### **REVIEW ARTICLES**

# Psychosexual education and training for adolescents with autism spectrum disorder: a systematic review

## Educação e treino psicossexual para adolescentes com perturbação do espetro do autismo: revisão sistemática

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#### ABSTRACT

**Introduction:** Adolescents with autism spectrum disorder (ASD) may have limited access to reliable information on puberty and sexuality, and the core symptoms of ASD can lead to problems in romantic and sexual functioning, like engaging in less appropriate sexual behavior. Therefore, these adolescents may benefit from specialized psychosexual training programs.

Objectives: To review the existing literature about psychosexual education and psychosexual training for adolescents with ASD.

Methods: Systematic literature review.

**Results and Discussion:** Sexual education programs targeting adolescents with ASD are scarce. The only adolescent-centered psychosexual training program that can currently be found in the literature is the Tackling Teenage Training (TTT) program, in which adolescents with ASD receive psychoeducation and practice communicative skills regarding topics related to puberty, sexuality, and intimate relationships. Statistically significant improvements in psychosexual knowledge, interpersonal boundaries, and social functioning are often described with the TTT program. On the other hand, the impact of the program on decreasing aggressive or problematic sexual behavior, decreasing worries about the future, and transferring the acquired knowledge to everyday life is more inconsistently reported.

**Conclusion:** TTT seems to be an effective psychosexual educational program for adolescents with ASD, but further research on the translation of acquired knowledge into practice, improvement of romantic relational skills, and prevention of problematic sexual behavior and victimization is required. Since adolescents with ASD have the right to date, greater investment should be placed in sexual education programs specifically addressing the needs of this population.

Keywords: autism spectrum disorder; psychosexual education; psychosexual training; social-sexual functioning

#### **RESUMO**

Introdução: Os adolescentes com perturbação do espetro do autismo (PEA) podem ter acesso limitado a informação de qualidade acerca da puberdade e sexualidade. Os principais sintomas de PEA podem resultar em problemas nas relações de intimidade e funcionamento sexual, bem como em comportamentos sexuais inapropriados. Assim, programas especializados de treino psicossexual poderão ser benéficos para estes jovens.

**Objetivos:** Rever a literatura existente sobre programas de psicoeducação e treino psicossexual para adolescentes com PEA. **Métodos:** Revisão sistemática da literatura.

Resultados e Conclusão: Os programas de educação sexual dirigidos a adolescentes com PEA são escassos. O único programa de treino psicossexual

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centrado em adolescentes atualmente disponível na literatura é o *Tackling Teenage Training* (TTT), no qual os adolescentes com PEA recebem psicoeducação e praticam estratégias comunicacionais relacionadas com puberdade, sexualidade e relações íntimas. A aplicação do TTT associase de forma consistente a aumentos significativos do conhecimento psicossexual, compreensão dos limites interpessoais e funcionamento social. Por outro lado, o impacto do programa na diminuição dos comportamentos sexuais agressivos ou problemáticos, diminuição das preocupações acerca do futuro e transferência do conhecimento aprendido para o dia-a-dia é descrito de forma mais inconsistente.

**Conclusão:** O TTT parece ser um programa de educação psicossexual eficaz para adolescentes com PEA, mas é necessária mais investigação acerca da aplicação prática do conhecimento adquirido, melhoria das competências de relacionamento romântico e prevenção de comportamentos sexuais problemáticos e vitimização. Deve ser feito um maior investimento em programas de educação sexual dirigidos às necessidades específicas desta população.

Palavras-chave: educação psicossexual; funcionamento socio-sexual; perturbação do espetro do autismo; treino psicossexual

#### INTRODUCTION

Dating can be challenging for everyone, but even more so for individuals with autism spectrum disorder (ASD).

A very small percentage of adolescents with ASD date and, unlike early reports in the literature, that often happens because they do not know how to, and not for being asexual or not wanting to date.<sup>(1–5)</sup>

A study from 2017 about sexual orientation, gender identity, and romantic relationships in 675 adolescents and adults with ASD from the Netherlands showed that 50% were in a relationship.<sup>(6)</sup> However, only 74 of these were adolescents. Another study focusing on adolescents and young adults (16–25 years of age) revealed that around 80% were not dating.<sup>(7)</sup>

In fact, most individuals with ASD report a general interest in solitary and dyadic sexual behaviors and express a desire to engage in romantic and/or sexual relationships.<sup>(3)</sup> Adults with ASD report comparable levels of sexual desire and sexual satisfaction as adults without the condition.<sup>(3)</sup> This desire seems to be even more relevant for higher-functioning individuals and females.<sup>(4,5)</sup>

