

**This is an accepted version of the article, which has been published in Autism and is available in its final version here: <https://doi.org/10.1177/13623613221097850>*

Autism as a Difference or a Disorder?: Exploring the Views of Individuals who use Peer-Led
Online Support Groups for Autistic Partners

Abstract

Approximately one third of autistics report intimate relationship experience, but few studies have explored neuromixed relationships from the perspectives of non-autistic partners. Non-autistic partners increasingly use peer-led online groups to seek support. The purpose of this study was to capture a theory that reflects the basic social experience of individuals who use these support groups using classic Glaserian grounded theory methodology. Online interviews were conducted with 162 non-autistics who believed that they were in neuromixed relationships. Data were concurrently collected and analyzed using constant comparative analysis. Participants described varying views of autism, from a difference to a disorder, that defined the context of their relationships. Five relationship profiles emerged, including: mutual partnership: viewed partners as equals; companionship: viewed partners as friends but lacked a deeper connection; caregiving: viewed partners as dependents and compared relationships to parent-child dyads; detachment: viewed relationships as broken beyond repair and isolated selves from partners; and discriminatory: believed and circulated negative generalizations about autism. Many participants who were dissatisfied in their relationships shared that their partners were not formally evaluated and did not self-identify as autistic. Future research should explore ways that autism labels are (mis)applied by the general public based on negative stereotypes about autism.

Keywords

Autism; intimate partners; qualitative; romantic relationships; social media

Lay Abstract

Individuals who use peer-led online support groups for partners of autistics describe diverse views of autism, with some describing autism as a difference and others describing it as a disorder. I conducted online interviews with 162 non-autistics who believed they were in relationships with autistics and who participated in online support groups on social media. I analyzed their responses by constantly comparing each interview to previous interviews to develop a theory about their social experiences. As many as one third of autistics participate in romantic relationships, and many of their partners seek support through groups on social media. Few studies explore what it is like to be a non-autistic person who is in a relationship with an autistic person. The way that participants viewed autism influenced the way that they viewed themselves, their partners, and their relationships. Many participants who were dissatisfied in their relationships shared that they believed their partners were autistic, but their partners had never been formally evaluated and did not self-identify as autistic. Future research should explore ways that autism labels are (mis)applied by the general public based on negative stereotypes about autism.

Online groups on social media have become an increasingly popular way for autistic individuals and their families to build networks of support. Autistics who participate in online communities often make meaningful connections, gather information about autism, and experience a sense of belonging (Brownlow et al., 2015; Thomas, 2018). Parents who participate in online support groups report receiving informational and emotional support and describe benefits for themselves and their children (Mohd Roffeei et al., 2015). Though these groups have shown benefits for individuals and their parents, little is known about peer-led online support groups for romantic partners of autistics.

Previous studies indicate that nearly three quarters of autistics without intellectual impairment have romantic relationship experience (Strunz et al., 2016). Since the defining characteristics of autism affect communication and socialization (American Psychiatric Association, 2013), autism inherently affects intimate relationships. Delayed diagnosis into adulthood is common and many people enter romantic relationships before self-identifying as autistic, which can complicate relationship dynamics (Hofvander et al., 2009; Lehnhardt et al., 2013; Lewis, 2017; Myhill & Jekel, 2008). Few studies explore the experiences of couples in neuromixed relationships, in which one partner is autistic and the other is not autistic.

In a previous study, I recruited participants via peer-led online support groups for partners of autistics (Lewis, 2017). While in these groups, I was exposed to discourse related to depression, trauma, and distress. I also received multiple emails and phone calls from partners requesting that I further research this community to understand and share their relationship journeys. Existing research on neurotypical partners of autistics indicates a need for further exploration. In a descriptive phenomenological study of ten current and former spouses of autistics, Rench (2014) found that participants perceived a pervasive pattern of intimate partner

abuse and identified examples of emotional, sexual, psychological, economic, and physical violence within participant accounts. Wilson et al. (2017) conducted a grounded theory study on prompt dependency in communication based on interviews with nine neuromixed couples and found a perceived lack of reciprocity in communication between partners, leading to non-autistic partners feeling disconnected from autistic partners. Participants in a qualitative content analysis on the experience of discovering that a partner was autistic described a loss of a hope for normalcy, felt they needed to make significant adaptations within their relationships, and wished for professional support (Lewis, 2017).

Many current and former partners of autistics have written books about their experiences in neuromixed relationships, including some accounts intended to assist couples in working through relationship challenges (e.g. Bentley, 2007) and others intended to warn of the perceived “dangers” of neuromixed relationships with discriminatory generalizations about autism based on their own relationship experiences (e.g. Ford, 2016). Across these accounts, partners emphasize that neuromixed relationships come with unique challenges and that more information is needed.

