

LOVE AND INTIMATE RELATIONSHIPS IN ADOLESCENTS AND ADULTS WITH AUTISM SPECTRUM DISORDERS

Ana Beato¹, & Mariana Correia²
¹Lusófona University, HEI-Lab (Portugal)
²Lusófona University (Portugal)

Abstract

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized, among other criteria, by the presence of repetitive/stereotypical behavior, interests, or activities, and by difficulties in interpersonal relationships and verbal and non-verbal communication with interference in various areas of functioning, such as intimate relationships and sexuality. Preliminary studies reveal that although most wish to relate to other people on an intimate level, several people with ASD tend to isolate themselves and engage in lonely sexual behaviors. Despite the importance of the subject, few studies have looked at it in depth, nor included the meanings of people with ASD about love relationship and sexuality. The main objective of this study is to explore the experience of love relations and intimacy in teenagers and adults with ASD. The design is qualitative, cross-sectional and exploratory. The study included 22 teenagers and adults diagnosed with ASD (63,6% female), to which a semi-structured interview was applied individually, specifically constructed for this study. The interviews were analyzed using thematic analysis. The results highlight the presence of three main themes: Love relationships, Sexuality and Sexual education. Understanding the difficulties and needs of people with ASD will enrich assessment and interventions with teenagers and adults in this area, as well as identifying sex education themes and tools adapted to these populations. The main results show that ASD symptoms negatively affect experiences in love/intimate relationships and in their sexuality. In this way, it becomes imperative to develop a more adequate Sex education program directed to the difficulties presented.

Keywords: *Autism, relationships, sexuality, sexual education.*

1. Introduction

Autism Spectrum Disorder (ASD) is chronic neurodevelopmental condition, characterized by deficits in two central areas – social communication and repetitive and restricted patterns of behavior, interests, or activities (Hosseini & Molla, 2021). Deficits in social communication encompass problems in reciprocity, relationship development and maintenance, and nonverbal communication, while restricted and repetitive patterns should cover at least two of the following: highly restrictive interests, insistence on monotony, hyper- or hyposensitivity to sensory stimuli, or stereotyped movements (American Psychiatric Association [APA], 2014). The diagnostic criteria for ASD in the Diagnostic and Statistical Manual of Mental Disorders – fifth edition (DSM-5) are divided into three levels of intensity: mild, moderate, and severe. In the present study, the emphasis will be on mild autism, also considered as well-functioning autism or Asperger's Syndrome, as it was called in the previous version of the diagnostic manual. This disorder is associated with clinically significant difficulties in social, occupational, or other important areas of current functioning (APA, 2014). Namely, in romantic and intimate relationships and that is why this is the focus of the present study. Consequently, this difficulty can negatively affect the adequate expression of sexuality (Pecora et al., 2016) and therefore the importance of addressing sex education in this study.

In romantic and intimate relationships, the literature has shown that there are usually difficulties in initiating and maintaining romantic and intimate relationships (Bennett et al., 2018). Compared to the neurotypical population, people with ASD show similar levels of interest in relationships (Soares et al., 2021). However, several studies highlighted some differences in this population, such as a delay in the beginning of love relationships (Barnett & Maticka-Tyndale, 2015), their duration seems to be shorter and they are more concerned with their ability to establish and maintain romantic and intimate relationships (Hancock et al., 2020). The difficulties in romantic relationships in this population seem to be due to weak social skills, such as the difficulty in interpreting and responding to communicative signals, language specifics, avoidance of eye contact and the social anxiety that is often felt (Parchomiuk, 2019).

Other difficulties include not knowing how to differentiate intimacy within different types of relationships, uncertainty, or lack of exploration of sexual orientation and difficulty in identifying and expressing one's emotions (Sala et al., 2020).

Regarding sexuality, preliminary studies demonstrate that individuals with ASD were thought to be predominantly “asexual”, as they did not show sexual interest when questioned by researchers (Sala et al., 2020). However, there is growing evidence that most people with ASD, especially those without cognitive impairment, are interested in sexuality (Pecora et al., 2020). Plus, various studies have consistently shown that sexual orientation in people with ASD varies significantly more than in the neurotypical population, with a predominance of non-heterosexual orientations (Dewinter et al., 2015). Gender identity seems to be related to autistic traits, and this population has higher percentages of discomfort with the sex at birth (Turban & van Schalkwyk, 2018).