Difficulties with social communication, social-emotional reciprocity, and relationship maintenance are not the only obstacles these individuals face. Other ASD symptoms, like repetitive or restricted behavior, sensory interest and challenges regarding sensory processing, or cognitive rigidity, can intensify those difficulties.<sup>(4,8)</sup> This can lead to problems in romantic and sexual functioning, like less appropriate sexual behaviors (e.g., public or excessive masturbation, indecent exposure, inappropriate heterosexual behavior, and paraphilic sexual interest).<sup>(2)</sup> In addition, comorbid psychopathology, history of sexual abuse, and community isolation can also be present.<sup>(9,10)</sup>

Adolescents with ASD can have limited access to reliable information on puberty and sexuality.<sup>(4)</sup> Psychosexual knowledge stems from education about concepts related to sexual activity, behavior, and emotions (e.g., understanding the meaning of "erection", "attraction", "boundary crossing behavior", etc.).<sup>(9)</sup> The literature reports that psychosexual knowledge improves decision-making regarding psychosexual behavior in neurotypical adolescents.<sup>(11,12)</sup> Therefore, adolescents with ASD are likely to benefit from specialized psychosexual education and training.

#### **OBJECTIVES**

The aim of this study was to review the available literature about psychosexual education and training for adolescents with ASD.

#### **METHODS**

A systematic literature review was conducted following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.<sup>(13)</sup> To do so, a search was conducted on PubMed, Embase, and Cochrane Library databases in September 2019 using the terms "psychosexual", "education", "training", "autism", "spectrum", and "disorder". The search strategy included all types of scientific articles. Of 13 records identified through database search, five were duplicates and therefore excluded. The remaining eight records were screened for relevance, resulting in the additional exclusion of one record. One additional record was identified through other sources (consultation of the Research Gate profile of one of the study authors), reaching the final number of eight studies included in the review (**Figure 1**).

Of the studies retrieved, the reviews by Hancock, Stokes, and Mesibov (2017) and Turner, Briken, and Schöttle (2017) were exclusively used in the 'Psychosexual Education' section. Of the two articles concerning the randomized controlled trial by Visser *et al.* (2017), one was the study protocol (Visser *et al.* 2015). A summarized description of the remaining five studies is depicted in **Table 1**.

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Figure 1 - Flowchart of the selection process of articles included in the review

#### **RESULTS AND DISCUSSION**

#### **Psychosexual Education**

The understanding of sexual, romantic, and social aspects of life is developed through a range of informal and formal avenues of sexual health education.<sup>(4)</sup> This is received informally through interaction with peers and family and formally through school-based curricula.

In general, individuals with ASD have a weaker understanding of these aspects because they have fewer opportunities for appropriate informal and formal sexual health education.<sup>(4)</sup> This is due to having less peer engagement and relationship experience, more parental guidance, and greater use of online materials; receiving more support from wellbeing services; having greater difficulty following and adhering to privacy norms, engaging in less social behavior; reportedly engaging in less appropriate sexual behavior; being subject to and having greater concerns about their future; and receiving less school-based sexual health education.<sup>(4)</sup> Higher levels of sexual and

gender diversity in this group, which is particularly relevant for those of the female sex, may also play a role.<sup>(4,5)</sup>

Romantic and sexual relationships become increasingly important and complex during adolescence. This makes the difficulties of adolescents with ASD more apparent because their subpar social skills fail to accompany the growing social demands of this period, on the one hand, and because they are often excluded from peer discussions about sexuality, on the other.<sup>(5)</sup>

Due to having fewer friends and close friendships compared to their neurotypical peers and to parents' reluctance in providing them with comprehensive sexual education, adolescents with ASD receive less information about sexuality from these sources.<sup>(14)</sup> This makes them more dependent on non-social sources, such as the internet, resulting in less (or less accurate) psychosexual knowledge. These adolescents usually have few intimate and sexual experiences and can report sexual frustration and preoccupations, which increase the risk of developing or becoming a victim of inappropriate sexual behaviors.<sup>(14)</sup>

Possibly due to support services and increased social behavior of

these individuals with age, the sexual health knowledge of adults with ASD seems adequate, despite the also apparent greater association with past inappropriate sexual behaviors and exposure to unwanted sexual contacts.<sup>(4)</sup> Additionally, being in a relationship with another autistic person is reported to lead to higher relationship satisfaction.<sup>(5)</sup>

