"WE WILL NEVER BE NORMAL": THE EXPERIENCE OF DISCOVERING A PARTNER HAS AUTISM SPECTRUM DISORDER

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Online forums and lay literature suggest that partners of individuals with Autism Spectrum Disorder (ASD) experience depression, distress, and trauma in their everyday lives, exacerbated during the time surrounding diagnosis. In this content analysis, 29 participants were provided with an online open-ended statement asking them to describe in writing their experiences of discovering that their partners had ASD during their relationships. Six themes emerged, including: facing unique challenges within relationships; insisting partners seek diagnosis; initial shock and relief; losing hope for normalcy; making accommodations within relationships; and wishing for professional support. Marriage and family therapists should help couples minimize blaming and promote self-awareness, appropriate relationship expectations, and mutual understanding. Future research should explore the overall experience of neuro-mixed relationships for both partners.

Approximately, 1 in 100 children worldwide has Autism Spectrum Disorder (ASD), and reports estimate that prevalence is similar in adults (Brugha et al., 2011; Centers for Disease Control & Prevention [CDC], 2016). Although intellectual disability is a common comorbidity, 46% of individuals with ASD have average to above average intelligence quotients (Centers for Disease Control and Prevention [CDC], 2014). Reports estimate that more than half of those with high-functioning ASD such as those previously identified as having "Asperger's syndrome" are undiagnosed, and very late diagnosis is common (Baron-Cohen et al., 2009). Up to half of these individuals enter long-term intimate relationships and many remain undiagnosed until after these relationships have begun (Hofvander et al., 2009; Lehnhardt et al., 2013; Myhill & Jekel, 2008).

According to the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5), ASD is characterized by "persistent deficits in social communication and social interaction" and "restricted, repetitive patterns of behavior, interests, or activities" that cause "clinically significant impairment in social, occupational, or other important areas of current functioning" (American Psychiatric Association [APA], 2013, pg. 50). Social communication and social interaction are critical components of most intimate relationships, and thus it must be assumed that such deficits impact the dynamics of neuro-mixed relationships (in which one individual has ASD and the other individual does not.)

Indeed, lay literature and non-peer-reviewed academic literature support this assumption. Many self-help books and handbooks exist for both partners of neuro-mixed relationships to guide couples in how to interact with one another and how to make relationships "work" within the context of ASD (Aston, 2009; Bentley, 2007; Miller, 2015; Moreno, Wheeler, & Parkinson, 2012; Simone, 2009, 2012). These books emphasize the unique struggles that these couples face and provide some practical strategies to overcome those challenges.

Likewise, public online forums of support for partners of individuals with ASD are replete with comments about the challenges of neuro-mixed relationships. In these comments, "neurotypical" (NT) partners, or partners who do not have ASD, describe feelings of depression, loneliness, distress, anger, confusion, and trauma. For example, some describe financial stress because their partners are unable to work due to symptoms of ASD; others describe partners who no longer participate in sexual relationships, and some report that their partners have uncontrolled anger issues. Many of these NT individuals express frustration with professionals, feeling that they are ignored and that marriage and family therapists do not believe their concerns about their partners.

Despite robust evidence of a need for support in lay literature and online community forums, few research studies have examined the experiences of NT partners of individuals with ASD. Studies have explored the experiences of parents, siblings, and grandparents of individuals with ASD (Gray, 2006; Margetts, Le Couteur, & Croom, 2006; Moodie-Dyer, Joyce, Anderson-Butcher, & Hoffman, 2014; Orsmond & Seltzer, 2007), but there is a dearth of research on partners. In fact, in a systematic review of literature on the life satisfaction of NT women in neuro-mixed relationships concluded that there is "a paucity of good quality, evidence-based literature on which to base any conclusions regarding the psychosocial wellbeing of the female NT partners of people with [Asperger Syndrome]" (Bostock-Ling, Cumming, & Bundy, 2012, p. 102).

Since then, in a descriptive phenomenological dissertation, Rench (2014) interviewed 10 current and former NT spouses of individuals with ASD and reported "a pattern of intimate partner abuse so pervasive that it emerged as the lifestyle of the couples" (p. 4) and recommended screening these partners for post-traumatic stress disorder. It is noteworthy that 3 of the 10 participants were divorced and one had plans to divorce her partner. Wilson, Beamish, Hay, and Atwood (2014) conducted a grounded theory study on communication patterns between NT and ASD partners and found that NT partners "reported frequent unmet needs due to limited or inadequate interactions with their [ASD] partner" (p. 5). They also found that NT participants believed their relationships differed from "normal" relationships and described a lack of connectedness in their relationships. There is significant need to further explore the experiences of NT individuals in neuro-mixed relationships.

