

First impressions of young women with Turner syndrome

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D.Clin.Psy. thesis (Volume 1), 2019

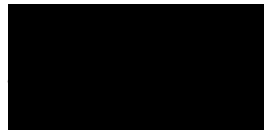
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UCL Doctorate in Clinical Psychology

Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Overview

This thesis explores the social difficulties of women with Turner syndrome (TS), and comprises of three parts. The first is a conceptual introduction, that consists of an extended discussion of the psychological and social functioning of women with TS. It considers the limitations of previous research and identifies that a gap in the literature seems to be that others' impressions of and attitudes towards individuals with TS have been largely overlooked, along with the social implications of such impressions. It then examines the different methods of investigating observer impressions, and their strengths and limitations.

The second part comprises of an empirical paper that investigates observer first impressions of women with TS. Young women with TS and typically developing controls were filmed participating in a social performance task. These clips were later presented to observers in various modalities (i.e. Audio-Visual, Video-only, Audio-only, Still Image, Transcript). The observers were asked to rate the women on various personal characteristics, as well as to consider their intentions to engage in further interaction with them. The findings indicated that observers judged women with TS more negatively on all personal characteristics explored in this study, and also reported reduced intent for social engagement with the participants with TS. Implications and limitations are explored.

The final part of this thesis is a critical appraisal, that reflects on the process of conducting the research as a whole and discusses the various methodological dilemmas and challenges that were encountered. It also considers in more depth the impact of the findings and their wider implications.

Impact Statement

The present study has various implications, both for academic research and clinical practice. Firstly, in terms of potential academic benefits, this study was to our knowledge the first to explore observer impressions of women with Turner syndrome (TS). This constitutes an important step forward in our understanding of social relationships in TS, and highlights the significance of considering the systemic factors that can contribute to social difficulties. The findings suggest that it would be useful for future research to investigate further the attitudes and social responses of others towards women with TS, and the factors that contribute to these. It would be particularly useful to further our understanding of the impact of these attitudes on the quality of life and the psychological and social functioning of women with TS, and to examine the interventions that may help with forming successful social relationships.

Moreover, this study employed an innovative methodology for assessing first impressions, that was replicated from the autism literature. This method appears to be more ecologically valid than previous techniques, as it involves filming unscripted social performance, which is then presented in various modalities to observer participants. This helps to assess observer impressions of more authentic social behaviour, but also to evaluate how the different visual and non-visual aspects of social expression may impact on observer responses. It is evident that it was feasible to use this method in a research of this scale. It might be of benefit if future studies also employ this or similar techniques to investigate the formation of perceptions and attitudes towards specific groups.

In terms of clinical implications, disseminating this research in clinical settings could help inform the work of psychologists and other professionals who work with girls and women with TS. For instance, it would be important to provide

support around the individual factors that may contribute to social difficulties, such as the social performance of females with TS (e.g. facial expressions, gestures, prosody). However, this study also highlights the importance of considering the view of multiple informants, including peers, when assessing social difficulties in TS, and then working with the system around the individual to promote better social adjustment.

Finally, the findings of this research emphasise the importance of adopting a more systemic perspective in relation to social difficulties, based on ideas from the social model of disability and community psychology. This has wider implications, as it suggests that problems should not be seen as individual deficits, but rather as relational impairments. Therefore, solutions need to be systemic and aimed at reducing social barriers that impact on individual wellbeing. For instance, promoting inclusion of those with differences in the educational system and in other societal structures, implementing anti-bullying programmes in schools and trainings to raise awareness with the aim to reduce stigma and discrimination and encouraging peer support. This does not only apply to women with TS, but also to any other group that may be experiencing social difficulties and that would benefit from a societal shift in attitudes.

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List of Acronyms

ADHD	Attention Deficit Hyperactivity Disorder
ANOVA	Analysis of Variance
ASD	Autism Spectrum Disorders
CBCL	Child Behaviour Checklist
DPA	Data Protection Act
GDPR	General Data Protection Regulation
IMR	Internet Mediated Research
IQ	Intelligence Quotient
PEERS	Program for the Education and Enrichment of Relational Skills
POF	Premature Ovarian Failure
SCPQ	Social Competence with Peers Questionnaire
SDQ	Strengths and Difficulties Questionnaire
SRS	Social Responsiveness Scale
SSI	Social Skills Inventory (Del Prette)
SSIS	Social Skills Improvement System Rating Scale
TD	Typically Developing
TRF	Teacher Report Form
TS	Turner Syndrome
TSSS	Turner Syndrome Support Society
YSR	Youth Self Report

Acknowledgements

I would firstly like to thank my supervisors, Dr Will Mandy, Prof David Skuse and Jeanne Wolstencroft. I am sincerely grateful for their invaluable support, knowledge, guidance and encouragement throughout this process. I am also thankful to the placement students and research assistants at the Institute of Child Health for their great help with the data collection at various stages of this research study. My gratitude also goes to Dr Daniel Faso and Dr Noah Sasson for their valuable advice about the design of the study, and for sharing their research materials with me.

A big thank you goes to the wonderful participants who kindly gave their time and effort to participate in this research; this could not have happened without them. Special thanks to the Turner Syndrome Support Society, and particularly Arlene Smyth, for advertising the study, for her enthusiasm, and for the impressive work that she does for the Turner syndrome community. Last but not least, I would like to thank my fellow trainees, my friends and my family, for their constant support, encouragement and compassion.

Part 1: Conceptual Introduction

**Social functioning and relationships in girls and women with Turner
syndrome**

Abstract

Turner syndrome (TS) is related to a complex array of physical, mental and social impairments that may pose challenges to social adjustment and cause distress (Gravholt, 2009). Studies examining the social competence of females with TS and the attitudes and behaviour of others towards them, have so far relied on reports from the individuals with the condition (Jež et al., 2018). However, judgments made by others can significantly impact social interactions and can pose barriers to social success (Sutton et al., 2005). This literature review will survey the existing research on the psychological and social difficulties of women with TS, and will discuss the usefulness of exploring observer first impressions of those with social problems. In addition, it will provide an overview of the relevant literature on how such first impressions are formed and the different methods for evaluating them. This summary of the literature will be used to explain the rationale behind the empirical study that was conducted as part of this thesis, which examines observer impressions of young women with TS.

Introduction

Turner syndrome (TS) is a chromosomal condition that is associated with a complex web of medical and psychosocial difficulties (Gravholt, 2009). This conceptual introduction will discuss two main areas of research, the first being the research and theory related to the psychological and social functioning of women with TS. Special attention will be given to the social skills and social cognition impairments that women with TS tend to experience, as well as to the potential causes of those difficulties. It will be illustrated that literature on the social functioning of females with TS mostly addresses individual deficits, and it will be argued that it is important to consider the contribution of systemic factors that may pose additional barriers to forming successful social relationships. More specifically, the first impressions that others form of individuals with social impairments can have significant social consequences. Secondly, this introduction will cover the factors that influence the formation of first impressions and the various methods that have been used to assess these. It will consider how such methods can be employed to investigate the involvement of systemic factors in the social difficulties of women with TS.

The literature is presented as a conceptual introduction as opposed to a systematic review, as studies on social problems in TS are limited and further research is required to determine the nature and the extent of these difficulties. A conceptual introduction therefore allows for a wider ranging overview of TS and a broader discussion of the psychosocial difficulties that women with TS might experience. The purpose of this conceptual introduction is to demonstrate the rationale behind the empirical study that was conducted as part of this thesis, and to justify the methodology that was employed. The empirical study intended to fill the gap in previous TS

research, by exploring observer first impressions of women with TS and typically developing controls, who were filmed taking part in a social performance task.

A number of different processes were used to identify relevant papers for this report. These included consulting with experts in the fields of social skills and TS, searching the reference sections of relevant articles, and running electronic database searches on PsycINFO. Overall, 116 papers were included in this conceptual introduction. Studies were considered eligible if they were published, had an English version, their topic was TS and their focus or outcomes were related to the symptomatology, psychological or social functioning of girls and women with TS. In addition, studies were included if they referred to first impressions, how these are formed and assessed, and their implications.

Studies were excluded if they were deemed to be less relevant to the topics addressed in this conceptual introduction; for instance, if they only referred to the medical or genetic problems in TS. The quality of the identified papers was determined through the analytical reading of the research; that is, by critically considering the relative methodological strengths and limitations of each study, the context it was conducted in, as well as the presentation and interpretation of the findings. The literature was synthesised and presented in a narrative format, and where relevant, study quality, strengths and weaknesses were discussed in order to contextualise the presented information.

Turner Syndrome

Turner syndrome (TS) is a genetic disorder which affects only females, with a prevalence of around 1 in every 2500 female births (Bondy, 2007; Jacobs et al., 1997; Jež et al., 2018). It is caused by a sex chromosome abnormality, where those affected

are either partly or completely missing an X-chromosome. TS is characterised by certain distinctive physiological features including short stature, webbed neck, low hairline and underdeveloped ovaries (Gravholt, 2009). TS is also associated with several health conditions, such as cardiac abnormalities, hearing and visual impairments and infertility (Gravholt, 2009). Females with TS most often present with delays or anomalies in their general growth, and sexual and reproductive development, and for most puberty does not start spontaneously (Gravholt et al., 2017). As a result, adolescence can be a period of additional challenges and vulnerability, psychologically, socially and physically (Jež et al., 2018).

Treatment and management of TS often involves regular medical checks and lifelong monitoring of the various physical health conditions (Gravholt et al., 2017). Women with TS appear to be a heterogeneous group with large variations in feature and symptom presence, development and severity (Gravholt, 2009). As such, an individualised approach to treatment is key so that each person's specific difficulties can be considered and person-centred support provided (Gravholt et al., 2017). A fundamental intervention for the majority of girls and women with TS involves endocrinological therapy and the use of growth and sex hormones, with the aim to maximise stature and facilitate the onset of puberty at an appropriate age (Main, 2009).

Hormonal treatment has been found by several studies to contribute to improved quality of life and psychological functioning for women with TS, as it can lead to improvements in physical health and higher self-esteem due to the increase in stature and pubertal development (Boman, Bryman, & Möller, 2004; Carel et al., 2005; Ross et al., 1996; Zuckerman-Levin et al., 2009). However, findings appear to be mixed as a few studies have not found any significant effects of hormone treatment on quality of life (Amundson, Boman, Barrenäs, Bryman, & Landin-Wilhelmsen, 2010;

Taback & Van Vliet, 2011). It has been suggested that hormone replacement later in childhood does not seem to improve cognitive and psychosocial functioning (Hong, Scaletta Kent, & Kesler, 2009), perhaps because the insufficient production of hormones happens early in life and has already impacted on development at a critical time. As such, earlier diagnosis and treatment are essential, as they can lead to better wellbeing and better adaptation (Boman et al., 2004).

Psychological Functioning in Women with Turner Syndrome

Emotional Problems in TS

The difficulties associated with TS can have a significant impact on the wellbeing, quality of life and psychological health of the women (Jež et al., 2018; Skuse, 2009). Some studies have shown that girls and women with TS tend to experience greater rates of depression, anxiety, low self-esteem and behavioural problems, compared to those without the condition (Kiliç, Ergür, & Öcal, 2005; McCauley, Ito, & Kay, 1986; Schmidt, Ross, Haq, & Bondy, 2006). Cardoso and colleagues (2004) found that women with TS show higher rates of lifetime affective disorders (47%), which is almost twice the rate of those in the community (24%).

However, it appears that there is some variability in findings regarding the rates of psychological difficulties in TS. Other studies have suggested there are no differences in the prevalence of emotional problems in women with TS as compared to their typically developing peers (Boman, Bryman, Hailing, & Möller, 2001; Lesniak-Karpiak, Mazzocco, & Ross, 2003). There are several possible explanations for these findings. One explanation could be that despite the difficulties associated with their medical conditions, women with TS cope well, especially when provided

with good social support and resources (e.g. financial, practical, medical, family) (Lesniak-Karpiak et al., 2003).

Moreover, the methodological limitations of the studies need to be considered when interpreting the findings. For example, Boman and colleagues (2001) only included participants with TS who were over 18 years old, and only had normative data from a community sample of women that were over the age of 28. The fact that younger girls with TS were not involved means that the study may have omitted important life stage transitions (e.g. adolescence) that may be more challenging for females with TS (Culen, Ertl, Schubert, Bartha-Doering, & Haeusler, 2017). Lesniak-Karpiak and colleagues (2003) did include younger girls, but the sample was small (n=29), which renders the results harder to generalise. It may also mean that the study did not have enough power to detect significant effects. Additionally, despite not finding higher rates of psychological difficulties in women with TS, both studies did find increased rates of social difficulties and social isolation. This, along with the aforementioned limitations of these studies suggests that the actual rates of emotional problems may be greater than some of the literature suggests.

Possible Causes of Emotional Problems in TS

Life dissatisfaction in girls and women with TS was closely linked with their self-perception, namely, seeing themselves as “handicapped” and “less socially acceptable and attractive” than their peers (Jež et al., 2018; van Pareren et al., 2005). Adolescence appears to be especially problematic for girls with TS, as it involves important mental, social and physical changes, which are often accompanied by increased comparisons with peers, and the desire to fit in and be accepted (Culen et al., 2017). For girls with TS, perceived differences in appearance from their peers, short stature and the delay of puberty could lead to negative body image and affect

self-esteem (Skuse, 2009). This in turn can lead to withdrawal from social activities and loneliness, which have also been associated with lower life satisfaction in TS (Jež et al., 2018).

Nevertheless, it would be an oversimplification to say that emotional and self-esteem problems in TS are attributable only to the specific physical characteristics of the condition. In fact, psychological distress seems to relate to a complex web of potential causes. Sutton and colleagues (2005) conducted qualitative interviews with 97 girls and women with TS aged 7-59 in the US, to explore the challenges associated with the condition that might be impacting on their psychological wellbeing. They found that four main issues seemed to be a major source of pain, lifelong distress and sadness. The primary issue was infertility, and the three other main challenges were short stature, sexual development and function, and general health problems. These concerns were common across individuals in all age groups and were found to have a significant impact on mood and self-esteem (Sutton et al., 2005).

Some have suggested that the increased risk of mood problems is not specific to TS, but is related to the presence of chronic and complex medical conditions. For instance, one study compared women with TS with women with premature ovarian failure (POF) and healthy controls, on various measures of psychological distress (Schmidt et al., 2006). They found that women with TS and women with POF showed similar rates of depression, social anxiety and shyness that were significantly greater than controls. The authors hypothesised that infertility could be linked with the increased risk of these difficulties. Nevertheless, the control sample had been screened for psychiatric problems, and as such the results may not represent a true difference in mood problems between women with and women without infertility difficulties. In another study, Cardoso and colleagues (2004) found that the rates of mood disorders

in TS were comparable to those stated in another report that assessed mood in women attending gynaecology clinics (Spitzer, Williams, Kroenke, Hornyak, & McMurray, 2000). One limitation, however, was that the two studies used different measures and methods for assessing psychological problems, and this may have affected the comparability of their findings.

Notwithstanding the limitations of the aforementioned studies, the link between psychological distress and health problems is well-established in the literature. Mental health problems have been found to be 2-3 times more likely in people with long-term physical health conditions such as diabetes, cardiovascular diseases, chronic obstructive pulmonary disease (COPD) and more (Bădescu et al., 2016; Naylor et al., 2012; Stopien, 2018). Possible causes include the ongoing stressors and uncertainty related to the physical health problems, the demanding and prolonged nature of the medical regimens, pain and discomfort and negative self-concept (Naylor et al., 2012).