Given the breadth of this topic and the limited research on this population, I selected a grounded theory methodology to broadly explore a topic with little known information. I focused on peer-led support group users because this population expressed particular vulnerability. These individuals represent a subpopulation of individuals who are actively seeking support in their relationships due to challenges that they believe are related to autism. The purpose of this study was to capture a theory that reflects the social experiences of individuals who participate in online support groups for partners of autistics and the social process they use to manage those experiences.

Methods

Research Design

I used a grounded theory method to allow a theory to emerge from data through constant comparative analysis. Grounded theory is a broad method that can be applied to quantitative and/or qualitative data, as one of the tenets of grounded theory is that “all is data” (Holton & Walsh, 2017). In classic Glaserian grounded theory (Glaser & Strauss, 1967/2010), a general research topic is selected, but there is no predetermined research question. Data collection and analysis occur concurrently. New data are constantly compared to existing data, and emergent findings guide the next steps of data collection, called theoretical sampling. The goal of grounded theory is to reach a level of conceptualization through abstraction of ideas rather than focusing on a concrete description of the topic of interest. Researchers engage in memoing, or stream of consciousness writing focused on theoretical relationships among data and abstraction, to assist in this process.

Data analysis begins with substantive coding, which is used to summarize the concepts in the data, and includes two phases: open coding and selective coding. In open coding, researchers search for the primary concern of the population of interest and the core variable, or the process they use to resolve that concern. The core variable accounts for most of the variation within the sample and will become the center of the theory. Once the core variable is identified, researchers begin selective coding, in which only data related to the core variable are coded to delineate properties of the core variable. After the properties of the core variable are fully explored, the researcher begins theoretical coding to identify relationships between substantive codes. Concurrent data collection, data analysis, and memo-writing continue until theoretical saturation is reached, at which point a theory has fully emerged from the data (Glaser & Strauss,

1967/2010).

Setting and Participants

I recruited participants from 11 peer-led online support groups for partners of autistics with permission from site moderators. Groups were hosted on Facebook ($n = 6$), Delphi Forums ($n = 2$), and independent platforms ($n = 3$). Some groups allowed both autistic and non-autistic members ($n = 4$) while most allowed only non-autistic members ($n = 7$). Two groups were limited to women only. All groups identified themselves as places of “support” for partners of autistics in their group descriptions.

Using theoretical sampling, eligibility criteria changed during the course of the study to intentionally and purposively identify sources of data that would further refine the properties of the core variable (Glaser, 1978). Initial inclusion criteria included individuals who were 18 years or older, did not identify as autistic, and were currently in a relationship for 1 year or longer with a partner who was formally evaluated and identified as autistic. As data collection continued and the core variable emerged, I expanded the sample to include individuals who were no longer in relationships with their partners but were still participating in online groups, as well as individuals who believed their partners were autistic (regardless of whether or not their partners self-identified as autistic). These individuals were included because it became clear that they continued to participate in online groups and their voices were influential in support spaces. For example, two key informants who were moderators of support groups, and therefore in positions of power within these communities, revealed that they were divorced from partners who they believed were autistic (their partners did not self-identify as autistic and never sought diagnoses).

Procedure

The University of Vermont Institutional Review Board approved this study. Online

consent was obtained prior to interviews. Interviews occurred asynchronously online through a secure survey platform. Participants were provided a survey link with interview questions and asked to respond in writing. Initial questions were broad, such as, “What works well in your relationship?” and, “What are some of the challenges you face in your relationship?” Questions evolved and became more specific to the core variable throughout the study based on emergent findings, such as, “Please tell me more about your experience with emotional intimacy in your relationship.” After reading responses, I created individualized survey links with additional follow-up questions and emailed a unique survey link to each participant. I repeated this process until I reached theoretical saturation of the category. Three individuals who participated in online interviews also contacted me by telephone to provide additional information.

Participant observation is a key element of data collection in grounded theory, but the ethics of researcher presence in online communities are debated (Gelinas et al., 2017). One key informant who participated in interviews was also a moderator of a small online support group (12 members) and, after checking with all members, invited me to join the group as an observer. I also read posts in two publicly available groups. In all cases, while observing support group interactions may have influenced my perspectives and development of interview questions, no data or quotes were collected directly from support group message boards.