To begin to examine the experiences of partners of adults with ASD, this study explored the seminal event in which NT partners discovered that their partners had ASD. On online support forums, NT partners expressed more comments describing depression, grief, and distress during the time leading up to and immediately following the discovery of their partner's ASD diagnosis.

Looking specifically at the experience of reaching a diagnosis of ASD, lay literature and online forums suggest that partners of these individuals may face similar challenges as parents of children in reaching a diagnosis. Parents of children with ASD describe feeling ignored and dismissed by healthcare professionals and schools, often told behaviors are a result of parenting styles not matching the child's needs or behavioral problems that the child would outgrow (Moodie-Dyer et al., 2014; Siklos & Kerns, 2007). They also report seeing an average of 4.5 professionals before a diagnosis is reached (Siklos & Kerns, 2007). By the time they reach a diagnosis, many distrust professionals altogether (Solomon & Chung, 2012).

Similarly, partners of adults on online forums describe therapy sessions in which problems are attributed to the ways they interact with their partners, or simply to incompatibility. Many others report that their partners refuse to go to therapy, so issues are never fully understood or addressed. Partners describe years of anger, anxiety, and depression as they sort through the symptoms in an attempt to reach a diagnosis. Yet, these reports are only anecdotal. Therefore, the purpose of this content analysis was to look specifically at the diagnostic experience and answer the research question: What is the experience of discovering a partner has ASD?

METHODS

Subjects

Inclusion criteria for this study were individuals who have been in a relationship for at least 2 years with a partner who was formally evaluated for ASD or informally evaluated by a mental health professional as meeting the diagnostic criteria for ASD. This timeframe of 2 years was selected to ensure that relationships were of a long-term nature. Participants self-reported that they

did not have ASD themselves. Partners of participants must have been age 18 years or older at the time of diagnosis with ASD. Participants' partners could have met the DSM-IV or DSM-5 criteria, since it was unlikely that individuals would have been re-diagnosed since the release of the DSM-5, and therefore could have been diagnosed with ASD, Asperger's syndrome, high-functioning autism, pervasive developmental disorder, or classic autism.

Data Collection

Approval was obtained from the University Institutional Review Board (IRB). Participants were recruited via a variety of public, private, and secret online message boards, forums, and support groups for partners of individuals with ASD with permission from site moderators. Online recruitment and data collection allowed access to a population that is otherwise difficult to reach. Although there are several active online communities of partners of adults with ASD, there are few in-person communities.

Interested participants were directed to the Secure Sockets Layer (SSL) encrypted study website where they were asked to respond in writing to the statement: "Please describe your experience of discovering that your partner had Autism Spectrum Disorder. Please share any thoughts, feelings, and specific experiences." Demographic information was also collected.

Data Analysis

Data were analyzed using Krippendorff's method of content analysis, which is "a research technique for making replicable and valid inferences from texts (or other meaningful matter) to the contexts of their use" (2013, p. 24). After reading all responses, "thematic units" were identified from each participant account to be used for analysis. A thematic unit was defined as any string of words that described a thought, feeling, or specific experience about being a partner to an individual with ASD surrounding the diagnostic process.

Once extracted, these thematic units were clustered, which Krippendorff defines as "forming perceptual wholes from things that are connected, belong together, or have common meanings, while separating them from things whose relationships seem accidental or meaningless" (2013, p. 205). Units that were very similar were lumped together and identified as clusters, and then these clusters were compared and lumped together based on sameness. This process was continued until there was nothing left to merge. Figure 1 provides an example of a dendrogram, which is a tree-like diagram that depicts how this clustering occurred. Ultimately, six themes emerged from this process of clustering.

Rigor and Trustworthiness

Morse recommends that qualitative researchers should return to examining "rigor" through reliability, validity, and generalizability of qualitative findings (2015). Morse describes validity as "how well the research represents the actual phenomenon" (2015, p. 1213). To ensure validity, the researcher provided rich quotes to illustrate themes. Thick data were ensured by increasing the sample size and continuing data collection until the researcher felt satisfied that saturation had been met in both quality and quantity of responses.

Negative case analysis was also used to examine validity, as Morse describes, "Negative cases often provide the key to understanding the norm" (2015, p. 1215). In this study, two cases were identified in which participants described very positive relationships with their partners with ASD (participant IDs: 04, 17). Unlike quantitative analysis, in which these might have been discarded as outliers, these cases were compared to the majority of cases in which negative aspects of relationships were described, which revealed differences between these experiences as a whole.

