table reveals, 86% of the individuals identified as on the spectrum came to this identification or diagnosis over the age of 30 with the greatest age group identified between 40 and 49. This is consistent with changing in diagnostic criteria updating the spectrum to include what was previously called Asperger's (AS) and High Functioning Autism (HFA). Based on the age range at identification, many were diagnosed under the Asperger's Syndrome classification. Notations of individuals who selfidentified noted that under DSM-5 (2015) criteria the clinician or counselor said they observed many autistic traits but without establishing childhood history or due to possible compensatory strategies the individual developed into adulthood they did not meet full DSM-5 [22] criteria. Some described being told they "fit" the Asperger profile but did not fully meet all DSM-5 [22] criteria. Thirty-one of the 108 individuals self-identified on the spectrum feeling the experience they read about online from other individuals on the spectrum fit their lived experience or they took an online assessment such as the Autism-Spectrum Quotient [39].

One participant, Participant 1 in the Southeast, who identified as a person of color stated that due to trauma in his childhood, he believes the autism was missed earlier in life stating, "there is additional stigma of autism for people of color." Participant 4 from the Southeast region of the United States (US) said, "Getting the diagnosis [later in life] can challenge your identity and you really have to understand your identity, it is not your diagnosis."

Participant 4 had been diagnosed with ADHD during the time where you could not have both ASD and ADHD as a diagnosis, but it was not until he was diagnosed with ASD, did he and his partner understand the challenges they had communicating daily. Participant 5 from Australia stated that finding out the diagnosis later in life had mixed feelings. On the one hand it explained so much of the difficulties he had over his life, but on the other hand he was distressed over missed opportunities for support and how the unknown diagnosis created so much impact on his marriage and family. Participant 15 from the Midwest region of the US responded to his reaction of having a later in life diagnosis as:

I see it as potentially a negative and here's the reason. When you say someone has autism, you think of the person that can't function or can't speak who only looks down or has no eye contact with flittering hands. So, I saw it as a negative. The earlier you find out the better.

Of the 23 adults interviewed on their initial reaction to discovering autism later in life, 9 adults indicated they saw this diagnosis in a negative light, 3 had mixed or no emotions to the identification, and 11 found the diagnosis to be positive or a sense of relief to understanding their differences. Three of those who had a negative view wished they and their spouse did not know stating that finding out the diagnosis felt like it brought hopelessness that their marital dynamics could change (Table 2).

Table 2: Diagnosis Given Prior to the Autism Diagnosis/Identification of the Autism Spectrum.

	N:108	% (rounded)
No Other Diagnosis Received	61	56
Depressive Disorders	31	28
ADD/ADHD	27	25
Anxiety Disorders (OCD, GAD)	23	21
Trauma Related Diagnosis	12	11
Social Phobia/Social Anxiety	8	7
Learning Disorder/Learning Challenges	7	6
Personality Disorder	4	4
Sensory Integration Disorder	3	3
ODD/PDA/Conduct Disorder	1	1

^{*}Participants were able to choose more than one from a list of diagnoses.

The reader will note that percentages do not add up to 100% as the participants were allowed to check as many diagnoses they had received prior to receiving an autism identification or diagnosis. In looking at individual survey responses of those who were diagnosed by a clinician as on the Autism Spectrum, at least 1/3 of those individuals received two or more diagnoses over their lifespan prior to the Autism diagnosis. The results indicated more than half had never received any form of diagnosis. This is explained by another question on the survey which asked the individuals how many of those they went to for marriage

help (from clergy to counselors to clinicians) were autism or neurodiversity aware or trained. The average response was that it took 5-7 counselors or clinicians to find someone who had additional training beyond graduate school, who were autism and neurodiverse aware, and specifically trained in adult autism and romantic relationships.

Researchers note that receiving an autism diagnosis after childhood can be quite challenging citing changes in diagnostic criteria [7,29], differing sensory presentations and profiles [40], missing special interests such as work or career focused

passionate interests [41], co- occurring or co-morbid issues or challenges [42] and atypical presentations from individuals with differing personality and temperament styles [43]. Flannery and Wisner-Carlson [44] stated that individuals on the autism spectrum have both challenges and strengths, but they quote Dr. Stephen Shore's reminder, "If you've met one person with autism, you've met one person with autism" (p. 319). Therefore, those assessing or diagnosing the autism spectrum should be familiar with many presentations and manifestations of autism in both men and women and understand undiagnosed adults have learned to camouflage or mask to fit into a neurotypical society, learned compensatory strategies, coping skills (positive or negative) (de Broize et al., 2022) and may have a co-occurring mental health or health issue making autism very rarely "autism pure" [42].

