

# Experiences of social interaction in young women with Turner syndrome: A qualitative study

Jeanne Wolstencroft<sup>1</sup>  | William Mandy<sup>2</sup> | David Skuse<sup>1</sup>

<sup>1</sup>The Great Ormond Street Institute of Child Health, University College London, London, UK

<sup>2</sup>Division of Psychology and Language Sciences, Faculty of Brain Sciences, University College London, London, UK

## Correspondence

Jeanne Wolstencroft, The Great Ormond Street Institute of Child Health, University College London, 30 Guilford Street, London WC1N 1EH, UK.  
Email: j.wolstencroft@ucl.ac.uk

## Funding information

Child Health Research CIO Studentship

## Abstract

**Background:** Turner Syndrome (TS; 45,X) is a sex chromosome aneuploidy associated with deficits in social interaction, for which clinical care guidelines have recently recommended trialling a social skills training intervention. The present study aimed to gather preliminary evidence to support a training programme for young women.

**Methods:** Semi-structured interviews and psychometric questionnaires about social ability were administered to young women with TS aged 16 to 25 years old (n=17) and their parents (n=20). Interview transcripts were analysed using thematic analysis.

**Results:** Although young women with TS experienced a “wide range of social competencies,” they attributed social challenges to “personal and contextual factors.” The magnitude of these challenges to social integration intensified during adolescence. They felt increasingly “out of sync” with their peers. They also considered their social abilities to be better than their parents did; on a scale of autistic traits (rated by parents), half had mild to severe autistic traits. Most expressed interest in taking part in a social skills programme.

**Conclusion:** Young women with TS are aware they experience difficulties in social communication, and they express interest in improving their social skills. Accordingly, social skills training during adolescence would be welcomed by them and their families. Any intervention should take account of their feelings of social dislocation arising from hearing difficulties together with limited recognition, and slow processing, of social cues.

## KEYWORDS

female autism, experiences of socialization, sex chromosome aneuploidy, social competence, social skills, Turner syndrome

## 1 | BACKGROUND

Turner syndrome (TS) is a sex chromosome aneuploidy resulting in the full or partial loss of one X chromosome, which affects 1 in 2,500 live female births (Jacobs et al., 1997). The physical phenotype of TS has been well characterized in the literature; it is associated with short stature, hearing difficulties, infertility, cardiac abnormalities, diabetes, and thyroid problems (Gravholt et al., 2017).

TS is associated with limited social skills, low self-esteem, and emotional disorders such as anxiety and depression (Cardoso et al., 2004; Chadwick, Smyth, & Liao, 2014; Reimann, Bernad Perman, Ho, Parks, & Comis, 2018; Schmidt et al., 2006). The prevalence of autism spectrum disorders (ASDs) is relatively high, at least 3–4% (Creswell & Skuse, 1999; Kesler, 2007; Knickmeyer, 2012; Saad et al., 2014). From early childhood, girls with TS generally experience more social interaction difficulties than their peers (Boman, Möllet, &

Albertsson-Wikland, 1998; Mccauley, Feuillan, Kushner, Ross, & University, 2001; McCauley, Kay, Ito, & Treder, 1987; McCauley, Ross, Kushner, & Cutler, 1995; Rovet & Ireland, 1994). These difficulties are exacerbated during adolescence (Wolstencroft & Skuse, 2018). Social communication is impaired by a range of cognitive deficits including poor face and emotion recognition, together with limited skills in interpreting direction of gaze and theory of mind (Hong, Dunkin, & Reiss, 2011; Hong & Reiss, 2012; Ross, Feuillan, Kushner, Roeltgen, & Cutler, 1997; Skuse, 2009; Skuse, Lawrence, & Tang, 2005). Taken together, these impact negatively on peer relationships (Hong et al., 2011) and on the ability to engage with social groups (Skuse, 2009).

Poor social skills have an adverse impact on both academic and social adaptation (Coie, Terry, Lenox, Lochman, & Hyman, 1995; Elliott, Malecki, & Demaray, 2001; Roff, Sells, & Golden, 1972; Spence, 2003). There are attendant risks of social isolation and depression, especially in adolescence and adulthood (Skuse, 2009). Recent TS Clinical Care Guidelines recommend a social skills training programme for preventive intervention (Gravholt et al., 2017). But first, we need to know how TS affects the individual's experience of friendships and social interaction. At present, we have little information on that subject other than questionnaire responses (Wolstencroft & Skuse, 2018). We need to understand more, in depth, about the social experiences and expectations of young women with TS. In adolescence, female social interaction becomes increasingly complex. Social competence requires rapid and reciprocal responses as well as the ability to provide emotional support and problem-solving skills (McLennan, Lord, & Schopler, 1993; Nichols, 2009; Solomon, Miller, Taylor, Hinshaw, & Carter, 2012). All these are potential challenges for young women with TS.

Most social skills programmes are designed for males with ASDs, so will require modification to take into account of the different needs, abilities, and interests of women with TS. Clinical observation suggests they often employ social imitation (of their typical female peers), which enables them to compensate for their social differences until adolescence. But in adolescence, the complexity of socialization increases, and compensation by imitation is no longer as effective. Like high-functioning females with ASD, during this developmental phase, they have increasing difficulties building relationships with same-sex peers (Cridland, Jones, Caputi, & Magee, 2014; Jamison & Schuttler, 2017; Sedgewick, Hill, Yates, Pickering, & Pellicano, 2016; Solomon et al., 2012). They are increasingly at risk of becoming targets of bullying and victims of gossip and social rejection, yet often lack insight into the reasons for their exclusion (Cridland et al., 2014; Sedgewick et al., 2016).

