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Addressing social skills deficits in adults with Williams syndrome



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ABSTRACT

Background: Individuals with Williams syndrome (WS) are hypersocial; yet, they experience social difficulties and trouble with relationships. This report summarizes findings from three studies examining the social functioning of adults with WS and the feasibility of a social skills training program for adults with WS (SSTP-WS) through the examination of performance on initial lesson plans.

Method: Study 1: 114 parents of adults with WS completed the Social Responsiveness Scale-2. Study 2: 10 adults with WS and 12 of their parents participated in focus groups to further describe the deficits identified in Study 1 and to discuss a SSTP-WS. Study 3: 30 adults with WS were randomly assigned to 2 lessons on either conversations or relationships and pre-post change in social skills knowledge was assessed.

Results: Study 1 indicates adults with WS experience severe social impairments in social cognition, and mild-moderate impairments in social awareness and social communication. Qualitative results in Study 2 indicate a SSTP-WS should address conversation skills and relationships. In Study 3, participants showed gains in social skills knowledge following completion of lessons.

Implications: A SSTP-WS may be beneficial for adults with WS. Future research should describe the social needs of individuals with WS at different ages and should further develop a SSTP-WS.

What this paper adds?

Although there is a large amount of research examining the social behaviors of individuals with Williams syndrome (WS), the findings have not been extended to the development of interventions designed to directly address their social skills deficits. This paper presents the iterative process to develop a social skills training program that meets the unique needs of adults with WS. This paper adds to the literature in three ways. First, this paper extends previous research on children with WS by assessing the social skills deficits of a large sample of adults with WS. We provide data that indicate that, similar to children with WS, adults with WS continue to experience the most impairments related to social cognition and least impairments related to social motivation. Second, this paper uses the results of the social skills survey to talk with parents and adults with WS about their social needs and the needs on which they feel a social skills training program should focus. Finally, this paper is the first to develop a social skills intervention for individuals with WS. Borrowing from the methods and curricula for social skills training programs for individuals with autism, this paper reports on how lesson plans were adapted to meet the unique needs of individuals with WS. We present results from an initial pilot of four lesson plans developed for an intervention specific for adults with WS. These lesson plans meet a critical need to address the social skills deficits of adults with WS.

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1. Introduction

Williams syndrome (WS) is a complex neurodevelopmental disability caused by a deletion of ~26 genes on chromosome 7q11.23 (Hillier et al., 2003). One of the most salient features of the WS behavioral phenotype is the extremely social personality (Klein-Tasman & Mervis, 2003; Mervis et al., 2003; Klein-Tasman, Li-Barber, & Magargee, 2011). Indeed, individuals with WS are often characterized as gregarious (Gosch & Pankau, 1997), charming (Fryns, Borghgraef, Volcke, & Van den Berghe, 1991), and disinhibited in their social approach behavior towards both familiar and unfamiliar people (Järvinen, Korenberg, & Bellugi, 2013). Despite their hypersociability, individuals with WS experience a number of social difficulties, including trouble establishing and maintaining peer relationships (e.g., Davies, Udwin, & Howlin, 1998; Sullivan, Winner, & Tager-Flusberg, 2003). Such difficulties result in nearly 75% of adults with WS reporting feelings of social isolation (Davies et al., 1998), 30% reporting difficulty forming friendships, and 49% reporting a poor understanding of the concept of friendship (Elison, Stinton, & Howlin, 2010).

While research has speculated that specific aspects of social skills impairments contribute to the social difficulties and isolation experienced by individuals with WS (Davies et al., 1998; Fisher, Moskowitz, & Hodapp, 2013; Jawaid et al., 2012; Mervis & Klein-Tasman, 2000), there is a dire need for systematic research to examine and address the social skills deficits experienced by adults with WS. Thus, this report describes the iterative approach to describe the social skills deficits and social needs of adults with WS and to use those findings to develop a social skills training program (SSTP) addressing those needs. Findings from three studies were used to (1) describe the most salient social skills deficits experienced by adults with WS; (2) identify the social needs and best approach to address these needs for adults with WS; and (3) pilot lessons developed for a SSTP to improve the social functioning and knowledge of adults with WS. Before describing these three studies, we first discuss the previous research related to social functioning of individuals with WS and describe why a SSTP might be an appropriate intervention for this population. We then briefly present the methods and results of the three studies.

1.1. Social functioning of individuals with WS

Before effective interventions can be developed to support the social needs of adults with WS, it is necessary to understand the paradox between hypersociability and the social isolation experienced by these individuals (Thurman & Fisher, 2015). Although no empirical studies have explicitly examined the link between social skills deficits and friendship difficulties among individuals with WS, certain deficits are hypothesized to relate to their friendship problems. For example, the tendency to display excessive chatter, make socially inappropriate statements, and engage in self-talk could be related to the high rates of peer rejection experienced by individuals with WS (Davies et al., 1998). Other studies suggest that difficulties conversing with peers lead to trouble establishing and maintaining friendships (Mervis & Klein-Tasman, 2000). Such speculation is further supported by research indicating that similar social skills deficits displayed by individuals with autism spectrum disorder (ASD) lead to problems with friendships, romantic relationships, social participation, and vocational success (Barnhill, 2007).

Indeed, a growing body of research has clearly highlighted that individuals with WS do have impairments in social skills. For example, compared to children with other genetic forms of intellectual disability, children with WS had poor social competence (Rosner, Hodapp, Fidler, Sagun, & Dykens, 2004) and, compared to children without disabilities, delayed social skills development (Mervis, Klein-Tasman, & Mastin, 2001). Klein-Tasman et al. (2011), van der Fluit, Gaffrey, and Klein-Tasman (2012) reported that while children and adolescents with WS had less difficulty with the prosocial aspects of social functioning, such as social motivation (e.g., desire to engage in social interpersonal behavior) and social awareness (e.g., ability to pick up on social cues), they had considerable deficits in the social cognitive aspects of social functioning, including social communication (e.g., expressive social communication) and social cognition (e.g., ability to accurately interpret social cues). Similarly, Lough, Flynn, and Riby, (2015, 2016) reported impaired social skills in all domains of social reciprocity, as well as poor personal space regulation, for children and adolescents with WS.

Although there have been fewer systematic examinations of the social functioning of adults with WS, there is some evidence indicating that the social behaviors of the majority of adults with WS continue to fall within the clinically significant range of social skills deficits (Järvinen, Ng, & Bellugi, 2015; Riby et al., 2014). Similar to children and adolescents with WS, Järvinen and colleagues reported that adults with WS continued to display deficits related to social cognition and social communication. Overall, previous research indicates that although individuals with WS are friendly and motivated to interact with others, they also demonstrate difficulties with interpersonal and social communication skills.

1.2. Social skills training programs

Given the link between social difficulties and poor social outcomes, it is vital that researchers move beyond describing the social skills deficits of individuals with WS to designing interventions to address these issues. SSTPs are an evidence-based practice implemented to improve social success in individuals with ASD and other developmental disability populations (e.g., Gresham, Sugai, & Horner, 2001). Most SSTPs involve direct training approaches, in which social skills are directly taught to the individual in either group settings or one-on-one. Although empirical support for the success of SSTPs exists for individuals at all stages of development and intellectual functioning (e.g., Bellini, Peters, Benner, & Hopfm, 2007; Gantman, Kapp, Orenski, & Laugeson, 2012), fewer programs have been developed for adults with disabilities. Further, programs for adults generally focus on those with ASD without co-occurring intellectual disability (e.g., Gantman et al. 2012). As such, it is unclear if the topics and training methods of currently existing SSTPs for adults with ASD would be effective for adults with WS.

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