Of the 23 individuals interviewed for the study, one double neurodivergent couple each partner reported they knew about their autism and that their partner knew of their autism diagnosis prior to marriage. Of the remaining 21, 12 of the adults had at least one other diagnosis prior to discovery of autism and 9 had never received any form of diagnosis prior to the autism identification.

Four of the five females in the study reported having had multiple diagnoses prior to the autism identification. Participant 7 from the Southwest region of the United States stated for clinicians, "It is important for you to understand we are all different. Please understand our different wirings." Participant 7 struggled at first with adult identification because he was unaware just how anxious he was daily and how much that unidentified anxiety impacted him and impacted his marriage and family life. Five of the 15 individuals married to NT partners spoke of shame and dark thoughts they experienced when they began to realize the impact of unknown diagnosis had on their daily lives and how it negatively impacted marriage and family relationships. Participant 6 from the Southeast region of the United States said, "Our marriage has been strained a long time. It's hurtful to hear how much pain I have caused". He continued that he struggles with knowing what is me, what is my autism how do I know the difference between the two? Three of the autistic spouses said since their wives found out about the diagnosis, they feel hopeless about the marriage which in turn makes them feel negatively about their diagnosis or the possibility of a fulfilling marriage in the future (Table 3).

Table 3: Reasons Given by Professionals that were Autism Unaware dismissing Autism Spectrum, the professional or counselor said, "You (or your spouse) cannot have Autism/Asperger's because...

Remarks Made		%
No remarks were made about autism		53
They/you have a friend(s) or appear social		21
They/you are successful at work		20
They/you are too smart/intelligent		20
They/you maintain eye contact well		18
Gave a reason from their experience of work or other stereotype around autism		15
The professional or counselor did not believe in labels or believes "everyone is somewhere on the spectrum"		13
They/you are too well liked		13
Their/your interests or passion is a normal interest and insinuated the interest itself must be weird, not useful, or a-typical	39	12
They/you got married. Autistic people prefer to be alone	34	10
They/you are not clumsy, in fact even athletic	24	7
A feature was mentioned, indicating they did not look autistic	5	2

*322 participants answered and were allowed to give multiple reasons from the larger survey population.

Noting the reasons given for not meeting autism criteria correlates with those who were not seen or evaluated by someone trained in diagnosing adults on the spectrum. Some reported in open-ended questions or their interview that they experienced asking for evaluation or assessment and were dismissed based on some of the reasons above. Anecdotally, this researcher has had clients bring in full psychological evaluations where all criteria of an autism diagnosis are met and observed by the clinician, but the clinician negate the possibility of autism due to intelligence or career achievement or the individual maintained what they felt was appropriate eye-contact.

For those interviewed, 12 who had a previous diagnosis stated that the challenges of the co-occurring issue were creating a need for support or medication and thus no further probing was done. Of the 9 who had no diagnosis, they had not been in counseling or any form of treatment until repeated marriage issues concerning communication, differing parenting styles, lack of compassionate care or the partner mentioned abuse or neglect in the marriage led to marital counseling. However, professionals, friends or family were prone to mentioning reasons listed in the above table to dismiss the possibility of autism. All but one 1 couple, came from a faith tradition. From those who came from a faith tradition

it was repeatedly said to them from Christian providers or clergy they went to for help would state things such as "all marriages have struggles" or "that is a man-thing" or "these are common male-female communication issues' (Table 4).

Table 4: Marital Satisfaction: A Comparison of AS and NT Partners.

Marital Satisfaction	ND%	NT%
Happily Married	18.52%	6.10%
Satisfied more than Dissatisfied	25.93%	20.19%
Satisfied/Content	9.26%	3.76%
I am fine but spouse is not	10.19%	0.47%
Do not feel satisfied or dissatisfied	5.56%	4.69%
Dissatisfied	12.96%	26.76%
Very Dissatisfied	13.89%	30.05%
I filed for Divorce	1.85%	6.57%
They Filed for Divorce	1.85%	1.41%

^{*322} participants responded. 108 AS/ND and 214 NT.