Our main objective was to identify personal experiences and perceptions of social interaction and friendships in young women with TS aged 16 to 25 years. We focused on three research aims: first, to record subjective experiences of socialization from childhood to emerging adulthood; second, to assess self-perception of social competence; and third, to discover whether a social skills training intervention would be of interest. Prior research suggests that when young people with social difficulties are asked about their relationships, they

### Key messages

- Young women with TS possess a wide range of social assets, but most lack fluency in social communication, which they attribute to personal and environmental factors.
- Social integration is inhibited by their difficulties interpreting verbal and nonverbal social cues, by limited attention and by slow processing of social perceptions.
- During adolescence, social demands from peer interactions become more complex, leading to increasing social dislocation.
- Many parents rated their daughters to have autistic traits.
- Most young women with TS expressed interest in improving their social skills by attending a social skills training programme.

tend to respond with a social desirability bias (Bauminger & Kasari, 2000) and minimize their social difficulties (Suzigan et al., 2011). We therefore balanced personal subjective reports with parental accounts of adjustment and quantitative data on measures of social ability.

## 2 | METHODS

### 2.1 | Participants

Participants were recruited from the Turner Syndrome Support Society or specialist Turner Syndrome clinics at University College London Hospitals. We aimed to conduct interviews with 20 young people (16–25 years) and their parents ( $n = 40$ ) in order to achieve theme saturation for the purpose of qualitative interview analysis (Sim, Saunders, Waterfield, & Kingstone, 2018). A diagnosis of TS was confirmed by obtaining genetic reports or clinic letters. Hormone treatment status and occupation were recorded by a medical history questionnaire.

### 2.2 | Measures

**Interviews:** A Social Competence Interview schedule for young people with TS was devised in consultation with clinicians (SCI; see Supporting Information A). It followed semi-structured interview guidelines (Smith, 1995) and comprised questions on friendships, bullying, group interaction, and the acceptability of a social skills intervention. Equivalent parent interviews were shorter, with questions about their daughter's history of friendships and the acceptability of conducting a social skills training intervention (Table 1).

**Social Responsiveness Scale 2 (SRS-2):** The SRS-2 is a measure of autistic symptomatology (Constantino & Gruber, 2012), which has convergent validity with ASD diagnostic tools such as the ADOS and ADI-R (Bölte, Westerwald, Holtmann, Freitag, & Poustka, 2011). It

**TABLE 1** Assessment schedule by respondent type

Assessment	Parent	Young person
Social Competence Interview	✓	✓
Social Responsiveness Scale 2	✓	✗
Strengths and Difficulties Questionnaire	✓	✓
Social Competence with Peers Questionnaire (adapted)	✓	✓

assesses Social Awareness, Social Cognition, Social Communication, Social Motivation, and Restricted Interests and Repetitive Behaviour. Raw scores are converted into T-scores normed for age and sex. Total T-scores in the mild range are indicative of clinically significant deficits in reciprocal social behaviour that have a mild to moderate impact on everyday social interactions. T-scores in the moderate range are indicative of substantial deficits in everyday social interaction and typically associated with ASD of moderate severity. T-scores in the severe range are strongly associated with a clinical diagnosis of an ASD. The SRS-2 was completed by parents (Table 1).

**Strengths and Difficulties Questionnaire (SDQ):** The SDQ is a 25-item behavioural screening questionnaire (Goodman, Lamping, & Ploubidis, 2010). It includes five subscales that measure emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, and prosocial behaviour. The first four scales are combined to create a total difficulties score. It has been validated for use in children aged 6–17 years in U.K. National studies of psychological adjustment, and a new form for young people aged 18 and over has recently been developed. The SDQ was completed by parents and young people (Table 1).

**Social Competence with Peers Questionnaire (SCP):** The SCP evaluates the consequences of children's interactions with peers, including questions about the existence and duration of friendships and social invitations (Spence, 1995). A modified version of the SCP was used in order to adapt the tool for use in young adults (available from authors upon request). The SCP was administered to parents and young people (Table 1).

**Indices of Multiple Deprivation (IMD):** Socioeconomic status was ascertained through postcode data using the IMD (Office National Statistics, 2015). IMD scores combine information from seven domains to produce a relative measure of deprivation. The domains take into account income, employment, education, health, crime, barriers to housing and services, and the living environment. IMD scores are ranked and organized into deciles; the first decile includes the most deprived postcodes, and the tenth decile includes the least deprived postcodes. IMD scores are available for England and Scotland.

## 2.3 | Procedure

Psychometric questionnaires were administered online or as pen and paper forms. Interviews were conducted with parents and young people separately by phone, Skype, or in person. Mean length of

interviews were as follows: TS participant 37 min ( $SD = 17$ ) and Parent 25 min ( $SD = 14$ ).

Audio footage was recorded and transcribed verbatim following an “alternative abbreviated instructions for transcribers” procedure (Poland, 2001). All transcripts were checked against the audio recordings by the primary author to ensure accuracy. Ethical approval for the study was obtained through the University College London Committee and the NHS REC West London GTAC (UCL REC:11837/001; IRAS: 219817). The datasets generated and analysed during the current study are not publicly available in order to protect the anonymity of those taking part but are available from the corresponding author on reasonable request.

## 2.4 | Analysis

Thematic analysis (Braun & Clarke, 2006) included (a) data familiarization, (b) generating initial codes, (c) searching for themes, (d) reviewing themes, (e) defining themes, and (f) report production. The inductive and recursive approach allows the identification of patterns within the complete dataset. Guidelines for good qualitative research were followed in order to increase the transparency and credibility of the analysis (Barker & Pistrang, 2005). The initial codes were generated by the primary author. They were audited by two researchers familiar with the social communication problems of females on the autism spectrum (DS and WM). Finalized codes were organized into themes and subthemes.

