TACKLING TEENAGE

A randomized controlled trial to examine a psychosexual training program for adolescents with autism spectrum disorder (ASD)

Kirsten Visser

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‘Laten we helemaal onszelf worden, niet wie we denken dat anderen wilden dat we waren’

Griet Op de Beeck

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CHAPTER 1

General introduction

AUTISM SPECTRUM DISORDERS

An autism spectrum disorder (ASD) is a neurodevelopmental disorder, characterized by difficulties in social communication, and restricted, repetitive behavior and interests (American Psychiatric Association, 2013; Lai, Lombardo, & Baron-Cohen, 2014). In the last decade, research has suggested that ASD exists at the extreme end of a social communication impairment continuum. In the general population, the continuum extends from zero or a few autistic traits to a very large number of traits, exceeding the threshold necessary to meet the criteria for a diagnosis of ASD (Constantino & Todd, 2003; Robinson et al., 2011). In the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5), the different pervasive developmental disorders from DSM-IV-TR (i.e. Autistic Disorder, Asperger's Syndrome, and Pervasive Developmental Disorder – Not Otherwise Specified), were replaced by one classification 'Autism Spectrum Disorder', that can be further specified in severity with the labels mild, moderate or severe (American Psychiatric Association, 2013). Someone can be classified with ASD when portraying persistent deficits across multiple social contexts on both domains of symptoms (i.e. 1. social communication and social interaction, and 2. restricted, repetitive patterns of behavior, interests or activities) (American Psychiatric Association, 2013). In this way, the classification became more stringent, because under DSM-IV-TR, it was still allowed to provide a diagnosis of PDD-NOS if a person only met criteria on one symptom domain. The participants in the study described in this thesis were diagnosed using the DSM-IV-TR criteria (American Psychiatric Association & American Psychiatric Association, 2000) since these were still used in the Netherlands at the time of data collection for the current study. More specifically, 18% of the participants had a diagnosis Autistic Disorder, and 82% a diagnosis of PDD-NOS/Asperger's Syndrome.

In the past decades, the awareness and knowledge of ASD has increased, especially identifying more people with ASD that are cognitively normal or high functioning (Lai et al., 2014). Recent studies show that approximately 55% of people with ASD have normal or even exceptionally high intellectual abilities (Goldberg Edelson, 2006; Lai et al., 2014). Furthermore, because more people know about ASD, there is an increased awareness among professionals and parents, improving recognition and detection. The understanding of ASD has evolved substantially in the past 70 years, with a rapid increase in scientific publications starting in the mid-90s (Lai et al., 2014). Due to an increase in available diagnostic services and the more widespread acceptance that autism can coexist with a range of other conditions (for instance together with attention deficit hyperactivity disorder; ADHD), more children are diagnosed with ASD (Baird et al., 2006; Baron-Cohen et al., 2009; Charman, 2002; Fombonne, 2003; Williams, Higgins, & Brayne, 2006). Finally, in recent years, more women are diagnosed with ASD, challenging the perception that ASD is a predominantly male disorder (Baron-Cohen et al., 2011; Begeer et al., 2013).

ASD is a pervasive disorder, meaning that the impairments are usually lifelong and noticeable across multiple contexts. However, the expression can vary across the lifespan (American Psychiatric Association, 2013). Although neurobiology and cognition are known to be involved in the development of ASD, until now, no drugs are available that target the core symptoms of ASD, and the most effective interventions are behavioral and educational (Lai et al., 2014). Therefore, most people with ASD need lifelong guidance and support and for that reason the economic impact of ASD is high (Jarbrink & Knapp, 2001). The communication and social difficulties that are the core of ASD can affect all areas of life. Adults with ASD are known to experience difficulties in engaging in socially appropriate behaviors and in gaining and maintaining employment and the majority of young adults with ASD remain dependent upon others, often their family (Howlin, Goode, Hutton, & Rutter, 2004). Approximately 58–78% of adults with ASD have poor or very poor outcomes in terms of independent living, educational attainment and employment (Billstedt, Gillberg, & Gillberg, 2005; Eaves & Ho, 2008; Howlin et al., 2004). In addition, due to their difficulties in developing and maintaining intimate relationships, only about 5-10% of the people with ASD succeed in an intimate relationship (Levy & Perry, 2011). These examples can result in long-lasting negative effects, including low quality of life, depression, anxiety, low self-esteem, and isolation (Billstedt et al., 2005; Eaves & Ho, 2008; Howlin et al., 2004). Higher childhood intelligence, communicative phrase speech before the age of 6, and fewer childhood social impairments predict a better societal outcome (Howlin, 2003). But even for people with ASD without an intellectual disability, adult outcome is often unsatisfactory in terms of quality of life and achievement of occupational potential (Howlin, Moss, Savage, & Rutter, 2013).

ADOLESCENCE AND ASD

Each transition in life can increase existing problems and create new problems for a person with ASD. Transitions can be considered stressful life events and as periods of increased vulnerability, due to increased uncertainty and loss of sources of social support (Beresford, 2004; Compas, 1987). In the period from childhood to adulthood, known as adolescence, a child is exposed to many transitions, for instance changing from elementary school to secondary education (Martínez, Aricak, Graves, Peters-Myszak, & Nellis, 2011). In adolescence many physical, social and emotional changes take place and the demands from society change. Adolescents require a whole set of new skills and knowledge to cope with these changes and changing demands (Dahl, 2004; Santrock, 2005). Due to the difficulties with changes that people with ASD experience, the physical developments as a result of puberty (e.g. the growth of secondary sex characteristics) can cause extra challenges, insecurity and anxiety and require the learning of new routines (e.g. menstruation hygiene)

(Delfos & Gottmer, 2008; Tissot, 2009). Several early studies regarding adolescence and ASD assumed that the physical development of adolescents with ASD was not different from that of adolescents in the general population and that the discrepancy between their physical development (that is usually normal) and their socio-emotional development (that is often delayed) can lead to difficulties, such as the likelihood of insecurity, inappropriate behavior and negative experiences (Haracopos & Pedersen, 1992; Hénault, 2006; Ousley & Mesibov, 1991). Recent studies however, found that due to different hormonal structures, also the physical development of adolescents with ASD seems to differ from that of typically developing adolescents, for instance girls with ASD have, on average, an eight month delay in the onset of the menarche (Knickmeyer, Wheelwright, Hoekstra, & Baron-Cohen, 2006). However, this field of research is still emerging (Ingudomnukul, Baron-Cohen, Wheelwright, & Knickmeyer, 2007).

In addition, in adolescence social interactions with peers become more important, intimate friendships are formed and adolescents become more independent from their parents (Santrock, 2005). These changes in social relations in adolescence ask for new socio-communicative skills and therefore the deficits of adolescents with ASD can become more noticeable (White & Roberson-Nay, 2009). The deficits in social communication can make understanding, developing and maintaining close personal relationships difficult for adolescents with ASD (American Psychiatric Association, 2013; Byers & Nichols, 2014; Mehzabin & Stokes, 2011). When children with ASD enter adolescence, they usually have the desire – and understand and recognize the importance – to be part of a social group, but they lack the social cognition on how to join these groups (Bauminger & Kasari, 2000; Mundy, Sullivan, & Mastergeorge, 2009). Especially adolescents with ASD with average or above average intellectual abilities become more aware that they cannot measure up to their peers socially (Delfos & Gottmer, 2008). Adolescents with ASD have fewer friendships (Bauminger & Kasari, 2000) and more negative social experiences, for instance more experience with teasing, being laughed at and bullying in their childhood (Samson, Huber, & Ruch, 2011). Children and adolescents with ASD, therefore, have lower general self-esteem and social competence than comparison children (Capps, Sigman, & Yirmiya, 1995; Vickerstaff, Heriot, Wong, Lopes, & Dossetor, 2007; Williamson, Craig, & Slinger, 2008) and their social difficulties can lead to self-criticizing, social withdrawal and isolation (Attwood, Debbaudt, Jackson, Overton, & Murray, 2005). To conclude, adolescence poses several challenges for all growing up, but adolescents with ASD can experience extra challenges in their physical, social and emotional development, as well as in their psychosexual development.

THE PSYCHOSEXUAL DEVELOPMENT OF ADOLESCENTS WITH ASD

Psychosexual functioning can be divided into three domains: psychosexual socialization (i.e. the interaction with peers, parents, siblings, and media in which individuals learn about and experience relationships and sexuality), psychosexual selfhood (i.e. intrapersonal functioning including self-esteem, self-perceived competence, and knowledge), and sexual/intimate behavior (Dewinter, Vermeiren, Vanwesenbeeck, & Nieuwenhuizen, 2013; Tolman & McClelland, 2011). In adolescence, the psychosexual development accelerates rapidly (Tolman & McClelland, 2011). Most adolescents fall in love for the first time and have their first romantic relationships and sexual experiences. These relationships and experiences are not only significant for the adolescents but also for adult functioning (Collins, 2003).

In the past, it was thought that people with ASD did not have a desire for social relationships and that they were asexual (Wing, 1975). We now know that most adolescents with ASD do have an interest in social relationships and sexuality, and that they have psychosexual needs and engage in sexual behavior (e.g. masturbation, dating and kissing) similar to typically developing adolescents (Dewinter, Vermeiren, Vanwesenbeeck, Lobbestael, & Van Nieuwenhuizen, 2014; Gilmour, Schalomon, & Smith, 2012; Hénault, 2006; Stokes & Kaur, 2005). However, more difficulties were found regarding the psychosexual socialization and psychosexual selfhood of adolescents with ASD (Dekker et al, 2017). Previous research describes inappropriate sexual behavior and sexual problems in adolescents and adults with ASD, ranging from reporting few intimate and sexual experiences, unfulfilled desires, sexual frustration in adolescents with ASD (Coskun & Mukaddes, 2008; Gougeon, 2010; Konstantareas & Lunsky, 1997; Murrie, Warren, Kristiansson, & Dietz, 2002; Stokes & Kaur, 2005) to asking inappropriate questions, touching others inappropriately and public masturbation (Coskun, Karakoc, Kircelli, & Mukaddes, 2009; Dozier, Iwata, & Worsdell, 2011; Hénault, 2006; Realmuto & Ruble, 1999; Ruble & Dalrymple, 1993; Stokes, Newton, & Kaur, 2007). These difficulties originate from limitations in their knowledge and skills required for appropriate psychosexual functioning and difficulties with adequately dealing with boundaries of others (Dekker et al, 2017). Case studies illustrated sexual offending behaviors in adolescents and adults with ASD (Chan & Saluja, 2011; Griffin-Shelley, 2010; Haskins & Silva, 2006; Kohn, Fahum, Ratzoni, & Apter, 1998; Murrie et al., 2002). Also, paraphilias, such as exhibitionism, voyeurism, paedophilia and fetishism, have been described in people with ASD (Cooper, Mohamed, & Collacott, 1993; Dozier et al., 2011; Early, Erickson, Wink, McDougle, & Scott, 2012; Fernandes et al., 2016; Hellemans, Colson, Verbraeken, Vermeiren, & Deboutte, 2007; Kellaher, 2015). Unfortunately, most of the previous publications on inappropriate sexual behavior and sexual problems in people with ASD are case studies or deal with methodological limitations, such as small sample sizes or no use of self-report measures. Although recently a study has found that in a group of adolescents and young

adults with ASD about one fourth portrayed inappropriate sexual behavior or struggled with paraphilias (Fernandes et al., 2016), such empirical information is currently not available for sexual delinquent behaviour. We do know, however, juvenile sex offenders have higher levels of ASD symptoms than healthy controls ('t Hart-Kerkhoffs et al., 2009).

Furthermore, difficulties with understanding the emotions of other people and the desire to be socially accepted can put adolescents with ASD at a higher risk to become a victim of sexual coercion, sexual bullying and sexual abuse (Brown-Lavoie, Viecili, & Weiss, 2014; Edelson, 2009; Mandell, Walrath, Manteuffel, Sgro, & Pinto-Martin, 2005; Sevlever, Roth, & Gillis, 2013).

Using a case report from the current study, I will illustrate the psychosexual development of adolescents with ASD, and both the normal development aspects as well as possible deviant development aspects will be described.

Michael (1)
Michael is a 15-year-old boy with an average intelligence. He was not diagnosed with ASD before, but his parents always knew he was different from other children. Michael barely connected with his classmates and never brought friends home. However, he sometimes played with other children in the neighborhood. Because there were no problems at school and at home, his parents had never been worried about Michael. Then, one day, Michael did something that shocked everyone. While playing in her room, he sexually abused a nine-year-old neighborhood girl. He touched her intimate parts and forced her to touch his penis. After the incident things happened quickly. The parents of the girl pressed charges and Michael and his parents were placed in an intensive multi system therapy program. Because of the incident, Michael and his parents were harassed by people from the small community they lived in. Stones were thrown through their windows and Michael could not go to school anymore. The probation officer was the first to notice how Michael made contact with people in a strange and awkward way. After a diagnostic trajectory Michael was diagnosed with ASD and referred for specialized psychosexual guidance for adolescents with ASD.

PSYCHOSEXUAL GUIDANCE FOR ADOLESCENTS WITH ASD

Generally, friends and parents are the main sources of information regarding sexuality (de Graaf, Kruijer, van Acker, & Meijer, 2012; White & Roberson-Nay, 2009). In addition, since the end of 2012, sexual education has become mandatory at schools in the Netherlands, and starts at an early age, around 10 years old (www.seksuelevoorlichting.nl). Usually, these sources of information are sufficient for typically developing adolescents (de Graaf et al.,

2012). However, because adolescents with ASD generally have fewer friends and fewer close friendships than their peers without ASD (Bauminger & Kasari, 2000), they receive less of this informal information about sexuality from their peers (Stokes et al., 2007). Parents report to be reluctant to provide comprehensive sexual education to adolescents with ASD (Ballan, 2012), and therefore adolescents with ASD are more dependent on non-social sources such as television or the internet, resulting in having less (or less accurate) psychosexual knowledge compared to their peers (Brown-Lavoie et al., 2014; Kellaher, 2015). Currently, education related to sexual and romantic functioning often does not occur until after an adolescents with ASD has been victimized or has committed a 'social error' that can include undesired touching or public masturbation, or even meeting criteria for a sexual offence (Griffin-Shelley, 2010; Hellemans et al., 2007).

The social, communicative, and behavioral characteristics of ASD require comprehensive and personalized curricula that directly teach adolescents with ASD the knowledge and skills that are often learned incidentally or through observation by others (Gougeon, 2010). Therefore, there is a well understood and described importance for psychosexual guidance and training programs especially designed for adolescents with ASD (Dewinter et al., 2013; Koller, 2000; Nichols & Blakeley-Smith, 2009). Few psychosexual training programs are available for this group. At the time we started the current study, two programs were published: 'Sociosexual education program for individuals with Asperger's Syndrome' by Isabelle Hénault (Hénault, 2006) and 'Seks@autisme.kom' by Hans Hellemans (in Dutch) (Hellemans, Vermeulen, Conix, & De Lameillieure, 2006). The program by Hénault is a 12-session group training for older adolescents and adults with Asperger's Syndrome and the program by Hellemans is an explicitly illustrated group training for adolescents and adults with ASD and a normal intelligence. To our knowledge, both training programs have not been studied for their effectiveness, and therefore no evidence-based individual training programs that we know of currently exists addressing the psychosexual development of adolescents with ASD. Therefore, in the Netherlands the Tackling Teenage Training (TTT) program was developed (Boudesteijn, Van der Vegt, Visser, Tick, & Maras, 2012; Dekker et al., 2014). In 18 sessions that cover several topics related to puberty, sexuality and intimate relationships, adolescents with ASD receive psycho-education and practice skills. A first systematic evaluation of the effects of the TTT program on psychosexual knowledge showed that adolescents with ASD had increased knowledge of puberty and psychosexual topics after following the program (Dekker et al., 2014).

Michael (2)
I met Michael and his mother at the intake meeting (the first appointment before the first session of the TTT program), because I was going to be the professional who would provide the TTT program to Michael. In this appointment, he told me he never wants to have a girlfriend, he never wants to have anything to do with girls anymore, and he never wants to have sex, because of what happened. Michael and his mother received information on the content of the TTT program, and together we agreed on a day and a time Michael would come for the 18 sessions and we agreed on the way I would inform the parents of Michael with the progress of the training program. Goals of the training program for Michael were first providing information about the physical changes in puberty for boys and girls, and explaining body functions, such as sexual arousal and second on discussing identifying boundaries of others and learning Michael about appropriate and inappropriate sexual behavior.

AIMS AND OUTLINE OF THIS THESIS

The current thesis evaluates the effectiveness of an individual psychosexual training program for adolescents with ASD, the Tackling Teenage Training (TTT) program. This thesis contributes to the emerging field of research on psychosexuality in adolescents with ASD. The participants that participated in the current study all have a full IQ above 85, thus the reader should notice that results can only be generalized to this subpopulation.

Chapter 2 describes the study protocol of the large randomized controlled trial (RCT) of the TTT program and the additional information on the content and the structure of the TTT program.

In chapter 3, we studied the perception of adolescents with ASD of sexual situations, using the baseline data of the RCT. We have investigated how adolescents with ASD and a comparable group of typically developing adolescents judge different sexual situations portraying appropriate and inappropriate sexual behavior.

Chapter 4 of this thesis describes parent-child informant discrepancy at the baseline measure of the RCT. This chapter describes how parents and children differ in their reports on the psychosexual development of the adolescent with ASD, and we compared these results with a matched sample of parent-child dyads with typically developing adolescents. Together with the information on the perception of adolescents with ASD regarding appropriate and inappropriate sexual behavior, this provides a framework in which the effectiveness of the TTT program can be examined.

Chapter 5 and 6 describe the results of the RCT on the effectiveness and social validation of the TTT program. Chapter 5 describes the effects of the TTT program on the main outcomes and chapter 6 provides information about satisfaction of the users of the TTT program and protocol adherence of the TTT program.

Finally, chapter 7 gives an overview of the preceding chapters, and an overall discussion of the findings. In addition, this chapter provides clinical implications and suggestions for future research to the psychosexual development of adolescents with ASD.

CHAPTER 2

Study Protocol: A randomized controlled trial investigating the effects of a psychosexual training program for adolescents with autism spectrum disorder

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ABSTRACT

Background: Previous research shows that adolescents with autism spectrum disorder (ASD) run several risks in their psychosexual development and that these adolescents can have limited access to reliable information on puberty and sexuality, emphasizing the need for specific guidance of adolescents with ASD in their psychosexual development. Few studies have investigated the effects of psychosexual training programs for adolescents with ASD and to date no randomized controlled trials are available to study the effects of psychosexual interventions for this target group.

Methods/Design: The randomized controlled trial (RCT) described in this study protocol aims to investigate the effects of the Tackling Teenage Training (TTT) program on the psychosexual development of adolescents with ASD. This parallel clinical trial, conducted in the South-West of the Netherlands, has a simple equal randomization design with an intervention and a waiting-list control condition. Two hundred adolescents and their parents participate in this study. We assess the participants in both conditions using self-report as well as parent-report questionnaires at three time points during one year: at baseline (T1), post-treatment (T2), and for follow-up (T3).

Discussion: To our knowledge, the current study is the first that uses a randomized controlled design to study the effects of a psychosexual training program for adolescents with ASD. It has a number of methodological strengths, namely a large sample size, a wide range of functionally relevant outcome measures, the use of multiple informants, and a standardized research and intervention protocol. Also some limitations of the described study are identified, for instance not making a comparison between two treatment conditions, and no use of blinded observational measures to investigate the ecological validity of the research results.

BACKGROUND

Adolescence is a transition phase in life with physical, emotional as well as social changes that offers several challenges for adolescents with autism spectrum disorder (ASD). People with ASD have impairments in social interaction and communication, and show limited, repetitive and stereotyped patterns of behavior, interests and activities (American Psychiatric Association, 2013). ASD is a pervasive disorder, meaning that the impairments are usually lifelong and are expressed across multiple contexts and in multiple areas in life, although this expression can vary across the lifespan (American Psychiatric Association, 2013). Due to the difficulties with change that many people with ASD experience, problems can increase during a transition to a new life stage, such as adolescence (Delfos & Gottmer, 2008).

The physical changes in adolescence, such as the growth of secondary sex characteristics, can cause insecurity and require the learning of new routines (e.g. menstruation hygiene) (Dahl, 2004; Santrock, 2005). In addition, in adolescence the psychosexual development matures rapidly (Tolman & McClelland, 2011): Most adolescents fall in love for the first time and have their first romantic relationships and sexual experiences, that are significant for adult functioning and for long term outcomes (Collins, 2003). The psychosexual development offers specific difficulties for adolescents with ASD (Dewinter et al., 2013), who seem to have similar psychosexual needs to typically developing adolescents, but lack the necessary knowledge and social skills to fulfill these needs (Hénault & Attwood, 2003; Mehzabin & Stokes, 2011; Ray, Marks, & Bray-Garretson, 2004). Therefore, adolescents with ASD usually have only few intimate and sexual experiences and can report sexual frustration and sexual preoccupations (Coskun & Mukaddes, 2008; Murrie et al., 2002; Ray et al., 2004). These problems increase the risk for adolescents with ASD to develop – or become a victim of – inappropriate sexual behavior, such as touching others inappropriately, stalking, public masturbation, sexual victimization and sexual coercion (Hénault & Attwood, 2003; Stokes & Kaur, 2005). Parents of adolescents with ASD frequently express concerns about the sexual behavior of their children, both about the possibility of sexual exploitation as well as concerns about the possibility their child will show inappropriate sexual behavior (Cridland, Jones, Caputi, & Magee, 2014; Nichols & Blakeley-Smith, 2009).

Changes in social relations ask for new socio-communicative skills; adolescents become more independent from their parents and intimate friendships are formed (Santrock, 2005). These intimate friendships are important for the forming of an identity and friends are an important source of information regarding sexuality (de Graaf et al., 2012). However, because adolescents with ASD generally have fewer friends and fewer close friendships than their peers without ASD (Bauminger & Kasari, 2000), they receive less information about sexuality from their peers (Stokes et al., 2007). Parents report to be reluctant to provide comprehensive sexual education to adolescents with ASD (Ballan, 2012), and therefore adolescents with ASD

are more dependent on non-social sources such as the internet (Kellaher, 2015), resulting in having less (or less accurate) psychosexual knowledge compared to their peers (Brown-Lavoie et al., 2014).

Given the possible risks that adolescents with ASD encounter and their problems with access to reliable information resources, several studies on puberty and sexuality in adolescents with ASD emphasize the need for guidance of these adolescents in their psychosexual development (Dewinter et al., 2013; Nichols & Blakeley-Smith, 2009). Interventions that focus on the transition into adolescence and in particular the psychosexual development of adolescents with ASD are however limited (Hellemans et al., 2006; Hénault, 2006). Therefore, in order to fulfill this need, an individual training program has been developed in The Netherlands targeting the psychosexual development of adolescents with ASD: the Tackling Teenage Training (TTT) program (Boudesteijn et al., 2012; Dekker et al., 2014). This program contains 18 one-on-one sessions, in which adolescents with ASD receive information regarding several topics (i.e. psycho-education), alternated with exercises (e.g. behavioral rehearsals, and knowledge and insight quizzes). More information on the TTT program can be found in the Intervention section. A first systematic evaluation of the effects of the TTT program on psychosexual knowledge showed that adolescents with ASD have increased knowledge of puberty and psychosexual topics after following the training program (Dekker et al., 2014). Given this promising evaluation, the effects of the TTT program are further examined within a randomized controlled design, described in this study protocol.

In the current study we investigate the effects of the TTT program on the psychosexual development of adolescents with ASD. The aims of the study were as follows: to investigate whether the TTT program (1) increases psychosexual knowledge; (2) increases skills needed for friendships and intimate relations; (3) increases insight in acceptable and inappropriate sexual behaviors; (4) reduces inappropriate sexual behavior and vulnerability; (5) increases self-esteem, and (6) reduces current concerns and concerns about the future of adolescents with ASD and their parents. We hypothesized that the TTT program is not only able to reduce the difficulties of adolescents with ASD in their psychosexual development, but also to promote a positive and normative psychosexual development in adolescents with ASD.

This paper describes the study design, the participants, the content and protocol of the TTT program and the research procedures.

METHODS/DESIGN

Participants

Participants are 200 adolescents in the age range of 12 to 18 years with a DSM-IV diagnosis of ASD. Recruitment for the study is performed in three ways within a population of adolescents with ASD.

1. Participants are recruited among patients of Yulius (n=100), a large expert mental health care institution in the South-West of The Netherlands that provides specialized care to children and adults with complex psychiatric problems.
2. Participants are recruited among students in schools with segregated settings for special education, in which students with a variety of complex psychiatric problems are educated (n=50). A large number of adolescents in these settings have a diagnosis of ASD.
3. Adolescents and their parents can apply for the study through open application. Research flyers are distributed through several mental health care centers in the region among adolescents with ASD and their parents and a study website was launched (n=50).

Eligibility criteria for participation are 1) a total score of 51 or above on the Social Responsiveness Scale (SRS) (Constantino & Gruber, 2002; Roeyers, Thys, Druart, De Schryver, & Schittekatte, 2011), and 2) an intelligence (IQ) level in the normal to high range (total IQ > 85). More information on the SRS and the intelligence specification can be found in the Procedure section.

Informed consent is obtained from all adolescents and their parents. This study is approved and guided by the medical ethical commission of the Erasmus Medical Center, Rotterdam (MEC-2013-040).

Sample size

Sample size for this study was determined in advance by power calculations based on the previous pilot study results (Effect size = .70) (Dekker et al., 2014). In order to detect differences on the outcome measures of medium effect size between the two conditions with 80% power (α = 0.05; two-sided) (Cohen, 1988), 64 adolescents are required per condition. With an anticipated drop-out of approximately 25% 150 adolescents will remain participating in the study, enabling us to investigate the effects of the TTT program. In addition, we will consider if it is possible to investigate the influence of potential moderators of treatment outcome.

Intervention

The Tackling Teenage Training (TTT) program is an individual intervention with 18 sessions that cover the following topics: discussing puberty (i.e. how and with whom), appearances, first impressions, physical and emotional developments in adolescence, how to become and maintain friends, falling in love and dating, sexuality and sex (e.g. sexual orientation, masturbation, and intercourse), pregnancy, setting and respecting boundaries and safe internet use (Boudesteijn et al., 2012; Dekker et al., 2014; Yulius, 2015). An overview of the sessions is displayed in Table 1. The TTT program is developed for adolescents with ASD from

12 and 18 years old with a normal or high intelligence. During the TTT program, the trainer and adolescent discuss one session per week, in which one topic is discussed and exercises are practiced in a structured manner in approximately 45 minutes. The training program can be provided in the school setting, in outpatient or inpatient facilities or at the home of the adolescent (if certain conditions can be met, such as a confined room and no disturbance from family members). All sessions are structured in the following way: First, the take-home assignment of the last session is discussed. After this, the adolescent receives information regarding different subtopics of the session (i.e. psycho-education), alternated with exercises (e.g. behavioral rehearsals, and knowledge and insight quizzes). At the end of each session, the adolescent receives a take-home assignment in which the topic of that session needs to be discussed or practiced outside of the context of the training, for instance conducting a small interview with one of the parents on the topic of the session, or arranging a get-together with a friend.

The training starts and ends with an appointment with the adolescent and the parents, who are weekly informed by mail on the progress of the training by the trainer, via structured contact reports. The contact reports consist of information on the topic of the session (i.e. psycho-education) and the take-home assignment of the child, in order to inform parents, but also to stimulate rehearsal of the skills that were taught in the session within the home environment. In addition, particularities (i.e. the strengths and difficulties of the child in the current session) are communicated with parents. The contact reports allow parents to be prepared for any questions or remarks of the adolescent in between sessions and foster an environment in which the adolescent can discuss or practice topics of the TTT program within the home environment and/or broader social environment with guidance of parents to enhance generalization to other contexts outside the setting of the training.

All trainers that provide the TTT program in the study have a bachelor or master in psychology or social services and experience in working with people with ASD. They have taken the two day train-the-trainer course, in which they received information on the psychosexual development in general, possible difficulties in the psychosexual development for adolescents with ASD and they were taught how to provide the training program in a standardized way, with particular suggestions on how it can be customized to the individual needs of the adolescent if necessary. In addition, all trainers participate in interdisciplinary meetings every three months, in which questions and case reports can be discussed with other trainers and the developers of the training program. The protocolized manual of the TTT program (Boudesteijn et al., 2012) is available in Dutch, English, Greek and Spanish.

