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Internet-delivered psychoeducation for older adolescents and young adults with autism spectrum disorder (SCOPE): An open feasibility study



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ABSTRACT

Background: There is a paucity regarding interventions in general, and especially internet-delivered treatment options, for adolescents and young adults with autism spectrum disorder (ASD), despite the group's capacity and willingness to utilize computer-mediated communication. This open feasibility study evaluated the new internet-delivered, psychoeducational intervention, SCOPE (Spectrum COmputerized PsychoEducation), for adolescents and young adults aged 16–25 years with ASD in the normative IQ range.

Method: The participation in SCOPE was facilitated by weekly contacts with disability service professionals (trained coaches) and the intervention consisted of eight ASD-themed modules. In an open feasibility study we evaluated treatment completion, treatment credibility and satisfaction, as well as preliminary efficacy. We assessed feasibility in an outpatient disability services context, regarding both participants' and coaches' experiences.

Results: Twenty-three out of the 29 included participants (79%) completed the intervention. The participants' experience of treatment credibility was increased during the SCOPE web course and the overall satisfaction with the treatment was high. The coaches reported high treatment credibility and good clinical feasibility of the internet-based delivered intervention. The participants' knowledge of ASD increased significantly from pre-intervention to post-intervention. The increased knowledge of ASD was not associated with negative effects on psychological well-being.

Conclusions: Our results suggest that the internet-delivered psychoeducational intervention SCOPE is a feasible intervention and could contribute to youth's sense of empowerment through increased knowledge of ASD and themselves. An ongoing randomized controlled study will generate further evidence concerning the SCOPE intervention.

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1. Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental condition of complex origin, entailing impaired social communication and interaction alongside repetitive, restricted behavior (DSM-5, 2013). The estimated prevalence of ASD is 1.5% in children in the USA (CDC, 2016) and even higher for adolescents and young adults in Stockholm County, Sweden (Idring et al., 2015). ASD has been increasingly diagnosed during the past few decades, although the reasons for this increase are not fully understood (Christensen et al., 2016; Idring et al., 2015; Wazana, Bresnahan, & Kline, 2007). In most cases, ASD persists into adulthood (Helles, Gillberg, Gillberg, & Billstedt, 2015) and the consequences of having ASD are profound, also in intellectually able individuals (de Schipper et al., 2016; Howlin, Goode, Hutton, & Rutter, 2004; Jonsson et al., 2017; Magiati, Tay, & Howlin, 2014). ASD is associated with long-term impairments in major areas of life, such as education (Shattuck et al., 2012), occupation (Taylor & Seltzer, 2011), and residential status (Anderson, Shattuck, Cooper, Roux, & Wagner, 2014). Furthermore, experience of high stress in everyday life (Hirvikoski & Blomqvist, 2015) and comorbid psychiatric conditions are common (Bakken et al., 2010; Caamano et al., 2013) and even as severe as a substantially increased risk of suicide (Hirvikoski et al., 2016).

The availability of effective and safe evidence-based treatment is not only a crucial matter for the well-being of the individual, but also for health care services in charge of managing an increase in ASD referrals. It has been noted in several studies that there is a lack of appropriate evidence-based services for the transitioning youth with ASD (Cheak-Zamora et al., 2014; Taylor & Henninger, 2015). The recommended support for older adolescents and young adults with ASD include interventions to facilitate coping with life challenges, as well as any psychiatric comorbidity, such as cognitive behavioral therapy, and social skills training in particular (Choque Olsson et al., 2017; NICE, 2013). Reviews of the literature on psychological interventions for adults with ASD (Bishop-Fitzpatrick, Minshew, & Eack, 2013), as well as for children and adolescents with ASD (Hirvikoski, Jonsson et al., 2015), provide support for the effects of these interventions, even though the number of studies with satisfactory quality is low, especially for transitioning young adults with ASD (Lounds Taylor et al., 2012). A further obstacle for young adults on the autism spectrum may be their reluctance to take part in behavior modification interventions, as they might perceive them as forced normalization attempts. To motivate active treatment participation and compliance, the perceived benefit of a treatment program must be greater than the required investment in time and (e.g., social) engagement in the treatment (Trudgeon & Carr, 2007). Involving persons with ASD provides information about their lived experience of autism – the importance of active involvement of persons with ASD in research projects on interventions and treatments has recently been highlighted (Gillespie-Lynch, Kapp, Brooks, Pickens, & Schwartzman, 2017; Pellicano, Dinsmore, & Charman, 2014). To ensure suitable interventions with a credible design, co-production between self-advocates, interest groups, clinicians and researchers might be a sustainable strategy (Bölte, 2017; Gillespie-Lynch et al., 2017; Pellicano et al., 2014).

In addition, treatment approachability may increase with stepped care models, including less demanding first-line treatments and diverse treatment deliverance models adjusted for the target group. In the context of ASD, psychoeducation has been recommended as a first-line post diagnostic intervention (NICE, 2013). Psychoeducation is a well-established, evidence-based intervention for several psychiatric disorders aimed at empowering patients with knowledge and directly asking them to take part in their own treatment (Hayes & Gantt, 1992; Hirvikoski, Waaler, Lindstrom, Bolte, & Jokinen, 2015). A concern with psychoeducational interventions is that they may reduce self-esteem despite otherwise positive treatment effects (Wiggins, Singh, Getz, & Hutchins, 1999), also internet-based interventions may incur negative side-effects such as symptom deterioration (Rozenal, Magnusson, Boettcher, Andersson, & Carlbring, 2017). Therefore, follow-up of participants' psychological well-being is of great importance. Only a couple of previous studies have described psychoeducational interventions for individuals with ASD, one of which is a group-based program for children and younger adolescents with ASD and parents in parallel sessions (Gordon et al., 2015), it was effective in teaching the participants about ASD, as well as increasing their self-awareness of their strengths and difficulties. The other, a multi-family group psychoeducational intervention for parents with a parallel social group for the adolescents, indicated an improved understanding of ASD by the parents, as well as improved parent-child relationships (Smith, Greenberg, & Mailick, 2012).

Surprisingly, internet-delivered treatment options for older adolescents and young adults with ASD have scarcely been developed and evaluated, considering the group's possible reservations to participate in interventions indicating "treatment" of ASD, as well as their capacity and willingness to utilize computer-mediated communication (Gillespie-Lynch, Kapp, Shane-Simpson, Smith, & Hutman, 2014; Gillespie-Lynch et al., 2015). Individuals with ASD report perceived benefits of computer-mediated communication with respect to increased comprehension and control over communication, access to similar others and the opportunity to express their true selves. A recent meta-analysis pertaining to children and adolescents with ASD gave support for the continuing development and clinical use of technology-based interventions (Grynszpan, Weiss, Perez-Diaz, & Gal, 2014). However, there have not been enough published studies focusing on the young adult and adult with ASD populations to conduct a similar meta-analysis (Bishop-Fitzpatrick et al., 2013).

The overall aim of the current study was to evaluate a new internet-delivered, coach-guided psychoeducational intervention, SCOPE (Spectrum CComputerized PsychoEducation), in older adolescents and young adults with ASD aged 16–25 and average range intellectual functioning. The study evaluated the technical functionality and geographical accessibility of SCOPE, as well as its content and user friendliness from both participant and professional perspectives. We also evaluated feasibility in a clinical context, treatment satisfaction and credibility, as well as preliminary efficacy. The main goal of the treatment was to impart knowledge of ASD to the participants. The current study was approved by the Regional Ethics Committee in Stockholm at Karolinska Institutet in 2014; this is in accordance with the Declaration of Helsinki (World Medical Association, 2013).

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