Reflexive journaling was also used in attempt to identify "pink elephant bias," or the idea that the researcher will unconsciously use data to "prove" preconceptions (Morse, 2015; Morse & Mitcham, 2002). In this case, the researcher has read extensively about ASD and has a family member with ASD, as well as experience researching adults with ASD in a prior study. The researcher's journal entries focused on her recollection of her family member's diagnostic process, beginning from the experience of hearing about ASD for the first time and ending with the emotions surrounding the diagnosis once reached. These entries included both positive and negative
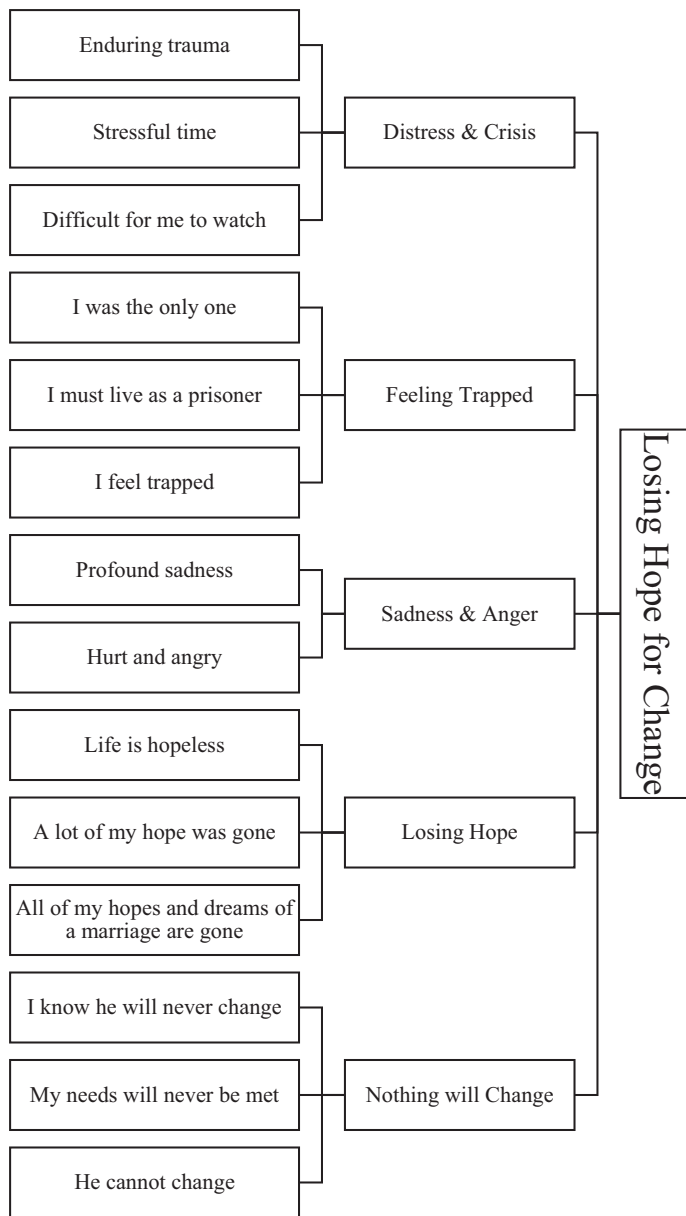
Figure 1. Example of dendrogram for Theme 4: Losing Hope for Change.

recollections, including personal feelings of shock, denial, acceptance, and growing understanding over time. Entries also described her positive and negative perceptions of her family member's therapy.

Data are "reliable" if the same results would be achieved through replication of the study (Morse, 2015). Morse suggests that member checking should primarily occur with individuals who have not already participated in the study, as "such replication determines normative patterns of behavior, hence achieves reliability" (2015, p. 1218). Once analysis was complete and themes were defined, the researcher recruited new participants and asked them to read the themes and their descriptions. These participants were asked to provide feedback on whether or not the analysis adequately captured the experience of discovering a partner's diagnosis of ASD. Six participants responded, including one who had participated in the previous phase of the study. Feedback from these participants was taken into consideration within the larger context of the analysis of findings.

For example, within the summary of findings offered to participants for feedback, the researcher wrote:

> Some described always knowing something was different, or always having difficulties in the relationship. Others described their partners as "actors," able to blend in and hide traits from the participant initially, and often able to hide issues from others outside the relationship.