For each training session, information about the motivation, resistance and openness of the adolescent, and the difficulty of the material for the adolescent, according to the trainer, is registered by the trainer. Motivation of the adolescent is scored by the trainer on a scale from 0 to 10 (i.e. 0 = no motivation to 10 = very motivated). The trainer rates how much

resistance and how much information the adolescent shares during the sessions, again on a scale from 0 to 10 (i.e. 0 = no resistance at all to 10 = very much resistance / 0 = very guarded to 10 = very open). Last, the trainer rates how difficult that particular session is for the adolescent on a scale from 0 to 10 (i.e. 0 = very easy to 10 = extremely difficult). All session scores are subsequently summed and then averaged to compute an index of overall motivation, resistance, difficulty and openness. During the training, neither the parents nor the adolescent are informed about these scores.

Furthermore, after each session the trainer reports to what extend the TTT protocol was followed through standardized short evaluation forms, in order to register adjustments that are made to the TTT protocol. Examples of adjustments are: changing the order of the sessions, spending more time to discuss a theme, or leaving out (additional) texts and questions. In this way, the adherence to the TTT protocol by the trainers can be monitored for each participant and each session.

After ending the training, the parents and adolescent fill out an evaluation form with 16 questions, for a more subjective evaluation of the topics the adolescent learned about in the TTT program and how parents and adolescents rate and appreciate the training (e.g. the texts, the illustrations, the relationship with the trainer, the communication with the trainer, the take-home assignments) on a scale from 0-10.

Table 1. Overview of sessions and themes in the Tackling Teenage Training program

Sessions	Themes
Session 1 Talking about puberty	Discussing puberty
Session 2 This is me	Appearances
Session 3 A good first impression	First impressions
Session 4 What do you call that?	Naming body parts
Session 5 Changes during puberty in boys	Male physical changes
Session 6 Changes during puberty in girls	Female physical changes
Session 7 Making love to yourself	Masturbation, rules and hygiene
Session 8 Friendship	How to become and maintain friends
Session 9 Being in love and stuff…	Falling in love
Session 10 Doubts and confusion during puberty	Sexual orientation
Session 11 Being in love and dating	Falling in love and dating
Session 12 Safe sex	Sexual intercourse, contraception and STD
Session 13 The first time	Sexual intercourse
Session 14 Pregnancy and birth	Pregnancy
Session 15 Where do you draw the line?	Setting and respecting boundaries
Session 16 Yours and other people's boundaries	Setting and respecting boundaries
Session 17 Internet and making contact	Safe internet use
Session 18 Bad boyfriends (session for girls)	Abusive boyfriends

Procedures

Figure 1 shows the planned CONSORT (Consolidated Standards of Reporting Trials) Study Flow Chart for this study. After application, eligibility criteria are confirmed. For this, all parents fill out the Social Responsiveness Scale (SRS) (Constantino & Gruber, 2002; Roeyers et al., 2011), together with the consent forms. The SRS is a 65-item questionnaire that covers the domains of social behavior, language, and repetitive/stereotypic behavior that are characteristic of ASD. A total score and five treatment subscales can be derived from the SRS: Social Awareness, Social Cognition, Social Communication, Social Motivation, and Autistic Mannerisms. The SRS provides a dimensional measure of autistic traits, with higher scores on the SRS reflecting greater degree of social impairment. Internal consistency of the SRS is excellent ($\alpha = 0.97$) (Constantino & Gruber, 2002). We used a total score of 51 or above on the SRS, because this is the preferred cut-off point based on research among clinical referrals and children from the Dutch general population (Roeyers et al., 2011).

Total IQ, verbal IQ (VIQ) and performance IQ (PIQ) are taken from the medical file of the adolescent and are used if the assessment is not older than two years old and if a valid and reliable instrument was used (for instance one of the Wechsler intelligence scales). In cases where no or no recent IQ measurement is available, IQ is assessed using the Wechsler Abbreviated Scale of Intelligence (WASI) (Wechsler, 1999). The WASI consists of four subtests: Vocabulary, Block Design, Similarities, and Matrix Reasoning. These four subtests compose a total IQ, a VIQ and a PIQ. The internal consistency, test-retest and inter-rater reliability of the WASI are good and it correlates strongly with full-scale Wechsler Adult Intelligence Scale-III (WAIS-III) IQ scores ($\alpha = 0.87$) (Wechsler, 1999).

In the current study we use multi informant questionnaires, both parent-report and self-report. The use of self-report in research with people with ASD is sometimes debated, because of their problems with identifying and describing feelings and emotions of others and themselves (Mazefsky, Kao, & Oswald, 2011). Still, self-report gives an indication of the perception of behavior and feelings of people with ASD (Nichols & Blakeley-Smith, 2009), which is indispensable when studying intimate and personal themes, such as pubertal development and psychosexual functioning. From research it also becomes clear that although people with ASD tend to have difficulty identifying, verbalizing, and analyzing their emotions, they experience emotions just like everyone else and that their self-reports have good internal reliability (Hill, Berthoz, & Frith, 2004; Mazefsky et al., 2011; Shalom et al., 2006).

All participating adolescents and their parents fill out questionnaires at three time points during one year: at baseline (T1), after inclusion criteria are confirmed; post-treatment (T2), directly after the TTT program (for adolescents in the intervention condition), or after six months on the waiting-list (for adolescents in the control condition), and for follow-up (T3), six months after the TTT program (for adolescents in the intervention condition), or after twelve

months on the waiting-list (for adolescents in the control condition). The adolescents fill out the questionnaires in the company of a research assistant (who is available for questions of the adolescent). The research assistants are blind to the condition of the adolescents. Parents fill out the questionnaires via the internet.

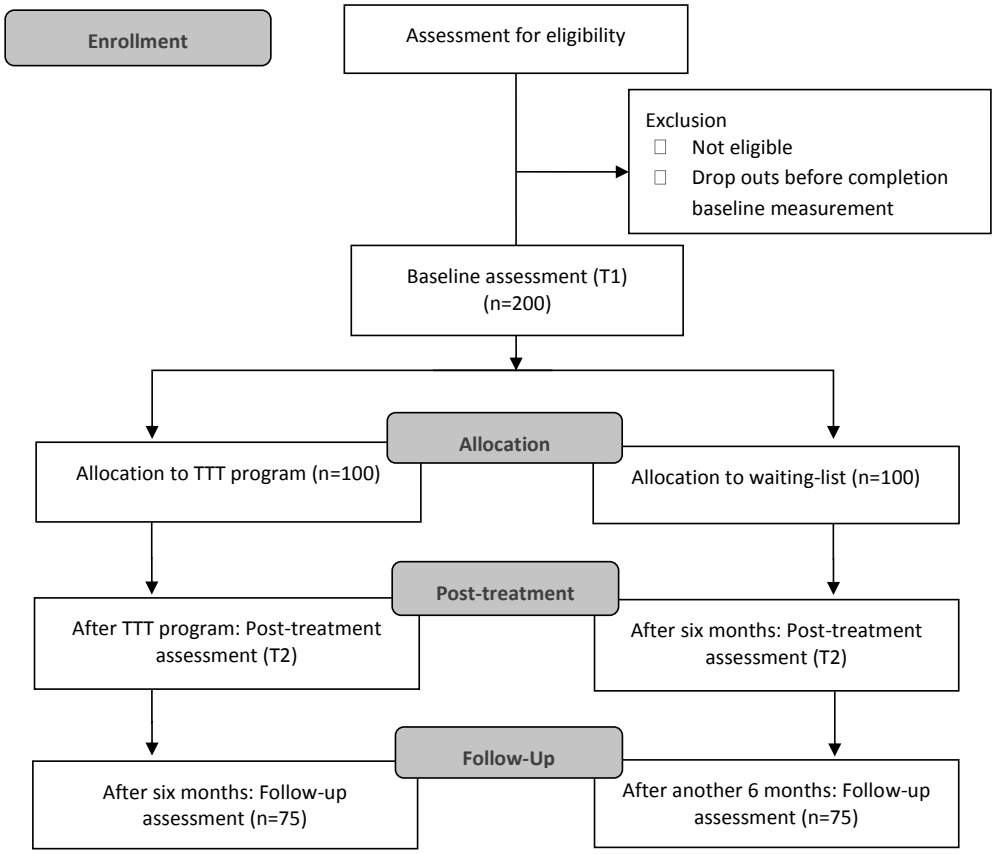

Figure 1. CONSORT Study Flow Chart

Randomization

Simple equal randomization (1:1) takes place at an individual level, after the baseline measurement (T1). Adolescents are randomly assigned to the intervention condition (n=100) or the control condition (n=100). A computerized allocation scheme is used, authorized by an investigator with no involvement in the current research. Adolescents in the intervention condition start the TTT program shortly after the randomization. The adolescents in the control condition are placed on a waiting-list. During the study, adolescents in both conditions can continue other interventions and medications.

Outcome measures

In order to investigate the effect of the TTT program on the psychosexual development of the adolescents with ASD, we used the Teen Transition Inventory (TTI) (Dekker et al., 2017) and several additional measures. Table 2 provides an overview of all questionnaires and tasks that we use in the study. The TTI is a self-report (186 items) and parent-report (148 items) questionnaire, that covers the experience of several transitions in adolescence, such as the school transition, physical change, psychosexual functioning and psychosexual problems and worries of the adolescents and their parents. The psychosexual functioning part of the TTI contains nine scales and several separate items that represent the three domains of psychosexual functioning: sexual selfhood, sexual socialization, and sexual behavior (Dewinter et al., 2013; Tolman & McClelland, 2011) (see Table 3 for an overview). All items are scored on a 3-point scale (0 = not true, 1 = somewhat or sometimes true, 2 = very true or often true), with the exception of a minority of separate items (i.e. age of onset). The scale scores reflect the average score of all the items on the scale, with scores ranging between 1 and 3. The scales showed sufficient to good internal consistency (Dekker et al., 2017). The self-report and parent-report version of the TTI is administrated at T1, T2 and T3.

Table 2. Overview of measures in the Tackling Teenage Research

Measures	For adolescents	For parents
Inclusion	WASI[1]	SRS
T1	ADOS-2	TTI parent-report
	Psychosexual knowledge test	CBCL
	TTI self-report	Child & family characteristics
	Flag system	
	NPV-2 – self esteem scale	
T2	Psychosexual knowledge test	TTI parent-report
	TTI self-report	SRS
	Flag system	CBCL
	NPV-2 – self esteem scale	
T3	Psychosexual knowledge test	TTI parent-report
	TTI self-report	SRS
	Flag system	CBCL
	NPV-2 – self esteem scale	

Note: [1] Only administered when no recent IQ measurement is available; WASI: Wechsler Abbreviated Scale of Intelligence; SRS: Social Responsiveness Scale; ADOS-2: Autism Diagnostic Observation schedule-2; TTI: Teen Transition Inventory; CBCL: Child Behavior Checklist

Table 3. Psychosexual functioning part of the Teen Transition Inventory

Domain	Scale / items	Parent-report	Self-report
Sexual socialization	Friendship skills of child	5 items	5 items
	Social acceptance by peers	3 items	6 items
	Romantic ability of child	-	3 items
	Openness about intimacy	4 items	3 items
	Adequate dealing with boundaries	8 items	-
Sexual selfhood	Bodily perception	3 items	6 items
	Self-esteem	-	12 items
	Perceived social competence	-	12 items
	Sexual knowledge of the child according to parent	9 items	-
Sexual behavior	Separate items on age or context appropriate behaviors, intimate experiences including age of onset and sexual orientation	33 items	41 items

(1) Psychosexual knowledge

To investigate whether the TTT program improves knowledge regarding psychosexual themes, a psychosexual knowledge test for adolescents (Dekker et al., 2014) is administered at T1, T2, and T3. The psychosexual knowledge test consists of 35 multiple choice questions and 2 open-ended questions in which parts of the (male and female) genitals have to be named correctly. Each question is rated as being either correct or incorrect, which leads to a score of one point per question. The total score on the psychosexual knowledge test represents the total number of correct answers, ranging from 0 to 37.

Parents are questioned about the knowledge of their children in the 'Sexual knowledge of the child according to the parent' scale of the TTI (Dekker et al., 2017).

(2) Skills needed for friendships and intimate relations

The 'Friendship skills' scale (self-report and parent-report version) of the TTI is used to measure the ability of the adolescents to make and maintain friendships. The 'Romantic ability' scale (self-report version) of the TTI is used to measure the self-perceived romantic relational skills of the adolescents (Dekker et al., 2017).

The Social Responsiveness Scale (SRS) (Constantino & Gruber, 2002) is used as a measure of ASD symptom severity and social impairments (Hus, Bishop, Gotham, Huerta, & Lord, 2013), but the treatment subscales can be used for assessment of treatment effect. The four treatment subscales in the social domain determine to what extent an adolescent is aware of social cues in his environment (Social Awareness), can appropriately interprets those cues (Social Cognition), is capable of a reciprocal reaction (Social Communication), and is motivated to engage in social-interpersonal behavior (Social Motivation) (Constantino et al., 2009). The treatment subscales of the social domain of the SRS have been shown to be sensitive to changes in social functioning among children with ASD (Laugeson, Frankel,

Gantman, Dillon, & Mogil, 2012; Tse, Strulovitch, Tagalakis, Meng, & Fombonne, 2007; Wood et al., 2009) and therefore we administer the SRS also at T2 and T3.

(3) Insight in acceptable and inappropriate sexual behaviors

To investigate whether the TTT program increases insight in different sexual behaviors, the 'Adequate boundaries' scale (parent-report version) (Dekker et al., 2017) is used. In addition to this, the flag system (Dutch: het Vlaggensysteem) (Frans & Franck, 2010), is administrated at T1, T2 and T3 to measure the accuracy of judgement of acceptable and inappropriate sexual behavior. The flag system contains drawn illustrations with children and adolescents displaying sexual behavior in different situations and is developed to discuss a range of sexual behaviors with children or adolescents. The scoring of the flag system is based on six criteria for judging sexual behavior: consent, equality, coercion, appropriate for age, appropriate for context, and self-respect (Frans & Franck, 2010; Ryan, Leversee, & Lane, 2011). The developers of the flag system used these six criteria to define four flags (green, yellow, red, and black). An expert panel of child health care professionals chose the 'correct' or most accurate flag for each illustration during the two year development of the flag system. In the current study the flag system is registered individually. The research assistant first explains the meaning and use of the four flags and then shows the adolescent 23 illustrations one-by-one. With each illustration, the research assistant asks the adolescent to choose a flag, best judging the sexual behavior shown in the illustration. The research assistant writes down the chosen flag, without giving feedback to the adolescent during the test, and continues to the next illustration. The chosen flags of the adolescents are compared to the chosen flags of the expert panel, and scored as either correct or incorrect. An incorrect flag could indicate a milder judgement or a stricter judgement, compared to the normative judgement of the expert panel. We calculate the average percentages of accurate judgements, milder judgements and stricter judgements for each illustration of the flag system.

(4) Inappropriate sexual behavior and vulnerability

To investigate whether the TTT program reduces inappropriate sexual behavior and vulnerability, several separate items of the TTI (self-report n= 8 and parent-report version n= 12) (Dekker et al., 2017) are used. Example items from the parent-report TTI are: "My child touches others where they do not like to be touched", "My child is able to set his/her boundaries regarding intimate contact", "Does your child ever masturbate at inappropriate times, in inappropriate ways or places?". Some example items from the self-report TTI are: "I keep contacting someone, even though that person has indicated he/she does not want any contact with me", "I touch others in places where they do not want to be touched", and "In general I am good at letting people know what I am comfortable with and what I am not comfortable with".

Furthermore, we use the Sex Problems scale of the Child Behavior Checklist (CBCL) (Achenbach & Rescorla, 2001; Verhulst & van der Ende, 2013) at T1, T2 and T3, to determine the occurrence of psychosexual problems. The Sex Problems scale consists of five items regarding sexual problems, thinking of sex too much, playing with own genitals in public, playing with own genitals too much and the desire to be from the other gender (Achenbach & Rescorla, 2001; Letourneau et al., 2004; Letourneau, Schoenwald, & Sheidow, 2004). Parents rate each item on the CBCL on a 3-point scale (0 = not true, 1 = somewhat or sometimes true, 2 = very true or often true). Research that included the CBCL Sex Problems scale for the purpose of measuring psychosexual problems by means of parent report has supported the content & concurrent validity of this scale as well as the discriminant validity (Friedrich, Davies, Feher, & Wright, 2003; Letourneau et al., 2004).

(5) Self-esteem

To investigate whether the TTT program increases the adolescents' self-esteem the Self-esteem scale of the Dutch Personality Questionnaire (NPV-2) (Barelds, Westing, & Luteijn, 2005; Luteijn, Starren, & Van Dijk, 2000) is administrated at T1, T2 and T3. The NPV-2 consists of 132 items, scored on a three-point scale (true, not true and not false, or false) and measures the following 7 personality traits: inadequacy, social anxiety, rigidity, resentment, selfishness (complacency), dominance, and self-esteem. In the current study, we use the self-esteem scale, consisting of 19 items that the adolescents answer about themselves. Examples of questions are: "I often feel insecure", "I can handle jokes" and "I can accomplish what I want". Norm data of multiple populations (e.g. general and psychiatric patients) are available and reliability and validity of the self esteem scale are good (α = .86) (Barelds et al., 2005).

In addition, the TTI scales 'Perceived social competence' (self-report version) and 'Self-esteem' (self-report version) are used to measure changes in the self-esteem of the adolescents (Dekker et al., 2017).

(6) Concerns of the adolescents with ASD and their parents

To investigate whether the TTT program can reduce current concerns and concerns about the future for adolescents with ASD and their parents, we use several questions in the TTI (parent-report version n=8; self-report version n=7) about current and future concerns, for instance: "I worry about the vulnerability of my child regarding social relationships in general", "I worry about my child on the internet", "I worry if my child will live with a partner" and "I believe it is possible that I will have social relationships in the future" (Dekker et al., 2017).

Other measures

We administer additional measures to investigate the influence of (1) ASD severity, (2) emotional and behavioral problems, and (3) child and family characteristics on the effectiveness of the Tackling Teenage Training program.

(1) ASD severity: The Autism Diagnostic Observation Schedule-2 (ADOS-2) (De Bildt & De Jonge, 2008; Lord et al., 2012) is administered at the baseline measurement (T1). The ADOS-2 is a semi structured, standardized measure to assess social interaction, communication, play, and stereotyped behavior for individuals suspected of having ASD. The ADOS-2 has four modules, each designed to be administered to different individuals according to their level of expressive language. Psychometric properties of the ADOS-2 are good (Lord et al., 2012). In this study the ASD severity is registered using the calibrated severity scores (Hus & Lord, 2014). The ADOS-2 is administered by psychologists who have completed the two-day research-training and have achieved sufficient reliability for administration and coding.

(2) Emotional and behavioral problems: We expect that emotional and behavioral problems of the adolescents might influence the effects of the Tackling Teenage Training program. Therefore, we use the Child Behavior Checklist (CBCL) (Achenbach & Rescorla, 2001; Verhulst & van der Ende, 2013) at T1 to register emotional and behavioral problems of the adolescents. The CBCL assesses anxious/depressed problems, withdrawn/depressed problems, somatic complaints, social problems, thought problems, attention problems, aggressive and delinquent behavior problems. These scales are combined into an internalizing score (anxious/depressed problems, withdraw problems and somatic complaints), externalizing score (aggressive and delinquent behavior problems), and total problems score. Psychometric properties of the CBCL are good (Achenbach & Rescorla, 2001; Verhulst & van der Ende, 2013).

(3) Child and family characteristics: Demographic characteristics, such as age, gender, family situation are administered in the baseline measurement (T1).

Furthermore, socio-economic status (SES) is determined by income level, educational level of both the mother and the father (or other caregivers), and occupational level of each primary caregiver, using the International Standard Classification for Occupations (CBS, 2016).

Ethnicity is determined by the birth country of both parents. If both parents are born in The Netherlands, the adolescent is categorized as ethnicity 'Dutch'. If one or both parents are born in another country than the Netherlands, the adolescent is categorized as ethnicity 'non-Dutch'.

In order to determine previous sexual education of the adolescent, the adolescents are asked if they previously received education or training on the subject of friendship, intimacy or sexuality, and if yes, from who they received this education or training (e.g. from parents, friends, at school, the internet). Parents are also asked if their child previously received education or training on the subject of friendship, intimacy or sexuality and if yes, from whom their child received this education or training.

Family values and attitudes regarding sexuality are determined with the TTI, with the 'Openness about intimacy' scale. Example items in this scale are: "Within our family we

discuss sexuality", "My child takes the initiative to talk about sexuality with me/us" and "I discuss my feelings and/or questions about intimacy/sexuality with my parents" (self-report and parent version) (Dekker et al., 2017).

Data analyses

Differences in baseline characteristics (age, gender, total IQ, ADOS severity score, scores on the SRS at T1 and the psychosexual knowledge test at T1) are examined with independent samples t-tests or chi-square tests. Baseline descriptors that differ significantly are taken into account in following analyses.

To investigate the effectiveness of the TTT program, we explore both within-subject effects (changes within adolescents in both conditions) and between-subject effects (changes between adolescents in the control condition versus the intervention condition). 'Time' is the within-subject variable, with three levels: T1 (baseline), T2 (effect), and T3 (follow-up). 'Condition' is the between-subject variable, with two levels: intervention condition and control condition. We use several continuous outcome measures: psychosexual knowledge, the scales of the Teen Transition Inventory (TTI), insight in acceptable and inappropriate sexual behaviors, self-esteem, and concerns about the future. And we use several dichotomous outcome measures, such as the separate items of the TTI measuring inappropriate sexual behavior. We correct for multiple testing using Bonferroni correction. Statistical analyses are performed using SPSS 19.0 statistical software (SPSS) (Nie, Bent, & Hull, 1975) and are two-sided, with a level of significance of $\alpha = 0.05$.

In addition to this, we investigate if potential predictors of treatment outcome (ASD severity, emotional and behavioral problems, and child and family characteristics) influence the effects of the TTT program.

Drop out analyses

For participants in both conditions (the intervention condition and the control condition), we examine the differences between the drop outs and the full participating individuals concerning several descriptors (age, gender, total IQ, ASD symptom severity) to investigate whether drop-out is selective or random.

DISCUSSION

The study described in this study protocol is the first randomized controlled trial (RCT) to investigate the effects of a psychosexual training program, the Tackling Teenage Training (TTT) program, for adolescents with autism spectrum disorder (ASD). The current RCT has a number of methodological strengths: The conduction of a first systematic evaluation of

the outcome of the TTT program on psychosexual knowledge (Dekker et al., 2014) in the years before the RCT contributed to the quality and the practicability of the TTT protocol, and made it possible to optimize the procedures and measures in the research protocol. The used sample size in the RCT will give the study enough power to investigate the effects of the TTT program and the wide range of functionally relevant outcome measures will guarantee the clinical importance of the results. In addition, we use multiple informants (self-report and parent-report questionnaires). As a final strength of the study, the adherence to the tested training protocol is carefully monitored. However, we also acknowledge certain limitations of the current study: Because in the Netherlands no other protocolized psychosexual training program is available, it is not possible to make a comparison between two interventions, and therefore the control condition is a waiting-list condition. Furthermore, because validated blinded observational measures to investigate changes in psychosexual functioning and sexual behavior are currently not available, we are limited to using parent- and self-report questionnaires reporting on psychosexual functioning and sexual behavior of the adolescents.

In conclusion, the results of the study described in this study protocol will be a valuable contribution to the growing knowledge of the psychosexual development of people with ASD, and aims to ultimately improve the support adolescents with ASD receive during the challenging life phase of adolescence.

CHAPTER 3

An exploration of the judgement of sexual situations by adolescents with autism spectrum disorders versus typically developing adolescents

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ABSTRACT

Background: Inappropriate sexual behavior, sexual problems and sexual victimization in adolescents with autism spectrum disorders (ASD) is regularly reported in previous research, but little is known about factors associated with these problems, nor about factors associated with a healthy sexuality development in adolescents with ASD. Investigating the judgement of sexual behavior can be a first step in acquiring insight into inappropriate sexual behavior in adolescents with ASD.

Methods: We assessed how 94 cognitively-able adolescents with ASD and 94 typically developing (TD) adolescents judged the appropriateness of different illustrations of sexual situations and we investigated the differences between the two groups.

Results: The highest level of agreement between the judgements of adolescents with ASD and the judgements of an expert panel was found for severely inappropriate sexual behaviors (89.2%) and the lowest agreement was found for appropriate (31.7%) and slightly inappropriate sexual behaviors (26.1%). No significant differences were found between the judgements of the adolescents with ASD and the TD adolescents. Regarding the divergent judgements, adolescents with and without ASD were mostly more strict (i.e. more conservative) than the expert panel in their judgement of sexual situations. Finally, a small percentage of adolescents with and without ASD showed milder (i.e. less conservative) judgements of sexual situations portraying behavior that was considered severely inappropriate by an expert panel.

Conclusions: Our findings showed that, overall, judgement of illustrations of sexual situations does not seem to be hampered in adolescents with ASD. More research is needed to clarify whether this also holds true for their judgements of – and actions in – more complex real life situations.

INTRODUCTION

In adolescence, many physical, emotional and social changes take place and the psychosexual development accelerates rapidly (Dahl, 2004; Santrock, 2005). During the transition from childhood into adulthood, adolescents require a whole set of new skills and knowledge (White & Roberson-Nay, 2009), making adolescence a challenging period. The development of a healthy sexuality is an important task during adolescence, and for adolescents with autism spectrum disorders (ASD) the physical changes and a clear interest in sexuality and intimate relationships occur similar to adolescents without ASD (Pecora, Mesibov, & Stokes, 2016). Previous research showed healthy sexual and relational functioning in people with ASD and regarding several behavioral aspects of sexuality (e.g. masturbation, dating and kissing) little differences were found between adolescents and adults with and without ASD (Byers, Nichols, & Voyer, 2013; Dewinter, Vermeiren, Vanwesenbeeck, Lobbestael, & Van Nieuwenhuizen, 2015; Dewinter, Vermeiren, Vanwesenbeeck, & Van Nieuwenhuizen, 2016a). In contrast to these studies reporting healthy aspects of sexuality in adolescents with ASD, other studies focussed on the challenges young people with ASD run into in adolescence and their psychosexual development (Ginevra, Nota, & Stokes, 2016; Stokes & Kaur, 2005; Stokes et al., 2007; Tissot, 2009). Adolescents and adults with ASD reported sexual frustration, lack of outlets for sexual tension, and sexual preoccupations (Murrie et al., 2002; Ray et al., 2004) and a broad variety of inappropriate sexual behavior has been described in a small group of people with ASD, ranging from asking inappropriate questions, touching others inappropriately, to stalking and public masturbation (Coskun et al., 2009; Dozier et al., 2011; Hénault, 2006; Realmuto & Ruble, 1999; Ruble & Dalrymple, 1993; Stokes et al., 2007). Case studies illustrated sexual offending behaviors in adolescents and adults with ASD (Chan & Saluja, 2011; Griffin-Shelley, 2010; Haskins & Silva, 2006; Kohn et al., 1998; Murrie et al., 2002). Also, paraphilias, such as exhibitionism, voyeurism, paedophilia and fetishism, have been described in people with ASD (Cooper et al., 1993; Dozier et al., 2011; Early et al., 2012; Hellemans et al., 2007; Kellaher, 2015). Very recently, a study has found that in a group of adolescents and young adults with ASD about one fourth portrayed inappropriate sexual behavior or struggled with paraphilias (Fernandes et al., 2016). Unfortunately, most of the previous publications on inappropriate sexual behavior in people with ASD are case studies or deal with methodological limitations, such as small sample sizes or no use of self-report measures. Adolescents with ASD are not only reported to be more at risk to portray inappropriate sexual behavior, but also to become a victim of sexual bullying or abuse (Edelson, 2009; Sevlever et al., 2013). The prevalence of sexual victimization in people with ASD was estimated on 16.6% (Mandell et al., 2005) and Brown-Lavoie et al. (2014) reported that people with ASD were between two and three times more likely to experience sexual victimization, sexual coercion and rape than people without ASD. All these potential risks cause concerns in parents of adolescents with ASD. Parents have

concerns both about the risk of sexual exploitation as well as about the possibility that their child will show inappropriate sexual behavior (Ballan, 2012; Cridland et al., 2014; Ginevra et al., 2016; Nichols & Blakeley-Smith, 2009; Stokes & Kaur, 2005).