Data were analyzed through constant comparative analysis. I identified a core variable through open coding, and interviews became shorter and more directed as the properties of the core variable developed through selective coding. I used memo-writing and theoretical coding to identify conceptual links between substantive codes. Community members were not involved in this study.

Theoretical Sensitivity: Researcher Perspectives

My personal views about autism were bracketed through reflexive journaling as I attempted to be theoretically sensitive and open to the data (Glaser, 1978). As part of this process, I acknowledge the perspectives that influence my own view of autism. My first understanding of autism was based on the medical model, influenced by my professional background as a nurse. In this model, autism is viewed as a disorder, and the role of the healthcare professional is to provide interventions to alleviate symptoms of the disorder.

Over the last 7 years, I have had extensive experience researching phenomena related to autistic adults, and my understanding has shifted based on communications with autistics and advocacy groups. My current understanding of autism is influenced by the Neurodiversity Movement, viewing autism as a neurological difference that is important to human diversity. In this model, the role of the healthcare professional is to advocate for environmental and social adaptations that increase accessibility and equity for autistic people and to manage common cooccurring conditions such as anxiety and depression. These personal perspectives were set aside in attempt to represent the data through the lens of participants.

I must also acknowledge that I did not expect the intensity and animosity that participants in this study described, and I struggle to present findings that can be perceived as biased and discriminatory against the autistic population. With that said, I feel it is important to honor the findings that arose from data in order to understand and, if necessary, intervene to promote healthy relationship dynamics in neuromixed relationships for *both* partners. Findings should be read in light of individual perceptions of an experience, and readers should note that the autistic voice is absent from this article. Readers should be warned that quotes in this article may be triggering and upsetting.

Results

Sample

In total, 162 individuals participated in online interviews. Background data are outlined in Table 1. Individuals were identified as being “formally diagnosed” if they received an evaluation and were determined to meet criteria for an autism diagnosis, “informally diagnosed” if they had not received an autism evaluation but were told by a health professional that they were likely autistic, “self-diagnosed” if they self-identified as autistic but had not otherwise discussed with a health professional, and “undiagnosed” if their non-autistic partner believed they were autistic but they did not self-identify as autistic. Individuals from 13 countries participated with the majority from the United States (63.5%), the United Kingdom (10.3%), Australia (6.9%), and Canada (5.5%). Five participants (3.6%) reported they were in same-sex relationships. Many (37.9%) were married prior to their relationship with the partner they believed to be autistic and most had at least one child (72.9%). Of those with children, 28.4% reported that they had at least one child who was formally evaluated and identified as autistic and an additional 25.5% reported they suspected at least one of their children was autistic. Specific data on socioeconomic status were not recorded.

Since participants were included even if their partner did not self-identify as autistic, I use the term “believed to be autistic” (BBA) to refer to participants’ partners, acknowledging that these individuals may or may not self-identify as autistic or meet diagnostic criteria for autism, and “non-autistic” (NA) to refer to participants themselves. Additional context on BBA partner’s diagnosis is included after each quote. All quotes are from participants currently in relationships unless otherwise specified.

Table 1

Demographic characteristics of sample (N = 162)

	<i>n</i>	%
Gender (missing: 23)		
Female	129	92.8
Male	9	6.5
Other	1	0.7
Age (missing: 21)		
Mean: 47.7 years		
Range: 20-78 years		
Race (missing: 21)		
White	134	95.0
Black	4	2.9
Multi-racial	3	2.1
Ethnicity (missing: 21)		
Hispanic or Latino	8	5.7
Not Hispanic or Latino	133	94.3
Partner's Diagnosis (missing: 16)		
Formally evaluation & diagnosis by a health professional	43	29.5
Informal evaluation by a health professional	37	25.3
Self-diagnosed	31	21.2
Undiagnosed (do not self-identify as autistic)	35	24.0

Length of Relationship (missing: 23)		
Mean: 16.8 years		
Range: 1-57 years		
Current Relationship Status with Autistic Partner (missing: 22)		
In a relationship	127	87.6
Living together	110	75.9
Married	95	65.5
Considering divorce	50	34.5
Divorced	12	8.3

Basic Social Concern: Imbalance in Need for Emotional Intimacy

When summarizing their experienced realities, many participants described an imbalance in the need for emotional intimacy between themselves and their BBA partners as a basic social concern. Participants often felt that their partners were unaware of, unconcerned about, or unable to provide the level of intimacy they sought in their relationships. One said, “We have varying needs of socialization and affection. It’s hard to gauge how he’s feeling, and he can’t always articulate it either, which can lead to confusion” (formally diagnosed). Another said:

When we are physically together in the same space, he is loving, caring, attentive. When we are physically apart, it feels like “out of sight, out of mind” and I begin to feel desperate for a response or interaction, while he is comfortable going days and days with no interaction at all. (informally diagnosed)

Participants often felt that their own needs were unmet and reported they were unable to identify the needs of their BBA partners.