Another potential cause of emotional difficulties in TS could be the direct neurological consequences of the syndrome. Some of the brain regions that appear to be affected in TS such as the amygdala, prefrontal cortex and the hippocampus, are regions that are also affected in mood disorders (Gravholt, 2009). Therefore, it is possible that the risk of developing a mood problem is increased due to the hormone deficiencies and brain differences associated with TS (Boman et al., 2004; Cardoso et al., 2004). Lastly, psychological functioning in women with TS has also been associated with systemic and contextual factors such as family coping and resources (Culen et al., 2017). For instance, lower parental socioeconomic status and more negative parental perception of the condition have been found to increase family stress and to relate to lower self-esteem in women with TS (Carel et al., 2006; Culen et al.,

2017). Other factors including later age at diagnosis and academic difficulties in school (Boman et al., 2004) have also been found to be associated with lower psychological wellbeing in TS, more so than differences in appearance.

Despite the array of psychological challenges that women with TS may face, many can live a satisfying and fulfilling life and cope well with their condition. It has been reported that they demonstrate resilience in relation to work situations and job competence, they perceive themselves as competent to perform tasks and present with fewer conduct problems (e.g. cheating, truancy) than matched controls (McCauley, Feuillan, Kushner, & Ross, 2001; Næss, Bahr, & Gravholt, 2010).

For those who do experience difficulties, however, very few psychological interventions have been tried with a focus on ameliorating psychological and cognitive function specifically in girls and women with TS (Chadwick, Smyth, & Liao, 2014; Hynes & Phillips, 1984; Watson & Money, 1975), and the existing interventions have several limitations. For instance, they did not utilise evidence-based approaches, have not been manualised, and the lack of randomized control trials means the effectiveness of these interventions cannot be ascertained (Wolstencroft & Skuse, 2018). Therefore, this is an important area for development in future studies and clinical work.

Social Functioning in Women with Turner Syndrome

Social skills are fundamental for forming fulfilling and enduring relationships, and contribute to physical, psychological and economic wellbeing across the lifespan (Cacioppo et al., 2002; Spence, 2003). Adaptive social competence can be especially critical in adolescence, as it facilitates acceptance by peers and enhances positive self-perception and self-esteem (Pope, McHale, & Craighead, 1988). Impairments in social competence can have a significant impact on the adaptive, psychological and academic

functioning of an individual and can lead to increases in isolation, rejection and bullying, as well as difficulties in making and sustaining close relationships (Cacioppo et al., 2002). Peer relationship problems in childhood are associated with a variety of enduring difficulties and poor outcomes in both mental and physical health, that persist in adulthood (Allen, Chango, & Szvedo, 2014; Gustafsson, Janlert, Theorell, Westerlund, & Hammarström, 2012). It is therefore imperative to provide effective assessment and support to individuals from an early age.

Defining Key Concepts

Social competence. Social competence has been defined in various ways in the literature, and there seems to be no agreed upon definition. A central component that is included in many of these definitions is the ability of an individual to function effectively in an interpersonal context, by using developmentally appropriate knowledge and skills to adapt to their social environment (Erdley, Nangle, Burns, Holleb, & Kaye, 2010; Spence, 2003). In the literature this concept is often used interchangeably with social functioning.

Social skills. These are age-appropriate verbal and non-verbal behaviours used by an individual to attain their social goals and perform effectively in social situations (Odom, McConnell, & Brown, 2008). Such skills can include: communication and conversation skills, affect regulation, interpersonal problem solving, body language and expression, prosocial behaviour, empathy and self-awareness, and more (Nangle, Hansen, Erdley, & Norton, 2010).

Social cognition. Social cognition refers to the psychological processes that help us make sense of the world, by correctly processing social and emotional cues in our social environment (Frith, 2008). This involves being able to observe and then

interpret social signals displayed by others (e.g. facial expressions, eye gaze) and understand and predict their intentions, which in turn influences our own social decisions and communication (Frith, 2008). Many of these processes are automatic and unconscious. An example of such a mechanism includes mirror systems in the brain that are activated when we or someone else perform an action or have a social experience (Cattaneo & Rizzolatti, 2009). Social cognition impairments therefore relate to social skills problems and can get in the way of effective social communication (Frith, 2008).

Social Problems in TS

Social competence problems. Many women with TS do not report difficulties in their relationships and are popular with their friends. Nevertheless, approximately one third of girls and women with TS present with social skills deficits and difficulties in sustaining relationships (Carel et al., 2006; Hong, Dunkin, & Reiss, 2011; McCauley et al., 2001). Women with TS report, on average, greater social isolation and loneliness than the general population (Amundson et al., 2010; Boman et al., 2001) and tend to engage in more individual activities (Suzigan, de Paiva E Silva, Guerra-Júnior, Marini, & Maciel-Guerra, 2011). It has also been reported that women with TS prefer having one close friend and could become dependent on them, but then have to face the emotional costs if that friendship breaks down (Skuse, 2009).

Romantic and sexual relationships tend to start later in life for women with TS and are more infrequent compared to women without the condition (Rolstad, Möller, Bryman, & Boman, 2007). They also tend to live with their parents for longer and are less likely to be married (Jež et al., 2018). Concerns regarding infertility and sexual dysfunction may negatively impact how women with TS interact with partners, as they may be hesitant to enter into relationships due to fears of rejection (Sutton et al., 2005).

Nevertheless, other evidence suggests that women with TS tend to be satisfied with their intimate relationships and sexual lives, despite some difficulties in sexual functioning (Rolstad et al., 2007).

Social skills problems. In terms of specific social skills difficulties in TS, it seems that basic language skills are intact; however, subtle deficits can be found in both the expression and comprehension of language, as well as in the skills that are necessary for effective social communication (Skuse, 2009). These difficulties can include inappropriate initiations, interrupting, challenges in constructing coherent narrative accounts, insensitivity to cues from the other person, literal understanding of language, and difficulties in turn taking (Skuse, 2009). Females with TS also have the tendency to show a limited range of facial expressions and social smiling, in comparison to their peers (Lesniak-Karpiak et al., 2003; Skuse, 2009). It has also been suggested that women with TS tend to not utilise non-verbal cues such as eye contact and gestures to support their communications appropriately, and can be fairly inexpressive in social situations (Skuse, 2009). Additionally, individuals with TS demonstrate rigidity and inflexibility in their routine and some report restricted interests (Skuse, 2009).

Such deficits certainly appear to be similar to autistic features. In fact, previous studies have found that the risk of having Autism Spectrum Disorders (ASD) is greater in females with TS, with a prevalence rate of 3% (Creswell & Skuse, 1999), in comparison to the general population that has an ASD prevalence rate of 1% (Baird et al., 2006). Nevertheless, difficulties such as repetitive behaviours, rigidity in routine, and restricted interests, although present in females with TS, tend to be milder than in people with ASD, and other stereotypical autistic symptoms such as motor behaviours do not tend to be present in TS (Skuse, 2009). There appears to be a lack of sufficient

investigations into the neurodevelopmental functioning of women with TS, and as such there is uncertainty as to how much their social communication deficits and behaviours differ from those with ASD, and how common they are in the population with TS.

Hong and colleagues (2011) reported that girls with TS have difficulties in using social skills effectively, but are keen to form relationships and express social motivation in comparable levels to their typically developing peers. Thus, social impairments in females with TS may be distinct from individuals with ASD or other conditions where social motivation sometimes appears to be diminished (Chevallier, Kohls, Troiani, Brodtkin, & Schultz, 2012; Hong et al., 2011). Although it is important to note that girls and women with ASD tend to show greater levels of social motivation than their male counterparts (Sedgewick, Hill, Yates, Pickering, & Pellicano, 2016), and thus may be more comparable to women with TS.

Additionally, Wolstencroft and Skuse (2018) suggested that social knowledge in girls with TS is attained in a similar way to their typically developing peers in early life, but that difficulties become apparent in adolescence when the complexity of the social landscape and social demands increase and surpass their capacity to meet them (Wolstencroft & Skuse, 2018). This is another parallel to the trajectory of social difficulties in females with autism, as these problems also tend to become more apparent in adolescence (Mandy, Pellicano, St Pourcain, Skuse, & Heron, 2018).

Social cognition problems. There is strong evidence in the literature to suggest that females with TS typically have a full-scale Intelligence Quotient (IQ) in the average range, with several studies reporting the average IQ in TS to be in the range between 95 and 102.6 (Mazzocco, 2006). Nevertheless, when examining IQ

subtests, females with TS appear to show a characteristic cognitive phenotype where Verbal IQ tends to be much higher than Performance IQ (Hong et al., 2009; Mazzocco, 2006). This has been attributed to deficits in visuo-spatial skills and executive functioning that are common in TS, and relate to further problems with working memory, processing speed, abstract reasoning and social communication (Hong et al., 2009; Lepage, Dunkin, Hong, & Reiss, 2013; Rovee & Ireland, 1994). Problems with attention and hyperactivity are also common during childhood, with 75% girls with TS presenting with such difficulties, and with an increased risk of Attention Deficit Hyperactivity Disorder (ADHD) (Culen et al., 2017; Russell et al., 2006; Skuse, 2009). These difficulties can have an impact on education and learning, as well as on social relationships (Culen et al., 2017).

In terms of social cognition, women with TS appear to misperceive social cues from others, which can in turn limit their capacity to accurately perceive social situations and the impact of their own behaviour on others (Hong & Reiss, 2012). Theory of mind deficits have been reported, suggesting that girls with TS have difficulties with understanding and inferring the thoughts and feelings of others, as well as with attributing mental states to others (Hong et al., 2011; Lawrence et al., 2007). Women with TS demonstrate difficulties with facial and emotional recognition in others and with understanding nonverbal signals (Bondy, 2007; McCauley, Kay, Ito, & Treder, 1987; Skuse, Morris, & Dolan, 2005).

Especially low accuracy has been reported with regard to the recognition of negative emotions, particularly fear recognition, and individuals with TS also report less experience of fear themselves (Lawrence, Kuntsi, et al., 2003; Mazzola et al., 2006). They also seem to find anxious and shy emotional expressions harder to identify in others (Lawrence, Campbell, et al., 2003; Skuse et al., 2005). Studies using eye-

tracking have shown that women with TS tend to focus on the mouth region when looking at others' faces, and fail to pay attention to the eye region, and as such can miss important cues from gaze and facial expressions (Hong et al., 2009; Mazzola et al., 2006).

The consequence of misperceiving social signals from others is that individuals with TS may respond in an unsuitable manner towards others or may struggle to judge whether a social interaction is progressing well (Hong & Reiss, 2012). This, along with difficulties with problem solving, may further exacerbate and maintain their social difficulties. Further research would be beneficial in elucidating our understanding of the cognitive strengths and weaknesses in TS, especially in relation to social cognition. This could also inform the development of interventions to support the women.

Discrepancies in reports of social problems. In a recent study by Suzigan and colleagues (2011), 52 girls and women with TS aged 15 to 35, and their typically developing sisters aged 16 to 43 completed the Del-Prette Social Skills Inventory self-report questionnaire and interviews (SSI; Del Prette, & Del Prette, 2001). Their parents also completed questionnaires about the social skills and social relationships of their daughters. The findings indicated that performance on the SSI self-reports was not significantly different between the two groups. Women with TS appeared to do better than their sisters in relation to meeting new people and in unknown social situations. In the interviews, some social difficulties were indicated by women with TS, but most did not spontaneously report these and did not complain about relationship problems. Nevertheless, mothers reported significantly more social problems and reduced social competence for their daughters with TS than their typically developing daughters.

Discrepancies between parent and child reports on social skills have been regularly described in the TS literature, with parents often reporting more social impairments than the individuals with TS themselves (Lesniak-Karpiak et al., 2003; McCauley et al., 2001). There are various possible explanations for these findings. Firstly, the fact that women with TS can perform well on self-report measures of social skills such as the SSI may indicate that they are able to identify the appropriate skills to use in social situations, but they may not be able to apply these skills in practice because of other factors such as anxiety, low self-esteem, fear of being teased, or misinterpreting the social cues from others (Schmidt et al., 2006; Suzigan et al., 2011).

Another possibility for these discrepancies could be that women with TS tend to minimise their social difficulties and underreport them, due to high levels of social desirability. Some studies showed that women with TS tend to score highly on social desirability bias scales when completing questionnaires on their social performance (McCauley et al., 2001; Suzigan et al., 2011). In relation to this, it has been suggested that women with TS are aware of their own social deficits and use camouflaging to hide them, as they show a tendency to model the behaviour of others and make intentional attempts at compensation in social situations (McCauley et al., 2001; Skuse, 2009). Social camouflaging has often been described in the autism literature, especially in relation to girls and women with autism. It refers to the use of various strategies such as mimicking, with the aim to hide one's social difficulties and appear as more socially competent (Hull et al., 2017). For some this may help achieve better social success, but for others it could come with costs such as increased anxiety, or may prevent others from recognising they are experiencing social difficulties, which may lead to less support (Hull et al., 2017).

A third possible explanation for these discrepancies could be that individuals with TS have limited self-awareness into their own social impairments due to the cognitive deficits that affect their attention and perception of nonverbal communications (Hong et al., 2009; Suzigan et al., 2011). Difficulties in identifying their own limitations may also relate to minimisation and denial of their problems, as a way to cope with the implications of a serious and complex medical condition (Boman et al., 2004). On the other hand, it is of course possible that women with TS are in fact aware of their social difficulties but do not feel that these cause major problems in their social lives, and this could explain the lack of complaints and reports about them (Suzigan et al., 2011).

Lastly, parental reports could be worse than child reports because of certain parental characteristics that influence their perceptions of the mental health of their child (De Los Reyes et al., 2015). For instance, previous studies have found that parental psychopathology may bias parent perception of child mental health problems and may lead to parents overreporting child difficulties (Kelley et al., 2017; Youngstrom, Izard, & Ackerman, 1999). Additionally, parental and family stress such as financial difficulties, divorce or other difficult life events, may also affect parent perception of child difficulties (De Los Reyes & Kazdin, 2005). Finding out that their daughter has a diagnosis of TS may cause psychological distress to parents (Faust, Rosenfeld, Wilson, Durham, & Vardopoulos, 1995), and some may find it difficult to adjust to their daughter's condition (Slijper, van Teunenbroek, de Muinck Keizer-Schrama, & Sas, 1998). Poor family functioning and parental unhelpful coping styles may have a further negative impact on adjustment and increase the chances of parental and child psychopathology (Faust et al., 1995), which in turn could affect reporting.

These findings and possible explanations highlight the importance of gathering reports from multiple informants such as self, parents, teachers, and peers when assessing social impairments in girls and women with TS. The triangulation of information would allow for more comprehensive assessments and better identification of social difficulties.

Possible Causes of Social Problems in TS

The complete or partial lack of an X-chromosome and the insufficient production of sex chromosomes inevitably disrupt development, both physically and functionally (Skuse, 2009). There is increasingly strong evidence that social difficulties in TS stem from the genetic effects on the brain, rather than the secondary effects of the condition such as differences in appearance (Molko et al., 2004). Structural and functional brain differences have been found in various regions, including the amygdala, the hippocampus, and the temporal lobes (Murphy et al., 1993; Rae et al., 2004). More specifically, in women with TS the amygdala appears to be enlarged, and augmented grey matter volume is also observed close to regions associated with emotional learning (Good et al., 2003). Additionally, anomalies in the structure and volume of the parietal and occipital lobes, the cerebellum and the superior temporal sulcus have been reported; these are brain regions that are involved in social cognition, visuospatial processing and executive functioning (Brown et al., 2002; Molko et al., 2004). Differences in the brain could thus explain to a large extent the deficits in the cognitive processing of social and emotional information that is often found in women with TS (Hong et al., 2009).