Study	Type of study	Sample	Main findings
Visser et al. (2012)	Pilot study (preliminary outcomes)	19 adolescents with ASD	Increase in psychosexual knowledge and social skills; decrease in adolescent worries about the future; increase in parental worries about the future autonomy of the adolescent
Dekker <i>et al.</i> (2015)	Pilot study	30 adolescents with ASD	Increase in psychosexual knowledge, particularly regarding sexual selfhood and behaviour and particularly for younger adolescents and those who showed more difficulty with the content of the sessions; transfer of the learned psychosexual knowledge to every-day life
Balcells <i>et al.</i> (2015)	Pilot study	28 adolescents with ASD	Increase in psychosexual knowledge
Calvo Escalona et al. (2016)	Pilot study	22 adolescents with ASD	Increase in psychosexual knowledge and social functioning, particularly for younger adolescents and those with a lower verbal IQ or greater severity of stereotyped behaviours and restricted interests; decrease in aggressive behaviour
Visser <i>et al.</i> (2017)	R a n d o m i z e d controlled trial	189 adolescents with ASD	Increase in psychosexual knowledge, insight in adequate interpersonal boundaries, social functioning, and romantic relational skills; decrease in problematic sexual behaviours for both the intervention and the control group over time; gains still statistically significant at 6 months follow-up

	Table 1 - Summary of	published studies investigating the effects of	TTT program in adolescents with ASD
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ASD, autism spectrum disorder, IQ, intelligence quotient; TTT, Tackling Teenage Training

#### **Psychosexual Training**

Psychosexual education programs targeting adolescents with ASD are scarce. Programs can be found, like the Supporting Teens with Autism on Relationships program, which is a parent trainingbased program, and the Organization for Autism Research (OAR) online Sex Education Guide for Self-Advocates, which is a sexuality and sex education resource specifically written for people on the autism spectrum aged 15 and above, currently not accessible in the literature.<sup>(15)</sup> However, the only psychosexual training intervention directly targeting adolescents currently available in the literature is the Tackling Teenage Training (TTT) program, developed in 2011 in the Netherlands.<sup>(16)</sup>

This training program is directed at adolescents aged 12 to 18 years old with ASD and a total intelligence quotient (IQ) of 80 or higher. It is customizable to the individual characteristics and needs of the adolescent and able to adapt the education of psychosexual and interpersonal abilities to his/her knowledge level and functioning. TTT consists of 18 one-hour-long individual weekly sessions with a trained psychologist (in a total duration of approximately six months), in which adolescents with ASD receive psychoeducation and practice communication skills regarding topics related to puberty, sexuality, and intimate relationships. The sessions cover the following subjects: discussing puberty, appearances, first impressions, physical and emotional developments in puberty, how to become friends and maintain a friendship, falling in love and dating, sexuality and sex, pregnancy, setting and respecting boundaries, and internet use. After each session, and with the adolescent's permission, the trainer also updates and psychoeducates parents, to prepare them for any questions or remarks, thus enhancing training generalization.<sup>(12)</sup>

Preliminary outcomes of a pilot study of this program with 19 adolescents with ASD were presented at the 20th World International Association for Child and Adolescent Psychiatry and Allied Professions (IACAPAP) Congress in 2012 and showed that training seemed to significantly increase psychosexual knowledge.<sup>(17)</sup> There was an increase in meaningful friendships and a decrease in the difficulty in establishing friendships and in adolescents' insecurity and worries about the future. However, there was an increase in parental worries about adolescents' future autonomy (**Table 1**).<sup>(17)</sup>

Three years later, the same team reported the outcomes of said pilot study, including 30 cognitively able (total IQ score  $\geq$ 75) adolescents aged between 11 and 19 years with clinical diagnosis of ASD, 23 of whom male.<sup>(12)</sup> Outcome data were retrieved through a pre- and post-training psychosexual knowledge test. Parental perception of their children's improvement was also evaluated. Results showed that the overall psychosexual knowledge significantly increased, particularly regarding sexual selfhood and behavior. Younger adolescents and those showing more difficulty with sessions' content had a greater increase in psychosexual knowledge. Most parents perceived a transfer of acquired psychosexual knowledge to the everyday life (**Table 1**).<sup>(12)</sup> However, this study had limitations, as the absence of a control group, small sample size, male preponderance, and the fact that it used the same pre- and post-training, which may have caused a learning effect and affected results.

Also in 2015, a Spanish team of researchers presented at the 16<sup>th</sup> International Congress of the European Society for Child and Adolescent Psychiatry (ESCAP) the results of their pilot study, which aimed to adapt the TTT program to the Spanish ASD adolescent population.<sup>(18)</sup> The study included 28 adolescents with ASD and IQ >80, but only 16, with a mean age of 15.62 years, completed the program. Researchers applied the Social Responsiveness Scale (SRS), Child Behaviour Checklist (CBCL), and Knowledge Test (KT) about human biology before and after training. Study results showed a significant improvement in sexual knowledge, but not in social communication skills or CBCL score (**Table 1**).<sup>(18)</sup>