Basic Social Process: Pathologizing Autism

Participants responded to this imbalance differently based on the degree to which they pathologized autism and its role in their relationship. When participants viewed autism as a “difference,” they often viewed relationship challenges as puzzles to be solved together, requiring mutual adaptation and compromise. Alternatively, when participants viewed autism as a “disorder,” they often attributed any negative aspects of their relationships to autism. They viewed their partners as disordered or broken and believed the challenges in their relationships were insurmountable. The degree to which the NA partner pathologized autism resulted in five general patterns that defined how partners viewed themselves, their partners, and their relationships. These relationship contexts are depicted in Figure 1 and described in detail in the following sections. Notably, these contexts are not necessarily discrete categories, and some participants described shifting between views or changing their views over time.

Mutual Partnership Context

The mutual partnership context was characterized by the view that NA and BBA partners were equals in the relationship. Participants in this context showed respect and gratitude for their partners’ contributions to the relationship and described mutuality, saying: “We each have ways that we care for each other and look after each other” (self-diagnosed), and, “We have mutual respect and appreciation of each other” (formally diagnosed).

While participants across contexts shared ways that they adapted to meet their BBA partner’s needs, participants in this context were unique in sharing ways that their BBA partners adapted to meet *their* needs as well, indicating a give-and-take within the relationship. For example, one participant described:

I have to be sensitive to how receptive he is at different times. He does try to be sensitive

to my needs too, like trying to remember to say goodnight even though he doesn't understand why it matters to me, and trying to come and talk to me when he is having a break from his studying even though he would mostly rather be alone. (informally diagnosed)

Participants in this context viewed their partners' needs as natural rather than disordered behavior. One participant explained that she had asked her husband to kiss her hello and goodbye and that he "graciously accommodated that request." She added: "Would I like more? Yup. But I also think he deserves to have his needs met too and if that is part of what works best for him so be it" (formally diagnosed).

Several participants noted that their BBA partners expressed love in unique ways, which required them to adjust their expectations for affectionate expression. They stressed the importance of recognizing their own assumptions, which often led them to misinterpret their partners' communications and caused them to feel rejected. One shared:

It is hard for me to understand that the way he loves me is not necessarily the way I do.

He doesn't care about important dates or romantic details. I try to understand what's important to him and that he has a different way to show love. (formally diagnosed)

One participant explained that her husband required alone time after they spend time together and said:

I have had to train myself to recognize that this is not a rejection and to understand that for him this is restorative. Once I realized that it was like a weight lifted for me.

Especially because I stopped wondering what went wrong and could be happy about the fact we had deep and rewarding discourse. (informally diagnosed).

Participants in this context viewed their BBA partners as different, not less, than themselves, and

both partners made effort to become aware of and adapt to their partners' needs.

Companionship Context

Participants in this context viewed their BBA partners positively, referring to them as "good" and "kind," but believed that autistic traits prevented them from being able to form a deep connection. For example, one participant shared:

My husband is a good man, but day to day living is often frustrating and not fulfilling for me. I know he genuinely loves and cares for me, but how he demonstrates that is primarily through loyalty and duty. We can't connect on the deeper aspects of life, which is very challenging for me. It is like we live on different planets when we interact with people. We both "hear" and "experience" a different story because we take it in through a different filter. While fascinating, it is very frustrating. (undiagnosed).

As a result, these participants viewed their relationships as companionships or friendships rather than as romantic. One said, "We have no emotional, physical, and sexual intimacy. ... We enjoy each other's company and give each other practical supportive things. We have shared interests and humor. Basically anything normally seen as a close friendship" (undiagnosed). Another shared, "We are not husband and wife as much as we are cohabitating friends and parenting partners" (informally diagnosed).

Participants expressed resentment at times, but explained that they did not blame their partners. Instead, they believed autism caused circumstances outside their partners' control. For example, one said, "There's a feeling of resentment: 'This is not what I signed up for!' But I know it is not his fault" (formally diagnosed). Participants in this context viewed their partners as lacking abilities that were necessary to form deep intimacy in their relationships due to autism. One participant shared:

I know that he is trying. Now I see the lack of connection between us is due to the fact that he cannot share, understand, or express deep emotions. Things that go along with emotions, that you wouldn't normally consider, are inextricably linked to emotions. Nostalgia, sharing experiences, sharing conversations – all of this is based in some part on emotion, and we can't share any of that. (formally diagnosed)

This participant attempted to understand her partner's perspective, but also saw his worldview as being restricted by autism. She described several things that he "*cannot*" do. In this context, participants pathologized autism in attempt to find understanding and to minimize blame and resentment towards their partner, but this pathologizing ultimately led them to view their partners as limited and left them feeling "lonely," "frustrated," and "wishing for more."