This contradiction in previous research, with some studies focussing on problematic sexual behavior, and others indicating a healthy sexual development in adolescents with ASD, calls for research to increase insight in factors associated with the development of (in) appropriate sexual behavior in adolescents with ASD. Investigating how adolescents with ASD judge sexual situations can be a valuable first step. In the present study, we aimed to get more insight in the judgement of sexual situations by adolescents with ASD, by using the flag system. The flag system can be used to get an indication of how children, adolescents, and adults judge the appropriateness of different sexual situations (Frans & Franck, 2010). We investigated judgement of a wide range of illustrations of sexual situations, and we compared the judgements of adolescents with ASD with the judgements of a matched sample of typically developing adolescents, by contrasting both groups to consensus judgements composed by an expert panel.

This is the first study that examines the judgement on the appropriateness of different sexual situations by adolescents with ASD. As such, this study has an exploratory nature. Possibly, adolescents with difficulties judging the appropriateness of sexual situations might also have difficulties in behaving appropriately in actual sexual situations. In other words, misjudgement of sexual situations might be associated with difficulties in both stating your own boundaries as well as taking other peoples boundaries into account and thereby increasing the chance of engaging in inappropriate sexual behavior. When adolescents with ASD indeed judge sexual situations differently than the expert panel, and than adolescents without ASD, this might be a first step in explaining the previously reported inappropriate sexual behavior and vulnerability to sexual victimization in adolescents with ASD.

METHODS

Participants

Participants in this study were 94 adolescents with ASD and 94 typically developing adolescents, all between 12 and 18 years of age. This study was approved by the medical ethical commission of the Erasmus Medical Centre, Rotterdam (MEC-2013-040).

The adolescents with ASD were derived from a larger group of 184 adolescents with a DSM-IV-TR diagnosis of ASD that participated in a large randomized controlled trial on the effects of a psychosexual training program for adolescents with ASD (Visser et al., 2015). Eligibility criteria for the adolescents with ASD were a total score of 51 or above on the Social Responsiveness Scale (SRS) (Constantino & Gruber, 2002), and an intelligence score in the normal range (total IQ ≥ 85).

The typically developing (TD) adolescents were also derived from a larger group of 180 adolescents, collected as part of a Master thesis project from the Erasmus University Rotterdam, and recruited from a large multi-ethnic high school with all education levels, in The Hague, the Netherlands. The control group consisted of adolescents from all education levels, with the majority (53.7%) attending lower general secondary education (in Dutch: VMBO). In the general population in the Netherlands approximately 60% of all students attend this type of high school (CBS, 2016). 32.7% of our control group attended higher general secondary education (in Dutch: HAVO) and 13.7% attended pre-university education (in Dutch: VWO).

Both age and ethnicity are factors that can influence the judgement of sexual behavior (de Graaf et al., 2012). Since the two groups differed significantly on these variables, we matched the samples at an individual level (ratio ASD:TD = 1:1) on age (maximum six months apart) and ethnicity (i.e. coming from a Dutch or a non-Dutch cultural background/up-bringing, e.g. a Moroccan, Turkish or Surinamese cultural background). This resulted in two subsamples of 94 adolescents. Table 1 shows the characteristics of the adolescents with ASD and the TD adolescents after matching on age and ethnicity. We tested the group differences after matching on age, gender and ethnicity with an independent sample t-test and chi squares and the magnitude of the difference with Cohen's *d* and phi. Only gender remained significantly different between the groups, with more boys in the ASD group.

Table 1. Characteristics of the adolescents with and without ASD

	Adolescents with ASD N=94	**TD adolescents N=94**	**Testing group difference**
Gender (male), n (%)	79 (84.0%)	63 (66.3%)	$\chi^2(1, N=188)=8.17$, $p<.01$, $\varphi=0.21$
Age (in years), M±SD (range)	15.38±1.37 (12.4-18.6)	15.47±1.34 (12.7-18.3)	$t(186)=-0.47$, $p=.64$, Cohen's $d=-0.03$
Ethnicity (Dutch), n (%)	67 (70.5%)	67 (70.5%)	$\chi^2(1, N=188)=0.000$, $p=1.00$, $\varphi=0.00$
Total IQ, M±SD (range)	104.37±12.30 (85-142)	-	
SRS total score M±SD (range)	96.18±25.46 (52-158)	-	
ADOS-2 calibrated severity score, M±SD (range)	6.1±2.13 (1-9)	-	

Note: M=mean; SD= standard deviation; SRS: Social Responsiveness Scale; ADOS-2: Autism Diagnostic Observation Schedule

Materials & design

For descriptive purposes, in addition to the SRS, a 65-item questionnaire filled out by parents, we used a clinical observation measure for ASD severity, the Autism Diagnostic Observation Schedule-2 (ADOS-2) (Lord et al., 2012). The ADOS-2 is a semi structured, standardized measure to assess social interaction, communication, play, and stereotyped behavior for

individuals suspected of having ASD. Both the SRS total score and the ADOS-2 calibrated severity score provide a dimensional measure of ASD symptom severity, with higher scores reflecting a greater degree of social impairment (Constantino & Gruber, 2002; Hus & Lord, 2014). The SRS total score and the ADOS-2 calibrated severity score in Table 1 show that the ASD sample consisted of adolescents with a wide range of ASD symptom severity. Furthermore, using the ADOS diagnostic algorithm, 44.6% of the ASD sample met the cut-off for ASD and 47.8% met the cut-off for autistic disorder.

The flag system (in Dutch: het Vlaggensysteem) (Frans & Franck, 2010) was administrated to assess judgement of sexual situations portraying appropriate and inappropriate behaviors. The flag system consists of a set of 44 drawn illustrations of children and adolescents displaying sexual behaviors in different situations. The flag system offers professionals who work with children and adolescents a tool to assess sexual behavior, to discuss it with colleagues and children and adolescents themselves and to respond appropriately. Six criteria were used by an expert panel to judge whether sexual behavior is regarded as appropriate or as inappropriate in a society (Frans & Franck, 2010; Ryan et al., 2011). The first criterion is 'consent', or mutual agreement. The second criterion is 'equality', meaning that in a sexual interaction both parties must be evenly matched, so that one does not dominate the other. The third criterion is 'free will', in other words, whether one party puts pressure on the other party, or uses a form of pressure in the sexual interaction (Ryan et al., 2011). The fourth criterion is 'appropriate for age', looking at if behavior is expected and accepted at a certain age, or is more appropriate in younger or older children or adolescents. The fifth criterion is 'appropriate for context', meaning that different contexts are associated with different rules and whether privacy rules are followed, for instance behavior may not be appropriate in the playground, but may be in the bedroom. The last criterion is 'self-respect', looking at the physical or psychological harm to the child that shows the behavior (Frans & Franck, 2010).

In the first step of the development of the flag system the developers used these six criteria to define four flags (green, yellow, red, and black). These flags are linked to how parents, caregivers and professionals can offer an appropriate response when they come across these behaviors. A green flag means that the sexual behavior meets the six criteria, for example explicit sex conversations at thirteen with same age peers, or showing and comparing intimate body parts with same age peers in a private place. Green flag behavior can be respected or confirmed. A yellow flag means that there are occasional and slight transgressions in one or several criteria, for instance not age-appropriate sexual contact with a same age peer or sexual experimenting between same age peers when mutual consent is uncertain or when peer pressure plays a role. Yellow flag behavior can be limited (but not forbidden). A red flag means more serious or repeated transgressions of the criteria, such as intimate contact between two adolescents who differ more than six years in age or sexual behavior with coercion from one party to the other. Red flag behavior should be forbidden.

A black flag is tantamount to sexual abuse or seriously risky sexual behavior, such as rape, forced sex or exhibitionism. Black flag behavior should be forbidden and followed up with setting boundaries, punishment or treatment (Frans & Franck, 2010). An example illustration for each colour category of the flag system is shown in Figure 1-4.

The second step in the two year development of the flag system was that multiple focus groups of health care professionals decided upon the most accurate flag for each illustration. Then, the flag system was tested out with typically developing adolescents, and in an expert panel of child health care professionals consensus on the correct flag was reached.

In this study, given the age range of our participants, the adolescents were shown 23 illustrations portraying younger adolescents (12-14 years, 11 illustrations) and older adolescents (14-17 years, 12 illustrations). At the bottom of each illustration, there is a line of text explaining the situation, for instance: 'A 15-year old boy shows his penis in front of a webcam'. The illustrations are explicit and the line of text is straight forward. The age of the portrayed adolescents is given in this line of text in order to judge the age-appropriateness of the behavior in the illustration. This is the first study to explore the flag system as a measure of judgement, as such the psychometric properties of the flag system are unknown.

Figure 1. Green flag illustration "Two 12 year old girls look together in a lingerie catalogue"

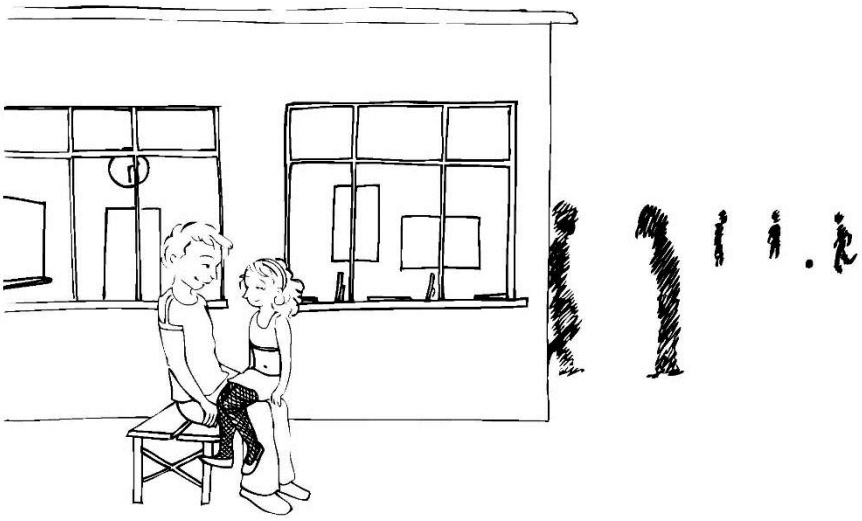

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Figure 2. Yellow flag illustration "A 12 year old girl sits on a 17 year old boy's lap"

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Figure 3. Red flag illustration "A 15 year old girl shows her breast on the internet in exchange for calling credit"

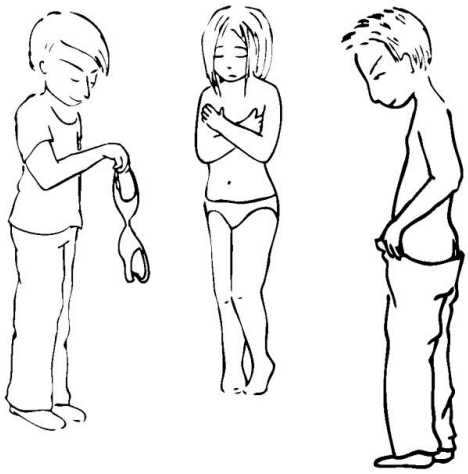

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Figure 4. Black flag illustration "Two 16 year old boys force a 14 year old girl to engage in sexual games"

Procedures

Written informed consent was obtained from all adolescents and their primary caregivers. Among the adolescents with ASD the flag system was administered individually. The research assistant first explained the meaning and the use of the four flags (green, yellow, red and black) that were visible on the table during the whole examination. Then the research assistant showed the 23 illustrations one-by-one in a random order to each participant. The order of the illustrations was the same for all participants. With each illustration, the research assistant read aloud the explaining line of text and then asked the adolescent to select one flag, best judging the sexual situation shown in the illustration. The first illustration was used as an exercise: After the adolescent chose a flag for the first illustration, the research assistant gave the adolescent feedback on the correct flag, and again explained the meaning of the four flags, in order to reassure the adolescent understood the procedure. For the other illustrations, the research assistant wrote down the chosen flag, without giving feedback to the adolescent during the test. The illustrations were shown in the same order for all cases, with the correct flags in a random order for the adolescents. The TD adolescents received the same verbal instruction and feedback and judged the illustrations in the same random order, but filled out the flag system on paper in a classroom setting. Neither group (ASD or TD) received any information on the six criteria used to judge the portrayed behavior.

For each illustration, a participant either chose the same (i.e. correct) or a divergent (i.e. incorrect) flag as compared to consensus judgements by the expert panel. A divergent judgement could indicate either a milder (i.e. less conservative) judgement or a stricter (i.e. more conservative) judgement, as compared to the judgements of the expert panel.

Analyses

Firstly, we calculated the average percentages of the same and divergent (i.e. milder or stricter) judgements for the adolescents with ASD and the TD adolescents for each illustration in the flag system, all illustrations together and per set of illustrations with the same colour, in comparison with the judgements of the expert panel. For the percentages divergent judgements only the sets of illustrations that make milder judgements possible (i.e. yellow, red & black), and only the sets of illustrations that make stricter judgements possible (i.e. green, yellow & red) were selected. Because the first illustration was used as an exercise illustration, we excluded this illustration in the analyses.

Secondly, we compared the judgements of the adolescents with ASD with the judgements of TD adolescents, by testing the differences in percentages same and divergent judgements between the ASD and the TD group with independent sample *t*-tests for all illustrations together (n=22) and for each set of illustrations with the same colour (green, yellow, red, and black). We considered results with a p value < 0.05 as significant. We have calculated effect-sizes for all results using Cohen's *d*, with 0.2 regarded a small effect, 0.5 a medium effect and 0.8 a large effect. With two groups of 94 participants and a power of 0.80 we would be able to demonstrate results with an effect-size of 0.366 (Cohen, 1988).

RESULTS

For both groups, the average percentages of the same and divergent (i.e. milder or stricter) judgements, compared against consensus judgements of the expert panel, overall and for each of the four colour sets of illustrations of the flag system, are shown in Table 2. When the 22 illustrations were considered together, the mean percentage of similarly chosen flags was not significant, meaning the judgements of the adolescents with and without ASD were equally similar to the consensus judgements of the expert panel. Also, when the four colour sets of illustrations were taken separately, we found no significant differences between the two groups on the same judgements. Regarding the divergent judgements, both groups showed higher percentages of stricter (i.e. more conservative) judgements than milder (i.e. less conservative) judgements and no significant differences were found between the adolescents with ASD and the TD adolescents on the overall percentages of stricter and milder judgements, nor when the colour sets of illustrations were taken separately.

Because of the still existing differences in gender between the two groups after matching, we explored whether the results were different when analyzing boys separately. Unfortunately, not enough girls with ASD participated to perform separate analyses for girls. For boys, we found a significant difference with a large effect-size between the groups on the percentage same judgements for the sexual behaviors that are severely inappropriate and

liable to punishment (black flag illustrations) ($t(8)=-2.886$, $p=0.02$, Cohen's $d=1.83$). Logically, we also found a significant difference with a large effect-size on the average percentages of milder judgements for these black flag illustrations ($t(8)=-2.687$, $p=0.03$, Cohen's $d=-1.70$). These results show that TD boys were less conservative in their judgements of sexual behavior that the expert panel considered severely inappropriate and liable to punishment, compared to boys with ASD.

Table 2. Percentage of chosen flags per set of illustrations

		Adolescents with ASD (n=94)			**TD adolescents (n=94)**			**Comparison ASD and TD group**		
Set of illustrations	N	Same judgements	Divergent judgements		Same judgements	Divergent judgements		Same judgements	Divergent judgements	
			Milder (i.e. less conservative)	Stricter (i.e. more conservative)		Milder	Stricter		Milder	Stricter
Overall	22	45.07%	16.68%	55.38%	37.89%	18.93%	62.93%	$t(42)=0.844$, $p=0.40$, Cohen's $d=0.25$	$t(30)=-0.265$, $p=0.79$, Cohen's $d=-0.09$	$t(32)=-1.002$, $p=0.32$, Cohen's $d=-0.34$
Green flag behaviors	6	31.74%	N.a.	68.26%	24.38%	N.a.	75.62%	$t(10)=0.820$, $p=0.43$, Cohen's $d=0.47$	N.a.	$t(10)=-0.820$, $p=0.43$, Cohen's $d=-0.47$
Yellow flag behaviors	6	26.06%	15.60%	58.33%	23.61%	14.79%	62.66%	$t(10)=0.358$, $p=0.73$, Cohen's $d=0.21$	$t(10)=0.265$, $p=0.80$, Cohen's $d=0.15$	$t(10)=-0.341$, $p=0.74$, Cohen's $d=-0.20$
Red flag behaviors	5	39.79%	23.83%	36.38%	24.64%	27.32%	48.04%	$t(8)=1.996$, $p=.08$, Cohen's $d=1.26$	$t(8)=-0.206$, $p=0.84$, Cohen's $d=-0.13$	$t(8)=-0.910$, $p=0.39$, Cohen's $d=-0.57$
Black flag behaviors	5	89.15%	10.85%	N.a.	84.90%	14.68%	N.a.	$t(8)=1.289$, $p=0.23$, Cohen's $d=0.81$	$t(8)=-1.148$, $p=0.28$, Cohen's $d=-0.72$	N.a.

Note: 22 illustrations of the flag system showing different sexual situations were used. In the flag system these illustrations are divided in four colour sets, based on the appropriateness of the portrayed sexual behavior. Displayed are the average percentages of the same and divergent (i.e. milder or stricter) judgements of the adolescents with ASD and the TD adolescents, compared against the judgements of an expert panel.

DISCUSSION AND IMPLICATIONS

The aim of this exploratory study was to investigate how cognitively-able adolescents with ASD judge the appropriateness of different sexual situations, using the flag system (Frans & Franck, 2010), because a divergent judgement might explain factors associated with the development of inappropriate sexual behavior that have been reported in adolescents with ASD. As a comparison, we also investigated how an age and ethnicity matched group of typically developing (TD) adolescents judged the illustrations of sexual situations, and whether their judgements differed from the judgements of the adolescents with ASD.

Results showed that approximately half of the adolescents with ASD judged the illustrations of sexual situations similarly to consensus judgements of an expert panel of health care professionals. Surprisingly, no significant differences were found between the judgements of the adolescents with ASD and the TD adolescents. The only difference was found between boys with ASD and TD boys, with the TD boys giving more milder judgements (i.e. being less conservative) regarding sexual behaviors that the expert panel considered severely inappropriate and liable to punishment, compared to the boys with ASD.

Both adolescents with and without ASD had most trouble judging perfectly appropriate sexual behaviors (i.e. situations portraying normal experimenting behaviors) and slightly inappropriate sexual behaviors (i.e. sexual behavior that violates one criterion, for instance not being totally age-appropriate or taking place in the wrong context). The results showed that all adolescents tend to be more cautious with regard to these sexual behaviors. A possible alternative explanation for this finding is that a comparison was made with an expert panel of child health care professionals, instead of norm data obtained from adolescents from Dutch and/or Belgian society. Possibly, the health care professionals in the panel were used to working with – and talking about – sexuality, making their views more liberal than the views in our society in general.

Furthermore, the vast majority of adolescents with and without ASD accurately identified sexual behaviors that are severely inappropriate and liable to punishment, for instance when they were asked to judge forced sexual contact or exhibitionism. However, 10% of the adolescents with ASD and 15% of the TD adolescents gave a milder (i.e. less conservative) judgement of these sexual situations, indicating that (at least on paper) they underestimated the dangers of these inappropriate sexual behaviors. This group might reflect those adolescents that are vulnerable to develop inappropriate sexual behaviors or to become a victim of sexual abuse. Underestimating the inappropriateness of sexual behavior might put adolescents at risk to develop inappropriate sexual behavior or to become a victim of sexual abuse, making it equally important to identify both these adolescents with and without ASD early and, if needed, provide them extra guidance and information regarding why certain sexual behavior is inappropriate.

Based on previous research reporting inappropriate sexual behavior as well as sexual vulnerability in adolescents with ASD (Edelson, 2009; Fernandes et al., 2016; Hénault, 2006; Sevlever et al., 2013; Stokes et al., 2007) we expected that especially adolescents with ASD would have the tendency to give milder (i.e. less conservative) judgements of sexual behaviors. In contrast, we found that their divergent judgements were more strict (i.e. more conservative) than those of the expert panel and comparable to the judgements of the control group of adolescents without ASD.

The current study demonstrated that adolescents with ASD at least have sufficient knowledge to adequately judge different sexual situations, which might seem in contradiction with existing research showing that adolescents with ASD often lack the knowledge required to successfully express their sexuality (Pecora et al., 2016). However, future research should further clarify whether adolescents with ASD cognitively know and are aware of the rules of appropriate and inappropriate sexual behavior, and subsequently, if they can act upon these rules in more complex real life situations.

Limitations and clinical implications

This study was the first to explore the judgement of different sexual situations by adolescents with ASD, and therefore some limitations that need to be addressed in future studies can be identified. Firstly, we acknowledge that the flag system is primarily a normative and pedagogical framework, developed as a tool to facilitate discussion about sexual behaviors of children or adolescents with parents, caregivers and professionals (Frans & Franck, 2010). In this study the flag system was explored as an assessment tool, while the psychometric properties are yet unknown. To our knowledge, no other instruments are available for measuring judgement of – or insight into – appropriate and inappropriate sexual behaviors, and the flag system thus might be a useful first starting point towards a more sophisticated measure. Also, even though the experts reached consensus on the most appropriate flag for each sexual situation, some of the portrayed sexual behavior is open for different interpretations on the appropriateness of the situation and the most suited flag. The difference in administration between the two groups (individual report to a research assistant for the adolescents with ASD versus on paper in a classroom setting for the TD adolescents) might have influenced how they each judged the portrayed behaviors. Also, more generally, reporting on a delicate matter like sexual situations might be influenced by social desirability which can be different for adolescents with ASD and TD adolescents. Therefore, future studies should reconsider the way of administration in all participants.

Secondly, we do not know how the adolescents reached their judgement, so whether the adolescents considered particular criteria to judge the illustrated sexual behaviors (i.e. consent, equality, coercion, appropriate for age, appropriate for context and self-respect). Therefore, it remains to be investigated why the adolescents give stricter or milder judgements

of sexual behaviors across different situations. Further research is needed to investigate the judgements of adolescents with ASD in more ecologically valid settings. Thirdly, sexuality is culture-specific (Barbaree & Marshall, 2008) and the flag system was developed based on research from Western Europe and North America. For instance, the developmentally appropriate ages for certain sexual behaviors cannot be generalised to other cultures and educational contexts (Frans & Franck, 2010). Future research could focus on whether the illustrations in the flag system and the allocation of a certain flag to a certain illustration are different for people (with and without ASD) coming from other countries or cultures.

Due to these limitations, we acknowledge that, although this exploratory study had a reasonable sample size, results should be interpreted with caution, and more research on both a healthy sexuality development as well as the development of inappropriate sexual behavior in adolescents with ASD is required. Furthermore, although we explored differences separately for boys, power was limited to do so, therefore future studies are also required on the differences in psychosexual development between boys and girls (Pecora et al., 2016).

Nevertheless, the outcomes of this study can be valuable for clinical practice. For long, the focus of guidance in adolescent sexuality has been on dangerous behaviors and pathology, rather than on normative, positive aspects. Currently, this viewpoint is changing towards a more positive and normative viewpoint on adolescent sexuality (Tolman & McClelland, 2011), which is in line with our findings of no aberrant judgement by adolescents with ASD. In general, adolescents acquire knowledge and skills through sexual exploration and experiences, and in this way they learn the rules of social, intimate and sexual interaction (Frans & Franck, 2010). Little room for sexual exploration and unfulfilled desires can increase the risk to develop sexual frustration (Hénault, 2006). The focus of parents of adolescents with ASD and health-care providers working with this group is, in our observation, still mainly on keeping these adolescents safe and preventing them from becoming either a perpetrator or a victim of inappropriate sexual behavior. We believe that focussing only on dangers can have an unintended downside: it might make adolescents with ASD over-cautious with regard to age appropriate sexual behaviors and might even deter adolescents with ASD from showing normative explorative sexual behaviors, and in this way may hamper sexual development and perhaps even increase sexual frustration. With this paper we would, therefore, like to add to the growing field of research to the psychosexual development of people with ASD. Clearly, more research is needed into why some people with ASD develop inappropriate sexual behavior and why some others are vulnerable for sexual abuse. Yet, just as importantly, future research should also focus on normative aspects of sexuality, with the purpose of promoting a positive and safe psychosexual development in adolescents with ASD.

CHAPTER 4

Insight in informant discrepancies between self-report and parent-report regarding psychosexual functioning of adolescents with and without autism spectrum disorder

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ABSTRACT

Background: Despite the known benefits of the use of multiple informants in clinical practice and research, in previous studies on the psychosexual development of adolescents with autism spectrum disorder (ASD) multiple informants were barely used. The private nature of psychosexual functioning implies that adolescents and their parents might have different views, which highlights both the importance of using multiple informants, as well as the importance of studying informant discrepancies.

Methods: To examine informant discrepancies between self-reported and parent-reported psychosexual functioning of adolescents with ASD, we first investigated informant discrepancy in reports on psychosexual functioning of adolescents with ASD for 136 parent-child dyads, using multilevel analyses. As a measure of psychosexual functioning we used the self-report and parent-report version of the Teen Transition Inventory (TTI). Second, we compared parent-child informant discrepancy of reported psychosexual functioning between the ASD dyads and 70 dyads with typically developing (TD) adolescents.

Results: Significant informant discrepancies were found in the ASD dyads regarding several domains of psychosexual functioning (i.e. Friendship skills, Social acceptance, Body image, Inappropriate sexualized behavior, and Online sexual behavior). Overall, the adolescents with ASD reported more self-esteem and skills than their parents, while parents reported more negative and risky sexual behavior than the adolescents with ASD. Secondly, informant discrepancies in ASD dyads were significantly larger than informant discrepancies in TD dyads in almost all domains of psychosexual functioning, with the exception of sexual experience.

Discussion: Given the discrepancies we found between parent-reported and self-reported psychosexual functioning, it is important to use both informant in research to psychosexual functioning and clinical practice for adolescents with and without ASD. This provides insight in both perspectives and experiences, and gives information on the degree of agreement between parents and their children.

INTRODUCTION

A growing interest in the psychosexual functioning of adolescents with autism spectrum disorder (ASD) has led to an increase in research, showing that adolescents and adults with ASD have a desire for intimate and sexual relations (Dewinter et al., 2014; Gilmour et al., 2012; Hénault, 2006; Stokes et al., 2007) and have similar experiences and behaviors compared to typically developing (TD) adolescents (Dewinter et al., 2014). On the other side, more difficulties in the psychosexual functioning of adolescents with ASD are found, such as inappropriate sexual behaviors (Dekker et al., 2014; Hellemans et al., 2007; Sevlever et al., 2013; Stokes et al., 2007); less appropriate sexual behaviors (Mehzabin & Stokes, 2011) and less psychosexual knowledge (e.g., Ginevra et al., 2016; Hellemans et al., 2007; Stokes & Kaur, 2005). However, underlying factors that contribute to the development of inappropriate sexual behavior or sexual problems are currently unknown (Visser et al., 2017), underscoring the importance of an accurate and complete measurement of psychosexual functioning of adolescents with ASD and possible problems. In order to do so, it is important to consult the right informants, and to get insight into the the degree of agreement between the informants.

The use of multiple informants has been emphasized in clinical practice and research, especially with children and adolescents, as all informants contribute unique information regarding the symptoms, problems, feelings and functioning of the child (De Los Reyes & Kazdin, 2005; Nicpon, Doobay, & Assouline, 2010; van der Ende, Verhulst, & Tiemeier, 2012). However, in research to psychosexual functioning of adolescents with ASD, generally the parents or caregivers are used as informants (Byers, Nichols, & Voyer, 2013; Byers, Nichols, Voyer, & Reilly, 2013; Dewinter et al., 2013; Gilmour et al., 2012; Hénault, 2006; Kuo, Orsmond, Cohn, & Coster, 2013; Mehzabin & Stokes, 2011). Self-report is barely used, which means most of the results found up to today mainly reflect the parent or caregivers point of view. We know that adolescents with ASD are less forthcoming with their parents about their lives (Stokes, Kornienko, Scheeren, Koot, & Begeer, 2016), and share less personal (e.g. psychosexual) information with them, possibly leading to less communication regarding sexual topics. In addition, parents of adolescents with ASD experience uncertainty in how to discuss psychosexual themes with their children (Ballan, 2012; Holmes et al., 2014; Nichols & Blakeley-Smith, 2009), they talk more with their children more about the dangers of sexuality and technical aspects, and focus less on positive elements of sexual functioning (Ballan, 2012; Ruble & Dalrymple, 1993). This questions the reliability of parents in reports to the psychosexual functioning of adolescents with ASD.