## 3 | RESULTS

### 3.1 | Situating the sample

Interviews were conducted with 20 parents and 17 young women with TS. The three young women that declined to take part experienced severe social difficulties. Most participants were from the United Kingdom and of White or Caucasian ethnic origin (Table 2). The IMD indicated no significant response bias (47% in deciles 1–5 and 53% in deciles 6–10). No participants were intellectually disabled; three received special educational needs assistance at school. The majority attended mainstream schools, colleges, or were studying at university. Mean age is 18.5 years ( $SD = 2.24$ ). All but one were on hormone replacement therapy treatment; mean age of commencement was 13.5 years ( $SD = 1.6$ ).

### 3.2 | Quantitative measures

Self-report and parent SDQ total scores were similar,  $t(17) = 0.78$ ,  $P = .44$ . Social competence with peers differed,  $t(17) = -2.46$ ,  $P = .025$ , but self- and parent-report correlated strongly (Pearson  $r = 0.82$ ,  $P < 0.0001$ ). Young people consistently rated themselves as more socially competent than their parents rated them (Table 3).

On the parent-rated autism scale (SRS-2), half scored within the normal range, 30% within the mild to moderate range, and 20%

**TABLE 2** Participant demographics

ID	Age	Genetics	Occupation	HRT start age	Country	IMD decile
1	16	Monosomy	School student	14	England	10
2	16	Complex mosaic	School student	15	England	8
3	16	Isochromosome	School student	12	England	5
4	16	Complex mosaic	School student	14	USA	—
5 <sup>a</sup>	16	Monosomy	School student	14	England	4
6	17	Isochromosome	School student	12	England	10
7	17	Mosaic XY	College student	14	Scotland	9
8	17	Mosaic XY	College student	11	England	2
9 <sup>a</sup>	17	Monosomy	College student	14	England	4
10	18	Isochromosome	College student	14	England	4
11	18	Partial deletion	College student	13	England	6
12 <sup>a</sup>	19	Monosomy	Unemployed	14	England	3
13	20	Monosomy	University student	14	England	9
14	20	Monosomy	University student	11 <sup>b</sup>	England	10
15	20	Mosaic	University student	16	England	3
16	20	Mosaic	Care worker	12	England	3
17	20	Isochromosome	Teaching assistant	16	England	2
18	21	Isochromosome	University student	14	England	9
19	21	Monosomy	University student	11	England	9
20	24	Monosomy	Care worker	15	England	9

Abbreviations: HRT, hormone replacement therapy; IMD Decile, Indices of Multiple Deprivation (1 = most deprived–10 = least deprived)

<sup>a</sup>Daughters did not take part in the interviews due to not feeling comfortable talking about friendships (Participants 5 and 12) or due to being too socially anxious to answer the interview questions (Participant 9).

<sup>b</sup>Not currently on hormone replacement therapy (HRT).

scored within the severe range of autistic symptoms, indicating many young people have autistic traits that interfere with their everyday social functioning (Table 4). The prevalence of autistic traits is much higher than typical controls. The sample's mean scaled SRS-2 score was 62.9 (*SD* = 16.29), which falls in the “mildly impaired” range.

**TABLE 3** Comparison of parent and young person SDQ and SCP ratings

Assessment	Parent <i>M</i> ( <i>SD</i> ) <i>n</i> = 20	Young person <i>M</i> ( <i>SD</i> ) <i>n</i> = 18	<i>P</i> (paired <i>t</i> test)
Strengths and Difficulties Questionnaire (SDQ)	11.44 (6.72)	12.5 (6.11)	.44
Adapted Social Competence with Peers (SCP)	8.30 (3.94)	10.39 (4.72)	.025

Note. Higher scores on the SDQ indicate more difficulties, whereas higher scores on the SCP are indicative of better social competence.

### 3.3 | Qualitative interviews

Three main themes and 19 subthemes were identified from the interview analysis (Figure 1). The central theme, “A wide range of competencies,” describes the history of socialization and current friendships. The second theme, “Explanatory factors,” identifies personal and contextual factors that shape the social experience. The third theme, “Out of sync,” describes the consequences of the social differences.

#### 3.3.1 | A wide range of competencies

##### Subtle social difficulties

Participants recounted diverse social experiences. Most had experienced difficulties with friendships growing up. Making and keeping friends was not something that came naturally to these young women:

“I did find it very, very hard friendship wise and still now I still struggle a bit, I'm much better than I was, but I still struggle” —[Young Person]

For the most part the nature of their daughter's socialisation difficulties were hard for their parents to articulate:

“She easily made friends, there's just a slight disconnect somewhere that's hard to put into words” —[Parent]

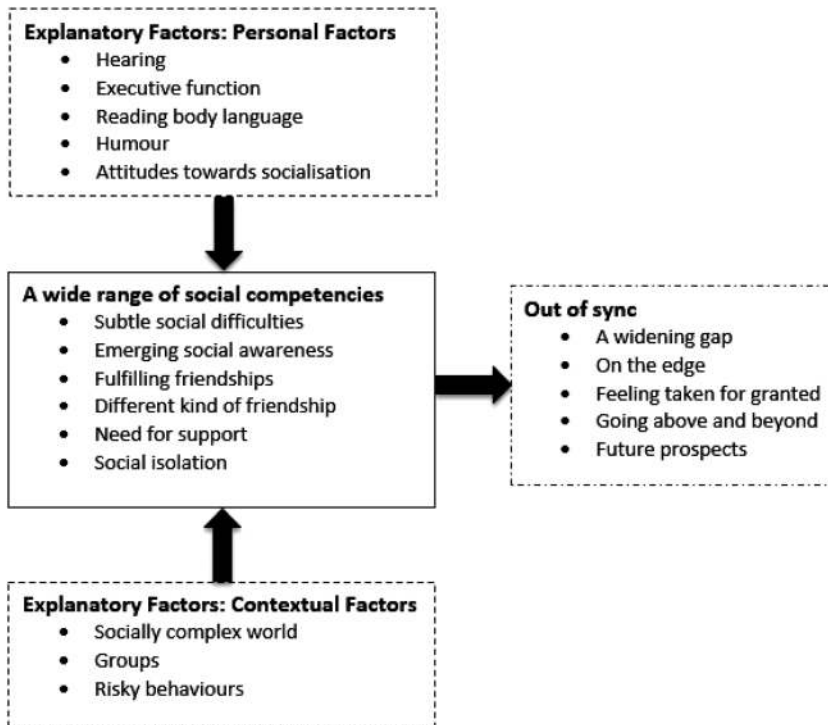
Social difficulties had more impact on their daughter's daily functioning than medical problems, in this age group:

“All the medical things, you can do your best and do tests and it is what it is. But the social skills thing: that's the thing that really impacts on their daily life the most” —[Parent]

**TABLE 4** Parent rating of daughters' autistic symptomatology on the SRS-2 compared with population norms

SRS-2 severity ratings ( <i>n</i> = 20)	Population norms (%)	TS (%)
Normal	84.1	50
Mild	9.2	15
Moderate	6.1	15
Severe	0.6	20

Abbreviations: SRS-2, Social Responsiveness Scale 2; TS, Turner syndrome.



**FIGURE 1** Theme map

### Emerging social insight

Some young people and their parents reported becoming aware of their social difficulties as they got older:

“She’s very much aware of it and now she is older, she tries to assess the situation a bit more”—[Parent]

“it’s something that’s been at the back of my mind since I was fairly young, maybe eight or nine, when I first properly started noticing it.”—[Young Person]

### Fulfilling friendships

Despite most of the interviewees describing friendship difficulties in childhood and adolescence, all those with friends affirmed that they were satisfied with their current friendships.

“I’m quite happy with the number of friends that I have because I find it a lot easier to feel more comfortable in that sort of (small) group size” —[Young Person]

For a few of the young women, lower levels of social interaction were satisfactory:

“Sometimes I’ll find it hard to talk to people for long periods of time or see people a lot and then still think of stuff to say, or still feel as comfortable. So I think that I’m happy with the situation that I have at the moment, were I can have a lot of time to myself, but still be close to them and still see them” —[Young Person]

Most interviewees were keen to get involved in a social skills group and to improve their social skills:

“I’ve got a lot of people that I know and I get on with, but I would like to have close friends again.” —[Young Person]

### A different kind of friendship

Most said they had friends. On closer enquiry they were often family friends or another girl with Turner Syndrome. Typically, they connected with others affected by TS in a positive way that they didn’t experience with their neurotypical peers:

“She’s always tried to fit herself into a hole that’s not quite the right shape, a lot of people have that without Turner’s, people have social difficulties. But because we go to the TS conference every year, I’ve noticed that she just belongs, they get on, they understand each other, there’s no edge, there’s no bitchiness” —[Parent]

One mother described how her daughter had established friendships with young women who themselves had social difficulties, and that this made the friendship more equitable:

“The other two girls are a bit different themselves, that’s probably more in an equal footing” —[Parent]

### Need for support

For those that had friends, the term “supportive” was often used. Other friendship descriptors included being kind, caring, reliable and protective:

"They're all really supportive of me and I always feel really comfortable when I'm around them, which I think is really important for me" —[Young Person]

Support implied providing reassurance and being accommodating of differences:

"I still do have trouble understanding sometimes and I really struggle to like read lips and stuff, but they (friends) come to expect that every now and then." — [Young Person]

### Social isolation

Some parents were concerned about their daughter's increasing social isolation, which could be associated with social anxiety.

"She went through school with no friends if I'm honest. Nobody disliked her at all, everybody liked her, but she never ever did have a best friend or even a group of people she hung around with." —[Parent]

## 3.3.2 | Explanatory factors

### Personal factors

The young women described difficulties reading social cues and body language, understanding humour, hearing adequately, and paying attention, whereas their parents highlighted differences in attitudes towards socialisation.

**Hearing** Those with hearing problems explained how they compensated for their difficulties:

"my hearing does go down a bit because of my surgeries. In terms of actually listening and hearing and stuff, sometimes it can be difficult and it's one of those things where you pretend that you've heard someone or laugh it off" —[Young Person]

**Cognitive difficulties** Cognitive deficits in attention and processing speed were often brought up as challenges in social interaction:

"I struggle to like concentrate in conversations, so I might not always know what they're on about and what's going on. Sometimes I'll zone out and then I'll just miss bits of the conversation" —[Young Person]

"I don't contribute as much 'cause I always want to sit back and think" —[Young Person]

Parents commented on slow social processing, exemplified by inappropriate interruptions of a conversation or speaking out of turn:

"She'll be listening to conversation and she'll want to say something and she might not come in at necessarily the appropriate point, (...) but by the time

there's a gap in the conversation, it's moved away, but she still wants to say her bit" —[Parent]

**Reading facial expressions and body language** Most expressed feeling confused by subtle facial expressions, body language, and other social cues especially in people that they didn't know well:

"There are some expressions and body language that are really easy to recognise for what it is. But it seems to be the much smaller details, like, where their eyes are going or whatever for example. I find that more difficult to recognise." —[Young Person]

"I'll probably get it wrong as judging by facial expressions. It's hard to know when to speak, when to let others, when to give something or when to sit back. When someone else is talking it's hard to find a balance, it's a bit hard to figure out" —[Young Person]

**Humour** Understanding humour and sarcasm was often highlighted as a challenge:

"I wouldn't understand their jokes, I think that's the thing with Turners sometimes, you take things very literally you don't see sometimes they were only intending a joke" —[Young Person]