Caregiving Context

Participants in the caregiving context viewed their partners as dependent and saw their relationships as being closer to parent-child dyads than equal partnerships. These participants viewed autism as disabling to their partners and believed that "curing" autism would resolve the issues within their relationships. For example, one said, "I wish I could remove the autism, so we could have a better husband/wife relationship (rather than a parent/child)" (self-diagnosed).

Another shared:

I wish he could be cured of his autism, or at least the more debilitating aspects of it. His disorder has created a caretaker relationship with someone who is not able to be truly conscious of how much work his care requires, and therefore he does almost nothing to alleviate the work, nor can he express gratitude for it in any way that is not extremely difficult and traumatic for him. (informally diagnosed).

Similar to the companionship context, these participants attempted to use pathologizing

as a coping mechanism to separate their partner from autism. However, unlike the companionship context, participants in this context did not speak positively about their partners. For example, one said:

I have to be his parent. Care of our family is mostly my responsibility and my needs go mostly unmet. I feel like a prisoner sometimes inside of all of this. As a woman, I feel like a sack of potatoes. I have to consciously and I mean CONSCIOUSLY remind myself over and over and over that this man is not neurotypical and I can't hold him to those standards or he is nothing but a jerk. I have to remind myself that he is not able to understand what is going on around him and he is constantly at a disadvantage. (self-diagnosed)

Some participants explained that they had initially made adaptations to their relationships willingly, but over time they began to resent these adaptations as their own needs were sacrificed to meet the needs of their BBA partners. This left participants feeling emotionally lonely despite their partners' physical presence. One participant explained:

We communicate best by email and text. But again, I began to feel like his personal assistant. "Put it in writing and send it to me so I can review" is not how an intimate, close relationship should be. Now, I feel terribly alone in my relationship with him despite seeing him all the time. (self-diagnosed; separated).

These participants felt they were single-handedly responsible for maintaining the relationship, which left many feeling "trapped" and "exhausted." Participants emphasized the burdens of the relationships and reported feeling "disappointment" and "sadness."

Detachment Context

Participants in the detachment context believed their relationships were no longer worth

their investment. These participants frequently described a prolonged period of living in the caregiving context prior to entering the detachment context, and eventually gave up on the relationship as a means of self-protection. For example, one participant blamed her relationship for causing her own depression: “I’ve kind of given up. I’m seeing two therapists and taking anti-depressants and am unemployed largely due to this relationship. I don’t have much hope for change. Now I am focusing on self-protection.” (formally evaluated & ruled out for autism diagnosis but NA partner still believes he is autistic). Another shared:

Prior to marrying my husband, I was happy, optimistic, well adjusted, adventurous, spiritual, and had a positive self-esteem. 8 years later, I have become so depressed that it is hard to get out of bed everyday. Some days, I don't recognize myself or my life. I feel like Autism sucked the life out of me! (undiagnosed)

Participants explained that they had lost their sense of self in their attempts to repair their relationships and viewed emotional disconnection as a survival mechanism. When asked what worked well in her relationship, one participant responded, “Nothing but avoiding it. My relationship with my [autistic] husband is the same as a beautiful juicy grape being slowly dried into a raisin. I became a smaller version of myself that is no longer recognized as a grape” (undiagnosed). Another shared: “He is hard wired to be the way he is and no amount of effort on my part will change it. My path to survival has been to completely disconnect emotionally from him” (informally diagnosed).

Participants in this context also described their partners negatively, even dehumanizing them in some cases. One participant shared:

I wish that he could be a feeling human being with genuine caring about me and other people. He has no understanding of my feelings and therefore our marriage is void of all

emotional connection and communication. Addressing our issues only made things worse. My finest strategy has been to give up. I'm being sincere, not sarcastic.
(undiagnosed)

By wishing that he could be a "*feeling human being*," this participant expressed such a level of pathologizing that she viewed her partner as lacking human characteristics. Another said, "He does not seem like a real person to me. I can relate to him, but he cannot do the same in return. There is no real affection. There is no substance to it" (undiagnosed). Others referred to their partners as "robotic" or "like a computer."