Satisfaction measures for defining satisfaction were not given nor required. Within the phenomenological approach, this researcher was more interested in how each person defined satisfaction to them personally, as it was possible those on the spectrum compared to those who are not may define satisfaction differently. The table shows that comparing the AS/ND versus the NT's marital satisfaction from the larger survey, the satisfaction levels are from the report of AS and NT experiences of the relationship. If you look at the statements that list a neutral/fine response to satisfied or fulfilled in the marriage, 68% of the

autistic partners had a favorable response to the relationship. However, compared to the NT partners' responses only 35% had a neutral to satisfied response. Comparatively, 32% of the AS partners chose dissatisfied to divorced, and 65% of NT partners chose dissatisfied to divorced. Themes in the tables below are described from the 23 autistic partners interview as to what emerged as contributing to satisfaction or dissatisfaction in marriage. Themes are mentioned in order of prevalence and dominance in the thematic coding (Table 5-7).

Table 5: Satisfaction or Contentment Themes From the AS/ND Perspective.

When there is not conflict	
When we are doing a shared activity that I enjoy	
When there are not demands or pressure on me	
When my spouse appreciates me or recognizes the positives I contribute	
Being respected/accepted as an individual and acceptance of my differences.	
Doing activities, we both enjoy, having fun together	
When we are acting as a team	
When they encourage me to do new things and pursue passions and interests	
When we were having sex or having sex more regularly or more physical touch (this was expressed from males primarily and only 1 female on the spectrum)	

^{*}Themes derived from 23 AS/ND partners from the semi-structured qualitative interviews.

Table 6: Themes of Dissatisfaction or Discontent From the Perspective of the AS/ND Partner.

Feeling the Autism/Asperger's is blamed for all our marital problems (noted primarily by those in a mixed-neurology relationship and 1 of the double-neurodivergent relationships)

Feeling criticized or that I am not enough or meeting needs or expectations

Not enough alone time to decompress or engage in my interests

Being told repetitively my spouse is not happy or healthy and I am the cause

Constant Conflict/Heightened Emotions in the home environment

Lack of physical affection, touch or sex, which is lacking or nonexistent due to marital strain or sensory issues (this was noted by half of the men and only 1 woman)

Feeling my spouse wants me to be neuro-typical

My spouse regrets marrying me or threatens divorce

We are in an in-home separation or living in separate rooms, which I do not want

Having children with autism or special needs and the added demands/costs of their needs (note that participants did not regret having children or adopting children with needs, but not knowing about their own autism and needs and increased pressure on marriage and family with children with needs was the theme that arose)

Table 7: Advice from Adults on the Spectrum to NT Partners.

Slow down, we have slower processing/ Give us time to think and respond

Alter your expectations/Will not ever be NT/ Please stop comparing our marriage to other NT-to NT marriages/I can't give you a Hallmark or Disney movie marriage

We love you, but we do not always know how to show it

We want to emotionally support you and connect we struggle with the how

When I am dysregulated give me time to regulate

Communicate one topic or need at a time

When there is a need or concern, a gentle start up or softer approach

I need appreciation or affirmation when I have done something well/only hearing my failing and mistakes is demoralizing/hurtful/discouraging/depressing/Encourage my strengths and what I do bring to the marriage or family

Everything feels all or nothing or pass/fail that I am one mistake away from separation or divorce and that affects my mental health

Just because you are NT does not mean I am by default incorrect, or my perspective is wrong

Discussion and Conclusions

There is much to learn about dynamics that occur in neurodiverse relationships. Current research focuses on the NT perspective of marital satisfaction and tends to focus on the dynamic of an AS/ND male with an NT female. While the one research mentioned couples who are both on the spectrum tend to have higher satisfaction, 2 of the 3 couples interviewed disagreed with that statement and found due to competing sensory profiles their marriage was very complex and challenged. One of the highest impactors of marital satisfaction was how long the couple had been together before knowing about their neurodiversity. Of the 18% of those AS/ND individuals and 6% of NT individuals who reported higher satisfaction, factors upon looking at individual surveys could be: starting the relationship

knowing about autism or earlier in marriage, the younger age of the diagnosis, whether the couple has children, whether or not the couple had children with needs, the perspective of the individual or couple about autism. Dynamics of satisfaction require further study as this study was exploratory in nature.