In research on the psychosexual functioning of typically developing (TD) adolescents, usually self-report is used (Schrimshaw, Rosario, Meyer-Bahlburg, & Scharf-Matlick, 2006). However, the use of self-report in people with ASD has been debated, due to difficulties that people with ASD are known to have in the cognitive processing of emotions, including

difficulties identifying and describing feelings (Hill et al., 2004; Ozsivadjian, Hibberd, & Hollocks, 2014). The validity and reliability of self-report questionnaires in people with ASD has been a topic of interest in ASD research and shows, contrary to expectations, a moderately positive picture: Children and adolescents with ASD are capable of responding adequately to questionnaires when asked to report their own emotions (Berthoz en Hill, 2005; Hill, Berthoz & Frith, 2004; Baron-Cohen et al., 2001). Furthermore, self-report questionnaires for adolescents with ASD have good internal reliability (Mazefsky et al., 2010) and good test-retest reliability (Berthoz en Hill, 2005, Baron-Cohen et al., 2001). The fact that adolescents with ASD understand the items in a questionnaire and can provide consistent answers shows that it is possible to use self-report in adolescents with ASD in addition to parent-report when investigating psychosexual functioning.

When multiple informants are used, usually informant discrepancies occur. It is known that parent-child informant discrepancies are larger for internalizing than externalizing themes (Barker, Bornstein, Putnick, Hendricks, & Suwalsky, 2007; Van der Meer, Dixon, & Rose, 2008; Verhulst & Ende, 1992) and larger parent-child informant discrepancies are found in ratings of adolescents than in ratings of children (Renk & Phares, 2004). As children enter adolescence, the parent-child relationship changes, which may be reflected in, for instance, an increased negative affect associated with more parent-child conflict and adolescents spending more time with peers (Collins & Laursen, 2004). These changes limit the communication between the adolescent and their parents, especially regarding intimate topics. From research it becomes clear that adolescents preferably discuss intimate topics with their friends rather than with their parents (de Graaf et al., 2012). The private nature of several aspects of psychosexual functioning (e.g. intimate and sexual behavior), implies that adolescents and their parents might have different views, which not only highlights the importance of using multiple informants, but also highlights the importance of studying the differences between these informants (i.e. informant discrepancies).

Until now, only one study compared self-reported and parent-reported sexual behavior of adolescents with ASD, showing that adolescent boys with ASD reported more sexual experiences than their parents reported their children to have (Dewinter, Vermeiren, Vanwesenbeeck, & Van Nieuwenhuizen, 2016b). This lower estimation of parents might also play a role in other domains of psychosexual functioning, but this is currently unknown (Dewinter, Vermeiren et al., 2016b), because our knowledge of the psychosexual functioning of adolescents with ASD is mostly based on parental, teacher, and caregiver reports (e.g. (Hellemans et al., 2007; Hellemans, Roeyers, Leplae, Dewaele, & Deboutte, 2010; Mehzabin & Stokes, 2011; Stokes & Kaur, 2005). Furthermore, due to the differences in used informants in research to the psychosexual functioning of TD adolescents and adolescents with ASD, comparing the findings can be difficult. More knowledge on the degree of parent-child informant discrepancy is a valuable contribution to the existing literature on ASD and

psychosexual functioning, because it can put previous findings, measured using either parent, clinician or adolescent reports in a clearer perspective. In addition, it may inform policies in clinical practice regarding the assessment of psychosexual functioning.

Therefore, in the current study we aimed to get more insight in parent-child informant discrepancies regarding the psychosexual functioning of the adolescents, by (1) investigating the degree of discrepancy between self-reported and parent-reported psychosexual functioning of adolescents with ASD and (2) comparing the parent-child informant discrepancy of reported psychosexual functioning between ASD dyads and dyads with typically developing (TD) adolescents. We investigated the three domains of psychosexual functioning, psychosexual socialization, selfhood and sexual/intimate behavior (see measures for more information) (Dewinter et al., 2013; Tolman & McClelland, 2011).

This is the first study looking at informant discrepancy in both ASD dyads and TD dyads, however, some hypotheses could be formulated based on previous research. Several studies regarding a variety of topics (e.g. social functioning, behavioral problems, internalizing problems) in general populations showed a generally low correlation between different informant reports (Achenbach, McConaughy, & Howell, 1987; De Los Reyes & Kazdin, 2005; Duhig, Renk, Epstein, & Phares, 2000; Jensen et al., 1999; Renk, 2005). As psychosexuality is a private, and thus potentially more intrapersonal, topic which is often measured from adolescence onwards we expected there to be informant discrepancies between all adolescents and their parents. As described above, previous research shows that parents of adolescents with ASD are uncertain about how to discuss psychosexual themes with their children (Ballan, 2012; Holmes & Himle, 2014; Nichols & Blakeley-Smith, 2009), possibly leading to less communication and therefore larger informant discrepancy in the ASD dyads than the TD dyads. We expected parents of adolescents with ASD to be less aware of the sexual behavior of their children than parents of TD adolescents, more specifically, that the adolescents with ASD would report more sexual behavior, similar (Dewinter, Vermeiren et al., 2016b). With regards to inappropriate behavior we also expected larger discrepancies in individuals with ASD and their parents compared to TD adolescents and their parents, as the difficulty with discriminating public and private behavior (Nichols & Blakeley-Smith, 2009), may also mean individuals with ASD do not realize their behavior is inappropriate thus not qualify certain inappropriate behaviors as such. On the other side, we hypothesized that parents and adolescents with ASD would differ more than parents and TD adolescents in their reports regarding sexual socialization (e.g. social acceptance and friendship skills), because adolescents with ASD are known to report lesser autistic traits, more empathic capabilities, and better social skills compared to their parents (Johnson, Filliter, & Murphy, 2009), while parents of TD adolescents attribute their children to have higher social skills than the adolescents attribute to themselves (Gresham, Elliott, Cook, Vance, & Kettler, 2010). As sexual selfhood (e.g. bodily perception) is generally understudied (Dewinter et al., 2013), no assumptions where formulated for this domain.

METHODS

Participants and procedure

In this study, 136 dyads with adolescents with autism spectrum disorder (ASD) and their primary caregivers participated, were labeled as the ASD group. In addition, 70 dyads with typically developing (TD) adolescents (i.e. from the general population) and their parents participated in this study, labeled as the TD group. The groups have been derived from larger samples, see Figure 1. The ASD group was derived from two samples that have been extensively described elsewhere (Dekker et al., 2017; Visser, Greaves-Lord et al., 2017). In the first ASD sample the questionnaire measuring psychosexual functioning, the Teen Transition Inventory (TTI, see measures) was administered in 178 parent-adolescent dyads as part of the baseline measure for a Randomized Controlled Trial (RCT) to investigate the effects of a psychosexual training program for adolescents with a DSM-IV-TR diagnosis of ASD (Visser, Greaves-Lord et al., 2017). The second ASD sample came from a larger clinical sample, participating in a follow-up epidemiological study at the Erasmus Medical Centre – Sophia's Children's Hospital in Rotterdam, the Netherlands (de Bruin, Ferdinand, Meester, de Nijs, & Verheij, 2007; Louwerse et al., 2015). The TTI was returned by 58 parent–adolescent dyads (more information on the sample see (Dekker et al., 2017), of which all the adolescents received a best-estimate ASD diagnosis (based on the Autism Diagnostic Interview-Revised and Autism Diagnostic Observation Schedule) (Falkmer, Anderson, Falkmer, & Horlin, 2013). The two ASD samples combined resulted in 236 parent-adolescents dyads with ASD.

The TD sample was drawn from a Dutch general population study (N = 1710) (Evans et al., 2012; Tick, van der Ende, & Verhulst, 2008). From this sample, all adolescents between the ages 12 and 21 years old and their parents were contacted to fill out the TTI (n=326). Of those who returned the questionnaires, we excluded adolescents with elevated autistic traits, as assessed with the Autism Quotient (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001), resulting in a TD sample of 91 parent–adolescent dyads (more information on the sample see (Dekker et al., 2017).

As several studies have shown that age may be an influential characteristic on informant discrepancies (De Los Reyes & Kazdin, 2005), and we aimed to compare informant discrepancies between the ASD and TD group, we matched the two groups based on age. Due to matching the samples (ratio ASD:TD = 2:1), the final ASD sample consisted of 136 adolescents with ASD of whom both a self-report and parent-reported TTI was available and the final TD sample consisted of 70 parent-adolescents dyads. After matching the samples, the mean age of the adolescents in the combined ASD group was 16.20 years (range 13.86-20.25, SD = 1.54) and the mean age of the adolescents in the TD group was 16.29 years (range 13.92-20.00, SD = 1.55). The adolescents in both groups did not differ in full IQ, but did differ in gender, with significantly more boys in the ASD group (83.8%) than the TD group (41.4%) (see Table 1).

Table 1. Demographics

	ASD group n=136	TD group n=70	χ^2/t Value
Gender, male, N (%)	114 (83.8%)	29 (41.4%)	$\chi^2(1, N=206) = 39.13$, p<.001**
Age (y), M±SD (range)	16.20±1.54 (13.86-20.25)	16.29±1.55 (13.92-20.00)	t(204)= .40, p=.69
Total intelligence, M±SD (range)	103.90±12.82 (71.00-140.00)	101.53±15.52 (64.19-151.59)	t(190)=-1.12, p= .26

Note: ASD: Autism Spectrum Disorder; TD: typically developing; M=mean; SD=standard deviation

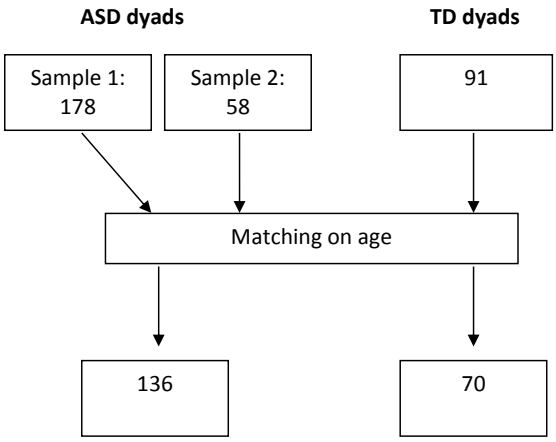


Figure 1. Sample description

Measures

The Teen Transition Inventory (TTI; (Dekker et al., 2017) measures psychosexual functioning, covering psychosexual socialization (i.e. the context in which psychosexual development takes place, such as friends, family and the internet), psychosexual selfhood (i.e. the internal functioning of people, for example sexual knowledge and self-esteem) and sexual/intimate behavior (i.e. behaviors and experiences with sexuality; (Dewinter et al., 2013; Tolman & McClelland, 2011). The TTI consists of a self-report (205 items) and parent-report version (148 items), which have considerable overlap. In the current study, only the scales of the TTI data that are similar in the parent-report and self-report version concerning psychosexual functioning and confidence in the future were used. The content of the scales was the same for both informants, although the scales could vary in the number of items, which is why in all the analyses the summated item scores divided by the number of items in the scales were used. We used seven scales: Friendship skills, Social acceptance by peers, Body image, Sexual experience, Inappropriate sexualized behavior, Online sexual behavior, and Confidence in the future.

The Friendship skills scale measured the ability of the adolescents to make and maintain friendships. Scores for these scales ranged from 0-2 (higher scores indicating higher abilities) and internal consistency was α = .69 (parent-report) and α = .86 (self-report). The Social acceptance by peers scale measured how the adolescents were socially accepted by peers. Scores for these scales ranged from 0-2 (higher scores indicating higher acceptance) and internal consistency was α = .60 (parent-report) and α = .79 (self-report). The Body image scale measured the bodily perception of the adolescents. Scores for these scales ranged from 0-2 (higher scores indicating higher confidence) and internal consistency was α = .60 (parent-report) and α = .67 (self-report). The Sexual experience scale measured the amount of sexual and intimate behavior (e.g. French-kissing) experienced by the adolescent. Scores for these scales ranged from 0-1 (higher scores indicating more experience with sexual behavior) and the internal consistency was α = .29 (parent-report) and α = .75 (self-report). The Inappropriate sexualized behavior scale measured the amount of inappropriate sexualized behavior (e.g. inappropriate touching of others) portrayed by the adolescent. Scores for these scales ranged from 0-1 (higher scores indicating more inappropriate sexual behavior) and the internal consistency was α = .56 (parent-report) and α = .54 (self-report). The Online sexual behavior scale measured the amount of online sexual and intimate activity experienced by the adolescent. Scores for these scales ranged from 0-1 (higher scores indicating more experiences with online sexual behavior) and the internal consistency was α = .66 (parent-report) and α = .58 (self-report). Finally, the Confidence in the future scale measured the level of confidence that the adolescent will find a job, live independently, and will have a relationship. Scores for these scales ranged from 0-2 (higher scores indicating higher confidence) and internal consistency was α = .94 (parent-report) and α = .86 (self-report).

Putative factors of influence

Possible factors of influence that were found in the discrepancy between parent-report and self-report in general population studies are gender, age and intelligence (van der Ende & Verhulst, 2005; Blakeley-Smith,2012, Vickerstaff, 2006 & Johnson, 2009; Renk & Phares, 2004; Stratis & Lecavalier, 2015). Age and gender of the participants were taken from the medical file of the adolescent and as measures for intelligence we used the Wechsler intelligence scales or abbreviated versions. Full IQ was also taken from the file and used if the assessment was not older than two years old, and if a valid and reliable instrument was used (i.e. WISC of WAIS). When no recent IQ measurement was available, in the ASD sample, full IQ was assessed using the Wechsler Abbreviated Scale of Intelligence (WASI; (Wechsler, 1999) and in the TD sample, two subtests of the Wechsler Intelligence Scale for Children were used, namely vocabulary and block design.

Data analyses

We conducted multilevel analyses with unstructured covariance matrices using SPSS version 21 (Nie et al., 1975) to investigate the parent-child informant discrepancy. Multilevel analyses were chosen because both informants report about the same child, which means the measurements are nested within individuals. To investigate the parent-child informant discrepancy between adolescents with ASD and their parents (aim 1), we ran several multilevel analyses for the ASD group. We were interested in the fixed effect of informant, which was coded 1 for parent- reports and 0 for self-reports. To investigate the differences in parent-child informant discrepancy between the ASD group and the TD group (aim 2), we included group-membership (either ASD or TD) as a factor, to investigate if discrepancy was related to group-membership. We were mainly interested in the interaction between the fixed effects of group (coded 1 for ASD and 0 for TD) and informant, to investigate if there is a difference in informant discrepancies between the two groups. Because of the known influence of gender, age and intelligence on informant discrepancy, we added gender, age and full IQ as covariates in all analyses.

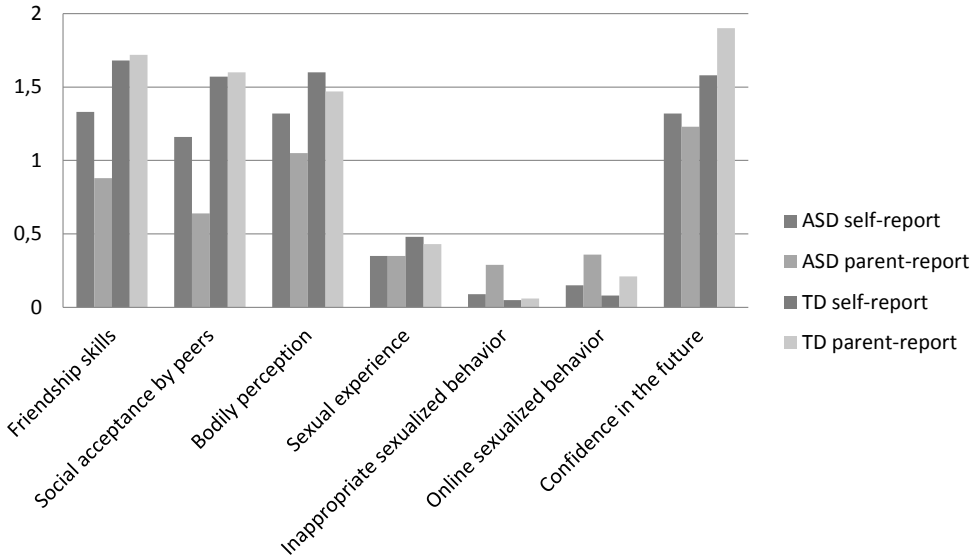
RESULTS

Mean scores on the scales of the TTI are shown in Table 2, and Graph 1.

Table 2. Scales of the Teen Transition Inventory (TTI)

		ASD group n=136	**TD group n=70**
Friendship skills, M±SD (range)	Self-report	1.33±0.45 (0-2)	1.68±0.30 (0.2-2)
	Parent-report	0.88±0.53 (0-2)	1.72±0.33 (0.3-2)
Social acceptance by peers, M±SD (range)	Self-report	1.16±0.47 (0-2)	1.57±0.37 (0.2-2)
	Parent-report	0.64±0.51 (0-2)	1.60±0.48 (0-2)
Body image, M±SD (range)	Self-report	1.32±0.37 (0.3-2)	1.47±0.37 (0.3-2)
	Parent-report	1.05±0.48 (0-2)	1.42±0.42 (0.3-2)
Sexual experience, M±SD (range)	Self-report	0.35±0.32 (0-1)	0.48±0.38 (0-1)
	Parent-report	0.35±0.32 (0-1)	0.43±0.37 (0-1)
Inappropriate sexualized behavior, M±SD (range)	Self-report	0.09±0.21 (0-1)	0.05±0.12 (0-0.5)
	Parent-report	0.29±0.25 (0-1)	0.06±0.11 (0-0.5)
Online sexualized behavior, M±SD (range)	Self-report	0.15±0.17 (0-0.9)	0.08±0.13 (0-0.7)
	Parent-report	0.36±0.36 (0-1)	0.21±0.27 (0-1)
Confidence in the future, M±SD (range)	Self-report	1.32±0.43 (0-2)	1.58±0.45 (0-2)
	Parent-report	1.23±0.46 (0-2)	1.90±0.17 (1.3-2)

Graph 1. Scales of the TTI



(1) Informant discrepancies in ASD

The results of the multilevel analyses regarding the informant discrepancies between the adolescents with ASD and their parents are portrayed in Table 3. Regarding reported Friendship skills (b=-0.46, t(126.72)=-9.26, p<.001), Social acceptance (b=-0.53, t(126.83)=-10.60, p<.001) and Body image (b=-0.26, t(126.87)=-5.20, p<.001) we found a significant difference between the ratings of adolescents with ASD and those of their parents. The negative b indicates that parents of adolescents with ASD reported their children to have lower friendship skills, less positive bodily perception, and less acceptance by peers than the adolescents with ASD reported themselves.

Significant informant discrepancies were also found for Inappropriate sexualized behavior (b= 0.21, t(127.65)= 8.27, p<.001) and Online sexual behavior (b= 0.21, t(123.50)= 6.73, p<.001), meaning that parents of adolescents with ASD reported to their children to experience more online sexual behavior and more inappropriate sexual behavior than the adolescents themselves. Thus, overall, parents reported their children to have lower skills and competence and higher levels of portrayed inappropriate behaviors than the adolescents themselves reported.

No significant informant discrepancies were found for Sexual experience (b= -0.01, t(117.76)=-0.30, p= .76), and Confidence in the future (b=-0.08, t(126.87)=-1.42, p=.16), indicating that adolescents with ASD and their parents reported similar levels of amount of sexual behavior and level of confidence in the future.

(2) Comparison of informant discrepancies between ASD and TD

Considering the interaction effects between group (ASD vs. TD) and informant (self-report vs. parent-report), we found significant interaction effects on Friendship skills (b= 0.50, t(184.12)= 6.34, p<.001), Social acceptance (b= 0.55, t(183.50)= 6.91, p<.001), Body image (b= 0.21, t(183.51)= 2.56, p=.01) and Inappropriate sexualized behavior (b= -0.20, t(185.00)= -5.04, p<.001), indicating a significant difference in informant discrepancies between adolescents with ASD and their parents versus TD adolescents and their parents. Regarding all of these scales, the informant discrepancies were larger in the ASD dyads than in the TD dyads. The adolescents with ASD reported higher friendship skills, a more positive bodily perception, and more acceptance by peers than their parents attributed to their children, while the reports of the TD adolescents and their parents did not significantly differ. Also, the adolescents with ASD reported to experience less inappropriate sexual behavior than their parents reported, while the reports of the TD adolescents and their parents did not significantly differ.

No significant interaction effect was found between group and informant for Sexual experience (b=-0.02, t(170.47)=-0.44, p=.66) and Online sexual behavior (b=-0.09, t(180.72)= -1.67, p=.10), meaning informant discrepancies were not significantly different in the ASD dyads compared to the TD dyads. In both dyads no significant differences were found between parents and their children in the amount of sexual experiences of the adolescents. Regarding the online sexualized behavior, in both the TD dyads as well as the ASD dyads the adolescents reported to experience less online sexual behavior than their parents reported on their children.

Finally, we found a significant interaction effect between group and informant for Confidence in the future (b= 0.41, t(185.00)= 4.48, p<.001), illustrating differences in informant discrepancies between adolescents with ASD and their parents compared to TD adolescents and their parents. For this scale the informant discrepancies were larger in the TD dyads than in the ASD dyads. The adolescents with ASD reported slightly higher confidence in the future than their parents (although not significant, see above), while the TD adolescents reported lower confidence in the future than their parents.

Table 3. Multilevel analyses for the scales of the TTI

		Model 1: ASD only			Model 2: ASD & TD		
		B	**SE**	**95% CI.**	**B**	**SE**	**95% CI.**
Friendship skills	Informant	-.46***	.05	-.56;-.36	-.45***	.05	-.54;-.36
	Group				.33***	.07	.20; .47
	Group x informant				.50***	.08	.34; .65
Social acceptance by peers	Informant	-.53***	.05	-.63;-.43	-.53***	.05	-.62;-.44
	Group				.42***	.07	.27; .56
	Group x informant				.55***	.08	.39; .71
Body image	Informant	-.26***	.05	-.36;-.16	-.26***	.05	-.36;-.16
	Group				.20**	.06	.08; .32
	Group x informant				.21*	.08	.05; .38
Sexual experience	Informant	-.01	.02	-.05; .04	-.01	.02	-.05; .04
	Group				.08	.06	-.03; .19
	Group x informant				-.02	.04	-.09; .06
Inappropriate sexualized behavior	Informant	.21**s*	.03	.16; .26	.21***	.02	.16; .25
	Group				-.03	.03	-.09; .03
	Group x informant				-.20***	.04	-.27;-.12
Online sexual behavior	Informant	.21***	.03	.15; .28	-.21***	.03	.15; .27
	Group				-.04	.03	-.09; .02
	Group x informant				-.09	.05	-.19; .02
Confidence in the future	Informant	-.08	.06	-.19; .03	-.08	.05	-.19; .02
	Group				.25**	.07	.10; .40
	Group x informant				.41***	.09	.23; .59

DISCUSSION

In the current study we investigated informant discrepancies between adolescents with autism spectrum disorders (ASD) and their parents regarding the psychosexual functioning of the adolescents. In line with our expectations, we found informant discrepancies between self-report and parent-report on the psychosexual functioning of adolescents with ASD in several domains. To put these results in better perspective, we also investigated the difference between parent-child informant discrepancies regarding psychosexual functioning between ASD dyads and TD dyads. Results showed that informant discrepancies in ASD dyads were significantly different from informant discrepancies in TD dyads. Adolescents with ASD and their parents agreed less on friendship skills, social acceptance, bodily perception, and inappropriate sexualized behavior of the adolescents, compared to TD adolescents and their parents.

As expected, adolescents with ASD and their parents disagreed – more than TD adolescents and their parents – regarding the friendship skills, the bodily perception and the acceptance by peers of the adolescents, with the adolescents with ASD reporting higher skills and higher self-esteem. This is in line with previous studies on parent-child informant discrepancies regarding social functioning in ASD, showing a consistent pattern of higher scores on social competence self-report among adolescents with ASD relative to parent-report (M. D. Lerner, Calhoun, Mikami, & De Los Reyes, 2012; Vickerstaff et al., 2007). Previous research investigating informant discrepancies in friendship characteristics in adolescents with ASD, also found that adolescent with ASD reported to have significantly more friends than their parents reported (Kuo et al., 2013).

Contrary to a previous study (Dewinter, Vermeiren et al., 2016b), no significant informant discrepancy was found on the amount of sexual experience of the adolescents with ASD. This might be due to a lower age of the participants in the current study, resulting in less sexual experiences and less relationships in the current population in comparison with the participants used in the study by Dewinter et al. (2016b). In addition, parents of adolescents with ASD reported their children to portray more negative (e.g. inappropriate touching, stalking) and risky behaviors (e.g. setting a date with someone met on the internet or watching pornography).

Possibly, the higher informant discrepancies in families with ASD can be explained by limited communication between parents and adolescents with ASD. It is known that parents have concerns regarding the psychosexual functioning of their children with ASD (Ballan, 2012; Holmes & Himle, 2014), which can influence their communication. Parent-child communication about sexuality in TD adolescents has been associated with reduced or delayed sexual behavior, including sexual risk behaviors (Jaccard, Dittus, & Gordon, 1998; Jaccard & Dittus, 2012; Somers & Paulson, 2000) and less sexual delinquency (Clark & Shields,

1997). It might be a challenge for parents to understand and discuss sexuality development in adolescents with ASD, and to deal with seemingly inappropriate sexual behaviors (Dewinter, Vermeiren et al., 2016b). This highlights the importance of stimulating communication between parents and their adolescent children with ASD regarding psychosexual themes, and helping parents to become comfortable about this communication, by means of professional support and reliable information for parents (Dewinter, Vermeiren et al., 2016b).

Regarding confidence in the future the informant discrepancies were larger in the TD dyads than in the ASD dyads, with the TD adolescents reporting lower confidence in the future than their parents, while finding no difference between the adolescents with ASD and their parents. This is contrary to a recent publication, finding informant discrepancy between adolescents with ASD and their parents regarding the quality of life of the adolescents, while not finding discrepancy in TD adolescent's quality of life self-report and parental report (Stokes et al., 2016). The authors concluded with saying "that parents of high-functioning children with ASD are unable to act as reliable proxies for their children with ASD", which, despite our results on confidence in the future, we believe is true for the other domains of psychosexual functioning.

Limitations and future directions

This study was the first to study informant discrepancies between parent-reported and self-reported psychosexual functioning of adolescents with ASD, and comparing parent-child informant discrepancy between ASD dyads and TD dyads, in a large group of adolescents with and without ASD. Certain difficulties and limitations of the current study can be addressed in future research. First, because the TD sample was drawn from a larger population study, the limited response rate could indicate selection bias. Second, regarding the used measurement, the TTI, was not primarily designed to investigate informant discrepancies and although the content of the scales is the same for both informants, the scales vary in the number of items. Third, in the comparison between adolescents with and without ASD the groups differed in gender, with less girls in the ASD group, comparable to the percentage girls in the whole ASD population (Lai et al., 2014). Even though we corrected for gender in the analyses the limited number of girls in the ASD dyads and knowing gender is a factor of influence for informant discrepancy, with higher informant discrepancies found between parents and sons (Leadbeater, Kuperminc, Blatt & Hertzog, 1999), leaves room for future research. Potentially parents may allow more freedoms for their sons, allowing them to live, to some extent, outside their parents supervision, which could explain a difference in discrepancies between parent-report and self-report for boys and girls. Finally, we do not have information on which parent reported on their child in the current study. We know from previous research that mothers and fathers communicate differently about sex and sexuality with their children (DiIorio, Pluhar, & Belcher, 2003), making it an interesting topic for future

research to investigate the differences between fathers reporting on their sons and mothers reporting on their daughters.

To conclude, in studies on psychosexual functioning in the general population, it is common to ask the adolescents themselves about their emotions and experiences (Daker-White, 2002; de Graaf et al., 2012), but in research to the psychosexual functioning in adolescents with ASD, until now, more often parents, caregivers or teachers are questioned, due to previous reported difficulties adolescents with ASD have with reporting about their feelings and emotions (Mazefsky et al., 2011). From the current research we know that both in ASD dyads and TD dyads informant discrepancies exist in reports on psychosexual functioning, and that the discrepancies are larger between adolescents with ASD and their parents. Adolescents with ASD reported more skills, more self-esteem and fewer inappropriate behaviors. Therefore, using only parent-report or only self-report measures provide researchers and clinicians with an incomplete picture of the psychosexual functioning of the adolescents with and without ASD. Using multiple informants can shed light on different views, for instance the opinion of parents and adolescents themselves, and allows for multiple perspectives to the current psychosexual functioning of the adolescent with and without ASD. Because of the discrepancies we found between parent-report and child-report, we believe it is always important to ask the adolescents themselves about their opinion and experiences. This is especially important researching a topic with a highly private nature such as psychosexual functioning. With the current study we hope to stimulate other researchers to use multiple informants into research to the psychosexual development of adolescents with ASD.