"If someone's joking and they don't show it on their face I won't realise" —[Young Person]

**Attitudes towards socializing: Initiation and flexibility** Parents often commented on their daughter's attitude to socialization, suggesting they lacked the necessary social initiative to maintain friendships. Some parents linked this to low self-confidence:

"I mean, just generally, she just didn't have very much 'oomph' - is the only way I can describe it - and it was really hard to parent her generally, because you're forever trying to 'gee' her up" —[Parent]

"I don't think she puts herself out there. She doesn't always initiate conversations and things like that, but then I think she's not bothered, so you know, you get fed of up of trying to prompt her" —[Parent]

Parents noted inflexible attitudes were a problem, for instance declining social invitations because their daughter was uninterested in the proposed activity (rather than taking part in order to please a friend) or going ahead with activities instead of re-scheduling them (rather than accommodating for last-minute changes in availability):

"Friends from school who come home from Uni in the summer are doing holidays together. Some of them are going inter-railing. I said to her: 'do you not fancy it?'

And she said 'oh they asked me on the group, but it's not for me'—[Parent]

"She will go out during the day by herself. She won't wait for people and she won't change her plans if people won't suddenly go, she'll still go"—[Parent]

### Contextual factors: Adolescence

**Socially complex world** Adolescence marks the beginning of a developmental period where the complexity of socialisation increases.

"As she's starting to mature she's found keeping up with that social interaction and the complexity of the conversations and different role-playing and things a little bit more difficult" —[Parent]

Whilst socialising with adolescent peers represented a challenge, interacting with younger children and adults was never described as a difficulty.

"She has a really good relationship with the adults that she meets, but in terms of girls, well anyone who's in her peer group, I think she struggles" —[Parent]

In adolescence girls start having more intimate social interactions, which include sharing secrets, but such intimacy was rarely described by parents of young women with TS.

"Very often they'll both quite happily sit together and not interact, they'll watch something or they'll sit and both read. When she does have a friend round they might do some cooking together but they often tend to sit and either watch something together, or they'll read a book together. There's very little actual interaction and chat" —[Parent]

**Groups** Group interactions with peers posed a particular problem, in part because of the relatively slow processing of overwhelming social cues, as well as impaired hearing:

"If it's a big group I feel like I am a bit swamped, there's too many interactions going on. Then I'm not really sure where to look, or if someone is talking to me then I won't be able to hear them"—[Young Person]

However, socializing in groups did also provide some advantages in regards to attention and concentration. Young people described how group situations allowed them to get away with zoning out in conversations. They also expressed some relief in not feeling that they had a responsibility to carry the conversations, which reduced anxieties around socialization:

"(In a group) I could easily drift in and out of the conversation and not feel that all the conversation is on me, whereas if I'm just one on one with another person I need to be directly involved"—[Young Person]

**Experimenting and risky behaviours** During adolescence young people are more likely to experiment and engage in risk-taking behaviours. Most of the interviewees that referred to drinking alcohol said that they steered clear of it, which set them apart from their peers, and at times made them subject to peer pressure:

"I don't not like drinking, but I don't like to get really drunk and tipsy. People make fun of me because I've never been drunk" —[Young Person]

### 3.3.3 | Out of sync

The interaction of the personal factors and the environmental changes appear to create a gap between the participants and their peers.

#### A widening gap

Parents felt their teenage daughters were less socially mature than their peers:

"It's the friends going through a normal teenage phase that she lost. I think certain friends she hasn't been able to keep because they've changed as she hasn't. They've grown up with boys, alcohol and parties and she's completely lost those friends because she's not like them" —[Parent]

#### On the edge

They were usually not part of the "popular" clique at school:

"I've never been the person who had lots of friends or had lots of parties, or been like in big friendship groups or anything particularly"—[Young Person]

#### Feeling taken for granted

The negative repercussions of "hanging-back" and little social initiation were that the young women sometimes felt taken for granted:

"With kind of being on the outside, you always feel like you're there if you're needed, but if you're not needed as much it's less important. It's a bit complicated, it's like you're less important to the group dynamic maybe, than some other members"—[Young Person]

#### Going above and beyond: vulnerable to exploitation?

The young women and their parents often described themselves as eager to please:

"Sometimes I'm a bit too nice and I'm too willing to do things for people, but I think "that's just me." It's not because I have to get them stuff to know that they're my friend. If I'd have got them something, they'll say thank you, but then part of me thinks they probably have taken advantage of me without me realising"—[Young Person]

Parents were often concerned about their daughter's ability to deny their friends favours and worried that people would exploit their daughter's kindness:

"She doesn't know when to say 'no'. If for example she's decided she's going to be doing something then somebody rings up and say 'can you do this for me?' she'll say yes, and then we'll be like 'you're tired, or you got to do this,' and she'll be like 'I'll do that later,' then she'll put herself out for people"—[Parent]

### Future prospects

Parents reported finding friends in early adulthood became more difficult. Having left school, their daughter had fewer opportunities to socialize with large groups of people their age.

"At the moment as she's not in education and she's not working, so obviously that's quite difficult in itself because she's not naturally going outside, she doesn't really socialise with anybody outside of the family and friends group"—[Parent]

## 4 | DISCUSSION

To our knowledge, this is the first account of the subjective experiences of friendship and social interaction among young women with TS, and it provides insights to inform the development of future social skills training interventions for women with TS.

Our thematic analysis shows that whereas some participants experience social isolation, others are thriving socially. Most describe social difficulties that interfered with everyday life, usually more noticeable during adolescence. Short stature has often been causally linked to reduced social competence in TS (Rovet & Ireland, 1994); yet, it was rarely mentioned by participants in this study, nor did they attribute reduced social integration to their physical appearance. Most had commenced estrogen replacement therapy at around 13.5 years. Hence, the induction of puberty was developmentally appropriate. Those that discussed height and puberty often said it made them feel different to their peers, but neither were perceived to be causally linked to social difficulties.