A participant responded, "Agree on all except the part in Theme 1 where it says partners 'hid their traits.' My partner never hid his quirks or traits" (participant ID: 27). Despite this participant's disagreement, the researcher determined that no changes were needed based on this participant's feedback since her individual experience should have still been captured. After obtaining feedback, only small additive changes were made to the final analysis.

Generalizability is achieved through "decontextualization" and "abstraction" of overarching themes (Morse, 2015). In this case, theme titles are presented as representative in-vivo quotes followed by abstract concept headings. Similarly, each theme is described abstractly with contextual examples of participant quotes to provide evidence of validity of the theme within the data.

RESULTS

Sample

This sample included 29 partners of individuals diagnosed with ASD in adulthood. Table 1 presents the demographic characteristics of this sample. This sample was primarily female (two male participants, IDs: 22, 29), White, married, and well educated. One partner indicated he was in a same-sex relationship (participant ID: 29). Most participants had children (89%), and of those with children, 13 out of 24 participants reported having at least one child with formally diagnosed (33%) or suspected (21%) ASD, while 2 of those 24 reported their child was too young to determine a diagnosis (8%). Of those who were married, 33% reported informally or legally separating from their spouse at least once during the marriage. Only one participant was separated from her partner at the time of participation (participant ID: 24), and one partner reported that she and her husband were married and "together" but lived in different houses (participant ID: 03). One-third (33%) reported that they were in a previous marriage before their relationship with this partner. None of the participants were aware that their partner had ASD at the start of the relationship, and only two participants were aware of the diagnosis at the start of marriage (participant IDs: 11, 17).

In total, 151 thematic units were extracted from protocols. Six themes emerged that captured participants' experiences of realizing their partners had ASD. In the first theme, participants described having some knowledge that their relationship was different from the start and realized that there were significant challenges as the relationship progressed. In the second theme, participants described finding out about ASD and concluding that their partners likely met the diagnostic criteria, and many reached a breaking point that resulted in their insistence that their partners be evaluated. The third theme emphasized the validation that participants felt initially after they discovered that their partners had ASD and the new understandings this diagnosis gave them. The fourth theme described the subsequent grieving period where participants felt that they lost hope for a "normal" relationship. In theme five, participants described ways in which they adapted their relationships with consideration to ASD. Finally, in the sixth theme, participants lamented the lack of support they and their partners received throughout the diagnostic process and beyond. Themes are detailed in the following sections. Participant identification numbers are provided after each quotation to illustrate the range of responses.

"Something Wasn't Right": Issues Crept In

Almost all participants described facing some kind of issues in their relationships related to their partners' ASD traits. For many, they "always knew something wasn't right" (21), and often struggled from the start of their relationships. One participant said, "Our relationship has always been difficult" (16), and another, "I had been married for 21 years to a man I couldn't figure out" (06).

Table 1
Demographic Characteristics of the Sample (N = 29)

	n	%
Gender (*n* = 27)		
Male	2	7
Female	25	93
Age (*n* = 27)		
Mean	43.6 years	
Range	21–65 years	
Diagnosis method (*n* = 27)		
Formal evaluation	17	63
Informal evaluation	10	37
Relationship Status (*n* = 27)		
Married, live together	18	67
Married, separated/do not live together	2	7
Not married, live together	6	22
Not married, do not live together	1	4
Length of Relationship (*n* = 27)		
Mean	13.2 years	
Range	2–33 years	
Length of Marriage (if applicable) (*n* = 20)		
Mean	12 years	
Range	1.3–32 years	
Highest Level of Education (*n* = 27)		
Trade/technical/vocational training	3	11
Some college	8	30
College graduate	9	33
Postgraduate degree	7	26
Race/Ethnicity (*n* = 27)		
American Indian	1	3
Hispanic	1	3
White	25	93
Country (*n* = 27)		
Australia	5	19
Canada	1	4
Thailand	1	4
United Kingdom	2	7
United States	18	66

Participants described relationship challenges that mirrored symptoms of ASD outlined in the DSM-5. For example, many participants described facing difficulties with communication that correspond with "deficits in social-emotional reciprocity" (APA, 2013, p. 50), such as "We do run into issues trying to communicate how we feel" (15) and "I would try to open a dialog and he would either ignore me altogether or say I don't know or I don't care" (09). Another reported that her husband provided "no emotional support" (04).

Several also described "lack of sex" (02). For example, one participant said, "When we were married sex stopped and he would only tolerate it once every 6 months or so and he made it clear that he hated it" (03). Another shared, "I am the one who initiates sex. He said he doesn't do it because he never knows when I want it" (09). These sexual challenges may be related to ASD symptoms such as "hyper- or hypo-reactivity to sensory input" and "deficits in nonverbal

communicative behaviors used for social interaction" (American Psychiatric Association [APA], 2013, p. 50).