The research of Rowland [5] addressing different structures that are different or impacted by autism are found in additional research; however, his opinion that autism is overdiagnosed or an "epidemic of false diagnosis" (p. 1), especially in adults seems to be a dissenting opinion. Rowland [5] stated that autism is not a mental health condition or medical condition but a neurophysiological difference in how the brain receives and processes information. There is still much to learn about adult autism and various expressions and manifestations of autism

^{*}Themes derived from 23 AS/ND partners from the semistructured qualitative interviews

^{*}Themes derived from 23 AS/ND partners from the semi-structured qualitative interviews

that may be challenging to assess due to masking, camouflaging, learned strategies, overriding or co-occurring issues, and various coping strategies through the lifespan or temperaments that may cloud assessment of adult autism. As Dr. Stephen Shore reminds us, "If you've met one person with autism, you've met one person with autism" Dr. Shore [44,45], reminds researchers and clinicians that there is great diversity in autism, and just like the rest of humanity, "Autism is an extension of the diversity found in the human gene pool" [46]. This exploratory study is a call for action on additional aspects of adult autism and various types of neurodiverse couples and their lived relationship experience.

References

- Helps S (2016) Systemic psychotherapy with families where someone has an autism spectrum condition. NeuroRehabilitation 38(3): 223-230.
- Volkmar F, Klin A (2000) Diagnostic issues in Asperger Syndrome. In A. Klin, F. Volkmar & S. Sparrow (Eds.) Asperger Syndrome (25-71) The Guildford Press.
- 3. Scalise E, Holmes S (2015) Light it up blue: Understanding autism spectrum disorder. Christian Counseling Today 20(2): 11-16.
- Bai D, Yip BHK, Windham GC, Sourander A, Francis R, et al. (2019) Association of genetic and environmental factors with autism in a 5-country cohort. JAMA Psychiatry 76(10): 1035-1043.
- 5. Rowland D (2020) Redefining Autism. Neurology Psychiatry & Brain Research 02: 1-7.
- 6. World Health Organization (2023) Autism.
- 7. Lai M, Baron-Cohen S (2015) Identifying the lost generation of adults with autism spectrum conditions. Psychiatry 2(11): 1013-1027.
- 8. Stoddart KP, Burke L, King R (2012) Asperger's Syndrome in adulthood: A comprehensive guide for clinicians. Norton Publishers.
- Mitran C (2022a) Challenges of licensed counselors and other licensed mental health providers working with neurodiverse adults: An instrumental case study. The Family Journal.
- Parker M, Mosley M (2021) Therapy outcomes for neurodiverse couples: Exploring a solution-focused approach. J Marital Fam Ther 47(4):962-981.
- 11. Smith R, Netto J, Gribble N, Falkner M (2020) 'At the End of the Day, It's Love': An Exploration of Relationships in Neurodiverse Couples. J Autism Dev Disord 51(9): 3311-3321.
- Strunz, S, Schermuck C, Roepke S, Ballerstein S, Ahlers C, et al. (2016) Romantic relationships and relationship satisfaction among adults with Asperger Syndrome and High-Functioning Autism. Journal of Clinical Psychology, 113-125.
- 13. Arad P, Shechtman Z, Attwood T (2021) Physical and mental well-being of women in neurodiverse relationships: A comparative study. Journal of Psychology & Psychotherapy 12(1): 1-22.
- 14. Bostick-Ling J, Cumming S, Bundy A (2012) Life satisfaction of neurotypical women in intimate relationship with an Asperger's partner: A systematic review of the literature. Journal of Relationships Research 1-11.
- 15. McDowell CN, Bryant ME, Parker ML (2022 Dec) Sexuality and Disability. Springer
- 16. Heasman B, Gillespie A (2018) Perspective-taking is two-sided: Misunderstanding between people with Asperger's Syndrome and their