According to the literature, this population has been harmed in terms of Sexual Education (SE), especially at younger ages. It appears that young people with ASD are getting less education about sexuality, both formally, through school or support services, or informally, through family or social networks. However, some improvements in information about sexual education and health in adults with ASD at an average age of 35 years have been urging, which suggests that sexual knowledge is only being acquired after adulthood (Hancock et al., 2020). In the study by Barnett and Maticka-Tyndale (2015), participants revealed that received SE tends to be thought of for the heterosexual population with neurotypical development. Knowledge about sexuality tends to be characterized by this population as selective and confusing, sometimes creating a distorted image of sexuality (Parchomiuk, 2019). In addition, there is a tendency to use non-formal information such as the internet, television, and pornography, which might reinforce even more distorted and unrealistic representations of sexuality (Teti et al., 2019).

In short, people with ASD, especially those without cognitive deficits, are interested in romantic relationships and sexuality, and difficulties in this area negatively affect the individual and psychosocial well-being of these individuals. Nonetheless, few studies have included the perceptions and personal opinions of ASD youth regarding their love and sexual experiences. The present study aims to improve knowledge about the experiences of romantic relationships and intimacy of people with ASD, to enrich the evaluation and intervention with young people and adults, as well as identify themes and tools of SE adapted to this population, with the intention of providing more positive experiences in these areas that are so important in human life.

2. Methods

The present empirical study has a qualitative, cross-sectional and exploratory design. A non-probabilistic convenience sampling was used, with the following inclusion criteria: a) being at least 15 years old; b) have a diagnosis of well-functioning ASD (level 1); c) without cognitive and/or language impairments.

Participated in the study 22 people diagnosed with ASD, five males (22,7%), 14 females (63,6%), one non-binary (4,5%), one undefined (4,5 %) and a demigirl (4,5%), aged between 15 and 45 years ($M = 23,73$; $SD = 9,89$) recruited in clinical center for autism and in autistic associations from the community. Another relevant sociodemographic characteristic is that almost half of the participants (40,9%) do not feel completely comfortable with the sex they were born into. Regarding sexual orientation, 50% of the sample identifies as heterosexual. It was also explored whether the participants were in a romantic relationship to which 10 participants (45,5%) answered yes.

2.1. Measures

A sociodemographic questionnaire was applied to collect information on age, gender, satisfaction with sex at birth, sexual orientation, location, schooling, marital status, cohabitation, among other relevant data. Subsequently, a semi-structured interview script was used, specifically developed to respond to the objectives of this investigation. The construction of this interview had the collaboration of a psychologist specializing in autism. This interview contained a set of open-ended questions that aimed to explore diverse areas such as the development of sexuality, aspects related to the body and nudity, the relationship with touch, experiences of intimate contacts and sexual behaviors, the development and maintenance of relationships, the characteristics of interest in a partner and the exploration of aspects related to sex education. The interview had an average duration of 40 minutes.

2.2. Procedures

The study was approved by the Scientific Research Ethics and Deontology Committee. It was later publicized in the PIN Autism Center and in the Voz do Autista Association, to bring the participants

together. Initially, assent was requested and then sent an email containing more information about the study and later, informed consent was sent with all ethical and deontological issues, both for young people and their legal representatives and for adults. Before starting the data collection, training in the application of the interviews was carried out. In turn, a pilot interview was carried out with a voluntary participant with ASD, to assess the validity, structure and effectiveness of the list and questions contained in the basic script. Consequently, some questions were adjusted, as well as the reformulation of questions to include clearer, more concrete and inclusive language.

The interviews were carried out from February to July of 2021, by two members of the research team through the Zoom. Before starting the interview, participants were reinforced that they could withdraw at any time and that they did not have to answer all the questions. A maximum limit of participants was not defined a priori, and the collection ended when an acceptable theoretical saturation point was reached.