CHAPTER 5

A randomized controlled trial to examine the effects of the Tackling Teenage psychosexual training program for adolescents with autism spectrum disorder

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ABSTRACT

Background: Previous research underscores the importance of psychosexual guidance for adolescents with autism spectrum disorder (ASD). Such guidance is provided in the Tackling Teenage Training (TTT) program, in which adolescents with ASD receive psycho-education and practice communicative skills regarding topics related to puberty, sexuality and intimate relationships. This randomized controlled trial investigated the effects of the TTT program on (1) cognitive outcomes (i.e. psychosexual knowledge, and insight in interpersonal boundaries) and (2) behavioral outcomes (i.e. skills needed for romantic relationships, and problematic sexual behavior).

Methods: A total of 189 cognitively-able adolescents with ASD, aged 12-18 years old, were randomized to an intervention condition (n = 95) or a waiting-list control condition (n = 94). We assessed outcomes using self-reported as well as parent-reported questionnaires at baseline (T1), post-treatment (T2; after six months) and follow-up (T3; after twelve months).

Results: Linear mixed model analyses showed significant treatment effects for psychosexual knowledge and adequate insight in boundaries, both post-treatment and at follow-up. All adolescents increased significantly over time in their social responsiveness and decreased their problematic sexual behavior, irrespectively of condition. The TTT program was most effective for younger adolescents with ASD; following the TTT program resulted in higher psychosexual knowledge, and higher social functioning for these adolescents.

Conclusions: The results of this study indicate that the TTT program is effective as a psycho-educational program to provide adolescents with ASD with the knowledge and insight they need to prepare themselves for a healthy psychosexual development. Further research is needed to investigate how this increased knowledge and insight can subsequently ameliorate improvements in romantic skills and prevent the development of problematic sexual behavior and victimization.

INTRODUCTION

Adolescence is a transition phase in life in which psychosexual development accelerates (Santrock, 2005) which offers several challenges for adolescents with autism spectrum disorder (ASD). In the past, it was thought that people with ASD did not have a desire for relationships and that they were asexual (Konstantareas & Lunsky, 1997). We now know that most adolescents with ASD do have an interest in social relationships and sexuality, and that they have psychosexual needs and want to engage in sexual behavior (Hénault, 2006; Stokes & Kaur, 2005). However, deficits in social cognition and communication can make understanding, developing and maintaining close interpersonal relationships difficult for people with ASD (American Psychiatric Association, 2013; Byers & Nichols, 2014; Mehzabin & Stokes, 2011). For instance, adolescents with ASD report few intimate and sexual experiences and more unfulfilled desires and sexual frustration (Coskun et al., 2009; Gougeon, 2010; Murrie et al., 2002; Stokes & Kaur, 2005; Stokes et al., 2007). Difficulties in psychosexual functioning of adolescents with ASD are not limited to problems with normative sexual behavior, but they can also lead to problematic sexual behavior for example touching others inappropriately, stalking, public masturbation or even sexual delinquency (Chan & Saluja, 2011; Griffin-Shelley, 2010; Realmuto & Ruble, 1999; Stokes et al., 2007; Sullivan & Caterino, 2008). In addition, because adolescents with ASD often have a propensity for repetitive and stereotyped behavior and often experience hyper- or hyposensitivity, they are at a higher risk to develop sexual preoccupations or paraphilias, such as fetishism or exhibitionism (Fernandes et al., 2016; Ray et al., 2004). Furthermore, difficulties with understanding the intentions of other people and the desire to be socially accepted can put adolescents with ASD at a higher risk to become a victim of sexual coercion, sexual bullying and sexual abuse (Brown-Lavoie et al., 2014; Edelson, 2009; Mandell et al., 2005). Consequently, there is a well understood and described importance for standardized evidence-based psychosexual guidance and training programs especially designed for adolescents with ASD (Dewinter et al., 2013; Ginevra et al., 2016; Koller, 2000; Nichols & Blakeley-Smith, 2009), but so far such training programs, and research on the effects of these programs, have been scarce (Sevlever et al., 2013).

An individual training program has been developed targeting a positive psychosexual development in adolescents with ASD: the Tackling Teenage Training (TTT) program (Boudesteijn et al., 2012). A first systematic evaluation among 30 adolescents with ASD on the effects of the TTT program on psychosexual knowledge showed that adolescents with ASD had increased knowledge of puberty and psychosexual topics after following the training program (Dekker et al., 2014). However, it is known that adolescents' knowledge develops rapidly on several domains during adolescence (Santrock, 2005; Shattuck et al., 2012), underlining the importance of further investigating the effects the TTT program in a randomized controlled trial (RCT).

The aims of the current study were firstly to evaluate the effects of the TTT program for adolescents with ASD on cognitive outcomes (i.e. psychosexual knowledge and insight in interpersonal boundaries) and secondly to investigate the effect of the TTT program on behavioral outcomes (i.e. social skills needed for romantic relationships and problematic sexual behavior). Based on the previous results, we hypothesized that the TTT program could improve psychosexual knowledge and insight in psychosexual themes. However, from general sexuality research we know that having psychosexual knowledge may not be sufficient for positive sexual functioning (Byers, Nichols, Voyer et al., 2013) and that a low correlation has been found between knowledge and behavior (Winn, Roker, & Coleman, 1995). In general, the ability to develop skilled performance of complex domains of behavior tends to develop more directly through experience rather than through the acquisition of knowledge (Hambrick & Meinz, 2011). Therefore, in the current study we explored whether a gain in cognitive outcomes could additionally cascade into actual behavior changes, because knowledge and insight might be necessary requirements to portray subsequent changes in social behavior.

METHODS

Participants and procedure

Participants were 189 boys and girls with ASD recruited between January 2012 and March 2014. All participants were between 12 to 18 years old, had a total score of 51 or above on the Social Responsiveness Scale (SRS, see measures) (Constantino & Gruber, 2002; Roeyers et al., 2011) and an intelligence quotient (IQ) score in the normal range (full IQ ≥ 85). In addition, all participants were previously diagnosed with ASD following DSM-IV criteria by a licensed psychiatrist or psychologist, and for the current study ASD severity was further determined using the ADOS. However, meeting the ADOS cut-off was not considered a prerequisite for participation, given that the sensitivity of the ADOS for detecting PDD-NOS or high-functioning ASD, especially in females, is not optimal (Lai et al., 2011). Participants were recruited for this study through referrals from professionals working with adolescents with ASD, either at Yulius, a large expert mental health care institution in the South-West of The Netherlands, in schools for special education or through open application. After the application, with permission of the parents and the adolescents, information about the study was sent to their home address together with the consent forms, and parents were asked to fill out the SRS. We used a total score of 51 or above on the SRS, because this is the preferred cut-off point based on research among clinical referrals and children from the Dutch general population (Roeyers et al., 2011). With the SRS it is possible to also identify children with less severe forms of ASD, such as Pervasive Developmental Disorder Not Otherwise Specified, in addition to the more classic or severe forms, such as Autistic Disorder (Constantino & Gruber,

2002). Written informed consent was obtained from all adolescents and their parents. Full IQ was taken from the medical file of the adolescent and used if the assessment was not older than two years old, and if a valid and reliable instrument was used (i.e. WISC of WAIS). In most cases (n=123) no or no recent IQ measurement was available, and IQ was assessed using the Wechsler Abbreviated Scale of Intelligence (WASI) (Wechsler, 1999). For descriptive purposes, the Autism Diagnostic Observation Schedule-2 (ADOS-2) (De Bildt & De Jonge, 2008; Lord et al., 2012) was administered in all adolescents at baseline to get an indication of ASD severity in the current sample, using the calibrated severity scores.The ADOS-2 has four modules, each designed to be administered to different individuals according to their level of expressive language. In this study, module 4 was used based on the age as well as the language abilities of the participating adolescents. Adolescents that portrayed offensive sexual behavior (i.e. law-violating behavior) were not eligible for this study. Because the professionals that referred subjects to the current study were familiar with the design of the study (explained in information sessions), and the possibility that an adolescent would be placed on a waiting list for one year, their clinical judgment excluded adolescents with too severe, offensive law-violating levels of sexual problems or inappropriate sexual behaviors.

This study was approved by the medical ethical commission of the Erasmus Medical Center, Rotterdam (MEC-2013-040) and registered in the Dutch Trial Register (NTR2860). A further detailed description of the design of this study is provided in Visser et al. (2015).

Participating adolescents and their parents filled out questionnaires at three time points: at baseline (T1), post-treatment (T2; after six months) and follow-up (T3; after twelve months). We used both self-reported and parent-reported questionnaires, in order to reflect both the perception of the adolescent with ASD itself and his or her parents. Adolescents were randomly assigned to the intervention condition (n = 95) or the control condition (n = 94) after completion of T1. Adolescents in the intervention condition started the TTT program shortly after randomization and the adolescents in the control condition were placed on a waiting-list for the duration of the study (one year).

Intervention

The Tackling Teenage Training (TTT) program is a psychosexual intervention aimed at adolescents with ASD aged 12 to 18 years old with a full IQ of 85 or higher (Visser et al., 2015). The TTT program consists of a manual for the professional and a workbook for the adolescent (Boudesteijn et al., 2012). The manual for the professional contains a detailed protocol, that guides the professional per session with a description of the exercises. The workbook for the adolescent contains texts, exercises and illustrations. Each week, the discussed session is added to the workbook of the adolescent, creating an extensive reference guide for the adolescent over the course of the training program. Furthermore, parents are weekly informed by mail on the progress of the training by the professional, via structured

contact reports. The contact reports consist of information on the topic of the session (i.e. psycho-education), the take-home assignment of the child, and particularities (i.e. strengths and difficulties of the child) during the specific session. This involvement of parents is built in to stimulate communication about delicate subjects between the adolescents with ASD and their parents, and to enhance generalization of learned knowledge, insight and skills to other contexts outside the setting of the training.

The TTT program consists of 18 individual sessions that cover the following topics: discussing puberty, appearances, first impressions, physical and emotional developments in adolescence, friendships, falling in love and dating, sexuality and sex (e.g. sexual orientation, masturbation, and intercourse), pregnancy, setting and respecting boundaries and safe internet use. The professional and adolescent discuss one session per week, in which one topic is discussed and exercises are practiced in a structured manner in approximately 45 minutes. The training program consists of a total of 112 exercises (e.g. knowledge and insight quizzes and role plays with the professional). At the end of each session, the adolescent receives a take-home assignment in which the topic of that session can be practiced outside of the context of the training, for instance a small interview with one of the primary caregivers on the topic of the session, stating your own boundaries to someone that crosses them, and arranging a get-together with a friend.

The TTT program can be used for two purposes: 1) for intervention purposes, because problems in psychosexual functioning have already occurred, or 2) for prevention purposes, to prepare adolescents with ASD for a healthy psychosexual development. Because of the ethical concerns of potentially placing adolescents with obvious problems in psychosexual functioning on a waiting list for one year (i.e. 50% chance of receiving the control condition), the focus of the current study is on the preventive psycho-educational effects of the TTT program.

The TTT program was provided by professionals who had a bachelor's or master's degree in psychology or social services and who had at least three years of working experience with people with ASD. All professionals took a two day train-the-trainer course and participated in interdisciplinary meetings every three months to discuss questions and case reports with other professionals and the developers of the training program. A total of 11 professionals provided the TTT program in this study.

Fidelity was investigated by looking at protocol adherence by the professionals providing the training program and looking at received sexual guidance during the study. Protocol adherence was monitored by means of standardized short evaluation forms that the professionals filled out after each training session. Two measures were used to measure protocol adherence: the number of exercises skipped and number of exercises adjusted by the professional in the whole training program. In addition to checking protocol adherence for the adolescents in the intervention condition, we also investigated whether the adolescents

in the control condition did not receive a sexual education intervention. At T2 and T3 we have asked all adolescents and their parents if and by whom they have received sexual education (i.e. from parents, teachers, or in a special intervention) in the last six months, in order to be able to control for this in the main analyses in case it turned out to be of influence on the outcomes.

Outcome measures

1. Cognitive outcomes: A psychosexual knowledge test for adolescents (Dekker et al., 2014) was used existing of 37 questions (see Appendix 2 for an overview of the questions). Scores were summed with one point for each correct response, ranging the total scores from 0 to 37. In addition, as a second measure of psychosexual knowledge, parents were questioned regarding their estimation of the knowledge of their child using a scale with 10 questions regarding psychosexual knowledge (example items: "My child understands the difference between friendship and dating", "My child has knowledge of the physical changes that occur during puberty"). Items were scored on a 3-point scale with 'Not at all true'; 'Somewhat or Sometimes true' and 'Definitely or Often true'. Mean scores for this scale ranged from 0-2 (higher scores indicating higher abilities) and the internal consistency of this scale in the current population was good (α = .89).

To investigate whether the TTT program increased insight in interpersonal boundaries, we created a scale that includes both the ability of the adolescent to recognize and indicate their own as well as other people's boundaries with seven items for parents (example items: "My child is able to recognize another person's boundaries regarding intimate contact", and "My child is able to set his/her boundaries regarding intimate contact"). Items were scored on a 3-point scale with 'Not at all true'; 'Somewhat or Sometimes true' and 'Definitely or Often true'. Mean scores for this scale ranged from 0-2 (higher scores indicating higher abilities) and the internal consistency of this scale in the current population was good (α = .86).

2. Behavioral outcomes: The Social Responsiveness Scale (SRS) (Constantino & Gruber, 2002) was administrated to assess potential changes in the social functioning of the adolescents. The SRS is a 65-item questionnaire that covers the various dimensions of interpersonal behavior, communication, as well as repetitive/stereotypic behaviors that are characteristic of ASD. The SRS provides a dimensional measure of autistic traits, with higher scores on the SRS reflecting a greater degree of social impairment. The SRS has been shown to be sensitive to changes in social functioning among children with ASD (Laugeson et al., 2012; Wood et al., 2009). In addition, we measured self-perceived romantic relational skills of the adolescents with a scale existing of three items (example item: "When I am in love with someone, I do not know what to do"). Items were scored on a 3-point scale with 'Not at all true'; 'Somewhat or Sometimes true' and 'Definitely or Often true'. Adolescents only received a score on this scale if they have had romantic experiences, therefore the sample for

this scale was lower than the other scales. Mean scores for this scale ranged from 0-2 (higher scores indicating higher abilities) and the internal consistency of this scale was acceptable (α = .78).

We used the Sex Problems scale of the Child Behavior Checklist (CBCL) (Achenbach & Rescorla, 2001; Verhulst & van der Ende, 2013) to determine changes in psychosexual problems. This scale consists of five items regarding sexual problems, thinking of sex too much, playing with own genitals in public, playing with own genitals too much and the desire to be from the other gender, that are rated by parents on a 3-point scale (0 = not true, 1 = somewhat or sometimes true, 2 = very true or often true) (Achenbach & Rescorla, 2001; Letourneau et al., 2004). Furthermore, similarly to Ginerva et al. (2016), we constructed a self-report and a parent-reported scale measuring specific ASD related inappropriate sexual behavior (see Appendix 1 for the items in these scales). Items were again scored on a 3-point scale with 'Not at all true'; 'Somewhat or Sometimes true' and 'Definitely or Often true'. Mean scores for these scales ranged from 0-1 (higher scores indicating more inappropriate sexual behavior). The internal consistency of these scales was low (parent-reported: α = .56; self-reported: α = .54).

Statistical analyses

Preliminary analyses

Baseline characteristics were calculated for adolescents in both conditions. For more in-depth information of the severity of problematic sexual behavior of our study population we calculated the percentages of this behavior (i.e. sexual problems measured by the CBCL, and inappropriate sexual behavior). By means of binominal tests we calculated whether the reported percentages of sexual problems in the current sample differed from the two norm samples used in the ASEBA manual (Achenbach & Rescorla, 2001).

We investigated the potential influence of fidelity, by looking at protocol adherence and received sexual education during the study. We also checked whether the time between T1 and T2 and between T2 and T3 differed between the two conditions. In case any of these factors turned out to be of influence on the outcome measures, or differed significantly between the groups, we controlled for these factors in the main analyses.

Main analyses

To investigate the effects of the TTT program on the cognitive and behavioral outcomes, we used linear mixed models (LMM) from the SPSS 19.0 statistical software package (SPSS; (Nie et al., 1975). LMMs are advantageous compared to repeated measures ANOVA in that they accommodate missing time points, utilizing all available data, and therefore can be considered truly intent-to-treat models (Hox, 2010). We thus used data from all 189 adolescents that had complete baseline data. Time (with three levels: baseline, effect and follow-up) was set as a

repeated variable, and condition (with two levels: intervention and control) was added to the models as a factor. We used an unstructured covariance matrix to allow all covariances (both slopes and intercepts were fixed). The interactions between condition and time directly tested whether there was a significant difference between the two conditions over time. To determine the magnitude of the effects, we calculated partial eta-squared for all interaction effects. With significant interactions, we looked at the estimates of fixed effects for T2 and T3 in order to determine the time of onset of treatment effects, and we calculated the effect size by means of Cohen's *d* separate at T2 and T3 (Durlak, 2009).

Finally, to evaluate the potential moderating influence of gender and age on the outcomes, we performed two additional sets of analyses, each including one of these factors in a three way interaction with time and condition in the LMMs. When age or gender showed to be a significant moderator, we performed stratified analyses in order to clarify for which subgroups the TTT program was most effective. For age, we stratified the groups into the three stadia of adolescent development: early (cases aged between 12 and 14 years old), middle (between 14 and 16 years old) and late adolescence (between 16 and18 years old) (Santrock, 2005).

RESULTS

Participant flow and baseline characteristics

Figure 1 provides the CONSORT Study Flow Chart of the current study, illustrating participant movement throughout the study. From the 189 participants that were randomized and completed the baseline measurement (T1), 163 adolescents (86%) participated post-treatment (T2) and 158 (84%) participated at follow-up (T3). Because parents were given the choice to participate separately in addition to their child, 182 parents participated at baseline (T1), 146 parents (80%) participated post-treatment (T2) and 143 parents (79%) participated at follow-up (T3). In total, 15% of the participants (n = 28; intervention condition n = 14; control condition n = 14) dropped out of the study, due to personal circumstances (e.g. lack of motivation of the adolescent or parents, changes in the family context; n = 20) or practical reasons (e.g. moving to a different location, changing schools; n = 8). All 83 adolescents that completed the TTT program followed all 18 sessions in the training program. The average time between T1 and T2 was significantly longer for adolescents in the intervention condition (M=0.64, SD=0.18) than for adolescents in the control condition (M=0.57, SD=0.11), $t(133.56) = 3.15$, $p < .01$, Cohen's $d = .47$, we therefore controlled for time between T1 and T2 in the main analyses. No significant difference was found between the two condition on the average time between T2 and T3 (intervention condition: M=0.57, SD=0.13; control condition: M=0.56, SD=0.14), $t(159) = 0.47$, $p = .64$, Cohen's $d = .07$.

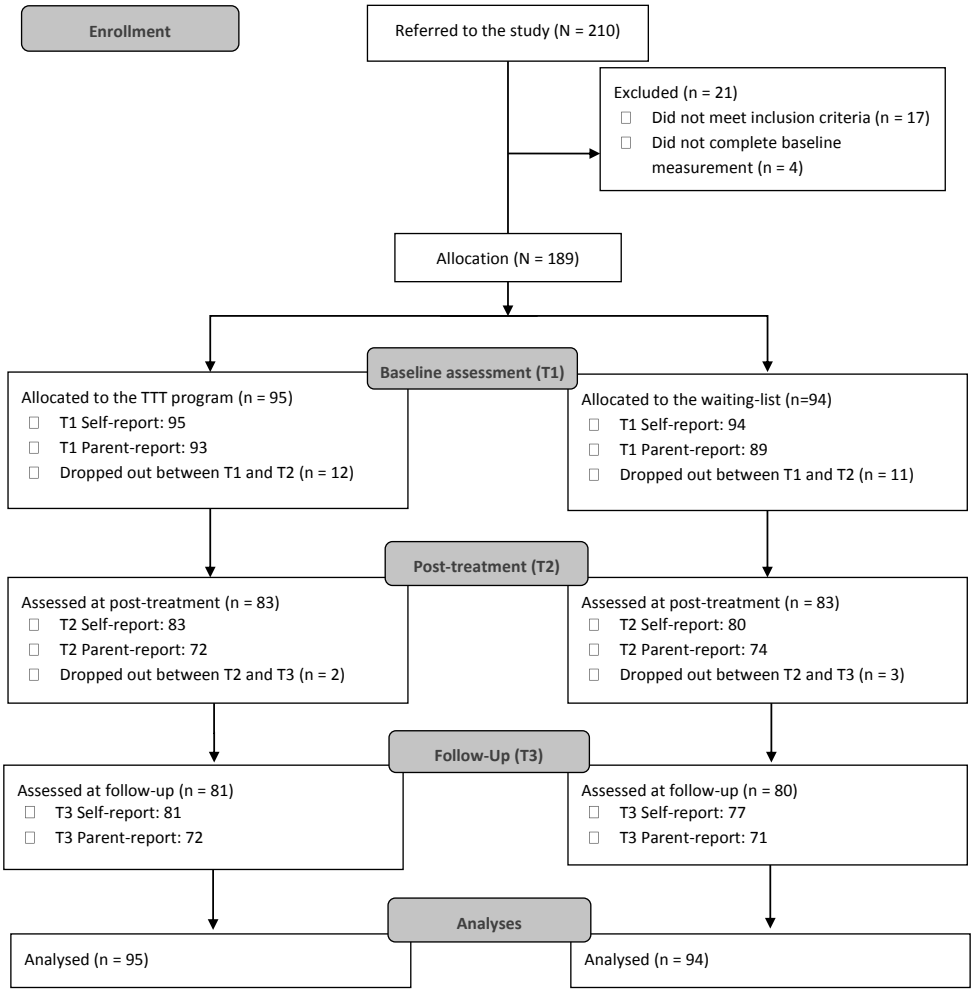

Figure 1. CONSORT Study Flow Chart

The characteristics of the 189 participating adolescents are presented in Table 1. Regarding problematic sexual behavior in the current population we found that, compared to the non-referred norm sample used in the ASEBA Manual (Achenbach & Rescorla, 2001), the percentages of all reported sexual problems in the current sample were higher for both boys and girls. Compared to the referred norm sample, differences were found for boys on two reported sexual problems: Parents of boys in the current sample more often reported that their son 'plays with his own sex parts too much' and 'thinks about sex too much'. The reported inappropriate sexual behavior varied from 7.7% (for parent-reported inappropriate masturbation) to 51.1% (for parent-reported inappropriate questions/remarks) (see Appendix 1 for an overview of the percentages of problematic sexual behaviors).

Table 1. Baseline descriptives (N = 189)

	Intervention condition n = 95	**Control condition n = 94**
Demographics		
Gender (male), n (%)	73 (77.7%)	79 (84.0%)
Age (in years), M±SD (range)	14.4±1.74 (12.1-18.8)	14.5±1.74 (12.0-18.5)
Full IQ, M±SD (range)	106±11.78 (86-140)	105±13.13 (85-143)
SRS total score, M±SD (range)	97±24.92 (52-153)	95±22.87 (52-158)
ADOS-2 calibrated severity score	6.3±2.09 (1-10)	6.1±2.03 (1-9)
ADOS-G classification		
No classification	7 (7.3%)	9 (9.6%)
ASD	43 (44.8%)	36 (38.3%)
Autism	44 (45.8%)	44 (46.8%)
CBCL externalizing problems, M±SD (range)	15.1±10.1 (0-55)	16.5±10.1 (0-43)
CBCL internalizing problems, M±SD (range)	19.7±9.7 (4-45)	18.0±8.7 (3-39)

Note: M=mean; SD=standard deviation; SRS: Social Responsiveness Scale; CBCL: Child Behavior Checklist

Fidelity

The TTT program consists of a total of 112 exercises. On average, per adolescent, 6 mandatory exercises (range: 0-56; 5.3%) in the training program were skipped by the professional and on average, 8 exercises (range: 0-82; 7.2%) were adjusted to the need of the adolescents. Protocol adherence (i.e. skipping or adjusting) had no influence on any of the outcome measures. And even though a percentage of the adolescents (8.6% from parents and 27.2% at school) and their parents (23.6% from parents and 21.1% at school) in the control condition reported to have received sexual education between T1 en T2 and T2 and T3, this did not influence the results.

Effects of the TTT program

Descriptive information on the outcome measures are summarized in Table 2 and the results of the statistical analyses comparing the two conditions, controlling for time between T1 and T2, over the three time points are displayed in Table 3.

Table 2. Descriptives on outcome measures for both conditions

		Condition	**T1**			**T2**			**T3**		
			M	SD	N	M	SD	n	M	SD	n
Cognitive outcomes	Psychosexual knowledge test	Intervention	25.71	7.71	93	32.09	4.28	82	32.70	4.30	80
		Control	26.43	7.88	93	28.79	6.95	80	30.81	5.38	77
	Parent-reported psychosexual knowledge of the child	Intervention	1.45	0.42	93	1.79	0.30	73	1.86	0.18	73
		Control	1.56	0.41	87	1.67	0.34	72	1.76	0.28	71
	Parent-reported adequate boundaries	Intervention	0.93	0.51	91	1.25	0.39	72	1.34	0.50	73
		Control	0.92	0.49	87	1.11	0.47	72	1.19	0.43	71
Behavioral outcomes	SRS total score	Intervention	97.46	24.92	95	84.44	24.66	73	78.49	26.90	70
		Control	95.18	22.88	92	86.24	21.93	72	83.42	23.47	73
	Self-reported romantic relational skills	Intervention	0.94	0.63	70	1.03	0.59	65	1.08	0.60	67
		Control	1.12	0.60	79	1.05	0.56	69	1.08	0.51	65
	CBCL Sex problems scale	Intervention	0.65	1.13	92	0.34	0.69	73	0.40	0.95	67
		Control	0.97	1.58	89	0.58	1.21	71	0.56	0.31	72
	Self-reported inappropriate sexual behavior	Intervention	0.12	0.24	95	0.08	0.16	83	0.12	0.22	81
		Control	0.10	0.20	93	0.10	0.19	80	0.11	0.23	77
	Parent-reported inappropriate sexual behavior	Intervention	0.34	0.27	93	0.25	0.22	72	0.22	0.22	73
		Control	0.34	0.28	87	0.28	0.32	72	0.28	0.25	71

Note: M=mean; SD=standard deviation; SRS: Social Responsiveness Scale; CBCL: Child Behavior Checklist

1. Cognitive outcomes: Compared to adolescents in the control condition, adolescents in the intervention condition demonstrated a significantly greater increase in psychosexual knowledge, as measured using the psychosexual knowledge test, $F(2, 161.62) = 13.51$, $p < .01$, $\eta^2 = .14$, as well as when using the parent-reported scale, $F(2, 146.53) = 9.36$, $p < .01$, $\eta^2 = .11$. More specifically, following the TTT program resulted in a significant increase in the psychosexual knowledge at T2 ($t(164.27) = -2.56$, $p < .01$, Cohen's $d = -0.40$) and at T3 ($t(154.76) = -2.67$, $p < .01$, Cohen's $d = -0.42$). Also, parent-reported knowledge of their child increased significantly more in the intervention condition than in the control condition at T2 ($t(152.46) = -3.91$, $p < .01$, Cohen's $d = -0.63$) but not at T3 ($t(137.23) = -0.42$, $p = .67$, Cohen's $d = -0.07$).

Regarding insight in interpersonal boundaries, a significant treatment effect was found on the parent-reported scale measuring adequate boundaries, $F(2, 141.77) = 2.92$, $p = .05$, $\eta^2 = .04$. Following the TTT program resulted in significantly more increase in parent-reported insight in adequate boundaries for adolescents in the intervention condition than adolescents in the control condition at T2 ($t(147.49) = -2.40$, $p = .02$, Cohen's $d = -0.40$) but not at T3 ($t(133.19) = -0.71$, $p = .48$, Cohen's $d = -0.12$).

2. Behavioral outcomes: A significant main effect for time was found on the SRS total score, $F(2, 154.24) = 21.70$, $p < .01$, $\eta^2 = .22$, indicating that adolescents in both conditions significantly increased their social functioning over time, irrespectively of condition. Significant main effects for time were also found on the Sex Problems scale of the CBCL, $F(2, 152.95) = 11.05$, $p < .01$, $\eta^2 = .13$, and on the parent-reported inappropriate sexual behavior scale, $F(2, 150.05) = 13.13$, $p < .01$, $\eta^2 = .15$, indicating decreased problematic sexual behavior in all participating adolescents, irrespectively of condition. No significant treatment effects were found on the SRS total score, the self-reported romantic relational skills scale, the Sex Problems scale of the CBCL, nor on the self-reported and parent-reported inappropriate sexual behavior scale.