Parents said their daughters had a different attitude to socializing, and different interests, to their neurotypical peers. During get-togethers they noticed that their daughters tended to engage in "doing things" rather than engage in intimate social conversation, possibly because of low self-esteem and confidence. Previous research has suggested that shying away from social interaction may be a coping strategy for those experiencing social difficulties (Lesniak-Karpiak, Mazzocco, & Ross, 2003). Some parents described traits of cognitive inflexibility, for instance, failing to engage with others in activities that were not of interest to them or going ahead with their own social plans even if their friends had dropped out (rather than re-scheduling). Many were not influenced by peer pressure.

Some participants had formed stable friendships with other young women with TS or with longstanding family friends, rather than neurotypical peers. Forming friendships with other young women affected by TS may be a protective factor. Building self-confidence helps develop a positive self-image, and that, in turn, facilitates the ability to make and to keep friendships (Parker, Rubin, Erath, Wojslawowicz, & Buskirk, 2015). Girls with TS need safe spaces to practice their social skills and develop their social understanding and self-confidence through social comparison (Berndt, 1999; Parker et al., 2015). Ameliorating a lack of confidence and promoting social initiation are key targets for any future social skills intervention. Most of our participants found socialization became easier during late adolescence and early adulthood. Most were satisfied with a small group of close friends, but opportunities to form new friendships were limited once they had left formal education. Early interventions to build social confidence and instil a repertoire of skills that can be drawn on later is essential to build resilience.

For the most part, parental accounts of friendships aligned with those of their daughters, but young women with TS typically rated their social abilities as more competent than they were perceived to be by parents. Similar patterns were seen in both quantitative ratings and qualitative interviews. Young people often exaggerated the frequency of their social contacts outside the family. Parents often needed to encourage get-togethers. Another area of concern, mentioned by many parents, was their daughters' failure to recognize when they were being exploited by others whom they thought were their friends. Possible explanations for the discrepancies between these accounts of socialization include a social desirability bias, similar to that described in young people (particularly girls) who have been diagnosed with an ASD (Bauminger & Kasari, 2000). Some thought they had acquired greater social insight during adolescence, and socially desirable responses could reflect the growth of social knowledge (Suzigan et al., 2011).

## 5 | STRENGTHS AND LIMITATIONS

Our interviews have provided a platform for young women with TS and their parents to discuss their experiences of social interaction. Clearly, this small sample is not representative of the TS community, but the findings are consistent with previous reports of social difficulties from around the world. It is possible that the sample were more socially competent than many with TS at recruitment: although we tried to include participants experiencing social isolation, this was not always possible. Three potential participants declined to take part because of the acute and severe issues they faced in terms of social anxiety. The interview schedule explored experiences of socialization but did not examine the meaning of friendship. Recent studies with children with ASD have shown that their understanding of friendship is qualitatively different to their neurotypical peers, with an emphasis on companionship rather than intimacy (Bauminger & Kasari, 2000). Future research will need to address whether the meaning of friendship is different for young women with TS. Future studies will also need to explore factors that



moderate friendship outcomes; these might include age of diagnosis, co-morbid mental health diagnoses, or karyotype.

## 6 | CONCLUSION

Individuals with TS typically experience a wide range of social interaction challenges throughout childhood, and these continue into adult life. Biological (limited hearing) and cognitive factors (poor executive functioning, failure to read body language) both play a role. Socialization becomes more difficult during adolescence, a period when the complexity of social interactions increases, and there is a consequent risk of social isolation and a retreat from social integration outside the family. Many young women with TS overrate their social abilities and the degree to which they have assimilated social skills. Clinicians need to be aware that many young women with TS may not acknowledge the extent of their difficulties in social relationships, consciously or not. Fortunately, many are willing to countenance receiving support from social skills interventions.

## ACKNOWLEDGEMENTS

We wish to acknowledge Arlene Smyth at the UK Turner Syndrome Support Society and Dr Caroline Brain for their support of this project.

## CONFLICT OF INTEREST

The authors declare that they have no competing interests.

## FUNDING INFORMATION

The SOAR study is funded by the Child Health Research CIO Studentship. Research conducted at the CRF UCL GOS ICH is supported by the NIHR. The funders played no role in the design of the study and collection, analysis, interpretation of data, or writing of the manuscript.

## DATA AVAILABILITY STATEMENT

The datasets generated and/or analysed during the current study are not publicly available in order to protect the anonymity of those taking part but are available from the corresponding author on reasonable request.