Previous studies have also explored the genetic underpinnings of social cognition impairments in women with TS and suggested that the parent of origin of the extant X-chromosome in TS influences genomic imprinting of that gene, which

has specific effects on brain morphology (Lepage et al., 2013). Individuals with TS with a single X-chromosome of maternal origin seem to show greater deficits in social cognition, whereas those with a single paternal X-chromosome seem to be better adjusted socially and psychologically (Creswell & Skuse, 1999; Skuse et al., 1997). This may indicate that paternally derived X-chromosomes potentially provide some protection against ASD-like features (Skuse et al., 1997). Impairments in social cognition are important to consider as they can lead to limitations in the social competence of women with TS, and may also affect how they are perceived by others. This can then impact on the social adjustment and relationships of the women with TS.

Age also appears to be relevant to the degree of social difficulties that females with TS experience. Suzigan and colleagues (2011) reported that older women (≥ 20 years old) with TS performed better on all areas of the Social Skills Inventory (SSI) and reported fewer problems in comparison to younger girls and women with TS (< 20 years old). One suggested explanation for this is that perhaps older women have had more time to learn and practise their social skills, as well as more time to adjust to their diagnosis. Moreover, during adolescence there are increased social demands and higher likelihood of teasing by peers, which together with the pubertal changes and complications that girls with TS face, may have contributed to worse social competence (Suzigan et al., 2011).

Social skills problems can also be exacerbated by the health issues related to the condition. For example, hearing impairments which are common in TS can lead to further social dysfunction and isolation (Bergamaschi et al., 2008). Due to their short stature and delayed puberty, individuals with TS are often perceived and treated as younger than they are, an experience which has been termed juvenalization (Keselman, Martinez, Pantano, Bergadá, & Heinrich, 2000). This can be a hindrance to

socialisation, as it may limit opportunities for social learning and for practising social skills with peers of a similar age. It also reduces the chances women with TS have to build on their independence and autonomy, as their abilities are often underestimated and they may be overprotected by friends and family (Suzigan et al., 2011).

Lack of resources and appropriate support can limit opportunities to acquire and practise social skills even further (Hong et al., 2009). Other issues such as immaturity and delayed development of puberty can also contribute to reduced abilities for successful social performance (Suzigan et al., 2011); for instance, it has been reported that girls with TS appear to be emotionally and behaviourally less mature than peers, for example by “acting young” or “clinging to parent” (Culen et al., 2017; McCauley, Ross, Kushner, & Cutler, 1995). Additional deficits such as coordination and motor skills can make the girls with TS less likely to be picked for teams, which further inhibits opportunities for social learning and social engagement (Skuse, 2009).

Assessing Social Competence in TS

Social problems in TS can often be subtle, and due to the severity and urgency of some of the medical conditions a young person is being treated for, emotional and social difficulties can be overlooked (Skuse, 2009). Nevertheless, these seem to cause significant concern to families and merit adequate assessment, recognition and support, in order to improve the quality of life of women with TS and their families.

Culen and colleagues (2017) recently made recommendations for employing a psychosocial assessment and treatment approach in relation to TS. They suggest that social behaviour should be regularly observed from infancy onwards, to ensure early detection of difficulties, and to offer appropriate support if needed across the lifespan.

Some of the measures that were recommended for assessing social competence and social skills in clinic settings with women with TS include the Social Skills Improvement System Rating Scale (SSIS; Gresham & Elliott, 2008), the Child Behaviour Checklist (CBCL; Achenbach & Rescorla, 2004), the Youth Self Report (YSR; Achenbach & Rescorla, 2004) and the Teacher Report Form (TRF; Achenbach & Rescorla, 2004). Additional measures used in research with individuals with TS (Lepage et al., 2013; Suzigan et al., 2011) include the Social Responsiveness Scale (SRS; Constantino & Gruber, 2012) and the Del-Prette Social Skills Inventory (SSI; Del Prette & Del Prette, 2013).

Culen and colleagues (2017) advise that if any social skills difficulties are detected then social skills interventions and group trainings should be offered with the goal to enhance social competence. To date, however, there is a lack of specific interventions available to support girls and women with TS with social competence problems. It has been suggested by the latest TS clinical practice guidelines that social skills programmes for ASD could be utilised or adjusted for use with women with TS (Gravholt et al., 2017; Wolstencroft & Skuse, 2018). Wolstencroft, Mandy and Skuse, (2018) are currently piloting the use of a social skills intervention, the Program for the Education and Enrichment of Relational Skills (PEERS), for women with TS. Given that the social skills problems exhibited by females with TS may differ from ASD features, it would also be important to develop or adjust assessment methods as well.

Social Problems as a Relational Issue

The majority of the literature on social communication difficulties involves the investigation of social skills problems in relation to their neurological or cognitive underpinnings (Hong et al., 2009), which can lead to a focus on the individual divorced

from their social context. Nevertheless, judgments made by others in the wider social environment can inevitably shape an individual's social success or cause barriers to their social integration (Woods, 2017). After all, social interactions and relationships involve more than one person, and it is important to consider how others contribute to the creation and maintenance of social problems.

For women with TS, bullying and teasing by peers is unfortunately common, with one study finding that up to 48% of individuals with TS reported they had experienced this, leading to increased distress and social withdrawal (Boman et al., 2001). Stigma and judgment of women with TS seem to relate to differences in appearance, especially short stature and delayed puberty (Boman et al., 2001; Sutton et al., 2006; Sutton et al., 2005). Negative societal stereotypes about short stature may also cause women with TS to perceive themselves as being different from their peers (Sutton et al., 2005). It has also been suggested that social communication problems and unsuitable social behaviour may also constitute another risk factor for bullying by peers (Skuse, 2009; Sutton et al., 2005).

Moreover, Jež and colleagues (2018) found that 2/3 of women with TS reported they had encountered negative attitudes by others. This can lead to considerable distress and has been found to be one of the most significant contributors to depression for women with TS (Rickert, Hased, Hendon, & Cunniff, 1996). It has also been associated with social rejection, lack of close friendships and lower quality of life for individuals with TS (Boman et al., 2001; Jež et al., 2018). This seems to also have a significant impact on confidence that persists into adulthood; low self-esteem is common in girls and women with TS and it tends to be lower than the general population (Boman, Mollet, & Albertsson-Wikland, 1998; Carel et al., 2006).

Studies that have explored attitudes towards women with TS mostly based their findings on reports from the women themselves on whether they have experienced teasing or negative attitudes (Jež et al., 2018). That provides us with valuable information into their experiences and the impact they have had on them. Nevertheless, it appears that there is a lack of direct investigation of how others perceive women with TS; for example, by asking peers to discuss their impressions of them. It would be of benefit to investigate this further, as it could improve our understanding of how positive or negative impressions by peers affect women with TS, and may further explain the difficulties that many of them experience in their social relationships.

First Impressions

Whenever we meet a new person we form first impressions of them, which are essentially judgments of the character traits, appearance and personality of that individual, as well as their intentions towards us (Ambady, Bernieri, & Richeson, 2000). These judgments are made quickly and often unconsciously, and are influenced by even quite subtle variations in someone's expression or behaviour (Grossman, 2015). The evolutionary purpose of first impressions is to allow us to make a quick judgment to determine safety or risk when meeting strangers (Ambady et al., 2000). We form first impressions when we observe another individual even without personal interaction; for example, when watching a video clip of them (Rule & Ambady, 2008). It is important to consider first impressions as they directly relate to our behavioural responses towards those we meet; after all, social experiences and relationships are not only about an individual, but they are about reciprocal interactions between people.

Factors that influence first impressions. Researchers have attempted to explore the factors that contribute to the formation of first impressions. It appears that when making judgments observers rely on various sources of information and

multisensory input (Rule & Ambady, 2008). Non-verbal characteristics and visual cues of the individual such as their physical appearance, facial features, gestures and facial expression have been found to influence first impressions and social decision-making (Olivola & Todorov, 2010).

In terms of visual cues, physical appearance can play an important part in social interactions and leads to judgments being made about a person based on their physical attributes (Talamas, Mavor, & Perrett, 2016). For instance, asymmetry in facial characteristics or even small deviations from what is considered to be the norm might be considered as less attractive (Rhodes, 2006) and relates to more negative inferences about the personal characteristics of that person, such as trustworthiness and likeability (Talamas et al., 2016). Increased attractiveness has been found to relate to higher perceived trustworthiness, whilst a wider jaw and broad brow are seen as less friendly and more dominant (Petrican, Todorov, & Grady, 2014). Another example is height, where being taller has been associated with better social and occupational status and more positive impressions (Blaker & van Vugt, 2014). Nevertheless, Sandberg, Bukowski, Fung and Noll (2004) assessed the social influence of height using peer informants who commented on the status of an individual in their social group. They demonstrated that height extremes in the general population do not seem to have a significant impact on status in peer relationships or on social adjustment.

Others have suggested that although static visual information does have some influence over impression formation, dynamic visual cues such as movement quality and speed provide stronger social signals to those we meet (Rule & Ambady, 2008). These can also have a greater impact on judgments as they give others more clues as to what that person is feeling and thinking (Krumhuber, Kappas, & Manstead, 2013). For example, reduced facial expressivity and atypical movements in people with ASD

led to them being judged as more awkward by observers (Faso, Sasson, & Pinkham, 2015; Grossman, Edelson, & Tager-Flusberg, 2013; Metallinou, Grossman, & Narayanan, 2013). First impressions are also influenced by verbal information and audio cues. Studies have found that listening to someone speak influences impressions more than just reading a transcript of what they said, suggesting that the content of speech may be less important than other audio cues, such as tone of voice and prosody (Rule & Ambady, 2008; Schroeder & Epley, 2015).

Judgments made by observers are subjective and do not necessarily reflect an accurate representation of the other individual (Rule & Ambady, 2008) and factors related to the observer may also influence the perceptions they form of others. For instance, having preconceived expectations about what others would be like could lead to perceptual confirmation; that is, the observer believes that their inaccurate expectation has been met, when in fact there is no confirmatory evidence from the other person (Willard, Madon, Gyll, Scherr, & Buller, 2012). This could explain in part how inaccurate stereotypes and stigma about certain populations are maintained and propagated (Chen & Bargh, 1997).

Additionally, other perceiver characteristics that may influence impression formation include gender and prior knowledge of a condition. Female observers and those with higher knowledge about a condition (e.g. ASD) tended to report more positive attitudes in some studies (Campbell, Ferguson, Herzinger, Jackson & Marino, 2004; Gardiner & Iarocci, 2014). Nevertheless, findings have been inconsistent as to the effect perceiver characteristics have on impression formation (Faso, 2016; Matthews, Ly, & Goldberg, 2015) and it would be beneficial for future research to investigate these further.

Impact of first impressions. Regardless of their accuracy, first impressions affect subsequent social decisions and behaviour (Human, Sandstrom, Biesanz, & Dunn, 2012). Positive impressions of a stranger predict positive behaviours towards them, such as choosing to approach and engage with that individual (Harris & Garris, 2008). On the other hand, negative first impressions relate to avoidance and rejection of that person (Harris & Garris, 2008) and social exclusion (Belch, 2005). First impressions also contribute to our long-term attitudes towards the people we meet (e.g. fondness towards someone or stigma against them), which can then persist over time and continue to influence the amount and quality of future interactions with that person (Human et al., 2012). For instance, if when we first meet someone, we perceive them as friendly and kind, we would be more likely to behave in a warm positive manner towards them and pursue further social exchanges with them. This then promotes the building and maintenance of a relationship over time (Horowitz et al., 2006).

This can be most problematic for people who are persistently negatively perceived and that seem to struggle the most in social interactions (Faso, 2016; Rule & Ambady, 2008). Negative first impressions of them could pose barriers to social integration and reduce opportunities for forming friendships (Human et al., 2012). For instance, several studies have demonstrated that typically developing children and adults alike tend to negatively appraise a child displaying ASD behaviours, and are less likely to interact further with them as a result (Campbell et al., 2004; Harnum, Duffy, & Ferguson, 2007; Iobst et al., 2009). Therefore, it is important to understand what contributes to negative first impressions of people from certain groups, as this would then help determine what may help shift these attitudes and promote better social integration.

Methods of evaluating first impressions. The section that follows discusses examples of assessing first impressions in the ASD literature, as such investigations have not been carried out in relation to women with TS. Previous studies have used a variety of methods to assess first impressions, and these usually involve observers being given information about participants with autism and participants without the condition. The observers are then asked to rate their impressions of the participants on specific personal characteristics (Matthews et al., 2015). For instance, typically developing children and adults were given various vignettes describing a child with autism, a child with ADHD, and a neurotypical child, and were asked to report their reactions towards them (Harnum et al., 2007). The participants were found to be more likely to dislike and to wish to avoid the child with ASD or ADHD described in the scenarios, than the neurotypical child. In another study, untrained observers were shown static photographs of adults with and without autism, and were asked to rate the facial expressivity of the participants in terms of intensity and naturalness (Faso et al., 2015). The observers rated the expressions of individuals with ASD as less natural and more intense.

Studies also increasingly adopted the use of ‘thin slices’, which are brief extracts of dynamic social behaviour (e.g. videoclips) presented to observers, who are asked to make a judgment as to the personality and other traits of a stranger (Ambady et al., 2000). For instance, Campbell and colleagues (2004) asked children to watch videotapes of actors pretending to either be a child with autism and displaying stereotypic autistic behaviours, or a typically developing child. Children rated the child displaying ASD behaviour more negatively. Grossman (2015) extended previous work by presenting adult raters with short clips (under 5 seconds) of children with and without ASD engaging in a storytelling task. The clips were presented in different

modalities, including visual, audio, audio-visual and image, so as to evaluate the impact of the different information channels on first impressions. Once again, the adults rated children with ASD as more socially awkward than their typically developing counterparts across all presentation modalities.

Although the methods adopted by these studies helped yield useful information and contributed to our understanding of first impressions of individuals with ASD, there are various limitations that impact on the ecological validity of the studies. Ecological validity refers to the extent to which the procedures employed by a study resemble the real world and in effect the extent to which the results would be generalisable (Barker, Pistrang, & Elliott, 2002). Naturalistic observations in the usual environment of an individual can provide valuable information and increase ecological validity; nevertheless, these are often difficult to conduct due to ethical considerations such as consent and confidentiality, as well as practical limitations such as cost and time (Erdley et al., 2010).

A limitation with non-naturalistic observations is the issue of validity, as one can question whether the analogue situations bear enough resemblance to real-world social situations, and understandably the behaviour of a person could be coloured by the fact that they know they are being observed (Erdley et al., 2010). Segrin (2000) secretly filmed in-vivo interactions between participants whilst they were in the waiting room and then compared those clips with videos filmed during an analogue social task where the participants knew they were being filmed. The results indicated that the social behaviour of the participants was consistently rated by observers as worse in the in-vivo waiting room observation rather than the analogue task. This may relate to the impact of social desirability, as participants may adjust their behaviour

when they know they are being filmed. This also may indicate that evaluations of social behaviour based on analogue tasks may overestimate social functioning.

Though researchers cannot completely control for this in non-naturalistic observation studies, efforts to increase ecological validity should be made. A limitation of the methods in the aforementioned first impressions literature was that the material presented to observers in some studies did not include any dynamic social cues as they were either static images or written scenarios (Faso et al., 2015; Harnum et al., 2007). However, dynamic information can have a significant influence on perception formation (Rule & Ambady, 2008). Another shortcoming was that some studies did not use stimuli of actual individuals with autism, but rather used written scenarios or actors portraying autistic behaviours (Campbell et al., 2004; Harnum et al., 2007; Iobst et al., 2009). Lastly, in several studies observers were only asked to rate one specific characteristic, or the task that was presented was scripted (e.g. story telling), and as such observers were not rating spontaneous authentic behaviour (Grossman, 2015).