2.3. Data analysis

The method used was the thematic analysis of Braun and Clarke (2006) as it is a method that allows to identify, analyze, and report patterns in the data, to organize and minimally describe the data set in rich detail and to interpret various aspects of the topic of the investigation (Souza, 2019).

The first step of the analysis was to ensure the familiarization of the data, which was carried out through the transcription and repeated reading of the interviews, to generate relevant initial codes of characteristics of interest in the data, which were later grouped by themes (Braun & Clarke, 2006). Codes were created only for excerpts of interest from the transcripts, there was no coding of the transcripts in full since theoretical thematic analysis was used to capture aspects of interest for the purposes of the study. The themes were reviewed by the second author of the study to check the agreement of the codes with the themes and consequently the relevance of each theme according to the objectives of the study and the existing literature (Braun & Clarke, 2006).

It was verified if the themes worked in relation to the excerpts and the data, to create the thematic map of the analysis (Braun & Clarke, 2006). Themes have been improved, with clear definitions and names. That said, and so that there was agreement in the results, a new analysis was carried out using the NVivo 12 program (QSR International), which confirmed the relevance of the chosen themes to the data.

3. Results

The answers given by the participants were globally rich and often included different themes and sub-themes, so the results do not represent different topics, but interconnected. Three main themes emerged from the thematic analysis - Love relationships, Sexuality and Sex education. On the topic of love relationships, the sub-themes of Development of relationships emerged, PEA has an impact on relationships, Benefits of the relationship, Characteristics of relationships, End of relationships, Characteristics of the partner and Maintenance of relationships. On the topic of sexuality, the sub-themes of (Dis)Interest, Masturbation, Touch, Hyper or hypo sensitivities and Sexual activity were addressed. On the topic of Sexual Education, the sub-themes of Sexual Knowledge, Sources of Information, Sexual Education aimed at people with neurodevelopmental disorders and Intervention in sexuality emerged.

4. Discussion

The majority of our participants revealed great interest in getting involved in romantic and intimate relationships, which is in line with exploratory studies carried out in other countries that pointed to the similarities between people with ASD and neurotypical people in relation to the need, motivation, appreciation of romantic relationships and of intimacy for their quality of life (Hancock et al., 2020). In addition, the results seem to show benefits, that is, the positive and probably protective role of romantic and intimate relationships in the individual well-being of people with ASD. For many of our participants, romantic and intimate relationships have an impact on the improvement of anxiety symptoms and are important reinforcers of their self-esteem. This result is in line with previous studies that have already verified that social support works as a moderator for depression levels in this population (Radoeva et al., 2021).

Participants are also aware of the impact that their ASD-associated characteristics have on romantic and intimate relationships. Weak social skills, namely difficulty in reading and meaning social cues, difficulty in interpreting other's (dis)interest, or problems in reciprocity, were described as obstacles to the development and maintenance of intimate relationships. These results are in line with results from previous qualitative studies that showed that autistic individuals have a different understanding of the

processes and mechanisms associated with social interactions (Hogan & Micucci, 2020), which reduces the proximity with peers and, consequently, with possible loving and intimate partners (Stokes et al., 2007). Participants were concerned about their difficulties in approaching the person of interest, in the process of flirting and dating. This result had also been evidenced in a preliminary study, demonstrating that people with ASD present higher levels of concern with the ability to develop and maintain romantic relationships, experiencing higher levels of anxiety in the first meeting and when they start a relationship with the person of interest when compared to neurotypical people (Hancock et al., 2020).

In fact, the results show that, in most cases, there is anxiety involved in the process of developing love relationships, specifically in the processes inherent to initiating a relationship (Mehzabin & Stokes, 2011). This anxiety seems to be interfering in the romantic and intimate relationships of people with ASD, reducing the attempts of loving approximations, as suggested by Glickman and Le Greca (2004), making it imperative to develop an intervention aimed at anxiety and flirt and dating processes, with the aim of helping this population in the processes of development and maintenance of romantic and intimate relationships.