## ORCID

Jeanne Wolstencroft  <https://orcid.org/0000-0001-6160-9731>

## REFERENCES

- Barker, C., & Pistrang, N. (2005). Quality criteria under methodological pluralism: Implications for conducting and evaluating research. *American Journal of Community Psychology, 35*(3–4), 201–212. <https://doi.org/10.1007/s10464-005-3398-y>
- Bauminger, N., & Kasari, C. (2000). Loneliness and friendship in high-functioning children with autism. *Child Development. WileySociety for Research in Child Development.* <https://doi.org/10.2307/1132001>
- Berndt, T. (1999). Friends' influence on children's adjustment to school (pp. 85–108).
- Bölte, S., Westerwald, E., Holtmann, M., Freitag, C., & Poustka, F. (2011). Autistic traits and autism spectrum disorders: The clinical validity of two measures presuming a continuum of social communication skills. *Journal of Autism and Developmental Disorders, 41*(1), 66–72. <https://doi.org/10.1007/s10803-010-1024-9>
- Boman, U. W., Möllet, A., & Albertsson-Wikland, K. (1998). Psychological aspects of Turner syndrome. *Journal of Psychosomatic Obstetrics & Gynecology, 19*(1), 1–1, 18. <https://doi.org/10.3109/01674829809044216>
- Braun, V., & Clarke, V. (2006). Qualitative Research in Psychology Using thematic analysis in psychology Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Cardoso, G., Daly, R. J., Haq, N. A., Hanton, L., Rubinow, D. R., Bondy, C. A., & Schmidt, P. J. (2004). Current and lifetime psychiatric illness in women with Turner syndrome. *Gynecological Endocrinology, 19*(6), 313–319. <https://doi.org/10.1080/09513590400021227>
- Chadwick, P. M., Smyth, A., & Liao, L.-M. (2014). Improving self-esteem in women diagnosed with Turner syndrome: Results of a pilot intervention. *Journal of Pediatric and Adolescent Gynecology, 27*(3), 129–132. <https://doi.org/10.1016/j.jpjg.2013.09.004>
- Coie, J., Terry, R., Lenox, K., Lochman, J., & Hyman, C. (1995). Childhood peer rejection and aggression as predictors of stable patterns of adolescent disorder. *Development and Psychopathology, 7*(04), 697–713. <https://doi.org/10.1017/S0954579400006799>
- Constantino, J., & Gruber, C. (2012). Social responsiveness scale (SRS). Retrieved from <http://www.kennisentrum-kjp.nl/wp-content/uploads/2018/04/Social-Responsiveness-Scale-SRS.pdf>
- Creswell, C. S., & Skuse, D. H. (1999). Autism in association with Turner syndrome: Genetic implications for male vulnerability to pervasive developmental disorders. *Neurocase, 5*(6), 511–518. <https://doi.org/10.1080/13554799908402746>
- Cridland, E. K., Jones, S. C., Caputi, P., & Magee, C. A. (2014). Being a girl in a boys' world: Investigating the experiences of girls with autism spectrum disorders during adolescence. *Journal of Autism and Developmental Disorders., 44*, 1261–1274. <https://doi.org/10.1007/s10803-013-1985-6>
- Elliott, S. N., Malecki, C. K., & Demaray, M. K. (2001). New directions in social skills assessment and intervention for elementary and middle school students. *Exceptionality, 9*(1–2), 19–32. <https://doi.org/10.1080/09362835.2001.9666989>
- Goodman, A., Lamping, D. L., & Ploubidis, G. B. (2010). When to use broader internalising and externalising subscales instead of the hypothesised five subscales on the Strengths and Difficulties Questionnaire (SDQ): Data from British Parents, Teachers and Children. *Journal of Abnormal Child Psychology, 38*(8), 1179–1191. <https://doi.org/10.1007/s10802-010-9434-x>
- Gravholt, C. H., Andersen, N. H., Conway, G. S., Dekkers, O. M., Geffner, M. E., Klein, K. O., ... International Turner Syndrome Consensus Group (2017). 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), 1–70. <https://doi.org/10.1530/EJE-17-0430>
- Hong, D. S., Dunkin, B., & Reiss, A. L. (2011). Psychosocial functioning and social cognitive processing in girls with Turner syndrome. *Journal of Developmental and Behavioral Pediatrics: JDBP, 32*(7), 512–520. <https://doi.org/10.1097/DBP.0b013e3182255301>
- Hong, D. S., & Reiss, A. L. (2012). Cognition and behavior in Turner syndrome: A brief review. *Pediatric Endocrinology Reviews: PER, 9* Suppl 2 (0 2), 710–712. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/22946281>