In a recent innovative study Sasson and colleagues (2017) employed a more ecologically valid approach for evaluating first impressions of people with social impairments. Their paper presented robust findings from three studies. In one of these studies, 20 adults with ASD and 20 controls were filmed taking part in a social performance task, which involved a mock audition for a reality TV show. The clips were then shown to 214 adult observers who rated them on a first impressions scale developed specifically for this study. The results indicated that observers' first impressions of participants with ASD were less favourable when compared to those of typically developing controls, but only for traits relating to social appeal (e.g. awkwardness and likeability), rather than those pertaining to competence (e.g. intelligence and trustworthiness). Negative impressions were also only made when

visual or audio information was present and the authors suggested that this may relate to the style of social expression of people with ASD rather than the content of the interaction. Lastly, observers reported they were more reluctant to engage further with individuals with ASD than the controls.

The study of Sasson and colleagues (2017) constituted a significant development in the field of assessing first impressions in ASD, as their methodology sought to overcome the limitations of previous research. Firstly, the number of presentation modalities the stimuli were displayed in was increased to five (i.e. audio-visual, silent-video, audio-only, static frame and speech content), so that the influence of both the dynamic and static elements of social presentation could be assessed. Secondly, observers were asked to report their impressions of multiple personal characteristics of those in the stimuli, rather than their impressions of a single trait (Grossman, 2015), which permits a more comprehensive evaluation of first impressions.

Thirdly, observers rated their social intentions towards the participants with ASD and the control participants (e.g. intention to hang out with them), which allowed the exploration of how first impressions affect social decisions. Exploring both first impressions and behavioural intentions can further our understanding of what contributes to social problems and can in turn inform us about how these barriers could be overcome. Lastly, the study included actual people with ASD taking part in an unscripted task, as opposed to using actors, vignettes or scripted tasks (Campbell et al., 2004; Grossman, 2015; Harnum et al., 2007). This increased the ecological validity of the study, since the behaviour in the videos could be considered to be more authentic.

Conclusion and Current Study

Girls and women with Turner syndrome can present with impairments in their social skills, social cognition and psychosocial functioning, and can experience significant difficulties in their relationships (Wolstencroft & Skuse, 2018). The work of Sasson and colleagues (2017) highlighted the importance of utilising ecologically valid methods to evaluate the impressions and attitudes of others towards those with social impairments. This is an area that has been largely neglected so far in the TS literature, as studies that have discussed peer attitudes have only included reports from women with TS themselves.

The current empirical study, which is described in Part 2 of this thesis, aims to fill this gap in the TS literature by employing the methodology used by Sasson and colleagues (2017) to investigate first impressions of women with TS. Young women with TS and typically developing controls took part in a filmed social performance task, and the clips were then presented to observers in different modalities. The observers were asked to rate their impressions of the personal characteristics of the women, and to report their behavioural intentions towards the women in the clips.

Shifting the focus from individual deficits to systemic and contextual barriers to successful social interactions could potentially offer valuable insights into the social problems experienced by individuals with TS. It could also have important implications for the assessment and treatment of social difficulties in TS. For example, by highlighting areas to target in social skills trainings, but also by designing systemic interventions that could be applied with peers and in the wider community. The aim of this would be to start to shift negative attitudes towards people with social impairments or differences, and to promote social integration.

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Part 2: Empirical Paper

First impressions of young women with Turner syndrome

Abstract

Aims. Women with Turner syndrome (TS) have been found to experience social and relational difficulties (Wolstencroft & Skuse, 2018). So far, studies have focused on assessing individual impairments in TS, whereas the attitudes of others towards women with TS and the social barriers these may cause have been largely overlooked. The current study aimed to investigate observer first impressions of women with TS and whether these related to intentions to pursue further social interaction with them.

Methods. Women with TS (N=12) and typically-developing controls (TD; N=13) were filmed taking part in a social performance task, and the films were used to create stimuli in different presentation modalities (i.e. Audio-Visual, Video-only, Audio-only, Still Image and Transcript). Observers (N=204) blinded to the clinical status of the women viewed the stimuli and provided ratings of their first impressions of the personal characteristics of the women and their intention to engage with them socially.

Results. Women with TS were rated less favourably than TD controls across all personal characteristics and five presentation modalities. Observers also reported reduced intention to engage in further social interaction with women with TS. The worst ratings for the TS group were given for the modalities that included dynamic social information (i.e. Audio-Visual, Video-only, Audio-only), rather than static information (i.e. Still Image, Transcript), suggesting that social performance may be driving negative impressions.

Conclusions. A more comprehensive systemic perspective should be taken with regards to social difficulties in TS, where individual social skills interventions are accompanied by programmes aiming at increasing awareness and reducing stigma and negative judgments. Implications and limitations are discussed.

Introduction

Turner syndrome (TS) is a chromosomal condition occurring in 1 in every 2500 women, and it is caused by the complete or partial loss of one X chromosome (Bondy, 2007; Jež et al., 2018). Typical health problems associated with the syndrome include infertility and reproductive problems, cardiac abnormalities, hearing difficulties and visual impairments (Gravholt, 2009). TS is also characterised by phenotypic differences including short stature, low hairline and webbed neck (Gravholt, 2009). It is worth noting that such differences can be subtle and there is large variability in symptomatology (Kesler, 2007). Women with TS require medical monitoring throughout life and interventions often include endocrinological therapy with growth and hormone treatments (Gravholt et al., 2017).

Many women with TS can lead independent and fulfilling lives; studies have found they can achieve the same or higher education and employment levels than controls (Gould, Bakalov, Tankersley, & Bondy, 2013; Næss, Bahr, & Gravholt, 2010), can have satisfying intimate relationships (Rolstad, Möller, Bryman, & Boman, 2007) and can cope well with their condition (Gould et al., 2013). Nevertheless, TS has also been associated with lower life satisfaction (Jež et al., 2018) and higher prevalence of lifetime emotional difficulties, including depression, anxiety and low self-esteem (Cardoso et al., 2004; Schmidt, Ross, Haq, & Bondy, 2006). Some factors that have been found to be related with psychological distress in TS include negative self-perception due to appearance differences from peers (Jež et al., 2018; van Pareren et al., 2005), infertility and sexual development challenges (Sutton et al., 2005), the impact of suffering from chronic and complex health conditions (Cardoso et al., 2004), reduced family coping and support (Culen, Ertl, Schubert, Bartha-Doering, &

Haeusler, 2017), and the neurological consequences of hormone deficiency affecting brain areas related to mood (Boman, Bryman, & Möller, 2004).

Social Competence Impairments in Turner Syndrome

Social competence is often defined as the effective functioning and adaptation in social contexts (Erdley, Nangle, Burns, Holleb, & Kaye, 2010). This is achieved through the successful employment of social skills, which are age appropriate verbal and non-verbal behaviours that are important in interpersonal contexts (Odom, McConnell, & Brown, 2008). Social competence deficits can significantly impact the psychological, academic and relational functioning of an individual, and lead to negative long-term consequences (Cacioppo et al., 2002).

Specific social skills impairments reported in TS include a limited range of facial expressions (Lesniak-Karpiak, Mazzocco, & Ross, 2003), reduced use of non-verbal gestures and eye contact (Lawrence, Kuntsi, Coleman, Campbell, & Skuse, 2003) and conversation skills deficits (Skuse, 2009). Additionally, women with TS have difficulties in recognising the facial and emotional expressions and intentions of others (Bondy, 2007; Skuse, Morris, & Dolan, 2005), which can result in the women employing inappropriate or ineffective social behaviours in their interactions with others (Lepage, Dunkin, Hong, & Reiss, 2013). Social problems seem to worsen in adolescence, as it involves increased demands and complexity in the interpersonal landscape, which women with TS may struggle to navigate (Culen et al., 2017). Certain social deficits in TS appear to be similar to the social communication problems found in Autism Spectrum Disorders (ASD), although the exact nature and extent of these similarities has not yet been determined (Skuse, 2009). In TS there is in fact an increased risk of ASD and Attention Deficit Hyperactivity Disorder (ADHD)

compared to the general population, which can further impact on the social difficulties women with TS can experience (Creswell & Skuse, 1999; Culen et al., 2017).

There is strong evidence in the literature to suggest that social impairments in TS arise from the genetic effects on brain development, that affect areas associated with social cognition, such as the amygdala and the prefrontal cortex (Hong & Reiss, 2012; Rae et al., 2004). Women with TS tend to have a normal IQ, but present with a neurocognitive profile specific to TS where verbal IQ is higher than performance IQ (Hong, Scaletta Kent, & Kesler, 2009; Mazzocco, 2006). Females with TS often present with impairments in visuospatial processing and executive functioning, including deficits in problem solving and working memory (Hong et al., 2009). Additionally, health issues related to the condition, such as hearing and visual impairments, may further impact on the capacity to employ existing social skills effectively (Bergamaschi et al., 2008).

Social problems in TS can be overlooked due to prioritising the monitoring of the various medical conditions the women can suffer from, nevertheless, the negative consequences of the social deficits can significantly impact quality of life and relationships (Wolstencroft & Skuse, 2018). Women with TS have been found to have more relationship difficulties and lower social competence than their typically developing peers (McCauley, Feuillan, Kushner, & Ross, 2001). They report that they have fewer friends (Skuse, 2009), fewer intimate relationships which often start later in life (Jež et al., 2018) and greater levels of loneliness and isolation than the general population (Amundson, Boman, Barrenäs, Bryman, & Landin-Wilhelmsen, 2010).

The Impact of Negative Perceptions on Social Difficulties

Social relationships by definition involve interactions between two or more individuals, therefore it is important to note that the factors which may be causing and maintaining social difficulties are bidirectional (Sasson et al., 2017). Two thirds of individuals with TS have reported they experienced negative attitudes from others, including bullying and teasing (Jež et al., 2018). The teasing has been reported to relate to the differences in appearance associated with the condition (Boman, Bryman, Hailing, & Möller, 2001), but it has also been suggested it may be linked to the women engaging in inappropriate social behaviours in their interactions with others (Sutton et al., 2005). Stigma and bullying have been linked to low self-confidence, social withdrawal, further psychological distress and lower quality of life for the women with TS (Carel et al., 2006; Jež et al., 2018).

The social model of disability posits that negative societal perceptions of those with disabilities along with intolerance of difference, can lead to stigma and discrimination; this in turn further hinders the social integration and social success of those individuals (Woods, 2017). Social decisions and responses to others in our social environment are often determined by the initial impressions we form of them (Ambady, Bernieri, & Richeson, 2000). First impressions are formed based on the processing of social information from multiple sources (Ambady et al., 2000). For instance, social expression that is characterised by dynamic social signals (i.e. visual and auditory cues that involve some form of movement or change, such as facial expressions, gesturing and tone of voice) plays an important role in the formation of first impressions (Rule & Ambady, 2008). Static information (i.e. visual or other signals that are fixed or still) such as the appearance of an individual (Hassin & Trope,

2000) or the content of a conversation (Nadig, Lee, Singh, Bosshart, & Ozonoff, 2010) also contribute to the impressions we form of other people.

In an innovative recent study, Sasson and colleagues (2017) examined the first impressions of people with ASD, made by typically developing observers. They reported robust findings from three studies that showed that individuals with ASD were evaluated less favourably than typically developing controls, and these negative judgments were related to reduced intentions to pursue further social interaction with them. The observers were not aware that some of the people they were rating had ASD, therefore their judgments did not seem to arise from the stigma that is sometimes associated with the label of autism. In one of the three presented studies (Sasson et al., 2017), observers rated stimuli of participants with ASD and controls engaging in a social performance task. These clips were shown in different presentation modalities (i.e. audio-visual, audio-only, silent-video, static frame, speech content) and the results revealed that negative first impressions were made only when visual or audio elements were presented. This suggested that observer negative judgments were based more on the expression and style of the social performance of the participants rather than their speech content.

In the TS literature the focus so far has been on identifying the individual neurocognitive, behavioural and developmental impairments that may be related to the social difficulties often faced by women with TS. These are important for informing individual treatment strategies and interventions. Nevertheless, social success or failure is also determined by the perceptions and judgments made by others in the social environment, which drive social decisions (Human, Sandstrom, Biesanz, & Dunn, 2012). This has been largely overlooked in the TS literature, as to our knowledge there have not been any studies exploring how others perceive women with

TS and whether this in fact contributes to social difficulties. Previous literature only included reports from the women with TS themselves, regarding the negative attitudes they might have experienced. Thus, it would be important to investigate and understand the factors contributing to positive and negative impressions formed by others about women with TS, and how these may influence their social environments. This would allow the identification of individual and systemic changes that can be pursued, which would aim to reduce stigma and discrimination and improve social relationships.

Current Study

The current study aimed to fill the gap in TS literature by examining the attitudes and impressions others form of women with TS and how these then may affect social interactions. To achieve this, the study replicated one of the methodologies employed by Sasson and colleagues (2017). Observers completed an online survey which included stimuli of women with TS and typically developing (TD) matched controls shown in different presentation modalities (i.e. Audio-Visual, Video-only, Audio-only, Still Image and Transcript). Separating these presentation elements would facilitate the exploration of how visual cues (e.g. facial expressions, gestures, appearance) and non-visual cues (e.g. sound, speech content), as well as dynamic and static signals, relate to observer impressions. The observers completed the First Impressions Assessment Scale for Observers (Sasson et al., 2017) in relation to each stimulus. This involved providing ratings regarding their impressions of the personal characteristics of the young women and their intention to pursue further social interaction with them.

This study comprised of two parts. Part A involved the recruitment of the TS and TD video participants and the creation of the study stimuli. Part B included the

construction of the online survey and the recruitment of the observer participants who completed the survey. The methodologies and results for Part A and Part B of the study will be discussed separately in more detail below. Ethical approval for this project was granted by the UCL Research Ethics Committee (UCL REC ID: 11837/001; see Appendix A for approval letter). All data was stored and handled securely in accordance to information governance procedures (i.e. GDPR) and guidance from the UCL Data Protection Office. More specific ethical considerations will be presented for each part.

Specific Study Aims

Aim 1. To explore whether observers evaluate the personal characteristics of women with TS more negatively than those of TD participants (as measured by the Character Traits subscale of the First Impressions Assessment Scale), and whether this varies as a result of presentation modality.

Aim 2. To investigate whether observers report reduced behavioural intention to engage socially with women with TS in comparison to TD participants (as measured by the Behavioural Intent subscale of the First Impressions Assessment Scale), and whether this varies as a function of the presentation modality.

Aim 3. To examine the relationship between the observer judgments of the personal characteristics of the women and the reported intention to engage with them socially.

Part A: Video Participants and Stimuli Construction

Method

Participants. In total, 25 young women aged 16-25 were recruited as video participants for Part A of the study. Of these, 12 were in the TS group and 13 in the TD control group. All video participants were asked to provide basic demographic information including their age and ethnicity. The sample characteristics for each group are described in Table 1.

Table 1

Video Participant Sample Characteristics

Characteristic	Turner Syndrome (n=12)	Typically Developing (n= 13)
Mean age (SD)	18.90 (2.23)	21.38 (2.34)
Ethnicity n (%)		
White British/White Other	10 (83.3%)	10 (76.9%)
Asian/Asian British	1 (8.3%)	2 (15.4%)
Mixed Ethnic Backgrounds	1 (8.3%)	1 (7.7%)

Opportunity sampling was used to recruit women with TS and TD controls. Participants with TS were recruited with assistance from the Turner Syndrome Support Society UK (TSSS; <http://tss.org.uk/>) who advertised the study on their social media, newsletter and annual conference. TD participants were recruited through a variety of means, including local universities, emails and social media. A £50 prize draw and course credit were offered to encourage participation.