Others described restricted thinking patterns: "His thinking is inflexible" (16) and "rigidity of thought" (04). Symptoms of meltdowns were also common, with individuals describing their partners as "quick tempered" (06) and having "anger issues" (04, 09), including one report that a participant's husband "kicked our son in a sudden fit of rage" (16).

Other participants reported that their partners were able to blend in and hide traits from the participant initially, and often able to hide issues from others outside the relationship. One called her husband an "actor," saying, "I figure that's how he got by so long because he mimics so well" (02). Another said his partner had a "Knight in Shining Armor image," saying that when he first met him "his put-togetherness was a huge attraction, as well as his grandiose presentation" (29). These participants described drastic changes upon moving in with or marrying their partners.

"Making the Link": Insisting on a Diagnosis

In many cases, participants began looking online or speaking to a therapist about issues in their relationship and came across a description of ASD. Others had a child with ASD, and realized upon the child's diagnosis that their partner also had ASD. Many participants asked their partners to take an online self-test for ASD or to seek counseling. One participant reported that his partner "avoided his counselor's advice to get tested, until I used the key words 'It would mean a lot to me if . . .'" (29).

Several participants described giving their partners an ultimatum, threatening to end the relationship if their partners did not seek formal evaluation and/or professional help. Participants said, "For 3 years I asked my husband to get tested and one day we had a huge argument and I threatened to leave if he didn't get help" (09) and "I told my husband that he had to go see a therapist. This was an ultimatum. Work on yourself or the marriage ends" (02). Another shared, "I let him know that I would seek a divorce unless he got evaluated for ASD" (23).

Lack of insight often played a role in partners' willingness to seek diagnosis. One participant explained, "He didn't recognize his illness so it was very difficult to get him into treatment. I didn't give him a choice and got him to a psychiatrist" (12). Another reported that her husband completed a self-assessment and scored highly "both without my help and with it (he did not recognize, for example, that he has obsessions)" (16).

In a few cases, the partner with ASD already knew of this diagnosis and disclosed it to the participant, often casually and without further information. One participant said, "My partner walked in the door and abruptly announced that he has Asperger's as I was getting ready for work" (13), and another, "He casually mentioned that he was 'slightly autistic'" (15).

"I Wasn't Crazy": Initial Shock, Validation, and Understanding

Once their partners were diagnosed, either formally or informally, many participants described feeling shocked despite having already suspected the diagnosis. Participants said, "At first I felt like the bottom had dropped out of the world" (10) and "A sense of being lost. What now? I don't even know this person. Everything I thought was, is not. What IS real???" (07). One participant questioned, "I mean, I'd know if I'd actually married someone who was autistic, right?" (03).

Shock gave way to "overwhelming relief" (01) and validation. Participants said, "It was in some way a relief to have confirmation" (14), and, "The validation was huge. I wasn't crazy, I had not been imagining things, this was real!" (07). Several participants used phrases like: "He wasn't just being an asshole" (01, 02, 18).

Many participants described having an explanation for specific behaviors or having "answers" (21, 22, 23). One participant said, "The first thought was relief to have a name for what was going on in his head and what had been going on for 31 years" (21). Participants re-evaluated their pasts with new understanding. One reflected, "My mind was racing as I thought of our 30 year history together, and his life growing up prior to meeting me. So many situations and conflicts, now easily explained with the new diagnosis" (23), and another,

It was like a light bulb going off in our brains as we realized and understood her reactions and mannerisms … It was a feeling of relief for both of us that there was now an answer to so many past questions and uncertainties (22).

One participant summarized, "After all those questions, the puzzle pieces of all kinds of confusing behaviors began to make sense" (02). Participants described initial hope that this diagnosis would be a new beginning for their relationship.

"We will never be Normal": Losing Hope for Change

After the initial relief, many participants described a period of mourning. They felt "lost" (07), "angry" (03), and "stressed" (04, 12). Most of all, they described feeling "hopeless" (02, 07, 10, 11, and 18) about the future. They felt that the diagnosis gave them clarity, but it also felt like the issues they had encountered in their relationships would be permanent and that their partners would not be capable of change. One participant shared, "It made a lot of my partner's behavior make sense for the first time, but at the same time I realized how different we were and I felt like a lot of my hope was gone" (10). Another said, "I felt bereft. It was then I knew he would not or could not change" (06), and another, "I was hurt and angry because I would never have a normal marriage I'd been working so hard for" (03).