Table 3. LMMs outcome measures (N = 189)

		F	Numerator Df	Denomenator Df	*P*
Cognitive outcomes					
Psychosexual knowledge test	Time	88.55	2	161.63	.00**
	Condition	2.55	1	166.32	.05
	Condition x Time	13.51	2	161.62	.00**
Parent-rep. sexual knowledge of the child	Time	52.87	2	146.53	.00**
	Condition	1.00	1	156.65	.32
	Condition x Time	9.36	2	146.53	.00**
Parent-reported adequate boundaries	Time	46.83	2	141.76	.00**
	Condition	3.29	1	152.46	.07
	Condition x Time	2.92	2	141.77	.05*
Behavioral outcomes					
SRS total score	Time	21.70	2	154.24	.00**
	Condition	0.16	1	161.06	.69
	Condition x Time	1.18	2	154.25	.31
Self-reported romantic relational skills	Time	0.45	2	129.26	.64
	Condition	0.44	1	140.56	.51
	Condition x Time	0.54	2	129.25	.59
CBCL Sex problems scale	Time	11.05	2	152.95	.00**
	Condition	1.58	1	163.78	.21
	Condition x Time	0.27	2	152.95	.73
Self-reported inappropriate sexual behavior	Time	1.02	2	160.27	.67
	Condition	0.40	1	164.44	.53
	Condition x Time	0.53	2	160.27	.59
Parent-reported inappr. sexual behavior	Time	13.17	2	150.05	.00**
	Condition	0.50	1	158.31	.48
	Condition x Time	1.20	2	150.05	.30

Note: SRS: Social Responsiveness Scale; CBCL: Child Behavior Checklist; * p < .05; ** p<.01

Moderators of outcome

1. Cognitive outcomes: The effect of the TTT program on psychosexual knowledge was moderated by age, shown in the three way interaction on the adolescent psychosexual knowledge test, F(5, 170.62) = 10.95, $p < .01$, $\eta^2 = .24$, and the three way interaction on the parent-reported psychosexual knowledge scale, F(5, 163.74) = 3.63, $p < .01$, $\eta^2 = .10$. Stratified LMM showed that on the psychosexual knowledge test following the TTT program was associated with more knowledge gain for the early adolescents, F(2, 79.53) = 10.42, $p < .01$, $\eta^2 = .21$ and the middle adolescents, F(2, 47.10) = 4.57, $p = .02$, $\eta^2 = .17$, but not for the older adolescents, F(2, 31.58) = 0.87, $p = .43$, $\eta^2 = .05$. The same results were found for the early adolescents, F(2, 73.22) = 10.08, $p < .01$, $\eta^2 = .22$, the middle adolescents, F(2, 42.04) = 5.46, $p = < .01$, $\eta^2 = .21$, and the older adolescents, F(2, 26.36) = 1.97, $p = .16$, $\eta^2 = .13$, on the parent-reported psychosexual knowledge scale. No moderation effects were found

for gender. The three way interaction with age and the three way interaction with gender for insight in interpersonal boundaries showed that neither of these factors were significant moderators.

2. Behavioral outcomes: A significant moderation effect was found on the SRS for age, with a significant three way interaction on the SRS total score, $F(5, 162.78) = 2.80$, $p = .01$, $\eta^2 = .08$. Stratified LMM for the early adolescents, $F(2, 75.00) = 3.15$, $p = .05$, $\eta^2 = .08$, the middle adolescents, $F(2, 45.56) = 2.36$, $p = .11$, $\eta^2 = .09$, and the late adolescents, $F(2, 29.08) = 1.07$, $p = .36$, $\eta^2 < .07$, showed that younger adolescents with ASD significantly increased their social functioning after following the TTT program. Gender did not moderate the effects on the SRS and no significant moderation effects were found for age and gender on the other behavioral outcomes.

DISCUSSION

In the current study, we used a randomized controlled trial design with an intervention condition and a waiting-list control condition to investigate the effects of a psychosexual training program for adolescents with autism spectrum disorder (ASD); the Tackling Teenage Training (TTT) program (Boudesteijn et al., 2012). Regarding the cognitive outcomes, the results showed that, after following the TTT program, adolescents with ASD in the intervention condition had more knowledge of psychosexual themes, indicated by scores on a knowledge test as well as a parent-reported questionnaire, compared to adolescents in the control condition.

Especially younger adolescents with ASD benefited more from the TTT program than older adolescents, which is partly in line with other studies that showed that psychosexual knowledge increases the most between the age of 11 and 14 (Winn et al., 1995), but it also shows that younger adolescents with ASD are able to profit more from psychosexual training. This indicates that the TTT program is an effective way to increase psychosexual knowledge in teens with ASD. In addition, parents of adolescents with ASD in the intervention condition reported their children to have more insight in interpersonal boundaries, more specifically being more capable of recognizing and indicating their own as well as other people's boundaries in social and intimate situations.

Regarding the behavioral outcomes we found that parents of younger adolescents with ASD reported significantly improved social functioning after following the TTT program. However, in the current study we did not find evidence that the TTT program improved skills needed for romantic relationships or reduced problematic sexual behavior. Several possible explanations exist for the lack of results in these outcome domains. Firstly, the focus of TTT program is not primarily on improving skills. Deficits in the social reciprocity skills is a core problem

of ASD (American Psychiatric Association, 2013) and increasing social and relational skills requires extensive group coaching (Matson, Matson, & Rivet, 2007; White, Keonig, & Scahill, 2007). The majority of the exercises in the TTT program is focused on checking knowledge and, because the training is individualized, adolescents are not provided with the chance to practice skills with peers during the training program. Secondly, the limited results on the behavioral outcomes might be due to the methodological limitations in the measures that were used, such as measurement errors and insufficient validity of the used questionnaires. Thirdly, the follow-up of six months might not be long enough for the adolescents with ASD to transfer their knowledge and insight into an actual behavioral change (i.e. improved skills) (Hambrick & Meinz, 2011), and more long term follow-up is required to investigate how these adolescents developed in the long run.

Interestingly, we found an improvement over time regarding almost all behavioral aspects of the psychosexual development of adolescents with ASD, irrespectively of whether the adolescents had followed the TTT program or not. It should be noted that this can partly be explained by retest effects, such as regression to the mean (Barnett, van der Pols, & Dobson, 2005) , but it might also provide us with information on the natural development of adolescents with ASD over the course of one year. Further long term research is needed to investigate whether adolescents with ASD can indeed improve aspects of their psychosexual development during adolescence and how their psychosexual functioning is further developed when they are adults.

Clinical considerations and limitations

The current study was the first randomized controlled trial on a psychosexual training program for adolescents with ASD, and some limitations that need to be addressed in future studies can be identified. Firstly, we relied upon questionnaire data and we did not use observational measures to directly observe changes in skills and behavior, such as the Contextual Assessment of Social Skills (CASS) (Ratto, Turner-Brown, Rupp, Mesibov, & Penn, 2011), due to funding and time constraints and because a direct observational measure focusing on relational and intimate behavioral skills was not available at the time we started the current study. Also, while using both self-reported and parent-reported questionnaires can be seen a strength of the current study, it is known from research in the general population that the correlation between the different informant reports is generally low (De Los Reyes & Kazdin, 2005; Duhig et al., 2000; Jensen et al., 1999; Renk & Phares, 2004). In the current study, agreement between self-report and parent-report were found, finding consistency between the reports on the significant and the non-significant results. However, the previous reported difficulties adolescents with ASD have with reporting about their feelings and emotions (Mazefsky et al., 2011) underscores the importance of further investigating informant discrepancies between self-reported and parent-reported psychosexual functioning of adolescents with ASD. Secondly, in the current study we did not find that the TTT program worked as an

effective intervention program to decrease problematic sexual behavior of adolescents with ASD. Given the possibility to be randomized to the control condition and placed on a waiting list for one year, it was not possible to include adolescents that already portrayed severe problems in psychosexual functioning. The results show that even though the occurrence of reported sexual problems in the current sample of cognitively able adolescents with ASD were higher than those of teens from the general population, they were comparable to teens referred for professional help for behavioral, emotional or social problems. Therefore, the current study investigated the effects of the TTT program as a preventive psycho-educational program rather than as a treatment program for sexual problems that already existed.

The results also show that, over the course of the research project, the reported problematic sexual behavior decreased in all adolescents with ASD. Thus, we found no evidence to support the reported concerns some parents of adolescents with ASD might have that talking about sexuality to their child will increase the problems the adolescents have, because they will wrongly interpret the information (Ballan, 2012; Nichols & Blakeley-Smith, 2009; Tissot, 2009). The current study thereby contributes to the growing number of publications promoting the discussion of psychosexual topics with adolescents with ASD (Koller, 2000; Nichols & Blakeley-Smith, 2009).

Conclusions and future directions

The results of this study indicate that the TTT program is effective as a psycho-educational program to provide adolescents with ASD with the knowledge and insight needed to be prepared for a healthy psychosexual development. Furthermore, the TTT program was most effective for younger adolescents with ASD, finding a higher gain in psychosexual knowledge and an increase in parent-reported social functioning for adolescents between 12 and 14 years old, which leads to the recommendation to offer the TTT program in early adolescence.

Increasing psychosexual knowledge and the recognition of their own boundaries may decrease the risk of becoming a victim of sexual coercion, sexual bullying or sexual abuse. Increasing knowledge and insight might therefore be an important first step towards reducing the risk of vulnerability of adolescents with ASD in the future. However, in the current study sample we did not find treatment effects regarding inappropriate sexual behavior and sexual problems. Thus, the effectiveness of the TTT program as a behavioral intervention for adolescents that already portray higher levels of problematic sexual behavior remains to be investigated. In addition, further research is warranted on how the effect of increased knowledge and insight of adolescents with ASD can lead to a satisfactory relational and sexual life in adulthood and prevent the development of problematic sexual behavior. Because a close relationship exists between sexual satisfaction and overall well-being of people with and without ASD (Byers & Nichols, 2014), future research should also examine the long term effects of psychosexual guidance on the overall well-being and quality of life of people with ASD.

CHAPTER 6

Evaluation of social validation of the Tackling Teenage Training program, offering psychosexual guidance to adolescents with autism spectrum disorder

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ABSTRACT

Objective: Research into the social validation of evidence-based interventions provides valuable information on the acceptability of the interventions by all those involved, which is crucial for the implementation. In the current study, we aimed to obtain insight in the social validation of the Tackling Teenage Training (TTT) program, targeting the psychosexual development of adolescents with autism spectrum disorder (ASD).

Method: We investigated (1) (selective) attrition, (2) user satisfaction with the TTT program from adolescents with ASD, their parents and professionals and (3) adherence to the TTT protocol by professionals within a large research project. In addition, we investigated whether several characteristics of the adolescents predicted their user satisfaction and adherence with linear regression analyses.

Results: Attrition was low (13%) and all users reported high satisfaction with the training program. Furthermore, in the context of the current research project, professionals mostly adhered to the TTT protocol. Professionals adjusted parts of the training program only based on their judgment of the motivation of the adolescent during the sessions, with lower motivation associated with more adjustments.

Conclusions: The TTT program is highly evaluated by all users. Professionals were able to customize the TTT program to the specific needs of an adolescent, given their wide range of prior knowledge, motivation and resistance, while protocol adherence and satisfaction remained high. The results of this study indicate that both the high user satisfaction and the high adherence support the social validity of the TTT program. Recommendations are provided for customizing the protocol to optimize user motivation.

INTRODUCTION

In the last decade, great effort has been made to provide evidence for the effectiveness of interventions for people with autism spectrum disorder (ASD). Unfortunately, such interventions are rarely successfully implemented in public mental health and education systems (Dingfelder & Mandell, 2011). This research-to-practice gap can be partly explained by differences between the use of an intervention in scientific research, and the practical use of an intervention (Roth & Fonagy, 2013). In clinical trials, interventions for children with ASD need to be provided through a standardized method to be able to replicate the results, while in clinical practice the general perception is that, because of the many different expressions of ASD, every individual requires customized guidance (Bölte, 2014; Lord et al., 2005). Effectiveness as reported in clinical trials, therefore, does not guarantee implementation in everyday practice.

Currently, the importance is stressed of involving stakeholders (e.g. patients, caretakers and clinicians) at an early stage in the development and effectiveness research of new interventions for people with ASD. However, little is known about how these stakeholders evaluate interventions (Lord et al., 2005), and thereby how likely it is that an intervention will be used in clinical practice. Social validation is a multidimensional construct that can be regarded as user satisfaction of those who receive and provide the intervention (Callahan, Henson, & Cowan, 2008), determined by a subjective evaluation of the relevance and importance of the intervention's goals, the adequacy of its procedures, and its clinical significance (i.e. effects), as well as an evaluation of the general satisfaction by users and investigating whether interventions are used effectively (Carter, 2009; Foster & Mash, 1999; Kazdin, 1977; Rivard et al., 2016; Wolf, 1978). This data can be collected through instruments assessing these perceptions, such as standardized, structured or open-ended questionnaires (Kazdin, 1977). Obtaining insight in the social validity of an intervention is equally important to an assessment of the treatment effect, because interventions that show strong effectiveness, and in addition have a high social validity, are most likely to be used and disseminated (Foster & Mash, 1999; Kazdin, 1977).

From 2011 onwards, a large randomized controlled trial (RCT) was executed to study the effectiveness of an individual intervention program targeting the psychosexual development of adolescents with ASD: the Tackling Teenage Training (TTT) program (Boudesteijn et al., 2012; Dekker et al., 2014; Visser et al., 2015), see www.tacklingteenage.com). The TTT program effectively provides adolescents with ASD with the knowledge and insight they need to prepare themselves for a healthy psychosexual development (Visser, Greaves-Lord et al., 2017). The TTT program was most effective for younger adolescents with ASD (12-15 years old). Following the TTT program resulted in higher psychosexual knowledge and better social functioning for younger adolescents.

In the current study, we investigated several components of the social validation of the TTT program in a group of adolescents with ASD (n=95) and their parents, who received the training program in the context of their participation in the RCT. More specifically, we investigated (1) (selective) attrition, to get a better insight into potential reasons for dropping out of the TTT program, (2) the user satisfaction with the TTT program from the adolescents with ASD, their parents and the professionals, (3) adherence to the TTT protocol, including the grounds on which professionals decided to adhere to or diverge from the protocol. In addition, we investigated whether several characteristics of the adolescents (i.e. age, gender, intelligence, ASD symptom severity, previous psychosexual knowledge and attitude of the adolescent during the training program) predicted user satisfaction and protocol adherence. More insight in how the training program was customized to the specific needs of adolescents is valuable for the implementation of the TTT program in clinical practice and dissemination in the field.

In the development of the TTT program, adolescents with ASD and their parents were involved and were asked to provide feedback on the content and procedures of the TTT program. Because the TTT program was developed by professionals in co-creation with adolescents with ASD and their parents, we hypothesized that adolescents with ASD, their parents and professionals would report a high satisfaction with the TTT program. Furthermore, because of the larger effectiveness of the TTT program for younger adolescents (Visser, Greaves-Lord et al., 2017), we also hypothesized that younger adolescents and their parents would be more satisfied with the TTT program. Since training and supervision were provided to the professionals, it was hypothesized that professionals would mostly adhere to the TTT protocol. Finally, we hypothesized that professionals would diverge from the protocol, and customize the TTT program, if adolescents had substantial prior knowledge or if the adolescent had a negative attitude towards the training program.

METHODS

Participants and procedures

Detailed information on the study design and the procedures of the randomized controlled trial (RCT) can be obtained in Visser et al. (2015). In short, a total of 95 adolescents in the age range of 12 to 18 years old and a DSM-IV-TR diagnosis of autism spectrum disorder (ASD) were assigned to start the TTT program in the RCT. Inclusion criteria were a total score of 51 or above on the Social Responsiveness Scale (SRS; (Constantino & Gruber, 2002; Roeyers et al., 2011), and an intelligence in the normal range (full IQ ≥ 85).

The adolescents with ASD and their parents were asked to each fill out a Satisfaction Questionnaire (SQ) after completion of the training program (more information see

Measures). The SQs were provided together with the other questionnaires as part of the research project, and the data were processed anonymously. While providing the training program, the professionals who provided the TTT program in the RCT were asked to write down and to motivate individualized adjustments for each adolescent on standardized protocol adherence forms after each session of the TTT program (see Appendix 1 for an example of a protocol adherence form). We also asked the professionals to judge the attitude of the adolescent with ASD for each participant at each session on the protocol adherence forms. Furthermore, at the end of the research project, we asked the eleven professionals to fill out a therapist-SQ (more information see Measures).

Written informed consent was obtained from all adolescents and their parents. The study was approved by the medical ethical commission of the Erasmus Medical Centre, Rotterdam (MEC-2013-040).

Intervention

The background, procedures and aims of the Tackling Teenage Training (TTT) program were previously elaborately described in (Boudesteijn et al., 2012; Visser et al., 2015). Briefly, the TTT program was developed to guide adolescents with ASD in their psychosexual development. The TTT program consists of a manual for the professional and a workbook for the adolescent. The manual for the professional contains background information on the psychosexual development of adolescents with ASD and a detailed protocol, that guides the professional per session with a description of the exercises and suggestions for the professional (Boudesteijn et al., 2012). The workbook for the adolescent contains texts, exercises and illustrations. Each week, the discussed session is added to the workbook of the adolescent, creating an extensive reference guide for the adolescent over the course of the training program. The TTT program contains 18 weekly individual sessions, covering several topics related to puberty, sexuality and intimate relationships. The training program consists of 112 exercises (e.g. knowledge and insight quizzes and behavioral rehearsals). Parents or other caregivers are closely involved in the intervention: With permission of the adolescent, the professional informs parents weekly by the via structured contact reports sent by email, consisting of information on the topic of the session (i.e. psycho-education) and the take-home assignment. This involvement of parents is built in to stimulate communication about delicate subjects between the adolescents with ASD and their parents and thereby to enhance generalization of learned knowledge, insight and skills to other contexts outside the setting of the training program.

In the current research project, the TTT program was provided by professionals who had a Bachelor or Master degree in psychology or social services and who had at least three years of working experience with people with ASD. Professionals learned in the two-day train-the-trainer course (Masterclass Autism and Sexuality) particular procedures on how the TTT

program can be customized to the individual needs of the adolescent. Four standardized options are available to modify the TTT program to the individual characteristics, qualities, communication style, and experiences in intimate relations and sexuality of the adolescent:

1. Session selection: The professional can discuss all 18 sessions with an adolescent, or make a selection from the 18 sessions, for instance to customize the training program to the level of existing knowledge and experiences of the adolescent.
2. Adjusting the order of the sessions: The professional can adjust the order of the sessions, for instance to prioritize a certain theme or to connect to the current specific needs of the adolescent.
3. Speeding up the pace of the TTT program: The professional can accelerate the pace of the training program by leaving out additional (i.e. not mandatory) text and exercises and/or discussing the content of two sessions within one appointment.
4. Slowing down the pace of the TTT program: The professional can slow down the pace of the training program by discussing all additional (i.e. not mandatory) texts and exercises and/or discussing the content of one session within two appointments.

In the RCT, the professionals were instructed to discuss all sessions with the adolescents, in order to investigate the effects of the complete program, therefore option 1 was not allowed, while options 2, 3 and 4 were allowed in the current research project. Professionals were instructed to provide the training program in the standardized way and to follow the procedures described in the protocol of the TTT manual as much is possible. We asked the professionals to register the adjustments (i.e. customizations) they made to the TTT protocol on the protocol adherence forms carefully.

Measures

Characteristics of the adolescents

Age and gender of the participants were taken from the medical files of the adolescents. Full IQ was also taken from the file and used if the assessment was not older than two years old and if a valid and reliable instrument was used (i.e. WISC of WAIS). In most cases (n=123) no or no recent IQ measurement was available, and IQ was assessed using the Wechsler Abbreviated Scale of Intelligence (WASI; (Wechsler, 1999). ASD symptom severity was assessed using the parent-report version of the Social Responsiveness Scale (SRS) , with scores ranging from 0-195 (Constantino & Gruber, 2002; Roeyers et al., 2011). To measure prior knowledge, we used a psychosexual knowledge test for adolescents, in which the 37 items were scored with one point for each correct response, ranging the total scores from 0 to 37 (Dekker et al., 2014). Finally, the attitude of the adolescents consisted of a judgment of the motivation and the resistance of the adolescent, scored on a ten point scale by the professional from 0-10 (i.e. 0 = no motivation to 10 = very motivated). For an overall average motivation and resistance score, we calculated the average scores for each adolescent from all sessions.

Satisfaction Questionnaires

The Satisfaction Questionnaires (SQs) for adolescents and parents contained 16 questions on how they appreciated several procedures of the training program, for instance texts, illustrations, the relationship with the professional, the communication with the professional, homework assignments, their overall satisfaction with the training program and their perception of the effects of the training program on the daily life of the adolescents. The adolescents were also asked whether they would recommend the training program to other adolescents.

The SQ for professionals contained 30 questions, and in addition to questions regarding their satisfaction with procedures of the TTT program, it also contained questions regarding the overall use of the TTT program in the research project (e.g. whether- and on what grounds - they diverged from the TTT protocol, adjusted the order of the sessions or added additional material). Two professionals that provided the training program in the RCT were also the developers of the TTT program. Given their potential conflict of interest, their evaluations were not taken into account, and we present data of nine professionals.

The questions in the SQs required a grade on a scale from 0-10, a true or false statement, or open-ended questions to expand on the answer of a previous question (e.g. "If the answer on question 8 is yes, please describe how").

Adherence measures

With the data from the protocol adherence forms, we created three measures for protocol adherence. The first was the adjustment of the order of the sessions (scored with yes or no). The second measure for adherence was the number of adjusted exercises (range 0-112). An example of an adjusted exercise is an exercise that was orally discussed with the adolescent instead of written down by the adolescent in the workbook. The third measure for protocol adherence was the number of skipped mandatory exercises (range 0-112).

Data analyses

First, we investigated (selective) **attrition**, by calculating the attrition percentages between drop out and completers of the training program and between participants with and without evaluation data. We used independent sample t-tests and Chi square tests with age, gender, full IQ and the SRS total score to investigate whether attrition was selective.

Second, to investigate **user satisfaction**, average scores for the questions on the satisfaction questionnaires were calculated for the adolescents with ASD, their parents and the professionals. Next, we examined associations between satisfaction scores and the characteristics of the adolescents with ASD (i.e. age, gender, full IQ, SRS total score, total score on the psychosexual knowledge test, motivation and resistance score judged by the professional) by means of linear regression analyses, to provide information on whether characteristics of the adolescents were associated with higher or lower satisfaction scores.

Third, to investigate **protocol adherence**, we calculated the average scores for all three measures of protocol adherence (i.e. adjustment of the order of the sessions, number of adjusted exercises and number of skipped exercises). Finally, to explore on what grounds professionals decided to adhere or diverge from the protocol, three multiple linear regression analyses were used to determine whether the characteristics of the adolescents with ASD (i.e. age, gender, intelligence, ASD symptom severity, previous psychosexual knowledge, motivation and resistance scores) predicted adherence to the TTT protocol.

RESULTS

Characteristics of the adolescents

Of the 95 participating adolescents, 73 (77%) were boys and 22 (23%) were girls. Their mean age was 14.4 years (SD = 1.74) at the moment that they started with the training program. Their mean full IQ score was 106 (SD = 11.78) and they had a wide range of ASD severity, as measured with the SRS (M = 97.12; SD = 24.92) and previous psychosexual knowledge (M = 25.71; SD = 7.71). Regarding the attitude of the adolescents judged by the professionals, the overall (for all sessions together) mean motivation score was 6.61 (SD = 1.30) and the overall mean resistance score was 2.11 (SD = 1.41). Correlations showed that the motivation score had a high negative correlation with the resistance score (r =-.878) indicating that the assumption of multicollinearity would be violated. Apparently, adolescents with a higher motivation also showed less resistance during the TTT program. Due to the importance of motivation for learning (Schunk, Meece, & Pintrich, 2012), we decided to only add the motivation score as a predictor in the multiple linear regression analyses.

There were 15 adolescents (19.3%) of the 83 completers that did not fill out the Satisfaction Questionnaire (SQ) and 16 parents (18.1%) that did not fill out the SQ. Comparing groups with and without self-reported SQ data revealed no significant differences, indicating no selective attrition regarding the evaluation data on age (t = 0.39, p = .70), gender (χ^2 = 0.07, p = .80), full IQ (t = 1.07, p = .29) and SRS total score (t = 0.08, p = .94). Comparing groups with and without parent-reported SQ data revealed no significant differences on age (t =-0.40, p = .69), gender (χ^2 = 0.20, p = .89), and SRS total score (t = 1.64, p = .10), but did reveal a significant difference on full IQ of the adolescent (t = 2.70, p < .01), with the cases without parent-reported SQ having a significant lower intelligence than the cases with parent-reported SQ. This could indicate that parents of adolescents with a lower intelligence might have a different opinion regarding their satisfaction of the TTT program than described in the current report.

(1) Attrition

Regarding the attrition data, results showed that of the 95 adolescents who were assigned to the TTT program, three dropped out before the start of the training program and nine adolescents dropped out and did not complete the training program (total attrition: 12.6%). Reasons for dropping out were moving (n=1), anxiety to discuss sexuality topics (n=1), not enough support from the family of the adolescent to for instance transport the adolescents to the sessions (n = 4) or a lack of motivation of the adolescent (n = 6). All adolescents who dropped out did so before the seventh session (of 18 sessions in total). No significant differences were found between the adolescents who dropped out and the completers on age (t = 0.38, p = .70), gender (χ^2 = 0.19, p = .66), full IQ (t = 0.87, p = .39) and SRS total score (t = 0.40, p = .69).

(2) User satisfaction with the TTT program

Table 1 shows that, on average, adolescents with ASD (M = 7.64, SD = 2.02), their parents (M = 8.64, SD = 0.96) and the nine professionals (M = 8.43, SD = 0.53) reported high overall satisfaction with the TTT program. Both the adolescents and the professionals also reported high satisfaction with several procedures of the TTT program, for instance the texts, role-plays and illustrations. In the open-ended questions, they provided suggestions to improve the TTT program. Some adolescents reported that they missed certain topics, for instance information regarding gender identity problems, fetishes or sex addiction. Fetishes and gender identity problems were also topics the professionals reported to be missing from the TTT program.

On average, adolescents indicated that they were very satisfied with their contact with the professional (M = 8.75, SD = 1.37), and the opportunity to ask questions (M = 9.06, SD = 1.27). Parents also indicated to be very satisfied with their contact with the professional (M = 7.82, SD = 1.08), the opportunity to ask questions (M = 8.76, SD = 1.05) and the information transfer between parents and professional (M = 8.76, SD = 1.02). More than three-quarters (75.8%) of the adolescents reported that they would recommend the TTT program to other adolescents. Regarding their perception of the effects of the training program, the majority of the adolescents (86.8%) and their parents (90.9%) reported that they believed the adolescents could transfer the knowledge they acquired in the TTT program to their everyday life.

The multiple linear regression models for overall satisfaction with the TTT program were not significant, neither for the adolescents (F(6,75) = 0.98, p = .44, r^2 = .07) nor for parents (F(6,75) = 0.98, p = .44, r^2 = .07), indicating that characteristics of the adolescent did not predict user satisfaction with the TTT program from adolescents with ASD or parents.

Table 1. User satisfaction with the Tackling Teenage Training (TTT) program

	Adolescents (N = 69) M (SD)	**Parents** (N = 69) M (SD)	**Professionals** (N = 9) M (SD)
Overall satisfaction with the TTT program	7.64 (2.02)	8.64 (0.96)	8.43 (0.53)
Contact between professional and adolescent	8.75 (1.37)	7.82 (1.74)	-
Contact between professional and parents	-	8.72 (1.08)	-
Opportunity to ask questions to the professional	9.06 (1.27)	8.76 (1.05)	-
Trustworthiness of the professional	8.97 (1.42)	8.09 (1.69)	-
Information transfer from the professional	-	8.76 (1.05)	-
Instructiveness of used texts	6.93 (2.31)	-	8.00 (0.58)
Instructiveness of the workbook	6.85 (2.24)	-	8.14 (0.38)
Instructiveness of role plays	6.09 (2.71)	-	7.42 (1.27)
Instructiveness of illustrations	6.62 (2.73)	-	8.57 (0.98)
Instructiveness of talking with the professional	7.99 (2.08)	-	-
Recommend training program to others	Yes: 75.8%	-	-
Can the adolescent transfer the knowledge they acquired in the TTT program in their everyday life?	Yes: 80.7%	Yes: 90.9%	

(3) Adherence to the TTT protocol

The protocol adherence forms showed that in 14 of the 83 (16.9%) completed training programs the order of the sessions was adjusted by the professional. The professionals reported that in all of these cases they chose to discuss certain topics, such as safe internet use or boundaries of the adolescent, earlier on in the training because there were specific questions, problems, or concerns regarding these topics. On average, per adolescent, 6 mandatory exercises (5.3%; SD = 9.27) in the training program were skipped by the professional and on average, 8 exercises (7.2%; SD = 11.79) were customized. In the evaluation forms, the professionals reported to base their decision to skip session material on the age, development, motivation and resistance of an adolescent.