In terms of the inclusion criteria, the age range of 16 to 25 was selected as adolescence and early adulthood are periods of increased vulnerability and difficulties in social relationships for women with TS (Jež et al., 2018). Those eligible to take part did not suffer from severe hearing and visual impairments, as this could have affected

their performance on the task and confounded the results. It was also decided not to exclude individuals with TS on the basis of their autistic traits, as these are common in TS (Creswell & Skuse, 1999), therefore excluding them would mean the sample would be less representative of the population. One participant with TS did have a confirmed diagnosis of Asperger's. Only women with TS who had not received social skills training were included in the study, so that their social competence could be explored unaffected by previous interventions. For TD participants, only those without a social skills impairment could take part, so that they could act as a non-clinical control group. The flow of participants through Part A of the study is presented in Figure 1.

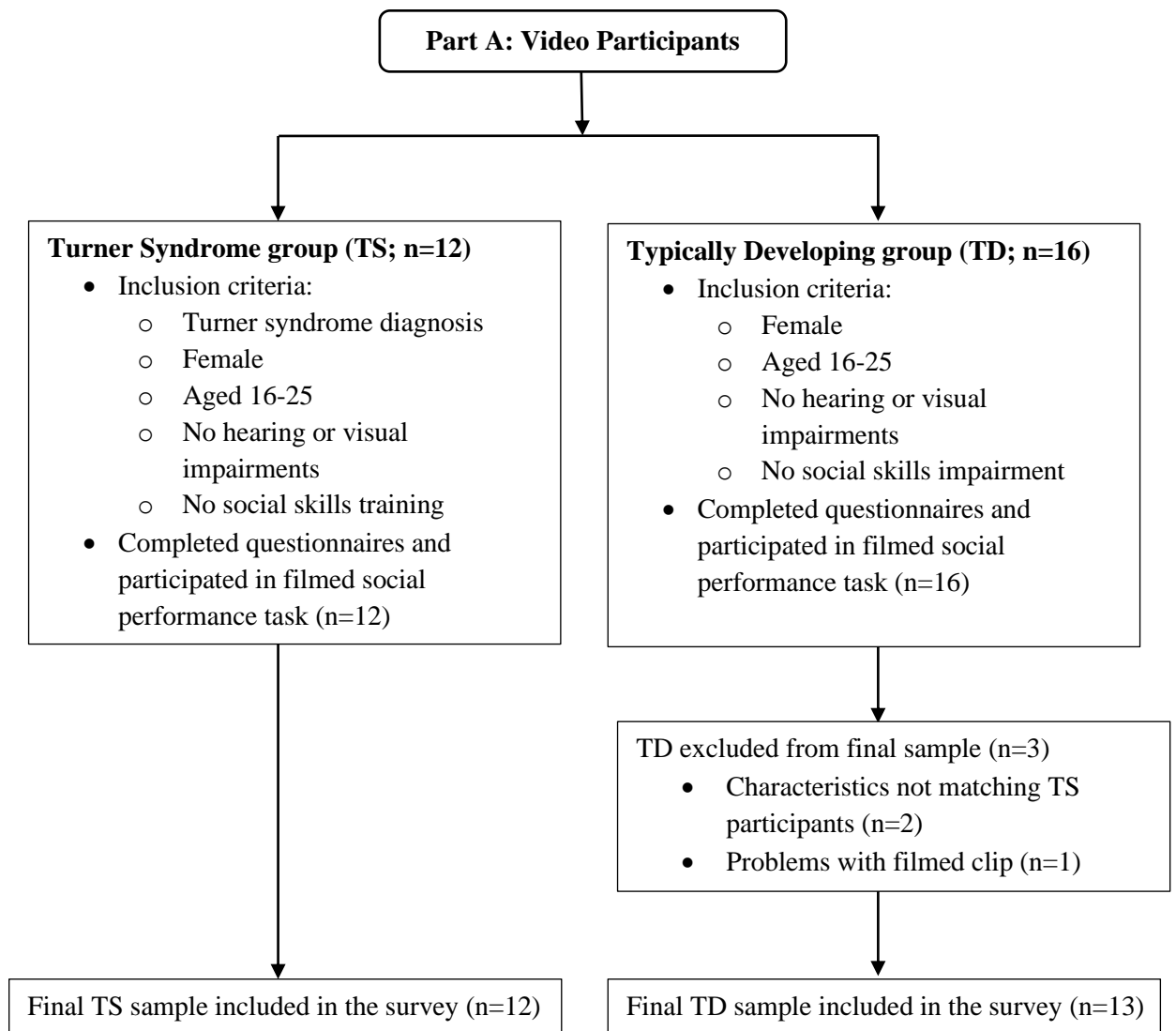


Figure 1. Flow chart describing the process of recruiting video participants.

Measures.

The Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997). The SDQ is a brief questionnaire widely used to screen the behavioural and emotional strengths and difficulties of a child or young person. The SDQ consists of 25 items, which are divided into 5 subscales, with 5 items each. These include: emotional problems (e.g. “I worry a lot”), conduct problems (e.g. “I fight a lot”), hyperactivity/inattention symptoms (e.g. “I am constantly fidgeting”), peer relationship problems (e.g. “I have one good friend or more”) and prosocial behaviour (e.g. “I often volunteer to help others”). Each item is rated on a 3-point Likert scale ranging from 0 (‘Not True’), 1 (‘Somewhat True’) and 2 (‘Certainly True’). In terms of scoring, 5 items are reverse scored. For each subscale, the summed scores can range from 0 to 10. A Total Difficulties score ranging from 0 to 40 can be calculated by summing the scores from all subscales, with the exception of the prosocial scale. Higher scores indicate a greater level of difficulty.

The Youth in Mind 4-band classification system (Youthinmind, 2016) is used to categorise SDQ scores into severity bandings, which represent the level of difficulties experienced by each child. The recommended cut-off scores were created based on a community sample in the UK (Youthinmind, 2016). According to these, the bandings for the SDQ self-report Total Difficulties scores are: 0-14 (‘Close to Average’), 15-17 (‘Slightly Raised’), 18-19 (‘High’) and 20-40 (‘Very High’).

The SDQ has young person, parent and teacher versions, as well as short and long versions, with the latter including a supplement assessing the impact of the difficulties on the child. For this study, the short young person self-report version for 11-17 year olds was used. The psychometric properties of the SDQ have been

extensively researched in the UK and internationally. The literature suggests that it has good internal consistency with α values ranging from 0.64 to 0.82 and test-retest reliability ranging from 0.62 to 0.88 (Goodman, Meltzer, & Bailey, 1998; Muris, Meesters, & van den Berg, 2003; Yao et al., 2009). Additionally, it has been found to have good concurrent and discriminant validity with other measures of general child psychopathology, such as the Child Behavior Checklist (CBCL), the Achenbach and Rutter scales and the Youth Self Report (YSR) (Lundh, Wångby-Lundh, & Bjärehed, 2008; Muris et al., 2003; Yao et al., 2009). It has also been found to discriminate well between clinical and non-clinical populations (Goodman et al., 1998).

The Social Competence with Peers Questionnaire (SCPQ; Spence, 1995).

The SCPQ is a short questionnaire designed to assess social competence in children and young people up to the age of 17, by investigating the outcomes and consequences of their social interactions with their peers. The SCPQ has a young person version which contains 10 items related to social competence both at home and at school (e.g. “I get on well with my classmates”, “other kids invite me to their homes”). There are also parent and teacher versions, each comprising of slightly different items. Items are rated on a 3-point Likert scale ranging from 0 (‘Not True’), 1 (‘Sometimes True’) and 2 (‘Mostly True’), with no reverse scored items. A total score is calculated by summing the scores of all items and can range from 0 to 20 for the young person report, with higher total scores indicating better social competence. In the current study the young person version of the SCPQ was administered. This has been found to have good reliability and validity ($\alpha= 0.75$, $r= 0.77$), as scores correlated with ratings by other informants and with ratings on the social skills questionnaire and peer sociometric nomination scales (Spence, 1995).

Questionnaire strengths and limitations. The advantages of using the SDQ and the SCPQ measures in the current study include that the questionnaires are easily and freely accessible online, they are short and quick and have good psychometric properties. A limitation, however, is that these measures have been validated for use with young people up to the age of 17, therefore they may be less applicable to an older population. In addition, these measures are designed to be screening tools, which means they can identify the possible presence of difficulties, but do not provide a diagnosis or detailed assessment of the problems experienced by an individual.

Nevertheless, it was deemed appropriate to use these measures for Part A of the current study, as the purpose was to obtain a description of the TS and TD video participant groups, rather than conduct an in-depth assessment of the difficulties of the participants. Secondly, in the case of the SDQ, there is an adult self-report version (Youthinmind, 2016), however its psychometric properties have not yet been established. The young person and adult versions of the SDQ are very similar, and only have minor differences in the wording of some of the items. In the current study some of the video participants were under 18 years old and some were over 18, therefore the same version of the measures was used across all participants in order to make the process more consistent and standardised.

Procedure.

Ethics. All video participants were firstly provided with information sheets and consent forms (see Appendix B). These highlighted that taking part in this study involved being filmed, and that their videos would be used as stimuli that would be shown to other research participants, as part of an online survey. Those under 18 were also given a parent information sheet and consent form (see Appendix C), which had

to be completed prior to participation. Young people and their parents had the opportunity to ask questions, they were reminded that participation is voluntary and that they could withdraw without having to give a reason. Time limits for withdrawing their data from the study were specified. It was made clear that after their videos were edited and the online survey was disseminated, it would not be possible to withdraw their video from the study. Before the survey was disseminated, they were given another opportunity at that point to withdraw from the study if they were not happy with their video to be included in the survey.

Data collection and filmed task. The data collection took place in two settings, and similar conditions were created with regards to the room set up. If the inclusion criteria were met and informed consent was provided, participants were given the paper questionnaires to complete. Following the completion of the questionnaires, the participants completed the High Risk Social Challenge task (HiSoC; Gibson, Penn, Prinstein, Perkins, & Belger, 2010), which is a social performance task that has been developed to assess social functioning and social skills. The task involves the participants being filmed for 45 seconds whilst engaging in a mock audition for a new TV show, where they have to tell the judges why they should be selected for the show.

The HiSoC task was initially developed for use with people at genetic high risk of psychosis (Gibson et al., 2010) and it involved trained observers coding the video clips using a HiSoC rating scheme, which was designed based on measures from the psychosis literature. More recently, the HiSoC task was used to explore how social performance influences observer first impressions of adults with ASD (Sasson et al., 2017). Sasson and colleagues (2017) used the filmed task to create stimuli, but then instead of using the HiSoC rating scheme they developed and used a scale to assess observer first impressions.

The current study employed the HiSoC task in a similar way, with the aim to create stimuli that would be rated by observers in the second part of the study, using the First Impressions Assessment Scale established by Sasson and colleagues (2017) (the scale will be described in more detail in Part B of the study). Before the filming of the HiSoC task, all participants were given a grey t-shirt with a simple plain design to wear, and were asked to remove their jewellery. The purpose of this was to control for clothing across all videos, so as to ensure that the outfit of the women did not influence the ratings of the observers. The participant then sat on a chair in front of a white background. They were given the same instructions read from a script and were filmed engaging in the task for 45 seconds. The aim of this was to standardise the filming process as much as possible.

Stimuli construction. Once all the video clips were collected, they were entered into a computer software programme and trimmed into 10 second clips that showed the video participant from the waist up. In order to make the trimming systematic, it was decided to cut out introductions (“Hi I’m ... and you should select me for the show because...”) and select the 10 seconds that followed. The 10 second clip length was chosen based on previous studies that used video stimuli, which suggested this length provided sufficient information on social behaviour for an observer to be able to then make reliable judgments (Faso, 2016). Neither the participants’ name nor clinical status (i.e. TS or TD) were included in any of the clips to protect confidentiality.

Each clip was then edited into five different presentation modalities: (1) Audio-Visual, (2) Video-only (clip without the sound), (3) Audio-only (sound clip with no image), (4) Still Image (static frame of the participant’s face and upper body, in an upright position when they are not speaking or gesturing), and (5) Transcript (written

speech content). After the editing was completed, the stimuli were sent to the video participants who took part in the filming and they were given the opportunity to withdraw from the study at that point if they did not wish for their video to be used.

Data analysis. For Part A of the study a series of independent samples t-tests was conducted, to explore whether the self-reported difficulties of women with TS were significantly different from those of TD participants. The purpose of the analysis was to better understand and describe the video participant sample, therefore a power calculation was not conducted. Instead, a sensitivity analysis (Faul, Erdfelder, Lang, & Buchner, 2007) was run to determine the smallest effect that could be detected with a 0.8 power level and a 0.5 alpha level, given the sample size of the TS (n=12) and TD (n=13) groups. The sensitivity analysis indicated that only large effects could be detected with the existing sample size (Cohen's $d = 1.03$).

The TS and TD groups were compared on the SDQ Total Difficulties scores and the five SDQ subscale scores, as well as on their SCPQ scores. Prior to running the analysis, the t-test assumptions were checked by assessing normality (i.e. Shapiro-Wilk test, skewness and kurtosis statistics and histograms). There was no evidence of departure from normality for any of the variables, therefore it was deemed appropriate to proceed with parametric tests. Cohen's d standardised effect sizes were calculated; these can be interpreted as small (0.20), medium (0.50), large (0.80), very large (1.20) or huge (2.0), according to the guidelines by Cohen (1988) and Sawilowsky (2009). A chi-squared test was also conducted to assess whether the frequencies in the SDQ severity bandings differed between the two groups.

Results

All video participants (i.e. TS and TD groups) completed the SDQ self-report measure and their Total Difficulties scores were used to classify them into the different SDQ severity bandings (see Table 2). A greater number of women with TS were categorised in the ‘Slightly Raised’ and ‘Very High’ categories, in comparison to TD participants. It should be noted, however, that a chi-squared test did not find a significant difference between the frequency of women with TS and TD controls that presented in the different SDQ bandings ($\chi^2(3) = 2.83, p=.419$).

Table 2

Number of Video Participants in each SDQ Severity Banding (Percentages in Parentheses)

Banding	Turner Syndrome (n=12)	Typically Developing (n= 13)
Average	7 (58.3%)	10 (76.9%)
Slightly Raised	3 (25.0%)	1 (7.7%)
High	1 (8.3%)	2 (15.4%)
Very High	1 (8.3%)	0 (0.0%)

The results of the independent samples t-tests showed that the TS and TD groups did not significantly differ in any of their SDQ total and subscale scores (see Table 3). With regards to the SCPQ scores, the difference between the groups was significant with a very large effect size, with TD women reporting better social competence than women with TS. Nevertheless, it cannot be confidently stated that these groups in fact experience the same amount of difficulties, because as the sensitivity analysis indicated, only big effects could be detected with the current sample size. It is therefore worth noting that with a larger sample comparing women with TS and TD controls, smaller effects and significant group differences could have been discovered.