Participants described deep feelings of "disappointment" and "loss." One shared, "I've given up. Despair is a constant companion" (self-diagnosed).

Discriminatory Context

Participants in this final context deeply pathologized autism to the point that they made negative generalizations about autism beyond their own relationships. Many discovered the autism label in online communities and applied it as an answer to the challenges they faced in their relationships. For example, one participant shared:

My main support is the internet and [support group name]. It was from the internet that I first realized I was in a [neuromixed] marriage and having online friends has had a life changing effect on me – sometimes even life saving when I have been suicidal.
(undiagnosed)

Several participants shared that they sought traditional counseling, but they felt that their partners "manipulated" counselors and were able to "play the part" to avoid a diagnosis. Many shared that traditional counseling was unhelpful and at times, further damaging. Participants described others in online support groups as their only source of validation and understanding and viewed

them as critical supports in navigating unhappy relationships. For example, one shared that joining a group was “the most important step to dealing with these challenges” (undiagnosed).

She shared that through “learning about autism” and talking to others in her group:

I learned to stop investing so much in my marriage and my husband ... It becomes a destructive sink-hole to try and invest in an [autism] partner the way you would invest in a neurotypical partner because the [autism] partner takes and takes and takes but gives almost nothing back.”

These participants felt an obligation to warn others about the “dangers” of neuromixed relationships, describing neuromixed relationships as “abusive” and “destructive.” They described their autistic partners as “cruel,” “psychopathic,” and “sociopathic.” They also blamed autistics for intentionally deceiving NAs into entering relationships. For example, one shared:

[Neuromixed] relationships are hidden, abusive, soul destroying and spirit breaking for the neurotypical who married in good faith and was conned by the person with [autism]’s ability to role play and deceive in a psychopathic way. ... I recommend no-one enter these relationships. Run away before you’re in too deep. (formally diagnosed but does not self-identify as autistic).

Another said:

I feel betrayed, cheated and robbed. He has never been capable of being a husband or father. I feel like the stupidest thing ever for thinking he would make a good spouse. ... I see now I was chosen because I'm highly empathic, strong, outgoing and not confrontational etc. I have been used and manipulated. I have been robbed and deceived of a real marriage and of myself. (formally diagnosed).

These participants felt that their autistic partners were responsible for causing them

emotional damage. For example, when asked how she attempted to overcome challenges in her relationship, one participant said, “Overcome? There’s no overcoming the behaviors of an [autistic] spouse. The only overcoming is divorce with zero contact after, an impossibility for spouses trapped by disability – usually disability caused by or accelerated by the [autistic] spouse” (formally diagnosed).

One leader of an online group shared her perspective on the dangers of neuromixed relationships:

Most [autistic] males look for a nice, pleasant, happy, out-going female to replace their mom, just another caregiver. The “actor” soon loses his “wonderful person” persona soon after he has hooked the unsuspecting female. It is all downhill for the [NA] partner. She loses her self-esteem, her self-confidence, her place in society, because her [autistic] spouse refuses to mingle with others...Soon she is a mere shell of who she was before...We do not believe that [neuromixed] relationships can be successful. Over the past 20 years we have only heard from a handful of “happy” [NAs], and possibly they were also along the spectrum. (undiagnosed; divorced).

Participants in this context viewed autism as a destructive disease that was not compatible with healthy intimacy.

Discussion

These relationship profiles shed light on the diversity of how autism is viewed by support group users. An important consideration in this study is that less than a third of participants' partners were formally evaluated and diagnosed as autistic, with most participants reporting their partners were informally diagnosed, self-diagnosed, or undiagnosed. In fact, nearly a quarter of participants reported that their partner did not self-identify as autistic. Alarmingly and

importantly, though, when a NA partner in a neuro-mixed relationship seeks support through online peer-led support groups, these are the voices and perspectives they are most likely to hear.

Participant accounts suggest that many individuals applied an autism label to a relationship in which they were already dissatisfied as a possible source of their frustrations. This is a critical distinction that must be explored in future research. While self-diagnosis is common in autism, there has been no research on the accuracy of proxy-diagnosis by partners, and an autism diagnosis should not be presumed. Misdiagnosis of autism even among professionals occurs frequently (Lai & Baron-Cohen, 2015), and therefore it is likely that many participants in this sample were misattributing traits to autism that may be related to other conditions (such as personality disorders or substance use disorder) or simply to differences in emotional maturity or compatibility. Regardless of the reality of the autism diagnosis as applied to these relationships, findings provide an important window into the ways that autism is viewed and discussed by members of “support group” communities for partners of autistics. In other words, findings may actually shed more light on how autism is understood by the general public than on the true nature of neuromixed relationships.