- Jacobs, P., Dalton, P., James, R., Mosse, K., Power, M., Robinson, D., & Skuse, D. (1997). Turner syndrome: A cytogenetic and molecular study. *Annals of Human Genetics*, 61(6), 471–483. <https://doi.org/10.1017/S0003480097006507>
- Jamison, T. R., & Schuttler, J. O. (2017). Overview and preliminary evidence for a social skills and self-care curriculum for adolescent females with autism: The girls night out model. *Journal of Autism and Developmental Disorders*, 47(1), 110–125. <https://doi.org/10.1007/s10803-016-2939-6>
- Kesler, S. R. (2007). Turner syndrome. *Child and Adolescent Psychiatric Clinics of North America*, 16(3), 709–722. <https://doi.org/10.1016/j.chc.2007.02.004>
- Knickmeyer, R. C. (2012). Turner syndrome: advances in understanding altered cognition, brain structure and function. *Current Opinion in Neurology*, 25(2), 144–149. <https://doi.org/10.1097/WCO.0b013e3283515e9e>
- Lesniak-Karpiak, K., Mazzocco, M. M. M., & Ross, J. L. (2003). Behavioral assessment of social anxiety in females with Turner or fragile X syndrome. *Journal of Autism and Developmental Disorders*, 33(1), 55–67. <https://doi.org/10.1023/A:1022230504787>
- Mccauley, E., Feuillan, P., Kushner, H., Ross, J. L., & University, T. J. (2001). Psychosocial development in adolescents with Turner syndrome. *Journal of Developmental & Behavioral Pediatrics*, 22(6), 360–365. Retrieved from <https://insights.ovid.com/pubmed?pmid=11773800>
- McCauley, E., Kay, T., Ito, J., & Treder, R. (1987). The Turner syndrome: Cognitive deficits, affective discrimination, and behavior problems. *Child Development*, 58(2), 464–473. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/3829787>
- McCauley, E., Ross, J. L., Kushner, H., & Cutler, G. (1995). Self-esteem and behavior in girls with Turner syndrome. *Journal of Developmental and Behavioral Pediatrics: JDBP*, 16(2), 82–88. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/7790519>
- McLennan, J. D., Lord, C., & Schopler, E. (1993). Sex differences in higher functioning people with autism. *Journal of Autism and Developmental Disorders*, 23(2), 217–227. <https://doi.org/10.1007/BF01046216>
- Nichols, S. (2009). Girls growing up on the autism spectrum: What parents and professionals should know about the pre-teen and teenage years. Jessica Kingsley Publishers. Retrieved from <https://books.google.com/books?hl=en&lr=&id=xRMQBQAAQBAJ&oi=fnd&pg=PP1&ots=egwmjeQFWC&sig=IGe71M3STQLENmY4pKjMyQe6i1c>
- Office National Statistics. (2015). English indices of deprivation 2015 - GOV.UK. Retrieved December 5, 2018, from <https://www.gov.uk/government/statistics/english-indices-of-deprivation-2015>
- Parker, J. G., Rubin, K. H., Erath, S. A., Wojslawowicz, J. C., & Buskirk, A. A. (2015). Peer relationships, child development, and adjustment: A developmental psychopathology perspective. In *Developmental Psychopathology* (pp. 419–493). Hoboken, NJ, USA: John Wiley & Sons, Inc. <https://doi.org/10.1002/9780470939383.ch12>
- Poland, B. D. (2001). Transcription quality. *Handbook of Interview Research: Context & Method*, 971. <https://doi.org/10.4135/9781412984492>
- Reimann, G. E., Bernad Perman, M. M., Ho, P.-S., Parks, R. A., & Comis, L. E. (2018). Psychosocial characteristics of women with a delayed diagnosis of Turner syndrome. *The Journal of Pediatrics*, 199, 206–211. <https://doi.org/10.1016/J.JPEDI.2018.03.058>
- Roff, M., Sells, S. B., & Golden, M. (1972). *Social adjustment and personality development in children*. University of Minnesota Press. Retrieved from <https://muse.jhu.edu/book/32408>
- Ross, J. L., Feuillan, P., Kushner, H., Roeltgen, D., & Cutler, G. B. (1997). Absence of growth hormone effects on cognitive function in girls with Turner syndrome. *The Journal of Clinical Endocrinology & Metabolism*, 82(6), 1814–1817. <https://doi.org/10.1210/jcem.82.6.4003>
- Rovet, J., & Ireland, L. (1994). Behavioral phenotype in children with Turner syndrome. *Journal of Pediatric Psychology*, 19(6), 779–790. Retrieved from <https://academic.oup.com/jpepsy/article-abstract/19/6/779/904640>, <https://doi.org/10.1093/jpepsy/19.6.779>
- Saad, K., Abdelrahman, A. A., Abdel-Raheem, Y. F., Othman, E. R., Badry, R., Othman, H. A. K., & Sobhy, K. M. (2014). Turner syndrome: Review of clinical, neuropsychiatric, and EEG status: An experience of tertiary center. *Acta Neurologica Belgica*, 114(1), 1–9. <https://doi.org/10.1007/s13760-013-0264-9>
- Schmidt, P. J., Cardoso, G. M. P., Ross, J. L., Haq, N., Rubinow, D. R., & Bondy, C. A. (2006). Shyness, social anxiety, and impaired self-esteem in Turner syndrome and premature ovarian failure. *JAMA*, 295(12), 1373. <https://doi.org/10.1001/jama.295.12.1374>
- Sedgewick, F., Hill, V., Yates, R., Pickering, L., & Pellicano, E. (2016). Gender differences in the social motivation and friendship experiences of autistic and non-autistic adolescents. *Journal of Autism and Developmental Disorders*, 46, 1297–1306. <https://doi.org/10.1007/s10803-015-2669-1>
- Sim, J., Saunders, B., Waterfield, J., & Kingstone, T. (2018). Can sample size in qualitative research be determined a priori? *International Journal of Social Research Methodology*, 21(5), 619–634. <https://doi.org/10.1080/13645579.2018.1454643>
- Skuse, D., Lawrence, K., & Tang, J. (2005). Measuring social-cognitive functions in children with somatotrophic axis dysfunction. *Hormone Research in Paediatrics*, 64(3), 73–82. <https://doi.org/10.1159/000089321>
- Skuse, D. H. (2009). Turner - Know your body! (C. Gravholt, Ed.). Gothenburg: Novo Nordisk.
- Smith, J. A. (1995). Semi-structured interviewing and qualitative analysis. In *Rethinking Methods in Psychology* (pp. 10–26). London: SAGE Publications Ltd. <https://doi.org/10.4135/9781446221792.n2>
- Solomon, M., Miller, M., Taylor, S. L., Hinshaw, S. P., & Carter, C. S. (2012). Autism symptoms and internalizing psychopathology in girls and boys with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 42, 48–59. <https://doi.org/10.1007/s10803-011-1215-z>
- Spence, S. H. (1995). Social skills training: Enhancing social competence with children and adolescents. Nfer-Nelson.
- Spence, S. H. (2003). Social skills training with children and young people: Theory, evidence and practice. *Child and Adolescent Mental Health*, 8(2), 84–96. <https://doi.org/10.1111/1475-3588.00051>
- Suzigan, L. Z., De Paiva, E., Silva, R. B., Guerra-Júnior, G. I., Marini, S. H., & Maciel-Guerra, A. T. (2011). Social skills in women with Turner syndrome. *Scandinavian Journal of Psychology*, 52(5), 440–447. <https://doi.org/10.1111/j.1467-9450.2011.00887.x>
- Wolstencroft, J., & Skuse, D. (2018). Social skills and relationships in Turner syndrome. *Current Opinion in Psychiatry*, 1, 85–91. <https://doi.org/10.1097/YCO.0000000000000472>

## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

**How to cite this article:** Wolstencroft J, Mandy W, Skuse D. Experiences of social interaction in young women with Turner syndrome: A qualitative study. *Child Care Health Dev.* 2020;46:46–55. <https://doi.org/10.1111/cch.12710>