Some participants lost hope that their partners would be capable of meeting their emotional needs: "The diagnosis gave me a glimmer of hope, but now the more I learn, the more I realize life is hopeless as an aspie's partner. … My needs will never ever be met in my lifetime" (18), and, "I was hit with a deep feeling of grief. All my hopes and dreams of a marriage are gone. … My husband may not be capable of being the husband I want and need" (01). Another shared, "I learned that I had no hope of him being a spontaneous or natural support system for me" (02).

Others described feeling "trapped" (06, 12). Participants said, "I must live as a celibate prisoner for the rest of my life, or be a bitter middle aged divorcee" (18) and "I no longer love him. … I feel trapped in a sham of a marriage" (06). Another shared, "There was no one else to help him, so I didn't feel that leaving him was an option" (12).

Several participants reflected on the damage done by their lack of knowledge of their partners' ASD over years of being together. One participant wrote, "The diagnosis made me realize that I had endured quite a bit of trauma, during many years" (23). Some described experiences of being misunderstood or ignored when they tried to vent their concerns to others. For example, one participant shared, "I was generally not believed or my comments were 'minimized' so I learned not to discuss these things" (14). Another wrote:

The frustration of years of not being heard, not being believed, being told I was the issue, having so many people look at Mr. Nice Guy and tell me how lucky I was, how wonderful he was (and he was in many areas!), the years of having my husband damage family relationships with his misinterpretations of social settings and people, all came together and almost unhinged me, at a time I was expecting to feel relief, hope and a sense of a renewed relationship. It just did not happen (07).

Participants worried about what the future would bring. As one participant wrote, "I'm not sure if things will heal enough for me to stay" (16).

Only one participant indicated that she felt her husband was able to support her in the way she had expected before she was aware of his ASD. She wrote, "I was very apprehensive of continuing a relationship with someone that I know would never understand. Boy was I wrong!" (17). She described playing a very supportive role in her relationship, but also indicated that her husband was willing to learn about ASD and work with her on improving their relationship.

"Changing my Mindset": Making Compromises and Accommodations

Participants reported learning all that they could about ASD. This knowledge allowed them to make changes that would accommodate their unique relationship needs. For example, one participant's husband disclosed his diagnosis at work, which relieved her concerns that he would lose his job "resulting from others not understanding my partner's responses in a busy office situation" (14). The diagnosis also empowered some participants to set boundaries in their relationships:

He may have Aspie traits but that doesn't mean I have to interact with them the way I used to. I won't ruminate with him. I won't have circular arguments. I will not stay if he engages in addictive behaviors again, I do not have to coddle a meltdown. He learned through his therapist that these behaviors are right and healthy. I'm grateful for that (02).

Many embraced the opportunity to alleviate areas that were challenging for their partners. One participant said, "I write lists, link our calendars, explain what I expect him to do each day, manage our finances and we're getting on much better. Life isn't without it's (sic) challenges but isn't everyones (sic)?" (04). Another wrote,

I accept that I will need to make more compromises and will need to be the one to work out what needs to be done, take my time to choose the right words and timing, and to be extra patient (26).

However, others resented the compromises they felt they had to make:

I find myself being the major role player in 95% of our marriage. I am everything, that is planner, organizer, problem solver, mother, ... and at the end of the day you end up feeling you play the role of his private therapist (20).

The thought of putting more work into the relationship was overwhelming for some: "I knew this wasn't going away but I was already sort of sucked dry and the thought of learning new ways of interacting sucked what little I had left" (02).

Several participants described wishing they knew about the diagnosis sooner so they could have made changes earlier in the relationship. One participant said,

The efforts I had put in to try to help our relationship grow and thrive, had been failing as I had not the right tools, not only the wrong tools but I was trying to apply them in the wrong language (07).

This process of learning to "speak the same language" was ongoing for most participants. As one wrote, "I am still trying to change my mindset to interact and communicate with him on his terms" (09).

Some participants felt that knowledge of their partners' diagnosis gave them more patience, understanding, and appreciation for what their partners had endured. One participant said, "Some of his behaviors frustrate me, but from the framework of ASD it makes sense and I can understand it. I also realize that I drive him up the wall at times" (26). Another wrote, "Now that I understand the difficulties he struggles with I'm amazed at how well he's able to cope and work around his disabilities" (12), and another, "I am also grateful for the positive influence my partner has had and continues to have on the way I look at life" (14).