Many participant responses illustrate negative stereotypes about autism that have been identified in previous research, such as autistics being unemotional (MacKenzie, 2018), “child-like,” infantile, or dependent (Botha et al., 2020; MacKenzie, 2018), or that they lack empathy (Fletcher-Watson & Bird, 2020). These stereotypes are not in line with autistic experiences or current understandings of autism (Botha et al., 2020; Nicolaidis et al., 2019). In looking at empathy, for example, current theories propose that there are more likely challenges with bidirectionality of empathy between autistics and non-autistics, that autistics may actually experience too much empathy, or that autistics may need more time to process emotions

(Nicolaidis et al., 2019). Yet, the idea that autistics lack empathy is a common stereotype that permeates general discourse about autism with potentially harmful repercussions.

The impact of media portrayals of autism in television and film (Anjay et al., 2011; Draaisma, 2009; Nordahl-Hansen et al., 2018) and books (Loftis, 2015) are known to contribute to misinformation and reinforcing inaccurate and negative stereotypes about autism. The present study suggests that these stereotypes may also be perpetuated within social media communities intended to support autistics and their families. Stereotypes may lead to exclusion and oppression of autistics as well as internalization of these negative perceptions (Botha et al., 2020; Treweek et al., 2019).

This study has several limitations, and findings should be viewed as a beginning exploration into a complicated area in need of significantly further research. First, this sample represents only individuals who were actively seeking support through online support groups, missing representation from autistics and from non-autistics who were satisfied in their neuromixed relationships. This sample also included many participants whose partners are likely not autistic and many who are no longer in relationships. Again, these findings represent views of those who utilize autistic partner support groups, not necessarily those who are in neuromixed relationships. Future research should explore the experiences of neuromixed couples from both partners' perspectives. This study is further limited by a lack of racial and ethnic diversity. Participants were overwhelmingly White, which limits transferability to non-White populations.

Finally, many participants in this study described poor mental health, troubling relationship dynamics, and unmet need. Their accounts indicate that many happened upon an autism label as a way to make sense of challenging experiences, particularly as many shared that their partners refused to attend counseling or that counseling was ineffective. Future research

should explore ways to support those who are dissatisfied in their relationships and seeking understanding without their partners' participation, primarily as a means to support these individuals, but also as a way of protecting the autism label from being inappropriately applied based on negative stereotypes.

Conclusion

Online support group users who believe their partners are autistic describe a diverse range in their views of autism and its impact on their relationships. A pathological view of autism is common among support group users, and an autism label may be misapplied to unsatisfactory relationships. Such views may be associated with negative relationship outcomes and can perpetuate negative stereotypes about autism. On the other hand, those in the mutual partnership context described relationships characterized by equality, gratitude, and a joint commitment to meeting both partners' needs. Future research should explore ways to assist neuromixed couples in minimizing blame, recognizing each other's strengths, and reciprocal adaptation to one another's differences.

References

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). Arlington, VA: Author.

Anjay, M. A., Palanivel, V., & Palanivel, J. (2011). Beyond stereotypes: A historical analysis of how autism spectrum disorder is depicted in movies, 1962–2010. *Archives of Disease in Childhood*, 96(Suppl 1), A44–A44. <https://doi.org/10.1136/adc.2011.212563.97>

Bentley, K. (2007). *Alone together: Making an Asperger marriage work*. Philadelphia, PA: Jessica Kingsley Publishers.

Botha, M., Dibb, B., & Frost, D. M. (2020). “Autism is me”: An investigation of how autistic individuals make sense of autism and stigma. *Disability & Society*. Advance online publication. <https://doi.org/10.1080/09687599.2020.1822782>

Brownlow, C., Bertilsdotter Rosqvist, H., & O’Dell, L. (2013). Exploring the potential for social networking among people with autism: Challenging dominant ideas of “friendship.” *Scandinavian Journal of Disability Research*, 17(2), 188–193. doi:10.1080/15017419.2013.859174

Draaisma, D. (2009). Stereotypes of autism. *Philosophical Transactions of the Royal Society B: Biological Sciences*, 364(1522), 1475–1480. <https://doi.org/10.1098/rstb.2008.0324>

Fletcher-Watson, S., & Bird, G. (2020). Autism and empathy: What are the real links? *Autism*, 24(1), 3–6. <https://doi.org/10.1177/1362361319883506>

Ford, K. (2016). *Broken: My story of my relationship with an undiagnosed Aspergers partner*. UK: Author.

