SOAR Study: New approaches to managing social skills deficits in Turner Syndrome

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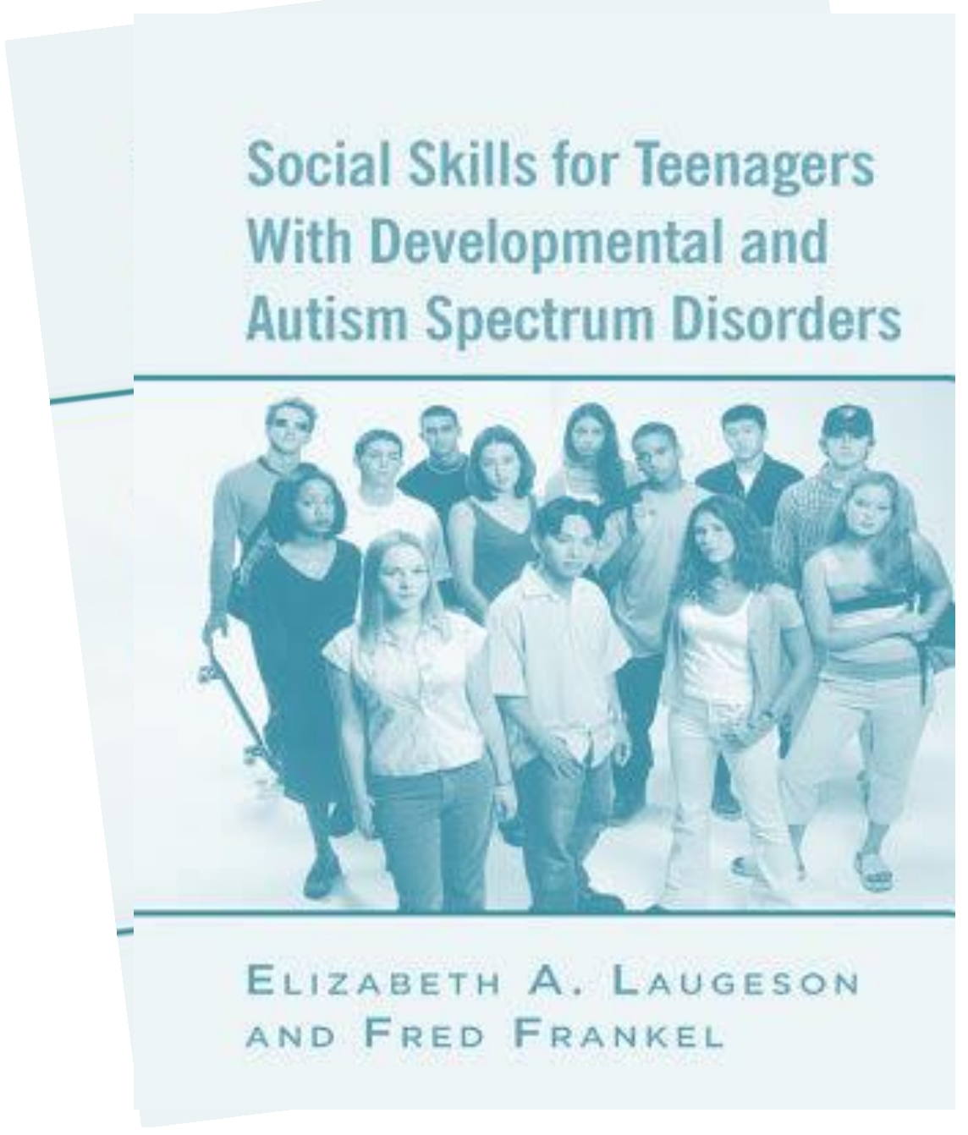
Background

Turner Syndrome (TS) is a sex chromosome aneuploidy (45,X) associated with social skill difficulties[1].



The 2016 Cincinnati TS clinical care guidelines recommend that the Program for the Education and Enrichment of Relational Skills (PEERS) social skills intervention is piloted[2]. PEERS has previously been used in face-to-face interventions with male adolescents with autism spectrum conditions.

PEERS consists of 14 weekly lessons and runs two concurrent groups; one for the young people (YP) and one for parents (P)[3]. The YP lessons are structured to provide didactic instruction as well as social skill rehearsal.

SOAR Study was set up in 2016 to examine the mental health, social skills and personal relationships of those affected by TS, and to pilot a novel intervention to ameliorate difficulties

This pilot project is the first to examine the feasibility and acceptability of delivering the PEERS protocol online.

Methods

Design: The pilot used an uncontrolled study design with multiple-case tracking.