The multiple linear regression model for adjustment of the order of the sessions was not significant (χ^2 (5,76) = 3.71, p = .59, adj. R^2 = .09) indicating that whether a professional decided to adjust the order of the sessions was not influenced by characteristics of the adolescent. The multiple linear regression model for the number of adjusted exercises was significant (F(6,75) = 3.32, p < .01, r^2 = .21). Motivation (t =-3.69, p < .01) was the only factor that had a significant influence in the model, indicating that the lower the motivation of the adolescent during a session according to the professional, the more exercises were customized. The multiple linear regression model for number of skipped exercises was not significant (F(6,75) = 0.98, p = .44, r^2 = .07) indicating that characteristics of the adolescent did not influence whether or not a professional decided to skip exercises.

DISCUSSION

Currently, little attention is given to the social validation of evidence-based interventions in research into autism spectrum disorder (ASD) (Callahan et al., 2008). Assessment of the social validation of an intervention is important, because interventions that show both strong outcomes and have a high social validity are more likely to be used and disseminated in clinical practice (Foster & Mash, 1999; Kazdin, 1977). Therefore, in the current study we aimed to obtain insight in the social validation of the Tackling Teenage Training (TTT) program, an evidence-based individual training program targeting the psychosexual development of adolescents with ASD (Visser, Greaves-Lord et al., 2017).

The results show that attrition was low and not selective, showing that there were no particular reasons to drop out of the training program. The results showed that the adolescents with ASD, their parents and the professionals who provided the TTT program reported an overall high satisfaction with the training program. The majority of the adolescents with ASD and their parents believed that the goals of the TTT program were met and were positive about the procedures used in the training program, such as texts, illustrations, role-plays and homework assignments. Both the adolescents and the professionals reported to miss certain topics, such as gender identity problems and fetish, giving the developers of the TTT program valuable information to improve the content of the TTT program further. Despite the known difficulties with generalization of learned knowledge and skills from one context to another in people ASD, the majority of the adolescents with ASD and their parents believed that the adolescents were capable of generalizing the knowledge they had acquired in the TTT program to their everyday lives.

An interesting finding from the evaluation data was that both the adolescents with ASD and their parents especially valued the relationship with the professional, emphasizing the importance of investing in a therapeutic relationship when discussing psychosexual themes with adolescents with ASD. In general, it is known that a therapeutic alliance improves treatment outcome in psychotherapy (Martin, Garske, & Davis, 2000), but research into the role of the therapeutic relationship in ASD therapy is currently scarce and inconclusive (M. D. Lerner, White, & McPartland, 2012). We believe the length of the TTT program (i.e. 18 sessions) and the content of the TTT program, with intimate and not so often discussed topics, contributed positively to the formation of this therapeutic alliance between the adolescents with ASD and their parents and the professional.

Furthermore, characteristics of the adolescent (i.e. age, gender, intelligence, prior knowledge and attitude of the adolescent during the training program) did not predict user satisfaction with the TTT program nor attrition.

Another aim of this study was to gain insight into how professionals adhered to the TTT protocol in the current study, because information on the use of the protocol in a research

context can provide valuable information for the implementation in clinical practice and dissemination in the field. The adherence data showed that trainers mostly adhered to the TTT protocol. The adjustments that were made were: 1) adjusting the order of the sessions, and 2) adjusting the pace of the training by leaving out or customizing a small percentage of the exercises. Thus, the standardized protocol was used in the majority of cases, and the needs of specific adolescents could be handled within the framework of the standardized training program, for instance by changing the order of the sessions according to specific questions or concerns from the adolescents with ASD and/or their parents. Surprisingly, the results of our adherence data also showed that the decision of professionals to customize the order of the sessions or to skip certain parts of the material was not associated with characteristics of the adolescents, such as age, gender or prior knowledge, even though in the subjective evaluation the professionals did report this. The decision to adjust parts of the training program was significantly associated with the motivation of the adolescents as judged by the professional. Possibly, when professionals noticed the motivation of an adolescent was low during the TTT program, they made more adjustments - perhaps even unconsciously -, for instance by letting the adolescents choose whether they wanted to discuss an exercise instead of writing the answers down. Previous research showed that although motivation is recognized as a pivotal area in which individuals with ASD can have deficiencies, several techniques have been identified to increase motivation in children with ASD, such as child choice and task selection (Koegel, Koegel, & McNerney, 2001). From the effectiveness study, we know that protocol adherence did not influence the effectiveness of the TTT program on the cognitive and behavioral outcome measures (Visser, Greaves-Lord et al., 2017), but perhaps professionals hoped to increase the odds of the adolescent completing the training program by increasing the motivation of an adolescent by making adjustments to the TTT protocol.

The current study showed that the TTT protocol is applicable to cognitively able adolescents with a wide range of age, ASD symptom severity, and motivation, without diverging from the protocol. Previously, professionals working with ASD reported discomfort in discussing psychosexual topics with adolescents with ASD and their parents (Holmes et al., 2014). Sufficient training on sexuality and ASD for professionals and the availability of standardized material is desired by professionals in order to comfortably discuss intimate and sexuality topics with adolescents with ASD. Knowing that it is possible to follow a protocolized training program without the need to improvise to adjust to each specific adolescent with ASD, can furthermore increase the comfort of clinicians in discussing psychosexual topics.

Strengths, limitations and future directions

The large sample size of the current study made it possible to evaluate components of the social validation of the TTT program in a quantitative way. In addition, the procedures used

(i.e. evaluation forms with also open-ended answering options) made it possible to also qualitatively evaluate the TTT program. Besides these strengths, also some methodological considerations should be made. First, we examined satisfaction and adherence in the context of a scientific research project, with well-trained professionals, that were instructed to follow the TTT protocol as much as possible and to write down and motivate individualized adjustments, which might make them not representative for professionals in general clinical practice. Second, because the adolescents and their parents were participants in an RCT, they are also possibly not fully representative of the overall population of adolescents with ASD. In the current study, participants had to meet certain inclusion criteria and adolescents and their parents were motivated to participate, and therefore possibly more motivated to complete the TTT program than usually would be the case in clinical practice.

The current study can be considered an important first step towards a community effectiveness study, in which the intervention is evaluated in real world settings provided by community clinicians (Smith et al., 2007). According to Smith et al. (2007), this should be the next and final phase in research to psychosocial interventions for people with ASD. Several differences exist between interventions in an RCT and interventions used in clinical practice (Weisz, Weiss, & Donenberg, 1992). An example of a difference for the TTT program is that in clinical practice it is possible to use a selection of the 18 sessions available; an option that was not allowed in the RCT context of the current study. It remains to be investigated whether the treatment satisfaction and protocol adherence of the TTT program changes in a community effectiveness study.

Conclusions and recommendations

The results of this study indicate that – in addition to increasing knowledge and insight in psychosexual themes for adolescents with ASD (Visser, Greaves-Lord et al., 2017) – both the high satisfaction with the training program by stakeholders and the high adherence to the TTT protocol support the social validity of the training program.

In order to increase the odds of successful implementation of the TTT program in clinical practice, our data suggest that it is important for professionals to invest in a good working relationship with the adolescents with ASD and their parents, because both the adolescents themselves and their parents reported to highly value this relationship. In the training and education of professionals (e.g. the Masterclass Autism and Sexuality), sufficient attention should be paid to this therapeutic alliance. Secondly, to facilitate the implementation in clinical practice, it is important to train, instruct and guide professionals that provide the training program in order to provide them with the needed knowledge and skills to execute the TTT program in the way it is intended. Just like previous research that has described that successful translation of an intervention from a laboratory setting into real world service settings depends on maintaining protocol adherence (Weisz et al., 1992), we recommend

professionals working with the TTT program to adhere to the available protocol as much as possible in clinical practice. However, as we also know from the effectiveness study that small customizations of the material did not influence the effectiveness of the TTT program (Visser, Greaves-Lord et al., 2017), we therefore also encourage professionals to consider the motivation of an adolescent during the training program, and customize certain parts to make the certain exercises more compatible with the motivation/learning style of the adolescent with ASD.

This study demonstrates how research on social validation can be an important addition to effectiveness studies, in order to increase implementation and effectiveness in clinical practice, which is much needed given the current research-practice gap in ASD interventions.

CHAPTER 7

General discussion

INTRODUCTION

Research has increased in the area of the psychosexual development of people with autism spectrum disorder (ASD) (Dekker et al, 2017), due to the recognition that people with ASD do have a desire for intimacy and sexuality but that they can experience several risks and difficulties. Previous research showed that adolescents with ASD often have limited access to reliable information on puberty and sexuality, emphasizing the need for specific guidance of adolescents with ASD in their psychosexual development (Dewinter et al., 2013; Ginevra et al., 2016; Koller, 2000; Nichols & Blakeley-Smith, 2009). Few studies have investigated the effects of psychosexual training programs for adolescents with ASD, and to date no randomized controlled trials (RCT) are available which study the effects of psychosexual interventions for this target group (Sevlever et al., 2013). In the current study, we used a RCT design with an intervention condition and a waiting-list control condition to investigate the effects of a psychosexual training program for cognitively able adolescents with ASD, the Tackling Teenage Training (TTT) program (Boudesteijn et al., 2012).

Furthermore, we used the data of the RCT to obtain more insight into the assessment of the psychosexual development of adolescents with ASD. First, we investigated the assessment of how adolescents with ASD and a comparable group of typically developing (TD) adolescents judged different sexual situations portraying appropriate and inappropriate sexual behavior. Second, we investigated how parents and adolescents with ASD differed in their reports on psychosexual development, and these results were compared to a matched sample of parent-child dyads with TD adolescents. In the current chapter the main results are discussed, and methodological considerations, implications for future research and clinical and policy suggestions are given. Before (I go on with) that, the use of the TTT program is illustrated by means of the case report from the Introduction.

Michael (3)

In my first meeting with Michael it became clear that he had a healthy interest in and normal curiosity towards sexuality, but that he lacked the information on how he could handle his changing feelings (e.g. sexual arousal) and his changing body (e.g. an erection). He became curious about the physical differences between boys and girls, leading up to the incident with the younger neighborhood girl. Even though Michael did not have social problems at school, he did not have close friends with whom he could share personal information. Michael also never asked his parents questions regarding puberty or sexuality. His parents assumed it was discussed at school and that if Michael would have additional questions, he would address them. Due to Michael not taking the initiative to talk about this, his parents also did not start the conversation, because they thought he was not (yet) thinking about sexuality. It was difficult for Michael to think

about the consequences of his actions for the younger girl and her feelings. The incident with the neighborhood girl seemed to be an impulsive act to deal with his arousal. After the diagnosis of ASD, parents received psycho-education regarding ASD and learned that it is often difficult for people with ASD to ask questions. After this, Michael started the TTT program.

MAIN FINDINGS

To my knowledge, the current study was the first RCT to the effects of a psychosexual training program for adolescents with ASD. A strength of this RCT was the large sample size (n=189), as many of the previous studies to the psychosexual development in adolescents with ASD were limited to small sample sizes (Gougeon, 2010). Other strengths of the current study were the wide range of functionally relevant outcome measures, the use of multiple informants, and a standardized research and intervention protocol (chapter 2).

The large sample size enabled us not only to test the effects of the TTT program, but it also provided the opportunity to investigate two aspects of the assessment of psychosexual functioning by means of a large group of adolescents with ASD and compare them with a comparable group of adolescents without ASD. Concerning the judgment of the appropriateness of different sexual situations, we found little differences in judgments between adolescents with and without ASD. The results showed that adolescents in our sample tend to be cautious with regard to their judgment of different sexual behaviors. Judgment of illustrations of sexual situations (i.e. how they judge the appropriateness of such sexual situations) does not seem less in adolescents with ASD than in adolescents without ASD (chapter 3).

Concerning informant discrepancies in the assessment of the psychosexual development of adolescents with and without ASD we found that, overall, the adolescents with ASD were more optimistic about their psychosexual functioning than their parents, as their parents reported more negative and risky sexual behavior than they did themselves. Furthermore, in general, informant discrepancies in ASD dyads were significantly larger than informant discrepancies in TD dyads, suggesting that they might discuss psychosexual topics together less often than TD dyads, and thus do not 'get on the same page' as much regarding the psychosexual behavior of the adolescent (chapter 4). Together with the information on the assessment of the perception of adolescents with ASD regarding appropriate and inappropriate sexual behavior, this provided a framework in which we could examine the effectiveness of the TTT program. Additionally, the adolescents in the control condition provided us with information on the natural development of adolescents with ASD over the course of one year.

The results of the RCT on the outcome measures showed that the TTT program increased psychosexual knowledge in adolescents with ASD, and increased insight in interpersonal boundaries, more specifically, increasing their capability of recognizing and indicating their own as well as other people's boundaries in social and intimate situations. Younger adolescents with ASD (i.e. 12-14 years old) also benefited from the TTT program with regard to the behavioral outcomes. We found that parents of younger adolescents with ASD reported significantly improved social functioning. The TTT program can therefore be considered effective as a psycho-educational program to provide adolescents with ASD with the knowledge and insight they need for a healthy psychosexual development. We did not find that the TTT program decreased problematic sexual behavior of adolescents with ASD (chapter 5). In addition, the occurrence of reported sexual problems in the current sample of adolescents with ASD were comparable to teens referred for professional help for behavioral, emotional or social problems, indicating no specific relationship between ASD and sexual problems in adolescence. Furthermore, we found an improvement over time regarding almost all behavioral aspects of the psychosexual development of adolescents with ASD and the reported problematic sexual behavior decreased in all adolescents with ASD, irrespectively of whether the adolescents had followed the TTT program or not (chapter 5).

In addition to effectiveness on the outcome measures, we also investigated the social validation of the TTT program, because interventions that have high effectiveness and high social validation are more likely to be implemented in clinical practice. We found that the TTT program was highly valued by all users and that it was possible to personalize the TTT program for adolescents with ASD with a wide range of prior knowledge, motivation and resistance, without diverging from the TTT protocol. These results indicate that, both the high satisfaction with the training program by stakeholders and the high adherence to the TTT protocol, support the social validity of the TTT program (chapter 6).

Michael (4)

When he started the training program, Michael was reluctant to share personal information and was resistant to adhere to the intervention. He did not want to have anything to do with sexuality and intimate relationships anymore and therefore did not find it necessary to learn about sexual themes. I started with the first sessions, providing information on the psychosexual development and used this period to build a working relationship with Michael. Once Michael realized I was not going to judge him regarding the deviant incident and the TTT program provided the opportunity to ask questions regarding a broad range of topics (e.g. regarding his changing body and changing feelings), he felt safer to discuss issues openly and his motivation to follow the TTT program increased. An important part of the intervention for Michael was teaching him to deal with his sexuality in a healthy way. An additional goal of the intervention for Michael and his parents was to

stimulate conversations about psychosexual themes among them in the home setting. His parents received guidelines on how to discuss sexuality with Michael, even if he did not ask questions. During the TTT program, Michael changed schools and he started at his new school. This provided the opportunity to focus the training program also on starting a conversation with people he did not know before and with developing friendships with peers. First time he went to his new school, his probation officer went with him, and Michael told his new class about his ASD and the incident that had happened. This was pre discussed and evaluated during the training sessions.

METHODOLOGICAL CONSIDERATIONS

The current study was the first randomized controlled trial on a psychosexual training program for adolescents with ASD, and some limitations that need to be addressed in future studies can be identified. First, regarding the study design, because in The Netherlands no other protocolized psychosexual training program for adolescents with ASD was available at the time we started the RCT, it was not possible to make a comparison between two interventions, and therefore the control condition was a waiting-list condition. Furthermore, we acknowledge that the follow-up of six months might not be long enough for the adolescents with ASD to portray an actual behavioral change (i.e. improved skills), especially because research showed that on many domains, skills are acquired through experience (Hambrick & Meinz, 2011). However, we believed many participants would have refused to participate in the study if the waiting list period had been longer than one year, creating selection bias. A solution to this could have been the use of a crossover design, in which the adolescents in the control condition could start the TTT program after six months, instead of the used parallel design (Concato, Shah, & Horwitz, 2000).

Second, regarding the sample, in the current RCT the percentage of boys that participated was much higher than the percentage of girls, due to the consistent predominance of males diagnosed with ASD (Fombonne, 2003). This can also be seen as a strength of the study, because other studies investigating adolescents with ASD have largely focused on boys (Dewinter et al., 2015; Hellemans et al., 2007). Research with adolescent girls with ASD is scarce (Cridland et al., 2014; Nichols & Blakeley-Smith, 2009), however, in the current sample it was not possible to compare boys versus girls or to perform separate analyses for girls, to increase our understanding of the psychosexual development of girls with ASD. In addition, we did not use the information on which parent reported on their child in the current study. We know from previous research that mothers and fathers communicate differently about sex and sexuality with their children (DiIorio et al., 2003), indicating this might have influenced the results. In addition, due to the possibility to be randomized to the control

condition and thus being placed on a waiting list for one year, it was not possible to include adolescents who already had severe problems in psychosexual functioning. Therefore, the current study investigated the effects of the TTT program as a preventive psycho-educational program rather than as a treatment program for (severe) sexual behavior problems that already existed.

Third, some considerations can be identified regarding the measurements. In the current study, we mostly relied on self- and parent-reported questionnaire data to investigate the effectiveness of the TTT program. The adolescents and their parents were aware of whether they followed the intervention or not and therefore, their internal frames of reference could have been changed between the pre and post measurements due to the influence of the TTT program (i.e. response-shift bias; (Howard, 1980). Furthermore, more generally, reporting on a delicate matter like sexual situations might be influenced by social desirability. Due to funding and time constraints, and because a direct observational measure focusing on relational skills was not available at the time we started the current study, we did not use observational measures. We explored whether the flag system could be used as a more objective assessment tool for measuring judgment of the appropriateness of sexual situations. The psychometric properties of the flag system were unknown, because it is primarily a normative and pedagogical framework, developed as a tool to facilitate discussion about sexual behaviors of children or adolescents with parents, caregivers and professionals (Frans & Franck, 2010). We acknowledge that, even though the experts reached consensus on the most appropriate flag for each sexual situation, some of the portrayed sexual behavior was open for different interpretations on the appropriateness of the situation and the most suited flag, questioning the appropriateness of the flag system as an assessment tool.

IMPLICATIONS FOR FUTURE RESEARCH

Continuing the methodological considerations, future research with the TTT program could focus on the effects of the training program using an active control condition and using both self- and parent-reported questionnaires and observational outcome measures – scored by coders blind for condition and time point – to more directly observe changes in skills and behavior. Further research could focus on whether the effects of increased knowledge and insight of adolescents with ASD due to the TTT program we found in the current RCT, lead to behavioral changes, and more specifically, prevent the development of problematic sexual behavior. Long-term follow-up research is needed to investigate whether and how the psychosexual functioning of adolescents with ASD has developed into adulthood. Given the discrepancies we found between parent-reported and child-reported psychosexual functioning, we believe it is important always to use both parent-report and self-report

measures regarding psychosexual functioning in research and clinical practice for adolescents with and without ASD.

In the current study, it was not possible to include adolescents that have (severe) inappropriate sexual behavior or sexual problems. Therefore, the effectiveness of the TTT program as a behavioral intervention for adolescents that already portray higher levels of problematic sexual behavior remains to be investigated. A pilot study in which the effects of the TTT program will be investigated in adolescents with ASD and sexual delinquent behavior can therefore be a valuable addition. In the current study, we showed that the previously described sexual problems and reports of inappropriate sexual behavior (Ginevra et al., 2016; Stokes & Kaur, 2005; Stokes et al., 2007; Tissot, 2009) could not be explained by how adolescents with ASD perceive and judge sexual situations. More research into the mechanisms that can explain the development of inappropriate sexual behavior in people with ASD is required. By means of investigating characteristics of adolescents with ASD with inappropriate sexual behavior and in long-term developmental research, more insight into why some people with ASD develop inappropriate sexual behavior and why some others are vulnerable for sexual abuse can be obtained.

Another interesting topic for future research is the quality and quantity of parent-child communication regarding psychosexual topics in adolescents with ASD. It is long known that communication plays an important role in the psychosexual development of adolescents. Parent-child communication regarding sexuality in typically developing adolescents has been associated with reduced sexual risk behaviors or delayed sexual behavior (Jaccard & Dittus, 2012; Somers & Paulson, 2000) and less sexual delinquency (Clark & Shields, 1997). We slightly touched this topic in our discrepancies study, indicating that parent-child communication was limited in ASD dyads. Previous research also showed that parent-child communication in families with an adolescent with ASD is mostly limited to discussing safety issues, preventing sexual abuse and personal hygiene (Cridland et al., 2014; Nichols & Blakeley-Smith, 2009), due to the concerns parents of adolescents with ASD express about the sexual behavior of their children (Ballan, 2012). Future research can focus on the question whether this communication can be increased for instance by means of the TTT program, by asking adolescents with ASD and their parents whether and how often they discussed psychosexual topics with each other before and after the training program. It is expected that parent-child communication increases, given that the take-home assignments for the adolescents, and the feedback towards parents in the training program fosters an environment in which adolescents and parents are stimulated to talk about the psychosexual themes the adolescents have discussed in the TTT program.

Furthermore, the Teen Transition Inventory (TTI; (Dekker et al., 2017) and the TTT program were developed based on research from Western Europe and North America, therefore future research could focus on using the TTI and the TTT program with adolescents with ASD from

other countries or cultures. In the last few years, the TTI and the TTT program were translated into several languages and cultures (e.g. English, Spanish, Greek, Portuguese), thus in several countries around the world professionals started working with the intervention. Currently, in several countries, pilot studies are being executed to test the effects of the TTT program in other cultures. Sexuality is culture-specific (Barbaree & Marshall, 2008), for instance the developmentally appropriate ages for certain sexual behaviors in The Netherlands cannot be generalized to other cultures and educational contexts (Frans & Franck, 2010). Due to this cultural diversity, it is important to check whether the content of the intervention is equally applicable to other countries and cultures. Potential further cultural adaptation of the TTT program will therefore be part of the pilot studies, for instance in Spain, Denmark and Ireland. In the coming years, results of these pilot studies will become available, providing a basis for more international findings on the effectiveness of the TTT program. The implementation of the TTT program will make professionals around the world more aware of the importance and sensitivities of discussing psychosexual themes with adolescents with ASD and their parents.

CLINICAL AND POLICY SUGGESTIONS

Due to the outcomes of the current study, and my clinical experience in working with adolescents with ASD, I became an advocate of the promotion of a positive psychosexual development of adolescents with ASD. Knowing that the majority of people with ASD have a sexual interest, regardless of ASD severity (Fernandes et al., 2016), providing adolescents with ASD with the required knowledge and skills, for instance by means of the TTT program, is essential. However, the availability of evidence based psychosexual training programs is not sufficient to ensure that adolescents with ASD will indeed receive psychosexual guidance.

Barriers in discussing psychosexual themes with adolescents with ASD

Currently, whether individuals with ASD receive sexuality education depends mainly on the decisions made by stakeholders who act on their behalf and for their welfare, such as parents, professionals and teachers (Gougeon, 2010). Both professionals and parents of adolescents with ASD acknowledge that it is their responsibility to provide accurate information about psychosexual functioning to these adolescents, but they all report barriers in discussing psychosexual themes with these adolescents (Holmes et al., 2014; Nichols & Blakeley-Smith, 2009). Examples of these barriers for parents are that they question their abilities to give comprehensive information to their child, they find it difficult to prioritize discussing sexuality when there are always other important topics to address and they fear that discussing sexuality will lead to fixation (i.e. obsessions or repetitive behaviors) in their child (Ballan, 2012). Barriers for professionals are among others acute issues that have priority to address,

a lack of access to accurate information and a lack of training (Holmes et al., 2014). Regarding barriers for teachers, since 2012 providing sexual education is mandatory on all primary and secondary schools in The Netherlands. However, much of the available education material is not suited for adolescents with ASD and the quality of the provided education depends on the perceived competence and experience of the teacher (Buston, Wight, Hart, & Scott, 2002). Due to the described barriers, a gap exists between the perceived need for psychosexual education and its actual provision to adolescents with ASD (Gougeon, 2010). In order to fill this gap, it is important in clinical practice (and for policy makers) not only to focus on providing adolescents with ASD the required knowledge, skills and insight for a normative sexual development, but also to focus on parents and professionals. Continues focus is required on providing sufficient training on sexuality and ASD for professionals and keeping standardized material available, in order to discuss intimacy and sexuality topics with adolescents with ASD comfortably.

Increasing parent confidence in discussing sexuality with adolescents with ASD

The results of the informant discrepancies data showed that adolescents with ASD and their parents have different opinions regarding the psychosexual functioning of the adolescents. We also believe that some parents of adolescents with ASD are insufficiently aware of the psychosexual development of their children and that they mistakenly assume sexuality does not play a role in their child's live. Because communication is important in a healthy psychosexual development (Jaccard & Dittus, 2012; Somers & Paulson, 2000), it is important to guide and support parents of the adolescents with ASD when providing a psychosexual intervention such as the TTT program (Gougeon, 2010). For all adolescents, but especially for adolescents with ASD, discussing sexuality should be done consistently, throughout a person's life (Realmuto & Ruble, 1999). However, some parents of adolescents with ASD are concerned that talking about sexuality to their child will increase the problems the adolescents have, because they will wrongly interpret the information (Ballan, 2012; Nichols & Blakeley-Smith, 2009; Tissot, 2009). The results of the RCT showed that the reported problematic sexual behavior decreased in adolescents with ASD after following the TTT program (chapter 5), finding no evidence to support these reported concerns. Therefore, we believe that it would be a valuable addition to the current available training program to develop a few parent-sessions, in which parents can discuss topics from the TTT program, and can learn and practice how to discuss certain topics with their children.

Parent involvement in the TTT program

Furthermore, we recommend professionals to be aware of the involvement of parents in the TTT program, because including parents in for instance social skills training for adolescents with ASD increases the effect of the intervention (Mikami, Lerner, Griggs, McGrath, & Calhoun,

2010). The results of our social validation study also showed that, next to the adolescents themselves, also their parents reported to highly value a good working relationship with the professional. Therefore, we recommend the professional providing the TTT program to use the first session to integrate the information from the questionnaires from the different informants, together with the adolescent with ASD and his or her parents. Also outside the research project, we ask the adolescent with ASD and parents to fill out a short questionnaire with concerns, expectations and personal learning goals (i.e. a short version of the TTI, available in the manual of the TTT program) before the start of the TTT program. We hope this will create consensus among all involved on the content, expectations and goals of the TTT program, increasing involvement in both the adolescents with ASD and their parents.

Psychosexual education for adolescents with ASD, for whom, when and how?

In the current study, we found that the TTT program was most effective for younger adolescents with ASD; therefore, we recommend providing adolescents with ASD with psychosexual guidance between the ages of 11-14. We acknowledge the high societal costs associated with providing psychosexual guidance on an individual level, for instance with the TTT program. Therefore, we are further developing parts of the TTT program to a group-based training with fewer sessions (i.e. the ROAD training) that can be provided for instance at schools for special education with multiple students with ASD. The goal of this group-based training program is to prepare the adolescents with ASD for a healthy psychosexual development by providing them with ASD friendly psycho-education, while promoting a positive and normative psychosexual development in the adolescents with ASD.

We also realize that for a percentage of the adolescents with ASD providing group-based psycho-education is insufficient, because they need more guidance in their psychosexual development. We believe that the TTT program can continue to be used as an intervention in specialized mental health organizations such as Yulius for adolescents with an indication for treatment in their psychosexual guidance. With well-trained professionals providing the TTT program, the focus can be on checking and increasing knowledge and practicing skills, but also on using cognitive-behavioral techniques (CBT) to identify negative thoughts and feelings and learning how to challenge them. Previous research showed that individualized CBT delivered in a flexible manner can be an effective tool for higher-functioning children with ASD, and may be considered an empirically validated efficacious therapy for this population (Sze & Wood, 2008).