Gelinas, L., Pierce, R., Winkler, S., Cohen, I. G., Lynch, H. F., & Bierer, B. E. (2017). Using social media as a research recruitment tool: Ethical issues and recommendations. *The*

American Journal of Bioethics, 17(3), 3–14. doi:10.1080/15265161.2016.1276644

Glaser, B. G., & Strauss, A. L. (1967/2010). *The discovery of grounded theory: Strategies for qualitative research*. Aldine Transaction.

Glaser, B. G. (1978). *Theoretical sensitivity*. Sociology Press.

Thomas, H. (2018). Voices of belonging: Building community among autistic adults (Publication No. 10980349). [Doctoral dissertation, University of California, Irvine]. ProQuest Dissertations & Theses A&I.

Hofvander, B., Delorme, R., Chaste, P., Nyden, A., Wentz, E., Stahlberg, O., et al. (2009). Psychiatric and psychosocial problems in adults with normal-intelligence autism spectrum disorders. *BMC Psychiatry*, 9,35. doi: 10.1186/ 1471-244x-9-35.

Holton, J. A., & Walsh, I. (2017). *Classic grounded theory: Applications with qualitative and quantitative data*. Thousand Oaks, CA: SAGE Publications, Inc.

Lai, M.-C., & Baron-Cohen, S. (2015). Identifying the lost generation of adults with autism spectrum conditions. *The Lancet Psychiatry*, 2(11), 1013–1027. doi:10.1016/s2215-0366(15)00277-1

Lehnhardt, F. G., Gawronski, A., Pfeiffer, K., Kockler, H., Schilbach, L., & Vogeley, K. (2013). The investigation and differential diagnosis of Asperger Syndrome in adults. *Deutsches Arzteblatt International*, 110(45), 755–763. doi: 10.3238/arztebl.2013.0755.

Lewis, L. F. (2017). “We will never be normal”: The experience of discovering a partner has autism spectrum disorder. *Journal of Marital and Family Therapy*, 43(4), 631-643. doi:10.1111/jmft.12231

Loftis, S. F. (2015). *Imagining autism; Fiction and stereotypes on the spectrum*. Indiana University Press.

MacKenzie, A. (2018). Prejudicial stereotypes and testimonial injustice: Autism, sexuality and sex education. *International Journal of Educational Research*, 89, 110–118.

<https://doi.org/10.1016/j.ijer.2017.10.007>

Mohd Roffeei, S. H., Abdullah, N., & Basar, S. K. R. (2015). Seeking social support on Facebook for children with Autism Spectrum Disorders (ASDs). *International Journal of Medical Informatics*, 84(5), 375–385. doi:10.1016/j.ijmedinf.2015.01.015

Myhill, G., & Jekel, D. (2008). *Asperger marriage: Viewing partnerships thru a different lens*. Retrieved from https://cdn.ymaws.com/www.naswma.org/resource/resmgr/imported/FCE_AspergerMarriage.pdf

Nicolaidis, C., Milton, D., Sasson, N. J., Sheppard, E., & Yergeau, M. (2019). An expert discussion on autism and empathy. *Autism in Adulthood*, 1(1), 4–11.

<https://doi.org/10.1089/aut.2018.29000.cjn>

Nordahl-Hansen, A., Øien, R. A., & Fletcher-Watson, S. (2018). Pros and cons of character portrayals of autism on TV and film. *Journal of Autism and Developmental Disorders*, 48(2), 635–636. <https://doi.org/10.1007/s10803-017-3390-z>

Rench, C. (2014). When Eros meets Autos: Marriage to someone with Autism Spectrum Disorder (Doctoral dissertation). Retrieved March 21, 2017, from PsycINFO. (3681894).

Strunz, S., Schermuck, C., Ballerstein, S., Ahlers, C. J., Dziobek, I., & Roepke, S. (2016). Romantic relationships and relationship satisfaction among adults with Asperger Syndrome and High-Functioning Autism. *Journal of Clinical Psychology*, 73(1), 113–125. doi:10.1002/jclp.22319

Treweek, C., Wood, C., Martin, J., & Freeth, M. (2019). Autistic people's perspectives on

stereotypes: An interpretative phenomenological analysis. *Autism*, 23(3), 759–769.

<https://doi.org/10.1177/1362361318778286>

Wilson, B., Hay, S., Beamish, W., & Attwood, T. (2017). The communication “roundabout”:

Intimate relationships of adults with Asperger’s syndrome. *Cogent Psychology*, 4(1).

doi:10.1080/23311908.2017.1283828