"I can't do it Alone": Desperate for Help

Many participants reported that their partners refused to seek help after being informally or formally diagnosed with ASD, crushing the hope they initially felt upon realizing the diagnosis. One participant said,

I thought [his diagnosis] would trigger some future action on his part, but he has not pursued any further help. When we started moving forward with a diagnosis, I had a lot of hope for a better life for him, and thus us. Without much change, it has been quite disappointing (11).

Some also described their partners were "in denial" (06), for example, saying, "He is not ready to accept help, or to acknowledge he needs help" (26).

Others described that their partners were willing to seek help but were unable to find any. One said, "I had to do all the work to seek care for my partner and I had very little idea of where to go for help" (12), and another, "The doctor didn't seem to help us any further with how to help him cope. ... Because he doesn't know how to cope it's a daily struggle still, till we find help ... " (21). Some received minimal help but did not feel that it made any real difference in their relationships. For example, one participant reported that professionals attempted to support her husband

without consideration of his ASD. She wrote, "Everything was treated under the NT umbrella with the expectation of my husband being able to utilize the strategies offered in an NT way – the wrong language" (07). Another participant reported that her cousin was diagnosed with ASD as a child and lost all support when he became an adult. Based on her previous experiences, she wrote, "I didn't expect much to improve after the diagnosis" (24).

Besides wishing for help for their partners, participants wished for support for themselves. One vented, "Why is there not more information for partners? How do I deal with this, as I don't want to leave my partner, I love him" (07). One participant explained how her lack of support contributed to a feeling of hopelessness:

> I was initially relieved because I thought that [the diagnosis] would mean some treatment, information, support networks, and hopefully tools such as new ways to communicate would be available to us that could maybe help save our marriage. Unfortunately, that has not been the case. He has no interest in finding out more and no support for partners seems to be available. I am now feeling hopeless and devastated (18).

Several joined or initiated online or in-person support groups, but most felt they needed more help. One participant concluded, "It's been 2 years and I'm still confused!" (03).

DISCUSSION

Participants in this study described a journey of isolation throughout the diagnostic process. They described facing unique challenges within their relationships that brought ASD to light, then worked with their partners to follow through and reach a formal diagnosis. Upon reaching a diagnosis, they experienced initial shock and relief, followed by periods of loss and mourning. Ultimately, they worked to make changes within their relationships, but felt that they were not able to resolve many of their conflicts because they lacked assistance from professional support systems.

Interventions to address the needs of neuro-mixed couples should be developed with this in mind: that *both members* of the couple must learn to *adapt to their differences*, *not to "fix" the person with ASD*. Results indicate that NT partners are often willing to make accommodations in their relationships to improve quality of life for themselves and their ASD partners, but lack the knowledge and skills to make real change without help.

Strategies such as those described in Aston's (2009) "Asperger's Couple's Workbook" might help partners to communicate more effectively. For example, couples might develop code words to use when they are overwhelmed during a discussion or argument to signify that the discussion should be continued at a later time, particularly if the ASD partner detects that he or she will soon experience a meltdown or a shutdown in communication. A code word might also be used for the ASD partner to communicate that he or she requires alone time. NT partners must be educated that it is reasonable for their ASD partners to need time alone and that they should not take this need as a personal insult, while couples must work together with marriage and family therapists to determine how much time is appropriate for each couple's unique needs (e.g., ASD partners requiring 30 minutes of quiet time each day versus 4 hours of quiet time each day).

Several participants in this study also described challenges in sexual relationships such as their partners not initiating sexual engagement because of their inability to understand cues. NT partners must be educated that their ASD partners might struggle with reading nonverbal communication and body language. The couple might create a clear signal for the NT partner to use to indicate to their ASD partner that they are interested in sex and would like their ASD partner to initiate sexual contact. Sexual counseling might also be warranted, particularly in couples in which the ASD partner struggles with physical contact or has extreme sensory hypersensitivity.

The use of social stories, in which individuals are presented with a guide and examples of social interactions in clear language to enhance their theory of mind skills, has been effective in helping children with ASD to respond appropriately in social situations (Wright et al., 2016). Given the examples from participants in the current study, adapted versions of these social stories might be useful in assisting couples to "speak the same language" by illustrating appropriate relationship behaviors and expectations, as well as resolving lingering pain from past conflicts. For example, one participant in this study described healing through re-examining her relationship

history within the ASD context. Couples might walk together through situations that have led to miscommunications in the past, and each can describe to the other how they interpreted the communication. This strategy can help with mutual understanding, self-awareness, and forgiveness for both partners that can improve future communication.