Another difficulty found in the present study is the maintenance of romantic and intimate relationships, as the participants reveal that they have difficulty in decentering themselves, their activities, tastes and routines, facing the acceptance and integration of the other as the main challenge. The literature indicates that reciprocal likes/interests are a determining factor that people with ASD consider when choosing a loving partner (Yew et al., 2021). Our participants point out in this regard having a neurodivergent partner can be a facilitator. This evidence suggests that people with ASD look for characteristics in romantic partners that are like their own, making this contribute to the maintenance, duration and satisfaction of the romantic and intimate relationship, even if it is not a guarantee of longevity of the relationship (Hancock et al., 2020).

In terms of sexuality, although there seems to be difficulty in identifying this interest, there was a relationship between humor and sexual interest insofar as humor influences (dis)interest. The results also demonstrate that there is discomfort with touch. The most frequent behavioral responses to touch are avoidance or strategies to withstand touch, and these responses are influenced by touch predictability, intentionality and mood. These results are consistent with the literature, that avoidance and aversion to social touch are associated with ASD traits, which seems to be a consequence of hypersensitivities, thus causing aversion to touch and possible stereotyped behaviors (Ujii & Takahashi, 2022). However, if it is a touch in an intimate context, it is already better accepted by these individuals, probably due to their underlying ideas of social norms and what is accepted/expected by society. Hypersensitivities also affect sexuality (e.g., intimate contact and masturbation) and intimate/sexual relationships (e.g., contraception). In parallel, masturbation was addressed and the associated feelings were shame, discomfort and dissatisfaction.

The results show that people with ASD have little knowledge about higher education, and the information they have was acquired through non-formal information sources. Higher education programs continue to focus on the mechanics of sex and contraception rather than on socio-emotional skills and intimacy. With these results, it was realized the need for a SE directed to this population, in which the specific difficulties of the diagnosis, such as social communication, non-verbal language interpretation, signs of reciprocity were addressed (Yew et al., 2021), processes underlying flirt, reduction of anxiety in approaching the person of interest, the process of initiating a romantic relationship and moving to the intimate/sexual part, if they so desire, as well as including the discovery of sexual and gender identity.

4.1. Limitations, future directions, and implications of the study

This study has some limitations, namely in terms of the characteristics of the sample and the possibility of reactivity to the assessment, as this is a sensitive and intimate topic. As this is a topic that has not yet been studied and there are many gaps in the literature, we suggest that further qualitative investigations be carried out. It would also be pertinent to explore these issues with more specific age groups, since our study included people at different stages of development. However, this study is already an important contribution to scientific research and clinical practice, in the sense that it allows the understanding of experiences related to romantic relationships and sexuality, the identification of the main difficulties in these areas and the pertinent themes to address for the intervention in sexuality among this population.

References

American Psychiatric Association [APA] (2014). *DSM-5: Manual diagnóstico e estatístico de transtornos mentais*. Artmed Editora.