Table 3

Results of T-tests Comparing the Video Participant Groups on the SDQ Total and Subscale Scores and the SCPQ Scores

Measure	Turner Syndrome group			Typically Developing group			<i>t</i>	<i>df</i>	<i>p</i>	95% CI		Cohen's <i>d</i>
	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>				<i>LL</i>	<i>UL</i>	
SDQ self-report												
Total	12.33	5.65	12	9.08	5.63	13	1.44	23	.163	-1.41	7.93	0.58
Emotional	3.92	2.11	12	3.62	2.57	13	.32	23	.753	-1.65	2.26	0.13
Conduct	.92	1.24	12	.62	.51	13	.81	23	.428	-.47	1.07	0.32
Hyperactivity	4.25	2.53	12	2.69	2.14	13	1.67	23	.109	-.37	3.49	0.67
Peer	3.25	1.14	12	2.15	2.15	13	1.61 ^a	19	.125	-.33	2.53	0.64
Prosocial	8.83	1.40	12	9.31	.86	13	-1.01 ^a	18	.326	-1.46	.51	0.41
SCPQ self-report	11.73	3.38	11	17.08	3.52	13	-3.78	22	.001*	-8.29	-2.41	1.55

Note. SDQ = Strengths and Difficulties Questionnaire; SCPQ= Social Competence with Peers Questionnaire; M= mean; SD= standard deviation; df= degrees of freedom; CI = confidence interval; LL = lower limit; UL= upper limit. Bonferroni correction used to adjust the α to $\alpha_{\text{Bonf}}=0.007$.

^aEqual variances not assumed.

* $p < .01$.

Part B: Observer Participants and Survey Construction

Method

Statistical power analysis. The current version of G*Power (Faul et al., 2007) does not support power analysis for designs with more than one within-subjects variables (A. Buchner, personal communication, May 20, 2019). Therefore, it was not possible to pre-determine the exact sample size that would be needed for Part B of the study. The methodology of this study is based on the work of Sasson and colleagues (2017) who recruited 214 participants. As it was not possible to conduct a power calculation, it was decided to aim for a similar sample size. A sensitivity analysis was conducted post recruitment to determine what effect sizes a sample of this size would be able to detect for each independent variable. The sensitivity analysis (Faul et al. 2007) indicated that with a 0.8 power level, a 0.05 alpha level and a sample size of 204, the analysis for Part B of this study would be able to detect even small effects for the Group (Cohen's $d_z = 0.17$) and the Presentation Modality (Cohen's $f = 0.08$) variables.

Participants. In total, 204 observers completed Part B and were primarily recruited from local universities. The study (with a link to the online survey) was advertised on social media and university pages, as well as through posters and emails. A prize draw for a £50 voucher and course credit were offered, to incentivise participation. Observers were asked to provide basic demographic information including their age, gender and ethnicity (see Table 4 for sample characteristics). They were also asked whether they had a social skills impairment and to rate their own social skills.

Table 4
Observer Sample Characteristics

Characteristic	Observers (n=204)
Mean age (SD)	22.97 (3.74)
Gender n (%)	
Female	158 (77.5%)
Male	46 (22.5%)
Ethnicity n (%)	
White British/White Other	126 (61.8%)
Asian/Asian British	54 (26.5%)
Mixed/Multiple Ethnic Backgrounds	9 (4.4%)
Black/African/Caribbean/Black British	4 (2.0%)
Other Ethnic Group	11 (5.4%)
Self-reported Social Skills n (%)	
Very Poor	3 (1.5%)
Below Average	24 (11.8%)
Average	95 (46.6%)
Above Average	64 (31.4%)
Excellent	18 (8.8%)

Strict inclusion criteria for the observers were avoided, as the aim was to capture the variety of people that is often found in the social environments of the women with TS and TD controls. The age criterion was extended to include observers of up to the age of 30, as small age differences are often found between peers in natural social environments. Four observers disclosed that they had a diagnosis that related to a social skills impairment (e.g. ASD), and similarly it was decided to include them in the sample as people with impairments are part of the real-world social environment.

Lastly, only observers without hearing or visual impairments were recruited in this sample, as such difficulties could compromise the perception of the stimuli and in turn affect the ratings. The recruitment process and participant flow of Part B of the study is presented in Figure 2.

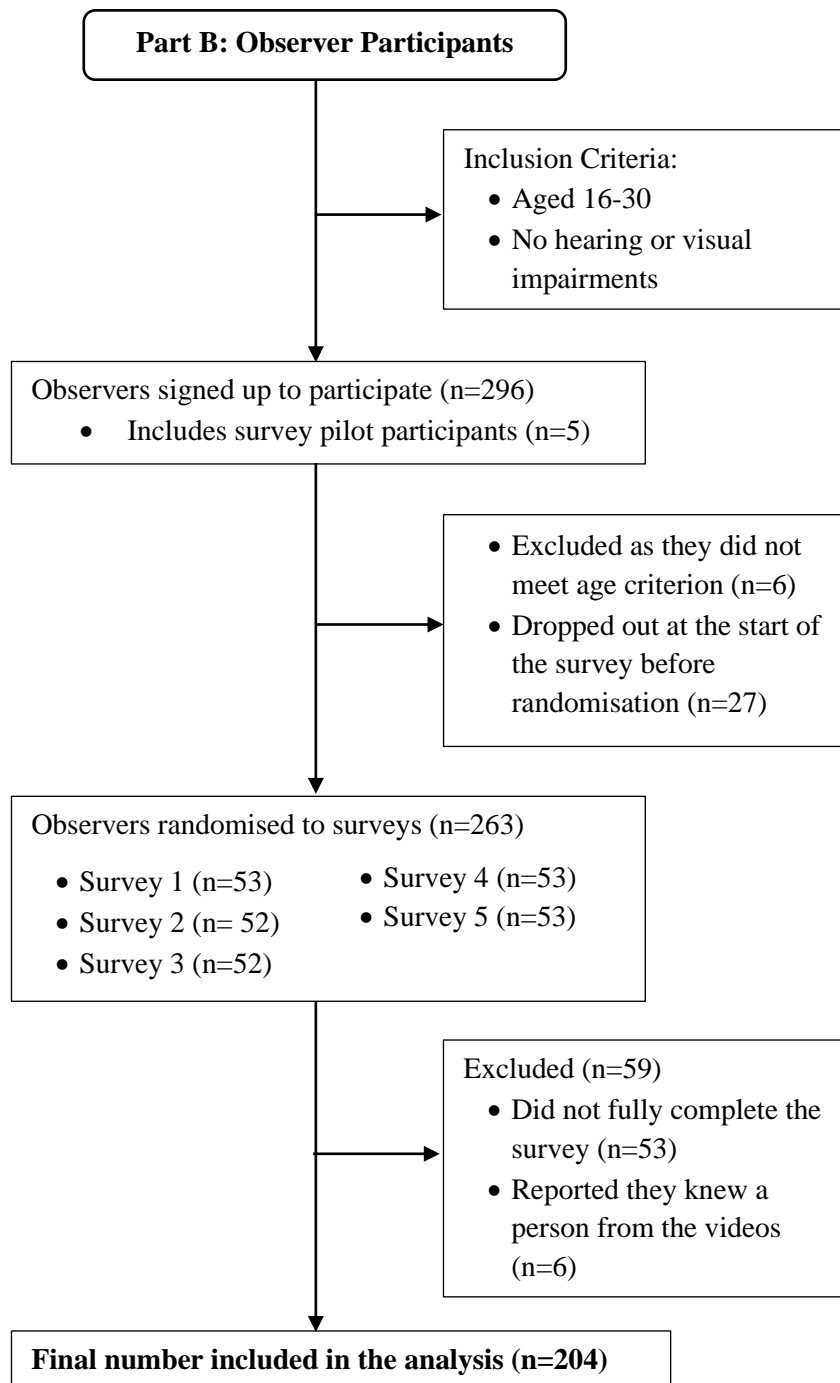


Figure 2. Flow chart describing the process of recruiting observer participants.

Measures.

First Impressions Assessment Scale for Observers (Faso, 2016; Sasson et al., 2017). This constitutes a 10-item rating scale that aims to evaluate observer first impressions of an individual in a social situation, and was designed to be used for the exact type of stimuli that the current study included. The scale items were adapted from previous literature (Findler, Vilchinsky, & Werner, 2007; Todorov, Said, Engell, & Oosterhof, 2008; Willis & Todorov, 2006). The first six items pertain to personal characteristics that have been found to be reliably perceived when making judgments about others in a social encounter (Grossman, 2015; Petrican, Todorov, & Grady, 2014). These are: awkwardness, attractiveness, trustworthiness, dominance/aggression, likeability and intelligence (e.g. “*This person is socially awkward*”, “*This person is trustworthy/honest*”). The remaining four items relate to social intentions; that is, whether the rater would be interested in engaging in further social interaction with the video participant (e.g. “*I would hang out with this person in my free time*”, “*I would be uncomfortable sitting next to this person*”).

Each item is rated on a 4-point Likert scale: 3 (‘Strongly agree’), 2 (‘Agree’), 1 (‘Disagree’) and 0 (‘Strongly disagree’). Items 1, 4, 8 and 9 are reverse scored. A total score that ranges between 0 to 30 can be produced by adding the scores of all items. Two subscale scores can also be calculated: (1) a Character Traits subscale score (sum of items 1-6; score ranging from 0-18) and (2) a Behavioural Intent subscale score (sum of items 7-10; score ranging from 0-12). Higher scores indicate more positive first impressions of character traits, and greater behaviour intentions towards that individual. No information on the psychometric properties of this scale are currently available; however, its internal consistency and reliability were evaluated as part of the current study.

Procedure.

Ethics. When observers entered the online survey, they were firstly shown an information page about the study and an outline of the data that would be collected; they could also download a PDF version of the information sheet (see Appendix D for information sheet and consent pages). This was followed by a consent page; observers had to read the consent statements and if they were happy to proceed, they could click the “I consent” button. This would allow them to continue to complete the rest of the survey. Participants who were ineligible to take part (e.g. because of the age criterion, or if they clicked “I do not consent”) were directed to the end of the survey without being shown any of the stimuli.

The online platforms used in this study were approved by the UCL Data Protection Office. In order to maintain confidentiality and the security of the stimuli included in the survey, further measures were employed. Observers completing the online survey were not able to download, save or share the videos, they were not able to access the survey more than once, their survey link expired after a specified length of time and the survey was closed once the target sample size was achieved. No personal information about the video participants (i.e. women with TS and TD controls) was shared with the observer participants. Lastly, data from partially completed surveys was not used in the final analysis, as a way to protect the right of observer participants to withdraw from online research. This is in accordance with internet-mediated research guidelines (British Psychological Society, 2017).

Survey construction and data collection. The Qualtrics survey platform (Qualtrics, 2019) was used to create the online survey, and participants were able to access the survey either on their personal computers or on their mobile devices. After

providing informed consent, each observer viewed and rated 25 stimuli, 5 from each presentation modality. Each stimulus pertained to one of the 25 video participants (i.e. women with TS and TD controls). To avoid carry-over effects, observers were presented with only one presentation modality for each video participant. Moreover, in order to ensure that each video participant was only viewed and rated once by the observers, but that all presentation modalities were viewed and rated, five survey versions were created (see Appendix E for a visual depiction of the survey construction process). The survey versions were randomly allocated to observers and the programme guaranteed that approximately equal numbers of participants would complete each version (see Figure 2 for numbers). All observers were given the same instructions for completing the survey (see Appendix F).

The stimuli were presented one at a time, and observers were asked to rate each one on the First Impressions Assessment Scale. To reduce order effects, stimuli were presented in a random order. The survey was designed as a single-blind study, as the clinical status (i.e. TS or TD) of the video participants was not disclosed to the observers, and there was no mention of TS in the survey. At the end of the survey, observers were asked to state whether they knew any of the video participants in the clips. This resulted in six individuals responding that they did know someone from the videos, therefore their data was excluded from the study as their ratings could have been biased. A likely explanation for this could be that video participants in the TD control group were recruited from the same institution as the observer participants.

The survey was first piloted with 5 observers, to ensure that it ran smoothly and that there were no problems with the presentation of the stimuli. Feedback was gathered and no adjustments were required after the piloting. As such, the piloting data was included in the final sample.

Design. This study was based on a fully within-subjects experimental design, as the observers were exposed to all conditions. Each observer participant rated video participants from both the TS and the TD groups, and from all five presentation modalities.

Data analysis.

Aims 1 and 2. The internal consistency of the First Impressions Assessment Scale and its two subscales was explored using inter-item correlations, and Cronbach's alpha tests. In order to pursue Aim 1, which was to investigate whether the personal characteristics of women with TS were evaluated more negatively by observers than those of TD controls, a 2 (Group: TS, TD) by 5 (Presentation Modality: Audio-Visual, Video-only, Audio-only, Still Image, Transcript) repeated measures Analysis of Variance (ANOVA) was conducted. Group and Presentation Modality were included as within-subjects independent variables, and the Character Traits subscale mean scores were treated as the dependent variable. The goal was to find the main effect of Group and Presentation Modality on the subscale scores, as well as the interaction effects between the two independent variables.

To achieve Aim 2, a similar two-way repeated measures ANOVA was conducted with Group and Presentation Modality as the within-subjects independent variables, and the Behavioural Intent subscale mean scores as the dependent variable. The goal was to evaluate whether observer intentions to engage with the women socially were different for those in the TS and the TD groups, and whether this varied as a function of Presentation Modality.

A further series of exploratory analyses was run, by conducting ten two-way repeated measures ANOVAs, one for each item in the First Impressions Assessment

Scale as the dependent variable. Additionally, a two-way repeated measures ANOVA was conducted with Group (TS, TD) and Item (the 10 items of the First Impressions Assessment Scale) as the independent variables and the mean item score as the dependent variable, as well as an ANOVA with Group and Presentation Modality as independent variables and mean modality score as the dependent variable. The aim of these analyses was to explore the group effects at the item and the modality levels. As multiple ANOVAs were conducted, the Bonferroni correction (Bonferroni, 1936) was applied when interpreting the significance of all tests, with the aim to reduce Type I error.

Aim 3. The final aim of the study was to evaluate to what extent ratings on character traits would relate to ratings on behavioural intent. To achieve this aim, two correlation tests were conducted to assess the relationship between the Character Traits subscale scores and the Behavioural Intent subscale scores for the TS and TD groups. Moreover, inter-item correlations were conducted between all the First Impressions Assessment Scale items, separately for the two groups, to further evaluate the associations between ratings on the different character traits and social intentions.

ANOVA assumptions. The data were inspected to determine whether they met the assumptions underlying repeated measures ANOVA. Twelve significant outlier values were detected in the data. ANOVA tests were conducted with and without the outliers, and their removal did not appear to affect the results. It was thus decided to report the results of the whole sample, rather than delete these values. The normality of the distributions of the dependent variables was checked using the Shapiro-Wilk test and by examining their histograms as well as the skewness and kurtosis statistics. These indicated departure from normality for some of the variables. Nevertheless, ANOVA tests are robust to violations of the normality assumption (Blanca, Alarcón,

Arnau, Bono, & Bendayan, 2017) and it has been suggested in the literature that with samples larger than 30 cases, normality deviations are not a cause for concern, due to the effects of the central limit theorem (Ghasemi & Zahediasl, 2012). Therefore, it was decided it would be appropriate to proceed with the ANOVA analyses, especially given that the sample of the current study was considerably larger than 30 ($N= 204$).

Mauchly's Test of Sphericity indicated that the sphericity assumption was violated by the data, for all the tests that were conducted. Consequently, the multivariate rather than univariate ANOVA test results were reported, as these are not influenced by sphericity violations (Hill & Lewicki, 2006). Partial eta-squared (η_p^2) standardised effect sizes were also calculated for the ANOVA results; these can be interpreted as small (0.01), medium (0.06) and large (>0.14) (Cohen, 1988). Cohen's *d* effect sizes were calculated for all post-hoc tests; these can be interpreted as small (0.20), medium (0.50) and large (0.80) (Cohen, 1988). Cohen's *f* effect sizes, which were previously reported for the sensitivity analysis, can be interpreted as small (0.10), medium (0.25) and large (0.40) (Cohen, 1988).