CONCLUSION

To conclude, the results of the current RCT showed that the TTT program is an evidence-based intervention targeting the psychosexual development of adolescents with ASD. The high social validation indicates that TTT program can also be used in clinical practice. More research to the psychosexual development of people with ASD is still necessary, for instance research into the mechanisms that can explain the development of inappropriate sexual behavior in people with ASD, but also on the long-term sexual development of adolescents with ASD. Regarding clinical and policy suggestions, we believe continues focus is required on providing sufficient training on sexuality and ASD for professionals and keeping standardized material available, in order to comfortably discuss intimacy and sexuality topics with adolescents with ASD. Furthermore, also increasing parent confidence in discussing sexuality with adolescents with ASD is a topic that requires attention in clinical practice, by providing parents with the required skills and confidence to discuss psychosexual topics with their children.

Michael (5)
In the evaluation meeting of the TTT program with Michael, his parents and me, we discussed Michael's development in the last six month. He gained psychosexual knowledge and insight in boundaries, and improved his social skills, such as making eye contact. Parents rated the intervention with an overall grade of 8.5 and Michael himself was moderately positive, rating a six in overall satisfaction with the TTT program. Because increasing his social skills was one of the main goals for the referral of Michael, and the focus of the TTT program is not primarily on improving social skills, I invited Michael to follow a more practical social skills training as a follow up intervention, but Michael declined, because he did not want more treatment. His parents told me they were now very much involved in Michael's life, and they talked more about puberty themes at home. At that point, they had a rather high control on his behavior, which was not appropriate according to Michael's age, but understandable considering their history. We offered parents additional meetings with a family therapist, providing the opportunity to guide parents in the age appropriate separation from their adolescent son. We ended the evaluation meeting with his parents appointing their pride of how Michael handled his start at the new school and his new social contacts.

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SUMMARY

The current thesis describes the results of a large (n=189) randomized controlled trial on the effects of the Tackling Teenage Training (TTT) program, a psychosexual intervention for adolescents with autism spectrum disorder (ASD).

Chapter 1 describes the background of the current study. For long, it was thought that people with ASD had no need for intimate relationships and sexuality, but currently we know that most people with ASD do have a desire for social and/or sexual contact and intimate relations. Research has increased in the area of the psychosexual development of people with ASD, showing that adolescents with ASD often have limited access to reliable information on puberty and sexuality, emphasizing the need for specific guidance of these adolescents in their psychosexual development. The current study is the first randomized controlled trial (RCT) on the effectiveness of a psychosexual intervention for adolescents with ASD, the TTT program.

Chapter 2 describes the design of the RCT and provides detailed information on the TTT program. We used an RCT design with an intervention condition (n=95) and a waiting-list control condition (n=94) in which adolescents with ASD and their parents participated for a year. The TTT program is designed for adolescents from 12 to 18 years old, with ASD and a normal to high intelligence, consisting of a manual with a structured protocol for the professional and a workbook for the adolescents. The training program consists of 18 individual sessions that cover the following topics: discussing puberty, appearances, first impressions, physical and emotional developments in adolescence, friendships, falling in love and dating, sexuality (e.g. sexual orientation, masturbation, and intercourse), pregnancy, setting and respecting boundaries, and safe internet use. The professional and adolescent have one session per week, in which they discuss one topic and perform exercises in a structured manner in approximately 45 minutes. The TTT program consists of 112 exercises (e.g. knowledge and insight quizzes, and role-plays with the professional). At the end of each session, the adolescent receives a take-home assignment in which the topic of that session can be practiced outside of the context of the training, for instance a small interview with one of the primary caregivers on the topic of the session, practicing with stating your own boundaries, or arranging a get-together with a friend. Parents are weekly informed by mail on the progress of the training program by the trainer, via structured contact reports, with information on the topic of the session (i.e. psycho-education), the take-home assignment of the child, and the strengths and difficulties of the child in the current session. The TTT program can be used for 1) for intervention purposes, because problems in psychosexual functioning have already occurred, and 2) for prevention purposes, to prepare adolescents with ASD on a healthy psychosexual development. Because of the ethical concerns of potentially placing adolescents with obvious problems in psychosexual functioning on a waiting list for one year

(i.e. 50% chance of receiving the control condition), the focus of the current study was on the preventive psycho-educational effects of the TTT program.

In addition to the effectiveness of the TTT program, the current study also provided the opportunity to obtain more insight into the psychosexual functioning of a large group of adolescents with ASD. Chapter 3 concerns the study on the perception of adolescents with ASD on different illustrations of sexual situations, using data from the baseline measure of the RCT. When asked to judge the appropriateness of different sexual situations, both adolescents with and without ASD accurately identified severely inappropriate sexual situations. Adolescents in both groups differed most from an expert panel of health care professionals in their judgment of appropriate (i.e. perfectly acceptable) and slightly inappropriate sexual situations. Adolescents with and without ASD were mostly more strict (i.e. more conservative) than the expert panel in their judgment of sexual situations. In conclusion, judgment of the appropriateness of illustrations of sexual situations on paper, displaying a wide range of appropriate and inappropriate sexual behaviors, does not differentiate between adolescents with and without ASD.

In chapter 4 of this dissertation, we also looked at the differences between adolescents with and without ASD using the baseline measure of the RCT, this time regarding the degree of parent-child informant discrepancies in reports on psychosexual functioning. Previous studies to the psychosexual development of adolescents with ASD have primarily used parent-reported data. Self-report data is barely used in this target group, due to the assumption that adolescents with ASD have difficulties with reporting on their own feelings, thoughts and behavior. However, the results showed that adolescents with ASD and their parents differed in their reports on multiple domains of psychosexual functioning, and these differences in reports were larger than between adolescents without ASD and their parents. In their responses, the adolescents with ASD were more optimistic about their psychosexual functioning than their parents, and parents reported more negative and risky sexual behavior than the adolescents reported. Thus, it is important to consider the reports of multiple informants when investigating a privacy sensitive subject such as psychosexual functioning, in particular in adolescents with ASD.

In chapter 5, the main findings of the RCT are described. We found that the TTT program was effective in significantly improving the psychosexual knowledge and insight in interpersonal boundaries of adolescents with ASD. Especially younger adolescents with ASD benefited more from the TTT program. Regarding the behavioral outcomes, we found that parents of the younger adolescents with ASD reported significantly improved social functioning after following the TTT program.

In chapter 6, we investigated the social validation of the TTT program, because interventions that have high effectiveness as well as a high social validity are more likely to be implemented in clinical practice. We found that the training program was highly valued

by all users and that it was possible to personalize the TTT program for adolescents with ASD with a wide range of prior knowledge, motivation and resistance, without diverging from the TTT protocol. These results indicate that both the high satisfaction with the training program by all stakeholders and the high adherence to the TTT protocol by professionals, support the social validity of the TTT program.

In the general discussion in chapter 7, the main results are discussed and methodological considerations regarding the study design, study sample and used measurements are described. Furthermore, implications for future research and clinical and policy suggestions are given. The results of the current RCT showed that the TTT program is an evidence-based intervention targeting the psychosexual development of adolescents with ASD. The high social validation indicates that TTT program will also be used in clinical practice. More research to the psychosexual development of people with ASD is still necessary, for instance research into the mechanisms that explain the development of inappropriate sexual behavior in some adolescents with ASD, but also on predictors of a long term positive sexual development of adolescents with ASD. A final suggestion is to continue with international research on the effectiveness of the TTT program in other countries and cultures given its cultural sensitivity.

Regarding clinical and policy suggestions, continued focus is required on providing training on psychosexuality and ASD for professionals and having standardized material available, in order to increase comfort in professionals to discuss intimate and sexuality topics with adolescents with ASD. Furthermore, another topic that requires attention in clinical practice is increasing parent confidence in discussing sexuality with adolescents with ASD, for instance by providing parents with the required skills and confidence to discuss psychosexual topics with their children.

SAMENVATTING

Dit proefschrift beschrijft de resultaten van een grote (n=189) effectstudie naar de effectiviteit van de Ik Puber-training, een interventie ter bevordering van de psychoseksuele ontwikkeling van jongeren met een autismespectrumstoornis (ASS).

In hoofdstuk 1 wordt de achtergrond van de studie besproken. Lange tijd werd er gedacht dat mensen met een ASS geen behoefte hebben aan intimiteit en seksualiteit, maar inmiddels is bekend dat de meeste mensen met een ASS wel verlangen naar intieme relaties en sociaal en/of seksueel contact. De afgelopen jaren is het aantal studies naar het psychoseksueel functioneren van jongeren en volwassenen met een ASS exponentieel toegenomen, waardoor we nu weten dat er een behoefte is aan goede interventies om deze doelgroep te voorzien van de juiste kennis en vaardigheden die nodig zijn voor een gezonde psychoseksuele ontwikkeling. Het Ik Puber onderzoek is, voor zover bij ons bekend, de eerste gerandomiseerde studie naar de effectiviteit van een dergelijke interventie, de Ik Puber-training.

Hoofdstuk 2 beschrijft het design van het Ik Puber onderzoek en geeft meer informatie over de Ik Puber-training. Het Ik Puber onderzoek is een gerandomiseerde effectstudie met een interventie conditie (n=95) en een wachtlijst controle conditie (n=94), waarin jongeren en hun ouders, gedurende een jaar, deelnemen. De Ik Puber-training is een individuele interventie voor jongeren van 12 tot en met 18 jaar met een ASS en een normale tot hoge intelligentie, bestaande uit een handleiding met een duidelijk protocol voor professionals en een werkboek voor de jongere. De training bestaat uit 18 sessies die gaan over de volgende onderwerpen: praten over de puberteit, uiterlijk/uitstraling, eerste indruk, fysieke en emotionele ontwikkeling in de puberteit, vriendschappen, verliefdheid en daten, seksualiteit (seksuele voorkeur, masturbatie en geslachtsgemeenschap), zwangerschap, grenzen van jezelf en anderen en veilig internet gebruik. Een trainer en een adolescent hebben één sessie per week en bespreken de lesstof op een gestructureerde manier in ongeveer 45 minuten. De Ik Puber-training bevat 115 oefeningen, bijvoorbeeld kennis- en inzichttoetsen en rollenspellen met de trainer. Aan het eind van iedere sessie ontvangt de adolescent een huiswerkopdracht waarin het onderwerp van de sessie nog eens geoefend kan worden buiten de context van de training, bijvoorbeeld door een klein interview met een van de ouders over het onderwerp van de sessie, te oefenen met je grenzen aangeven aan een ander en een afspraak maken met een vriend(in). Ouders ontvangen wekelijks een via email een rapportageverslag, met informatie over de besproken sessie (psycho-educatie), de huiswerkopdracht en bijzonderheden van de jongere in de huidige sessie. De Ik Puber-training kan voor twee doeleinden gebruikt worden: 1) als geïndiceerde interventie, wanneer problemen in de psychoseksuele ontwikkeling al hebben plaatsgevonden, of 2) als preventieve interventie, om jongeren met een ASS voor te bereiden op een gezonde puberteitsontwikkeling. Vanwege het ethische bezwaar om

jongeren die al substantiële problemen laten zien in hun psychoseksuele ontwikkeling voor een jaar op de wachtlijst te plaatsen, richt het huidige onderzoek zich voornamelijk op de effectiviteit van het preventieve gebruik van de Ik Puber-training.

Het Ik Puber onderzoek biedt naast de studie naar de effectiviteit van de Ik Puber-training ook de mogelijkheid om meer informatie te verkrijgen over het psychoseksueel functioneren van een grote groep jongeren met een ASS. In hoofdstuk 3 worden de resultaten besproken van de studie naar de beoordeling van seksuele situaties van jongeren met een ASS in vergelijking met een op leeftijd gematchte controlegroep jongeren zonder ASS. De verwachting was dat het seksueel grensoverschrijdend gedrag, zowel als dader of als slachtoffer, van jongeren met een ASS dat beschreven wordt in de literatuur mogelijk (gedeeltelijk) verklaard kon worden doordat jongeren met een ASS moeite hebben met het juist inschatten van seksuele situaties. Door middel van het Vlaggensysteem werd aan de jongeren met en zonder een ASS gevraagd van verschillende afgebeelde platen te beoordelen of het afgebeelde seksuele gedrag in meer of mindere mate gepast of ongepast was. Ondanks dat het Vlaggensysteem oorspronkelijk niet is ontwikkeld als meetinstrument, gaf het ons de mogelijkheid om het verschil in beoordeling tussen jongeren met een ASS en zonder een ASS te onderzoeken. Opvallend genoeg waren er geen verschillen tussen de twee groepen, en vonden we geen aanwijzingen dat jongeren met een ASS minder goed zijn in het inschatten van de gepastheid van seksueel gedrag wanneer zij papieren afbeeldingen moeten beoordelen. Toekomstig onderzoek zou gebruik kunnen maken van meer ecologisch valide metingen om nader te verhelderen hoe deze inschatting verloopt in meer complexe, dynamische situaties in het echte leven.

Ook in hoofdstuk 4 hebben we gekeken naar de verschillen tussen jongeren met en zonder een ASS, maar nu naar de mate van overeenstemming in rapportage over het psychoseksueel functioneren van de jongeren tussen de jongeren zelf en de ouderrapportage. Eerdere studies naar de psychoseksuele ontwikkeling van jongeren met een ASS hebben voornamelijk gebruik gemaakt van ouderrapportage. Zelfrapportage wordt bij jongeren met een ASS maar af en toe gebruikt, vooral vanwege de veronderstelling dat mensen met een ASS moeite hebben met het rapporteren over hun eigen gevoel, gedachten en gedrag. Echter, de resultaten van de huidige studie laten zien dat jongeren met een ASS en hun ouders op meerdere domeinen van psychoseksueel functioneren van elkaar verschillen in hun rapportage, en deze verschillen in rapportage blijken groter dan tussen jongeren zonder een ASS en hun ouders. De jongeren met een ASS zijn zelf optimistischer over hun vaardigheden en zelfvertrouwen dan hun ouders, terwijl ouders meer ongepast seksueel gedrag rapporteren dan de jongeren met een ASS zelf. Dit onderstreept het belang om, zeker bij een privacy gevoelig onderwerp als psychoseksueel functioneren, altijd gebruik te maken van meerdere informanten, in het bijzonder bij jongeren met een ASS.

In hoofdstuk 5 worden de resultaten van het Ik Puber onderzoek op de primaire uitkomstmaten besproken. De Ik Puber-training vergroot significant de kennis van

psychoseksuele thema's en het inzicht in eigen en andermans grenzen bij jongeren met een ASS. De grootste effecten worden gevonden voor jongere adolescenten (12-14 jaar), voor deze groep wordt naast de grootste stijging in kennis ook een significante stijging gevonden in sociale responsiviteit, gerapporteerd door ouders. De Ik Puber-training blijkt dus een effectieve preventieve interventie om jongeren met een ASS te voorzien van de benodigde kennis en inzichten om hen voor te bereiden op een gezonde psychoseksuele ontwikkeling.

Hoofdstuk 6 richt zich op de sociale validatie van de Ik Puber-training, door de gebruikerstevredenheid en de naleving van het Ik Puber protocol door professionals te onderzoeken. Sociale validatie kan er naast wetenschappelijke evidentie voor zorgen dat een interventie daadwerkelijk in de praktijk geïmplementeerd wordt. De Ik Puber-training wordt hoog gewaardeerd door jongeren met een ASS, hun ouders en professionals die de training hebben gegeven. Bovendien houden professionals zich goed aan het protocol van de Ik Puber handleiding bij het geven van de Ik Puber-training. Ondanks dat onze onderzoeksgroep bestond uit jongeren met een grote range in leeftijd, intelligentie, mate van autismekenmerken en voorkennis van psychoseksuele thema's, lukte het de professionals om de gestandaardiseerde training in het merendeel van de gevallen te handhaven.

In de discussie in hoofdstuk 7 worden de belangrijkste resultaten van het huidige proefschrift weergegeven en methodologische beperkingen van het onderzoeksdesign, de onderzoeksgroep en de gebruikte meetinstrumenten besproken. Daarnaast worden mogelijkheden voor toekomstig onderzoek en implicaties voor de klinische praktijk en beleid gegeven. De effectiviteit van de Ik Puber-training en de hoge sociale validiteit laten zien dat de Ik Puber-training een *evidence-based* en bruikbare interventie is om jongeren met een ASS te voorzien van de benodigde kennis en inzicht. Meer onderzoek naar de psychoseksuele ontwikkeling van adolescenten met een ASS is nodig om inzicht te krijgen in de mechanismen betrokken bij het ontwikkelen van ongepast seksueel gedrag en seksuele problemen van adolescenten met een ASS, maar ook naar voorspellers van een gezonde psychoseksuele ontwikkeling van jongeren met een ASS op de lange termijn. Tot slot dient de effectiviteit van de Ik Puber-training ook onderzocht te worden in andere landen en culturen gezien de culturele sensitiviteit van de inhoud van de training.

Wat betreft implicaties voor de klinische praktijk en beleid blijft het belangrijk dat er aandacht blijft voor de training van professionals over seksualiteit en ASS en dat professionals gestandaardiseerd materiaal ter beschikking hebben, om ervoor te zorgen dat zij zich meer comfortabel voelen om intieme en seksuele onderwerpen met adolescenten met ASD te bespreken. Daarnaast is het verhogen van de competentie van ouders om seksualiteit te bespreken met adolescenten met ASD ook een onderwerp dat aandacht vereist in de klinische praktijk, bijvoorbeeld door ouders de nodige vaardigheden en het vertrouwen te geven dat zij psychoseksuele onderwerpen met hun kinderen kunnen bespreken.

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CURRICULUM VITAE

Kirsten Visser werd op 2 mei 1985 geboren in Alblasserdam. Na het behalen van haar middelbare schooldiploma aan het Johan de Witt gymnasium in Dordrecht in 2002, studeerde ze Psychologie aan de Erasmus Universiteit te Rotterdam. Ze behaalde haar Bachelor en Master diploma in de afstudeerrichtingen Klinische Psychologie en Onderwijs en Ontwikkelingspsychologie. Tijdens haar stages en bijbanen werkte ze bij de Palier, PsyQ, de Fortagroep, de William Schrikker Jeugdbescherming en Yulius (toen nog het RMPI). Bij Yulius werkte ze na afronding van haar studie een jaar als junior onderzoeker binnen de 4u Studie, een onderzoek binnen het speciaal onderwijs Cluster 4. Ook werkte ze mee aan de ontwikkeling van de Ik Puber-training en de subsidieaanvraag voor het gerandomiseerde wetenschappelijk onderzoek naar de effectiviteit van de Ik Puber-training. Nadat de subsidieaanvraag gehonoreerd werd, werkte Kirsten vanaf 2011 gedurende vier jaar als promovendus aan het Ik Puber onderzoek, een samenwerking tussen Yulius en het Erasmus MC – Sophia Kinderziekenhuis. Binnen dit promotieonderzoek was Kirsten verantwoordelijk voor de projectorganisatie, dataverzameling, –verwerking en –analyse van een grote effectstudie waaraan meer dan 190 jongeren en hun ouders deelnamen. Kirsten heeft zich uitgebreid verdiept in de psychoseksuele ontwikkeling van jongeren met een autismespectrumstoornis (ASS) en heeft vele intervisies, workshops en lezingen gegeven over dit thema. Daarnaast heeft ze nationaal en internationaal professionals opgeleid om met behulp van de Ik Puber-training jongeren met een ASS te begeleiden in hun psychoseksuele ontwikkeling. De resultaten van haar promotieonderzoek worden in dit proefschrift beschreven. Vanaf september 2015 werkt Kirsten naast haar promotie als psycholoog in opleiding tot GZ-psycholoog bij Yulius.

LIST OF PUBLICATIONS

Visser, K., Greaves-Lord, K., Tick, N.T., Verhulst, F.C., Maras, A., & van der Vegt, E. J.M. (2017). A randomized controlled trial to examine the effects of the Tackling Teenage psychosexual training program for adolescents with autism spectrum disorder. *Journal of Child Psychology and Psychiatry, 58 (7)*, 840-850.

Visser, K., Greaves-Lord, K., Tick, N.T., Verhulst, F.C., Maras, A., & van der Vegt, E. J.M. (2017). An exploration of the judgement of sexual situations by adolescents with autism spectrum disorders versus typically developing adolescents. *Research in Autism Spectrum Disorder, 36*, 35-43.

Visser, K., Greaves-Lord, K., Tick, N.T., Verhulst, F.C., Maras, A., & van der Vegt, E. J.M. (2015). Study protocol: a randomized controlled trial investigating the effects of a psychosexual training program for adolescents with autism spectrum disorder. *BMC psychiatry*, *15 (1)*, 207.

Visser, K., Greaves-Lord, K., Dekker, L.P., Boudesteijn, F., Maras, A., & van der Vegt, E.J.M. (2014). De psychoseksuele begeleiding van jongeren met een autismespectrumstoornis: Toepassing van de Ik Puber-training. *Wetenschappelijk Tijdschrift Autisme, 13 (4)*, 132-137.

Dekker, L. P., van der Vegt, E.J.M., **Visser, K.**, Tick, N.T., Boudesteijn, F., Verhulst, F.C., Maras, A., & Greaves-Lord, K. (2014). Improving psychosexual knowledge in adolescents with autism spectrum disorder: Pilot of the tackling teenage training program. *Journal of Autism and Developmental Disorders, 45(6)*, 1532-1540.

Visser, K., Greaves-Lord, K., Dekker, L.P., Boudesteijn, F., Maras, A., & van der Vegt, E.J.M. (2012). "Ik Puber" Een onderzoek naar de effectiviteit van de Ik Puber-training. *Wetenschappelijk Tijdschrift Autisme, 11(2)*, 64-67.

Boudesteijn, F., van der Vegt, E.J.M., **Visser, K.**, Tick, N.T., & Maras, A. (2011). *Psychoseksuele ontwikkeling bij adolescenten met een autismespectrumstoornis; Ik Puber-training.* Van Gorcum, Assen.

PHD PORTFOLIO

Summary of PhD training and teaching

Name PhD student: Kirsten Visser Erasmus MC Department: Child and Adolescent Psychiatry and Psychology	PhD period: April 2011-April 2015 Promotor: Prof. dr. F.C. Verhulst Supervisors: dr. K. Greaves-Lord & dr. E.J.M. van der Vegt

1. PhD training

	Year	Workload (ECTS)
General courses		
- Ik Puber Train-the-trainer	2011	1
- Training psychologie van de beïnvloeding	2011	2
- BROK (Basiscursus Regelgeving Klinisch Onderzoek)	2011	1
- Cursus Access	2011	0.5
- Basiscursus statistiek in SPSS	2011	1
- Training Refworks	2011	0.5
- ADOS training	2011	1
- 3di training	2011	0.5
- Writing in the Sciences (Coursera)	2012	1
- PEERS training	2014	1
- Biomedical English Writing and Communication	2014	3
Seminars and workshops		
- Symposium Standardized Assessment of Child Psychopathology: New Developments, Rotterdam, Nl	2011	0.5
- Workshop evidence based zoeken in Ovid, Nl	2011	0.5
- ZonMw congres “Lieve Lust”, Amsterdam, Nl	2012	0.5
- NVA congres, Utrecht, Nl	2012	0.5
- Bijeenkomst Professionele kracht, vrijwillige kracht, eigen kracht: samen voor jeugd, Amsterdam, Nl	2012	0.5
- Nationaal Autisme Congres, Rotterdam, Nl	2013	0.5
- Workshop Bloggen, Rotterdam, Nl	2013	0.5
- Workshop ‘Subsidieaanvragen voor praktijkmedewerkers’, Rotterdam, Nl	2013	0.5
- CDSCS 2014, Rotterdam, Nl	2014	1
- NVA congres, Utrecht, Nl	2014	0.5
Presentations		
- Lezing ‘Ik Puber, Een training voor de begeleiding van de psychoseksuele ontwikkeling van adolescenten met een autismespectrumstoornis’ Wetenschapsmarkt Yulius	2012	1
- Lezing ‘ Inzicht in ouder-kind verschillen in de beoordeling van de psychoseksuele en puberteitsontwikkeling van jongeren met autismespectrumstoornissen (ASS)’ Wetenschapsmarkt Yulius	2013	1
- Lezing ‘Autisme en seksualiteit’ GZ curriculum commissie	2013	0.5
- Lezing ‘Ik Puber onderzoek een wetenschappelijk onderzoek naar de psychoseksuele ontwikkeling van jongeren met autisme’ NIP avond seksualiteit	2014	0.5
- Lezing ‘Het Ik Puber onderzoek: Een Randomised Controlled Trial naar de effectiviteit van de Ik Puber-training’ Hofreferaat Yulius	2015	0.5
- Lezing ‘De relationele en seksuele ontwikkeling van pubers met autisme: Gestandaardiseerde assessment en behandeling’ Wetenschapsmarkt Yulius	2015	1

(Inter)national conferences		
- Poster Presentation 'Preliminary outcomes of a pilot study on a psychosexual training program for adolescents with autism spectrum disorder (ASD); the Tackling Teenage Training' IACAPAP 2012, Paris, France	2012	1
- Poster Presentatie 'Een psychoseksueel trainingsprogramma voor adolescenten met Autisme Spectrum Stoornissen (ASS); De eerste uitkomsten van de Ik Puber-training' Nationaal Autisme Congres, Rotterdam, Nl	2013	1
- Lezing ' Inzicht in ouder-kind verschillen in de beoordeling van de psychoseksuele en puberteitsontwikkeling van jongeren met autismespectrumstoornissen (ASS)' NVvP voorjaarscongres 2013, Maastricht, Nl	2013	1
- Oral Presentation 'A psychosexual training program for adolescents with autism spectrum disorders (ASD); the first effects of the Tackling Teenage Training' IMFAR 2013, San Sebastian, Spain	2013	2
- Oral Presentation 'A psychosexual training program for adolescents with Autism Spectrum Disorders (ASD): The first effects of the Tackling Teenage Training' ESCAP 2013, Dublin, Ireland	2013	2
- Oral Presentation 'The Tackling Teenage Research: A Randomized Controlled Trial to the effects of the Tackling Teenage Training Program' IMFAR 2015, Salt Lake City, USA	2015	2
- Oral Presentation 'Assessment of ASD: The use of Autism Diagnostic Observation Schedule (ADOS-2) in clinical practice' Campinas, Brasil	2015	2
2. Teaching		
Lecturing		
- Train-the-trainer TTT program, Barcelona, Spain	2011	2
- Workshop 'autisme en seksualiteit' Boba, Dordrecht, Nl	2012	1
- Workshop ouderavond 'autisme en seksualiteit' Stichting voor Elkaar, Rotterdam, Nl	2012	1
- Workshop ouderavond 'autisme en seksualiteit' Stichting Sanare, Rotterdam, Nl	2012	0.5
- Workshop ouderavond 'autisme en seksualiteit' Stichting Bijzonder Gewoon, Den Bosch, Nl	2012	0.5
- Workshop 'autisme en seksualiteit' Adolescentenkliniek Erasmus MC, Rotterdam, Nl	2012	0.5
- Train-the-trainer TTT program, Volos, Greece	2013	2
- Train-the-trainer Ik Puber-training, Rotterdam. Nl	2013	2
- Workshop 'autisme en seksualiteit' ambulante schoolbegeleiders Yulius, Rotterdam, Nl	2013	0.5
- Workshop 'autisme en seksualiteit' CED/Rutgers WPF, Utrecht, Nl	2013	0.5
- Workshop 'autisme en seksualiteit' verwijzersdag Yulius, Alblasserdam, Nl	2013	0.5
- Workshop 'autisme en seksualiteit' AIC Rotterdam, Nl	2014	0.5
- Workshop 'autisme en seksualiteit' William Schrikker Stichting, Dordrecht, Nl	2014	0.5
- Train-the-trainer Ik Puber-training, Rotterdam, Nl	2014	2
- Train-the-trainer TTT program, Galway, Ireland	2014	2
- Workshop 'autisme en seksualiteit', NIP thema-avond seksualiteit, Utrecht, Nl	2014	0.5
- Train-the-trainer Ik Puber-training, Rotterdam, Nl	2014	2
- Train-the-trainer Ik Puber-training, Rotterdam, Nl	2015	2
- Train-the-trainer TTT program, Copenhagen, Denmark	2015	2
- Lecture Universiteit Utrecht 'autisme en seksualiteit', Utrecht, Nl	2016	0.5
Supervising Master's theses		
- Guiding Masterstudents (7x)	2011-2015	5
- Guiding Bachelorstudents (4x)	2012-2014	3

TOTAAL: 54.5 ECTS