Couples might also find it helpful to discuss and explore how they learn best, for example by taking an online survey such as Barsch's "Learning Style Inventory" (1980). Each partner can then decipher how they would most like to discuss important information. For example, for an auditory learner, it might be helpful for a partner to explain the important information to their partner and then leave a voice message of the information. Visual learners might find it helpful for their partner to send them an email or text to discuss important information rather than to have an oral conversation. As one participant identified, keeping a shared calendar might also be helpful. Again, these strategies require compromises from both partners. NT partners might be frustrated with the extra efforts required for successful communication, and marriage and family therapists should be prepared to validate these frustrations and work toward positively embracing successful communication approaches.

In some cases, participants described tolerating behaviors that were abusive and unhealthy in any relationship (e.g., explosive anger, physical violence toward children, withholding sex or discounting partner's sexual needs, etc.). Others described anger and sadness about their relationships that indicated their own potential to subject their ASD partner to emotional abuse (e.g., blaming, belittling). Healthcare professionals must be vigilant in observing for signs of domestic violence from either partner when working with neuro-mixed couples and educating couples on appropriate boundaries and expectations. For example, NT partners must be taught about meltdowns and educated on how to respond (e.g., allowing space and privacy for self-soothing, postponing important discussions), but both partners should also be educated that physical violence even during a meltdown is unacceptable.

Marriage and family therapists should not underestimate the power of awareness and validation. As with parents of children diagnosed with ASD, findings indicate that outcomes are improved with earlier diagnosis (Sansosti, Lavik, & Sansosti, 2012). For some, by the time a diagnosis could be made, the relationship was beyond repair. Even in mild cases of ASD, awareness can mean the difference between relationship success and failure.

Outside of the diagnostic experience, participants in this study described that aspects of their relationships caused them to feel "trapped," "depressed," "lonely," and "hopeless." They also described "enduring trauma" in their relationships before they had knowledge of ASD, which had lingering effects. A study on the overall mental health of partners of individuals with ASD is warranted, including examining prevalence of depression, anxiety, and traumatic stress symptoms. Future studies should also examine the overall experience of living with a partner with ASD outside of the diagnostic experience.

It is noteworthy that 54% of those who participated in this study are not only partners to an adult with ASD, but are also parents to a child with suspected or diagnosed ASD. Those stresses known to exist among parents are compounded with the stresses of participating in a neuro-mixed relationship. There are few studies investigating the parenting styles of individuals with ASD (Lau & Peterson, 2011). Future studies should examine the family impact of neuro-mixed parenting from the perspectives of ASD partners, NT partners, and children of neuro-mixed relationships.

Limitations

This study was limited by a homogenous sample with nearly all participants being White females. Although the sample was geographically diverse, representing participants from five countries and 14 of the states in the USA, the unique experiences of other racial backgrounds should be explored. Similarly, relationships between same-sex couples and couples in which both members have ASD warrant further research.

Recruitment also targeted forums for partners of individuals with ASD, indicating that participants were likely receiving online support. Results should be viewed in light of the fact that these are the individuals who are receiving what help is available, and with the knowledge that many partners receive no support at all. Future research must also examine the experiences of individuals who report that their partner is self-diagnosed with ASD. Self-diagnosis is a common phenomenon

among adults with ASD, and significant barriers exist that prevent those who are likely to have ASD from reaching a formal diagnosis (Lewis, 2016). Many participants in this study also reported their partners' initial resistance to seeking help and viewed the formal diagnosis as a turning point in their relationships. Future research must examine the experiences of NT individuals whose partners likely have ASD but who are unable or unwilling to seek formal diagnosis.

Using open-ended written responses rather than traditional interviews was another limitation. The researcher was unable to ask follow-up or clarifying questions in an attempt to protect the privacy of those with ASD whose NT partners participated in this study. The researcher opted not to collect personal identifying or contact information from participants since consent was not obtained from the individual with ASD, which would have likely biased the sample to include only partners of those who were accepting of their ASD diagnoses. A larger sample size was used to ensure saturation and to ameliorate this limitation.

Conclusion

Neuro-mixed relationships can be uncomfortable for both partners at times, as both individuals must be willing to work outside their neuro-norms to communicate effectively and ensure that their partner's needs are met. Both individuals must be trained in strategies to promote mutual understanding, effective communication, and setting healthy relationship boundaries. They might also need support as they mourn the loss of the relationship they had planned. Marriage and family therapists must help NT partners' transition from feeling a loss of hope for normalcy to adjusting to a new normal.

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