Results

Character Traits subscale. Prior to running the analyses, the internal consistency of the Character Traits subscale was assessed and revealed acceptable reliability of the subscale (Cronbach's $\alpha= .72$, average inter-item correlation $r= .33$). A 2 (Group) by 5 (Presentation Modality) repeated measures ANOVA found a large and significant main effect of Group ($F (1, 203) = 269.14, p<.001, \eta_p^2=.57$), indicating that women with TS were rated significantly differently from TD women on their character traits. A large and significant main effect of Presentation Modality was also found ($F (4, 200) = 8.85, p<.001, \eta_p^2=.15$), suggesting that ratings differed based on which modality was observed, regardless of the effect of Group. A medium

significant interaction effect between Group and Presentation Modality was also found ($F(4, 200) = 7.48, p < .001, \eta_p^2 = .13$) demonstrating that the effect of Group differed across the various modalities (see Figure 3; note that higher scores indicate more positive impressions).

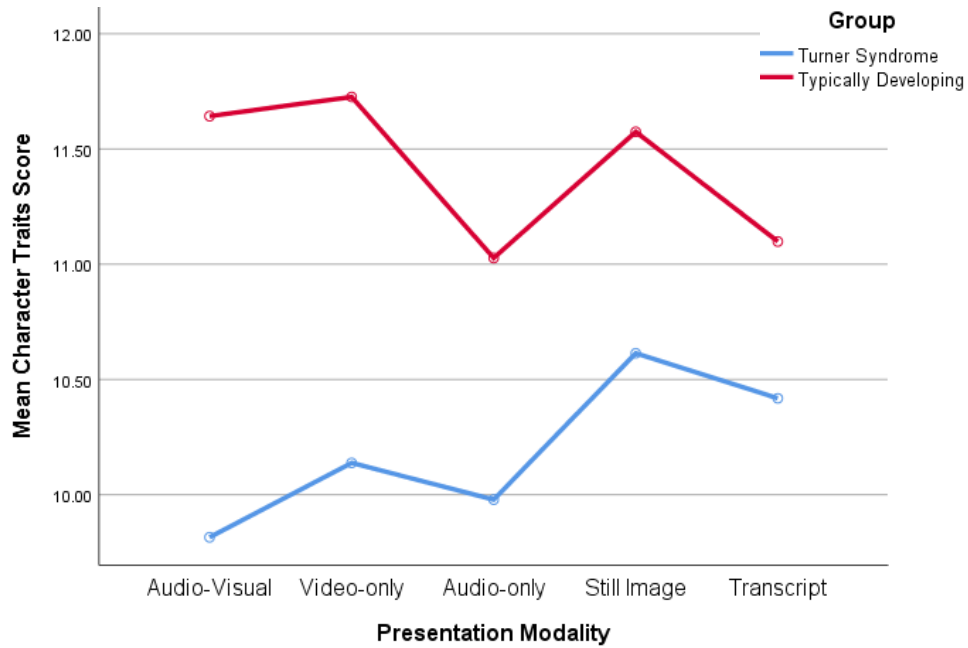


Figure 3. Line graph of Character Traits subscale mean scores by Presentation Modality and Group.

Post hoc tests using the Bonferroni correction showed that women with TS were rated significantly more negatively than TD participants across all modalities, as seen in Table 5 and Figure 3. Moreover, within the TS group, the worst ratings were given in the Audio-Visual modality and best ratings in the Still Image modality. The TD group was rated the lowest in the Audio-only modality and the highest in Video-only modality.

Table 5

Post Hoc Tests of Group Means within each Modality, for the Character Traits and Behavioural Intent Subscales

Modality	Turner Syndrome		Typically Developing		95% CI		p^a	d
	Mean	SD	Mean	SD	LL	UP		
Character Traits Subscale								
Audio-Visual	9.82	2.16	11.64	1.81	1.47	2.18	<.001**	0.91
Video-only	10.14	1.86	11.73	1.85	1.31	1.87	<.001**	0.86
Audio-only	9.98	2.13	11.03	1.80	0.75	1.35	<.001**	0.53
Still Image	10.61	1.68	11.57	1.76	0.71	1.21	<.001**	0.56
Transcript	10.42	2.57	11.10	2.02	0.26	1.10	.002*	0.29
Behavioural Intent Subscale								
Audio-Visual	7.23	1.80	8.48	1.64	1.00	1.49	<.001**	0.73
Video-only	7.59	1.61	8.37	1.66	0.58	0.99	<.001**	0.48
Audio-only	7.49	1.70	7.97	1.67	0.26	0.71	<.001**	0.28
Still Image	7.85	1.64	8.27	1.71	0.22	0.62	<.001**	0.25
Transcript	7.58	2.00	8.00	1.71	0.13	0.72	.005*	0.23

Note. For the Character Traits subscale, scores can range from 0 to 18, with higher scores indicating more positive impressions. For the Behavioural Intent subscale, scores can range from 0 to 12, with higher scores indicating greater intention to engage with that person. SD= standard deviation; CI = confidence interval of the mean difference; LL = lower limit; UL= upper limit; d = Cohen's d .

^aBonferroni corrected.

* $p < .01$. ** $p < .001$.

Behavioural Intent subscale. The internal consistency of the Behavioural Intent subscale was also acceptable (Cronbach's $\alpha = .74$, average inter-item correlation $r = .42$). Similar to the findings from the character traits analysis, a 2 (Group) by 5 (Presentation Modality) repeated measures ANOVA revealed a large and significant main effect of Group ($F(1, 203) = 125.63$, $p < .001$, $\eta_p^2 = .38$), a medium significant

main effect of Presentation Modality ($F(4, 200) = 5.35, p < .001, \eta_p^2 = .10$) and a large significant Group by Modality interaction effect ($F(4, 200) = 9.02, p < .001, \eta_p^2 = .15$) on the behavioural intent subscale scores, indicating that the effect of Group varied as a result of the presentation modality (see Figure 4; note that higher scores indicate greater intention to engage socially).

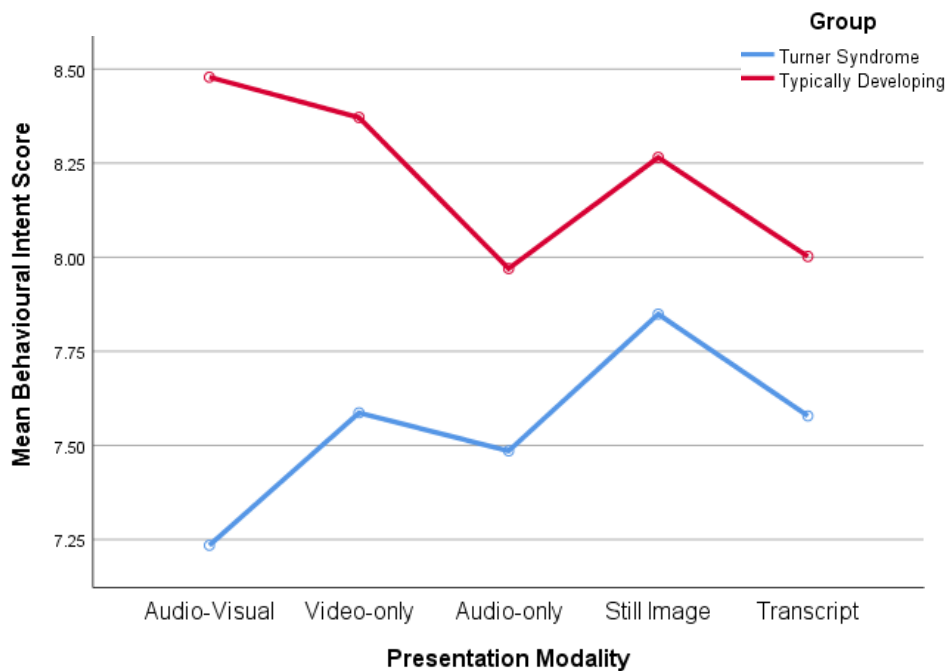


Figure 4. Line graph of Behavioural Intent subscale mean scores by Presentation Modality and Group.

Post hoc tests using Bonferroni correction were all significant. Observers gave women with TS lower ratings on the behavioural intent questions than TD controls, suggesting they would be more reluctant to engage socially with them. This was the case across all modalities (see Table 5). Women in the TS group were given the lowest ratings in the Audio-Visual modality and the highest in the Still Image modality, as was also the case for the character traits scores. TD participants were rated the lowest in the Audio-only modality, as before, and the highest in the Audio-Visual modality.

Individual item and modality scores. Given the significant findings of the subscale tests, a further 2 (Group: TS, TD) by 10 (Item: the individual items on the First Impressions Scale) ANOVA was conducted to explore the group effects at the item level. This revealed a large significant main effect of Group ($F(1,203)= 285.62$, $p<.001$, $\eta_p^2= .59$), a large significant main effect of Item ($F(9,195)= 60.96$, $p<.001$, $\eta_p^2= .74$) and a large significant interaction effect between the two ($F(9,195)= 26.77$, $p<.001$, $\eta_p^2= .55$). Post hoc tests indicated that that women with TS were rated significantly worse than TD controls on all individual items of the questionnaire, with the biggest differences in the Awkward and Attractive items (see Figure 5 for graph and Table 6 for post hoc test results).

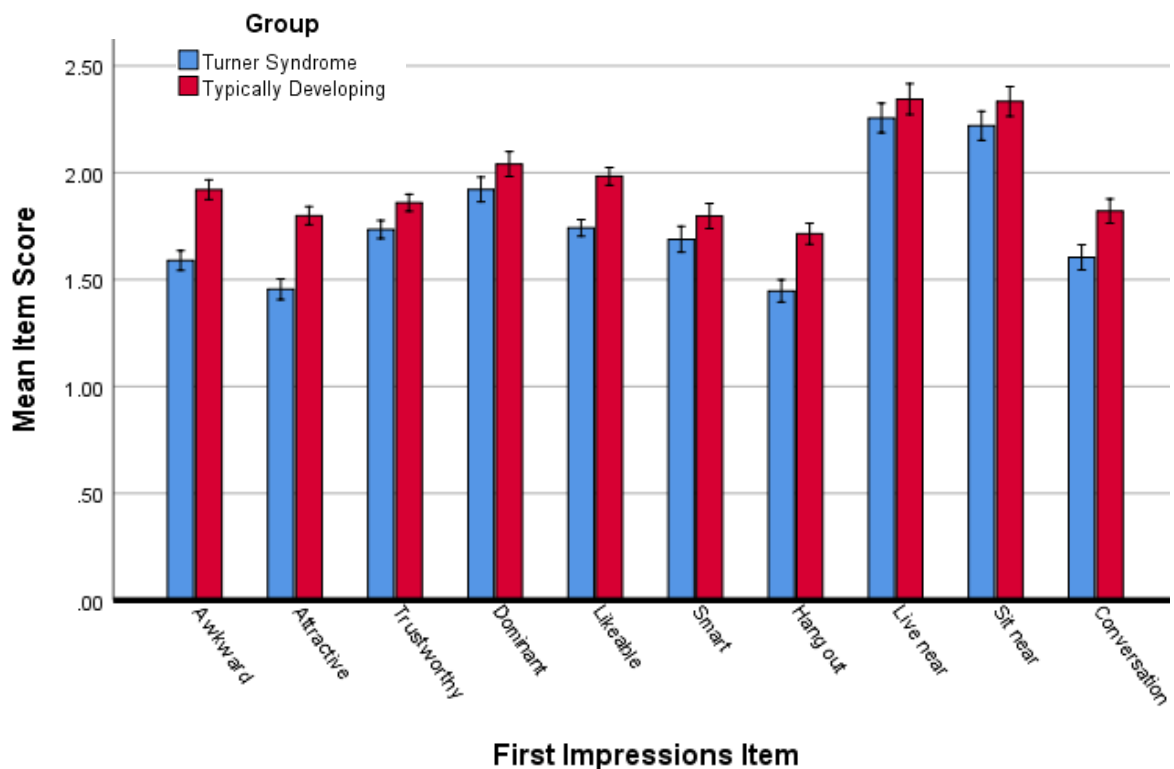


Figure 5. Bar graph of the TS and TD group mean scores on each item of the First Impressions Assessment Scale, with 95% confidence intervals.

Table 6

Post Hoc Tests of Group Means within the First Impressions Assessment Scale Items and within each Presentation Modality

Item	Turner Syndrome		Typically Developing		95% CI		p^a	d
	Mean	SD	Mean	SD	LL	UL		
Awkward	1.59	.34	1.92	.33	0.29	0.38	<.001**	0.98
Attractive	1.45	.35	1.80	.31	0.31	0.38	<.001**	1.06
Trustworthy	1.73	.30	1.86	.29	0.09	0.16	<.001**	0.44
Dominant/ Aggressive	1.92	.42	2.04	.42	0.08	0.16	<.001**	0.29
Likeable	1.74	.28	1.98	.30	0.21	0.28	<.001**	0.83
Smart	1.69	.44	1.80	.43	0.08	0.14	<.001**	0.25
Hang out	1.45	.38	1.71	.36	0.23	0.31	<.001**	0.70
Live Near	2.26	.50	2.34	.52	0.06	0.12	<.001**	0.16
Sit Near	2.22	.49	2.33	.50	0.08	0.15	<.001**	0.22
Conversation	1.60	.42	1.82	.41	0.18	0.25	<.001**	0.53
Modality								
Audio-Visual	1.71	.36	2.01	.32	0.25	0.36	<.001**	0.88
Video-only	1.77	.31	2.01	.32	0.19	0.28	<.001**	0.76
Audio-only	1.75	.34	1.90	.32	0.11	0.20	<.001**	0.45
Still Image	1.85	.30	1.98	.32	0.10	0.19	<.001**	0.42
Transcript	1.80	.43	1.91	.34	0.04	0.18	.001*	0.28

Note. Scores can range from 0 to 3, with higher scores indicating more positive impressions. SD= standard deviation; CI = confidence interval of the mean difference; LL = lower limit; UL= upper limit; d = Cohen's d .

^aBonferroni corrected.

* $p < .01$ ** $p < .001$.

A 2 (Group: TS, TD) by 5 (Presentation Modality) ANOVA was then conducted to explore the group effects at the modality level. This revealed a large significant main effect of Group ($F(1,203)= 237.59, p<.001, \eta_p^2= .54$) and of Modality ($F(4,200)= 8.70, p<.001, \eta_p^2= .15$) and a large significant interaction between these two ($F(4,200)= 9.17, p<.001, \eta_p^2= .16$). Post hoc tests indicated that that women with TS were rated significantly worse than TD women on all five modalities, with the worst scores in the Audio-Visual, Video-only and Audio-only modalities (see Figure 6 for graph and Table 6 for post hoc test results).