Screening measures:

- Peer Relationships: *Strengths and Difficulties Questionnaire (SDQ) Peer difficulties scale (P report)*
- Motivation: *PEERS screening interview (P & YP report)*

Primary Outcome measure – Parent report :

- Social performance: *Social Competence with Peers (SCP)*

Administered: 3x pre-, 3x during and 1x post- intervention

Secondary outcome measures:

- Anxiety: *Spence social anxiety scale (YP report)*
- Self-esteem: *Rosenberg self-esteem scale (YP report)*
- Social knowledge: *PEERS Test of Adolescent Social Skills Knowledge (YP report)*
- Autistic symptomatology: *Social Responsiveness Scale-2 (P report)*

All administered pre- and post- intervention

Delivery: PEERS was modified to be delivered primarily online. Face-to-face sessions took place at the start, middle and end of the program. All other sessions were conducted online using Adobe Connect Meetings.

Results: Trends in social performance scores (SCP)

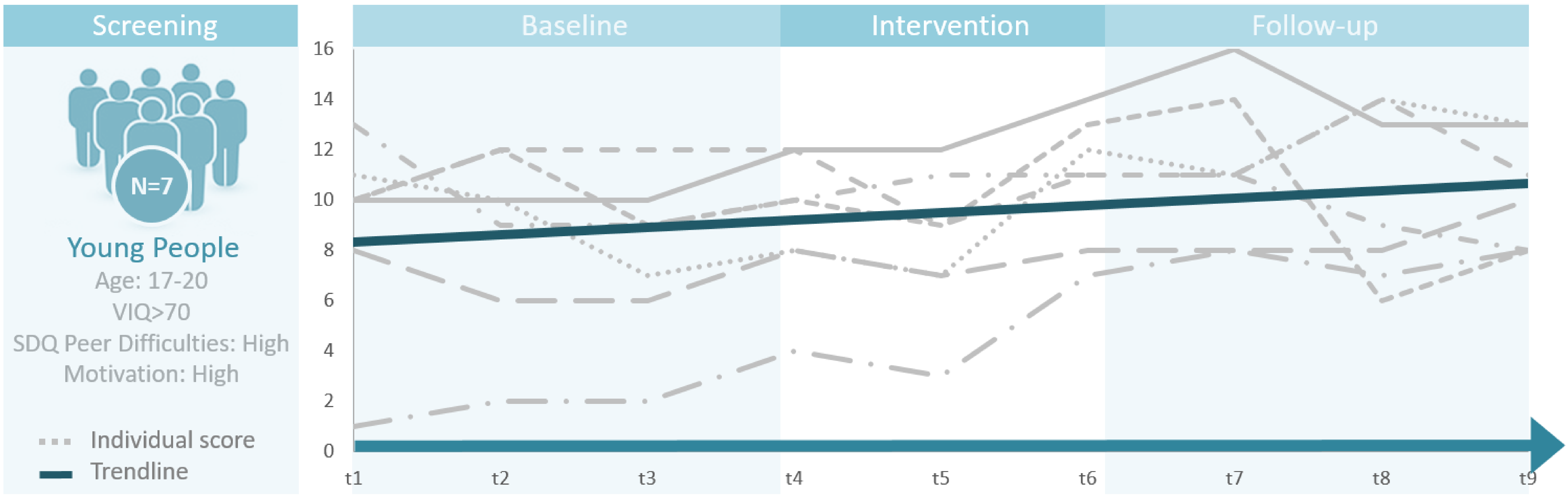


Figure 1. Participant demographics and primary outcome measure, multiple case tracking

Participants: PEERS was piloted with 7 young women with TS and their mothers.

Screening: Participants scored in the 'abnormal' range on the SDQ peer difficulties scale ($t_{(6)}$=4.66, p=0.003; P report) compared to typical female population norms. Motivation to take part in the intervention was high (YP and P report; Figure 1).

Primary Outcome: Social performance was significantly improved on the SCP (p=0.045; δ=0.64; P report). Gains were maintained at follow up (Figure 1).

Secondary Outcomes: Improvements in social knowledge (p<0.0001; δ=4.25; YP report) and reduced autistic symptomatology (p=0.036; δ=0.46; P report). No change occurred in self-report measures of anxiety and self-esteem.

Adherence to the intervention was high (>86%) and 100% of participants rated PEERS as 'very helpful' and reported improvements in the young person's social ability.

Conclusion

The young women and their parents were highly motivated to improve their daughter's social functioning.

Online administration could substantially broaden the accessibility of social skills interventions in a cost-effective way to more young women with TS and other rare genetic disorders.

References

1. Wolstencroft, Jeanne, and David Skuse. "Social skills and relationships in Turner syndrome." Current opinion in psychiatry 32.2 (2019): 85-91.
2. Gravholt, Claus H., et al. "Clinical practice guidelines for the care of girls and women with Turner syndrome: proceedings from the 2016 Cincinnati International Turner Syndrome Meeting." European journal of endocrinology 177.3 (2017): G1-G70.
3. Laugeson, Elizabeth A., et al. "Evidence-based social skills training for adolescents with autism spectrum disorders: The UCLA PEERS program." Journal of autism and developmental disorders 42.6 (2012): 1025-1036.