The following year, the same Spanish group presented the results of a second pilot study at the 63<sup>rd</sup> Annual Meeting of the American Academy of Child and Adolescent Psychiatry (AACAP), this time with the previously Spanish-translated version of the TTT program.<sup>(19)</sup> They aimed to examine the feasibility and treatment efficacy of the Spanish version on the adolescent ASD Spanish population. The study included 22 adolescents aged 12–18 years (mean age of 15.05 years) with diagnosis of ASD and verbal IQ >80. SRS, KT, and CBCL were applied pre- and post-training. Significant improvements in social impairment and sexual knowledge and decreased aggressive behavior were reported among adolescents. Lower pre-treatment age and verbal IQ and greater severity of stereotyped behaviors and restricted interests were positively associated with greater improvement in social impairment and sexual knowledge (**Table 1**).<sup>(19)</sup>

Finally, in 2017, the Dutch team that developed the TTT program published the results of their one-year randomized controlled trial investigating the effects of the program on cognitive outcomes (as psychosexual knowledge and insight in interpersonal boundaries) and behavioral outcomes (as skills needed for romantic relationships and problematic sexual behavior).<sup>(14,20)</sup> The study included 189 adolescents with ASD and IQ >85, aged 12-18 years old, who were randomized to an intervention group and a waiting-list control group. Adolescents displaying offensive sexual behaviors were not eligible for the study. Researchers applied self-reported and parent-reported questionnaires (psychosexual knowledge test, interpersonal boundaries scale, SRS, CBCL) at baseline, post-treatment, and sixmonth follow-up. The TTT program resulted in higher psychosexual knowledge and better insight of adequate interpersonal boundaries for all the 83 adolescents with ASD who completed it. It also resulted in higher social functioning in younger adolescents completing the program. These gains remained statistically significant at the sixmonth follow-up (i.e., 12 months from baseline). In addition, this study reported a statistically significant increase in social functioning and romantic relational skills and a statistically significant decrease in problematic sexual behaviors over time, both for the intervention and control groups (Table 1).<sup>(14,20)</sup> The authors proposed that these findings could translate the natural development of ASD adolescents over the course of one year and/or could represent retest effects. This study found no statistically significant differences between the intervention and control groups regarding an improvement in romantic relational skills or a decrease in problematic sexual behaviors. As possible explanations for this, the authors suggested that the improvement of relational skills was not the primary program focus, as training was individualized and adolescents were not given the chance to practice skills with peers; measurement errors; insufficient validity of the questionnaires used; and insufficient follow-up time, as six months might not be long enough for ASD adolescents to transfer their knowledge and insight into actual behavioral changes.

#### CONCLUSION

Adolescents with ASD may have difficulty accessing appropriate informal and formal sexual health education. These difficulties can lead to poor future outcomes and great personal concern about the future.

Although the evidence suggests that adolescents with ASD have specific needs for specialized training programs about psychosexual functioning, TTT is the only psychosexual educational program currently found in the literature specific for this population.

The literature consistently describes statistically significant increases in psychosexual knowledge in adolescents with ASD who complete the TTT program, and that these seem to be stronger in younger adolescents and in those with greater difficulty with sessions' content, lower verbal IQ, greater severity of stereotyped behaviors, and restricted interests.

Statistically significant improvements in interpersonal boundaries' insight and social functioning, particularly in younger adolescents, are also often described with TTT. Conversely, decreased aggressive or problematic sexual behaviors, less worries about the future, and transfer of acquired knowledge to the everyday life are more

inconsistently reported. The most recent study focusing this program also indicates that gains obtained are maintained for up to six months post-treatment.

Although the natural development of ASD adolescents is associated with improved social functioning and romantic relational skills and decreased problematic sexual behaviors with age, the TTT program appears to be an effective psychosexual educational program for this population, particularly for younger adolescents and those with more socially impairing symptoms and higher likelihood of social exclusion or victimization.<sup>(4,19,20)</sup> Although the program has only been studied in normal IQ youths so far, results retrieved from the present analysis suggest that it might also be useful for low-functioning ASD teenagers with inappropriate sexual behaviors (hypermasturbation, public masturbation, inappropriate romantic gestures, inappropriate arousal, and exhibitionism), for whom data about effective educational interventions is sparse.<sup>(21)</sup>

Research is lacking about teenagers' ability to put the acquired knowledge into practice, improvement of romantic relational skills, and prevention of problematic sexual behaviors and victimization. It is important to understand if the considered intervention has a long-term positive impact in decreasing the sexual vulnerability of ASD adolescents and in promoting a safer and better-informed transition into a satisfactory sexual and romantic life in adulthood. More randomized controlled trials with larger samples, longer follow-up, and direct observation of relational and intimate behavioral skills are required.

The individual's social and sexual wellbeing has a central role in his/her quality of life, and a healthy psychosexual development may sometimes require specialized assistance. Since adolescents with ASD have the right to date, greater investment should be placed in sexual education programs specifically addressing the needs of this population.

#### **AUTHORSHIP**

Luísa Duarte – Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Project administration; Resources; Visualization; Writing – original draft; Writing – review & editing

Raquel Figueiredo - Data curation; Formal analysis; Investigation; Writing – review & editing

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