- Barnett, J. P., & Maticka-Tyndale, E. (2015). Qualitative exploration of sexual experiences among adults on the autism spectrum: implications for sex education. *Perspectives on sexual and reproductive health, 47*(4), 171- 179. <https://doi.org/10.1363/47e5715>
- Barnett, J. P., & Maticka-Tyndale, E. (2015). Qualitative exploration of sexual experiences among adults on the autism spectrum: implications for sex education. *Perspectives on sexual and reproductive health, 47*(4), 171-179. <https://doi.org/10.1363/47e5715>
- Bennett, M., Webster, A. A., Goodall, E., & Rowland, S. (2018). Intimacy and romance across the autism spectrum: Unpacking the “Not Interested in Sex” myth. In *Life on the Autism Spectrum* (pp. 195-211). https://doi.org/10.1007/978-981-13-3359-0_10
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*(2), 77-101. <https://doi.org/10.1191/1478088706qp063oa>
- Dewinter, J., Vermeiren, R., Vanwesenbeeck, I., Lobbetael, J., & Van Nieuwenhuizen, C. (2015). Sexuality in adolescent boys with autism spectrum disorder: Self-reported behaviours and attitudes. *Journal of autism and developmental disorders, 45*(3), 731-741. <https://doi.org/10.1007/s10803-014-2226-3>
- Glickman, A. R., & La Greca, A. M. (2004). The Dating Anxiety Scale for Adolescents: Scale development and associations with adolescent functioning. *Journal of Clinical Child and Adolescent Psychology, 33*(3), 566-578. https://doi.org/10.1207/s15374424jccp3303_14
- Hancock, G., Stokes, M. A., & Mesibov, G. (2020). Differences in romantic relationship experiences for individuals with an autism spectrum disorder. *Sexuality and Disability, 38*(2), 231-245. <https://doi.org/10.1007/s11195-019-09573-8>
- Hosseini, S. A., & Molla, M. (2021). Síndrome de Asperger. Em StatPearls. StatPearls Publishing. <https://pubmed.ncbi.nlm.nih.gov/32491480/>
- Mehzabin, P., & Stokes, M. A. (2011). Self-assessed sexuality in young adults with highfunctioning autism. *Research in autism spectrum disorders, 5*(1), 614-621. <https://doi.org/10.1016/j.rasd.2010.07.006>
- Oliveira, G. G. D. (2005). Epidemiologia do autismo em Portugal: um estudo de prevalência da perturbação do espectro do autismo e de caracterização de uma amostra populacional de idade escolar (Doctoral dissertation). <http://hdl.handle.net/10316/848>
- Parchomiuk, M. (2019). Sexuality of persons with autistic spectrum disorders (ASD). *Sexuality and Disability, 37*(2), 259-274. <https://doi.org/10.1007/s11195-018-9534-z>
- Pecora, L. A., Mesibov, G. B., & Stokes, M. A. (2016). Sexuality in high-functioning autism: A systematic review and meta-analysis. *Journal of autism and developmental disorders, 46*(11), 3519-3556. <https://doi.org/10.1007/s10803-016-2892-4>
- Radoeva, P. D., Ballinger, K., Ho, T., Webb, S. J., & Stobbe, G. A. (2021). Brief Report: Risk and Protective Factors Associated with Depressive Symptoms among Autistic Adults. *Journal of Autism and Developmental Disorders, 1-6*. <https://doi.org/10.1007/s10803-021-05085-7>
- Sala, G., Pecora, L., Hooley, M., & Stokes, M. A. (2020). As Diverse as the Spectrum Itself: Trends in Sexuality, Gender and Autism. *Current Developmental Disorders Reports, 1-10*. <https://doi.org/10.1007/s40474-020-00190-1>
- Soares, L. S., Alves, A. L. C., Costa, D. D. S., Malloy-Diniz, L. F., Paula, J. J. D., Romano-Silva, M. A., & Miranda, D. M. D. (2021). Common Venues in Romantic Relationships of Adults with Symptoms of Autism and Attention Deficit/Hyperactivity Disorder. *Frontiers in Psychiatry, 12*, 958. <https://doi.org/10.3389/fpsy.2021.593150>
- Teti, M., Cheak-Zamora, N., Bauerband, L. A., & Maurer-Batjer, A. (2019). A qualitative comparison of caregiver and youth with autism perceptions of sexuality and relationship experiences. *Journal of Developmental & Behavioral Pediatrics, 40*(1), 12-19. <https://doi.org/10.1097/DBP.0000000000000620>
- Turban, J. L., & van Schalkwyk, G. I. (2018). “Gender dysphoria” and autism spectrum disorder: Is the link real?. *Journal of the American Academy of Child & Adolescent Psychiatry*. <https://doi.org/10.1016/j.jaac.2017.08.017>
- Ujiie, Y., & Takahashi, K. (2022). Associations between self-reported social touch avoidance, hypersensitivity, and autistic traits: Results from questionnaire research among typically developing adults. *Personality and Individual Differences, 184*, 111186. <https://doi.org/10.1016/j.paid.2021.111186>
- World Health Organization [WHO]. (2019). Autism spectrum disorders. <https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders>
- Yew, R. Y., Samuel, P., Hooley, M., Mesibov, G. B., & Stokes, M. A. (2021). A systematic review of romantic relationship initiation and maintenance factors in autism. *Personal Relationships*. <https://doi.org/10.1111/pere.12397>