- family members. Autism 22(6): 740-750.
- 17. Kanner L (1943) Autistic disturbances of affective contact. Nervous Child 2(3): 217-250.
- Rosen N, Lord C, Volkmar F (2021) The diagnosis of autism: From Kanner to DSM-III to DSM-5 and Beyond. Journal of Autism and Developmental Disorders 51: 4253-4270.
- 19. American Psychiatric Association (1980) Diagnostic and statistical manual of mental disorders (3rd ed.) American Psychiatric Publishing.
- 20. Ingersoll B, Wainer A (2014) The broader autism phenotype. In F. R. Volkmar, S. J. Rogers, R. Paul, & K. A. Pelphrey (Eds.), Handbook of autism and pervasive developmental disorders ($4^{\rm th}$ ed, 28–56) Wiley.
- 21. Silverman C (2015) NeuroTribes: The legacy of autism and the future of neurodiversity by Steve Silberman. Anthropological Quarterly 88(4): 1111-1121.
- 22. American Psychiatric Association (2013) Diagnostic and statistical manual of mental disorders (5th ed.) American Psychiatric Publishing.
- 23. American Psychiatric Association (1994) Diagnostic and statistical manual of mental disorders (4th ed.) American Psychiatric Publishing.
- 24. Klin A, Volkmar FR (1997) Asperger syndrome. In D. J. Cohen & F. R. Volkmar (Eds.), Handbook of autism and pervasive developmental disorders (pp. 94-122) Wiley.
- 25. Wing L (1981) Asperger's syndrome: A clinical account. Psychological Medicine 11: 115- 129.
- 26. Gillberg IC, Gillberg C (1989) Asperger syndrome—some epidemiological considerations. Journal of Child Psychology and Psychiatry 30: 631-638.
- 27. Tantam D (1988a) Annotation: Asperger's syndrome. Journal of Child Psychology and Psychiatry, 29(3), 245-255.
- 28. Szatmari P, Bremner R, Nagy JN (1989) Asperger's syndrome: A review of clinical features. Can J Psychiatry, 34(6), 554-560.
- 29. Klin A,Volkmar F, Sparrow S (2000) Asperger Syndrome. The Guilford
- 30. Asperger H (1979) Problems of infantile autism. Communication 13: 45-52
- 31. Mitran, C (2022b) A new framework for examining impact of neurodiversity in couples in intimate relationships. The Family Journal 30(3): 437-443
- 32. Parker M, Diamond R, Auwood L (2020) Exploring exceptions and discovering solutions: A care presentation of autism and the family. Family Process 59(4): 1891-1902.
- 33. Leavy P (2017) Research design: Quantitative, qualitative, mixed methods, arts-based, and community based participatory research approaches. The Guilford Press.
- 34. Patton M (2015) Qualitative research & evaluation methods (4 $^{\rm th}$ ed.) Sage.
- 35. Groenewald T (2004) A phenomenological research design illustrated. International Journal of Qualitative Methods, 3(1): 2-26.
- 36. Moustakas C (1994) Phenomenological research methods. Sage.
- 37. Yin RK (2013) Validity and generalization in future case evaluations. Evaluation 19(3): 321-332.
- 38. Nicolaidis C, Raymaker D, Kapp S, Baggs A, Ashkenazy E, et al. (2019) The AASPIRE practice-based guidelines or the inclusion of autistic adults in research as co-researchers and study participants. Autism 23(8): 2007-2019.

- 39. Baron-Cohen S, Wheelright S, Skinner R, Martin J, Clubley E (2001) The autism-spectrum quotient (AQ): Evidence from Asperger syndrome/ high-functioning autism, males and females, scientists and mathematicians. Journal of Autism and Developmental Disorders 31(1): 5-17.
- Brown C, Dunn W (2022) Adolescent/adult sensory profile users' manual. Psychological Corporation.
- 41. Kirchner J, Dziobek I (2014) Toward the successful employment of adults with autism: A first analysis of special interests and factors deemed important for vocational performance. Child and Adolescent Psychiatry and Psychology 2(2): 77-85
- 42. Gillberg C, Fernell C (2014) Autism plus versus Autism pure. Journal of Autism and Developmental Disorders, 44, 3274-3276.

- 43. Huang Y, Arnold S, Troller J, Foley KR (2020) Diagnosis of autism in adults: A scoping review. Autism 24(6): 1311-1327.
- 44. Flannery K, Wisner-Carlson R (2020 April) Autism and education. Child and Adolescent Psychiatric Clinics of North America, 29(2): 319-343
- 45. International Board of Credentialing and Continuing Education Standards (2023) Interview with Dr. Stephen Shore: Autism Advocate & On the Spectrum.
- 46. Center for Disease Control (2023) Data & statistics on autism spectrum disorder.



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