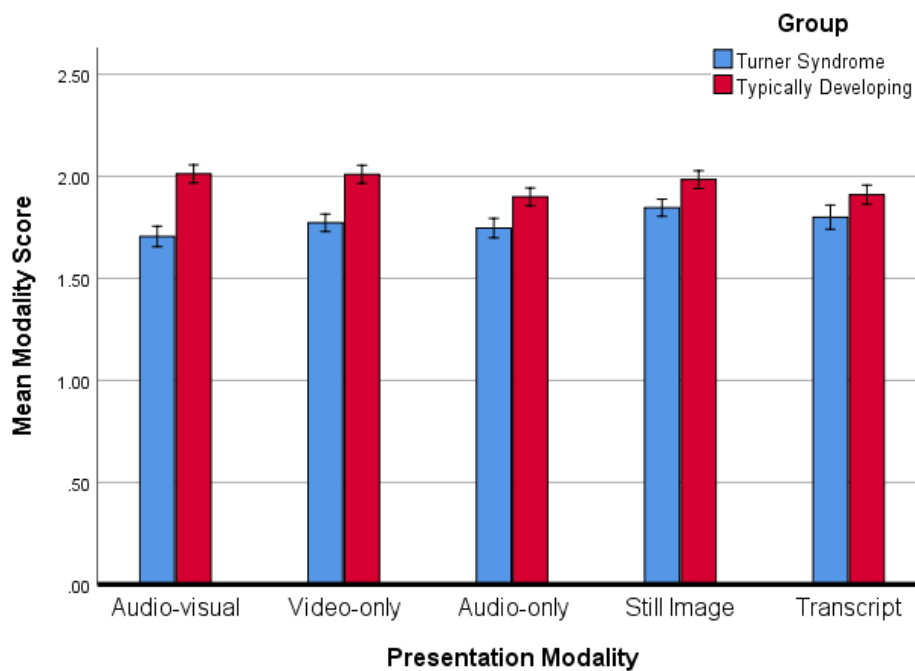


Figure 6. Bar graph of TS and TD group mean scores for each presentation modality, with 95% confidence intervals.

Ten exploratory two-way ANOVAs, one for each individual item of the First Impressions Scale were conducted, comparing the Group and Presentation Modality variables (see Appendix G for detailed results). For the Awkward, Likeable, Dominant/Aggressive and Smart items, there was a significant main effect of Group, a significant main effect of Presentation Modality and a significant interaction effect,

indicating that women with TS were rated substantially differently from TD controls on these items, and this varied as a function of presentation modality. For the Attractive, Hang out, Sit Near and Conversation items, there was a main effect of Group and an interaction effect, but the main effect of Presentation Modality was not significant, meaning that for those items the presentation modality by itself did not contribute to differences in the item scores, however the Group did and this also varied across the different modalities.

Lastly, for the Trustworthy and Live Near items, there were significant main effects of Group and Presentation Modality, but no significant interaction effect, suggesting that the group differences did not vary as a result of modality. In these exploratory analyses, the main effect of Group was always significant, whereas the main effect of Presentation Modality and the interaction effect varied in their significance. This may indicate that the Group variable was the most significant contributor to observer responses.

Correlations. A strong positive correlation was found between the character trait scores and behaviour intent scores, both for the TS group ($r = .65$, $p < .001$, $n = 204$) and the TD group ($r = .71$, $p < .001$, $n = 204$), suggesting that more positive scores on character traits related to greater reported likelihood of engaging with that person socially.

Further inter-item correlations were conducted for both groups (see Table 7). For the TS group, attractiveness, trustworthiness, likeability and intelligence showed strong positive correlations with the intention to hang out ($r = .50-.66$, $p < .01$) and to have a conversation with that person ($r = .40-.56$, $p < .01$). Additionally, likeability showed strong positive correlations with trustworthiness, attractiveness and

intelligence ($r=.55-.69$, $p<.01$). For the TD group, likeability showed strong positive correlations with all the behavioural intent items ($r=.43-.70$, $p<.01$) and with attractiveness and trustworthiness. Moreover, trustworthiness and intelligence showed moderate to large positive correlations with the behavioural intent items ($r=.32-.59$, $p<.01$). Attractiveness also seemed to relate to how likeable, smart and trustworthy TD participants were perceived to be ($r=.46-.54$, $p<.01$). For both the TS and TD groups dominance seemed to show the smallest correlations to all other items, with the exception of the Live Near or Sit Near items, suggesting that observers are more likely to wish to be near someone who appears more submissive and less aggressive.

Table 7

Summary of Intercorrelations for Scores on Each Item of the First Impressions Assessment Scale

Item	1	2	3	4	5	6	7	8	9	10
1. Awkward	–	.23**	.20**	.07	.33**	.30**	.22**	.22**	.24**	.20**
2. Attractive	.16*	–	.48**	-.02	.60**	.52**	.60**	.14*	.19**	.43**
3. Trustworthy	.23**	.53**	–	.25**	.69**	.43**	.50**	.26**	.31**	.40**
4. Dominant/ aggressive	.18**	-.03	.20**	–	.17*	-.00	.06	.30**	.30**	.07
5. Likeable	.38**	.54**	.72**	.24**	–	.55**	.66**	.27**	.33**	.56**
6. Smart	.18**	.46**	.53**	.13	.60**	–	.52**	.23**	.29**	.44**
7. Hang out	.24**	.51**	.59**	.15*	.70**	.56**	–	.07	.20**	.64**
8. Live Near	.37**	.16*	.34**	.38**	.43**	.32**	.29**	–	.83**	.18*
9. Sit Near	.37**	.13	.32**	.43**	.45**	.35**	.32**	.88**	–	.30**
10. Conversation	.22**	.40**	.40**	.15*	.58**	.42**	.65**	.30**	.35**	–

Note. Intercorrelations for the Turner Syndrome group are presented above the diagonal (in blue) and intercorrelations for the Typically Developing group are presented below the diagonal (in red).

* $p < .05$. ** $p < .01$.

Discussion

This study examined observer first impressions of women with TS and TD controls, based on brief stimuli of real-world social performance presented in various modalities. The aims included: 1) to explore observer impressions of the personal characteristics of the women, 2) to investigate observer behavioural intention to engage in further interaction with the women, and 3) to evaluate the relationship between first impressions and behavioural intentions.

Aim 1: Impressions of Personal Characteristics

Women with TS were rated significantly less favourably than TD controls on the Character Traits subscale of the First Impressions Assessment Scale and on all the individual traits assessed, and this was the case across all five presentation modalities. The lowest ratings for women with TS were given for attractiveness, which also had the largest group effect size amongst the individual traits. One potential explanation for the lower attractiveness ratings could be the physical abnormalities caused by the syndrome, such as low hairline, webbed neck and droopy eyelids (Gravholt, 2009). Even though the women with TS included in this sample did not present with significant physical differences and stature could not have affected the ratings as the women were shown from the torso upwards in the clips, it is possible that observers were sensitive to even subtle variations in facial characteristics. This would be in line with previous research indicating that facial asymmetry or abnormalities that deviate from the average lead to the individual being deemed as less attractive (Rhodes, 2006).

Appearance, especially facial characteristics, influences perceptions of traits such as likability (Olivola & Todorov, 2010). Greater perceived attractiveness has also

been found to relate to more positive perceptions of personality and other traits of that person, such as perceived trustworthiness and intelligence (Talamas, Mavor, & Perrett, 2016), as well as to more favourable treatment by others (Langlois et al., 2000). Therefore, it is a possibility that lower scores in other character traits of the women with TS in this study were affected by an attractiveness halo effect. Despite the low scores on the attractiveness item, the highest (i.e., most favourable) scores on the Character Traits subscale for women with TS were in fact given in the Still Image and the Transcript modalities, whereas scores for the Audio-Visual, Video-only and Audio-only modalities were lower. This may indicate that lower attractiveness scores were not about how the women looked or what they said, but may relate more to how they performed in the dynamic modalities.

The second worse rating for women with TS was in terms of the awkwardness item, where they were judged to be significantly more awkward than TD controls. This was the case across all modalities except Transcript, indicating that the issue may not be their speech content but the visual and auditory characteristics of their social expression that leads to these judgments. To our knowledge there is no literature into observer judgments of women with TS, therefore there are no directly comparable studies. There are, however, several studies in the ASD literature that have demonstrated that individuals with ASD are judged as more socially awkward than controls on video and audio clips as short as 1 second, and this seems to relate to atypicality of facial expressions and prosody (Grossman, 2015; Grossman, Edelson, & Tager-Flusberg, 2013). Additionally, Sasson and colleagues (2017) who used the same methodology as this study, also found that adults with ASD were judged more

negatively on their character traits than controls, with the largest effect size for the awkwardness item.

In previous research, women with TS have been reported to have social competence impairments (Skuse, 2009; Wolstencroft & Skuse, 2018). Hong, Dunkin and Reiss (2011) assessed girls with TS using the Social Responsiveness Scale (SRS; Constantino & Gruber, 2012), a parent rated questionnaire designed to assess the social ability and severity of social impairment related to autistic traits in children. They found that the SRS scores for girls with TS were higher than those of controls, and were often in the clinical range, indicating greater social dysfunction similar to that found in ASD. It could therefore be hypothesised that the social communication deficits associated with TS lead to the girls being perceived as more socially awkward, in a similar way to those with ASD, which could also have affected how they were rated on other traits as well.

Aim 2: Behavioural Intentions

Observers reported significantly reduced behavioural intention to engage socially with the women with TS as compared to TD controls, across all presentation modalities. The worst ratings were given in the Audio-Visual modality and the best in the Still Image modality. When the behavioural intent items were analysed individually, it was found that the highest scores for women with TS were given for the Live and Sit Near items, which involve proximity rather than interaction. The worst scores were given for the Hang Out item, where women with TS were rated significantly worse than TD women on all modalities, apart from the Transcript one. This may indicate that observer reluctance to engage in further social interaction with women with TS does not seem to be related to what they say, but rather it may be

linked to the visual and auditory elements of their presentation. There are no directly comparable results from the TS literature, however, these findings are similar to outcomes from the ASD literature that demonstrated that observers reported reduced willingness to interact with individuals with ASD than controls (Matthews, Ly, & Goldberg, 2015; Sasson et al., 2017).

These findings are also in line with research reporting greater levels of loneliness and fewer friendships and relationships in TS (Jež et al., 2018; Wolstencroft & Skuse, 2018). In the current study, the women with TS themselves reported having fewer friendships and peer interactions on the SCPQ than the TD controls did. It could thus be hypothesised that having fewer social relationships may in part relate to reluctance from others to socially interact further with the women.

Aim 3: Relationship between Trait Impressions and Social Intentions

A strong association was found between character trait scores and behavioural intention scores, suggesting that more positive judgments of the personal characteristics of the women led to a greater reported wish to engage in further social interaction with them. This is in line with recent findings that show that less favourable judgments of the character traits of adults with ASD were associated with observers' decreased behavioural intentions to engage with the individuals with ASD further (Faso, 2016; Sasson et al., 2017). These results are supported by research suggesting that first impressions can have a lasting impact on observer attitudes and judgments, which then influence subsequent behaviour and social decisions towards that person (Sunnafrank & Ramirez, 2004). Positive first impressions can promote the development and maintenance of friendships and often also determine the quality of those relationships (Human et al., 2012).

In the current study, the likeability trait was highly associated with most other items, especially the behavioural intent items. This is not surprising, given that the more we like someone and the more positive impressions we have of them, the more likely we would be to want to spend more time with that individual (Ambady et al., 2000). On the other hand, a negative first impression can lead to more avoidant rather than approach behaviours, such as rejection or social exclusion (Belch, 2005; Harris & Garris, 2008). The findings of this study may also relate to ingroup and outgroup dynamics that can often implicitly influence social behaviour (Brewer, 1999). Based on social identity theories, people are more likely to behave favourably towards their ingroup members, with whom they identify and feel they share similar characteristics, as this creates a sense of belonging and group identity (Brewer, 1999). On the other hand, people are often biased against those who they perceive to be different, even in subtle ways, and as a result may be less motivated to engage in positive social behaviours towards those considered to be in the outgroup (Hobson & Inzlicht, 2016).

The Impact of Presentation Modality

Women with TS were repeatedly rated worse than TD women across all modalities, in all the tests that were conducted. Nevertheless, a consistent finding was that the ratings for women with TS were better on the static modalities (i.e. Still Image and Transcript), than the dynamic modalities (i.e. Audio-Visual, Video-only, Audio-only). The best ratings for women with TS were given in the Still Image modality, which seems to contradict the idea that the visual characteristics of the syndrome drive social judgments. Rather, a possible reason for the current findings may relate to the dynamic social presentation of the women with TS. Dynamic differences and even subtle changes in movement (e.g. gestures, facial expressions) that appear atypical can

affect judgments and perceptions of that person's character and emotional states (Bould & Morris, 2008; Krumhuber, Kappas, & Manstead, 2013; Metallinou, Grossman, & Narayanan, 2013). On the other hand, static or still images provide observers with less social information.

Nonverbal communication includes the use of signals such as smiling, eye contact and gestures, but also relates to the way these are delivered, for instance their timing, intensity and naturalness (Schachner, Shaver, & Mikulincer, 2005). Through the use of effective nonverbal behaviours, individuals can signal to others what their needs are, which in turn can increase the likelihood of eliciting a response that would meet those needs (Schachner et al., 2005). In addition, nonverbal communications can convey the affective state and social intentions of an individual, and others can use this information to make inferences about that person; for instance, whether they are friendly or approachable (Rule & Ambady, 2008).

As a result, deficits in nonverbal communication can have a significant adverse impact on the quality of social interactions and relationships (van Beek & Berg, 2019). For instance, it has been found that reduced nonverbal signals by an individual are related to conversation partners reducing their nonverbal behaviours in response, or responding more negatively towards that person (van Beek & Berg, 2019). In the ASD literature, deficits in non-verbal dynamic signals, namely facial expressions and tone of voice, have been found to be associated with more negative judgments, and perceptions of people with ASD as socially awkward (Faso, Sasson, & Pinkham, 2015; Grossman, 2015; Grossman et al., 2013). The findings of the current study are in line with the aforementioned literature on the impact of nonverbal communication, as previous studies have suggested that women with TS show reduced facial movements

in comparison to controls (Lesniak-Karpiak et al., 2003) and poor oral fluency (Temple, 2002), which may in part explain their social difficulties.

The worst ratings for women with TS were given in the Audio-Visual modality. A possible explanation is that this modality contains both visual and auditory signals, so it provides observers with greater social information from multiple sensory channels than the other modalities (Ambady et al., 2000). As such, it may have a cumulative impact on judgments in social interactions, as any social skills impairment would be more evident to others. The almost opposite pattern was found for TD controls, who seemed to obtain the highest scores on the modalities containing visual information (i.e. Audio-Visual, Video-only and Still Image). It thus appears that for TD controls visual information was helpful for getting more positive judgments from observers. It is possible that better social skills and social performance allowed them to use dynamic and visual information to their advantage. This is a similar finding to the pattern found for TD controls in the study by Sasson and colleagues (2017).

Limitations

The findings of the current study need to be considered in light of several limitations. Firstly, given the large variability in symptoms often found in TS, both in terms of the physical characteristics of the syndrome as well as the social skills deficits (Gravholt et al., 2017), the results of this study cannot be generalised to all women with TS. Rather, the findings represent a first attempt at understanding observer impressions of high functioning women with TS aged 16-25, that future studies can expand and build on. Secondly, the social performance task aimed to resemble real life authentic behaviour, nevertheless, it may not have fully reflected real life interactions between people that affect first impression formation (Sasson et al., 2017). Future

research could investigate actual interactions between women with TS and others in their social environment, so that natural social performance and conversation can be evaluated.

Another limitation was that the current study only obtained video participant (i.e. TS and TD) self-ratings with regards to their own difficulties using brief screening tools and did not collect informant ratings or more in-depth assessments of the social difficulties of the video participants. It would be interesting for future studies to obtain both self and informant reports of the social difficulties of women with TS, in order to investigate possible discrepancies in these reports, and also to compare self and informant perceptions to observer-perceptions.

Lastly, observer characteristics that may have influenced the results were not investigated. It is possible that the decision to give high or low ratings was associated with observer characteristics, such as their personality, their own social competence, their mood at the time of completing the survey or their pre-existing biases or stigma towards people with differences (Ambady & Skowronski, 2008; Morrison, DeBrabander, Faso, & Sasson, 2019; Willard, Madon, Guyll, Scherr, & Buller, 2012). Judgments are after all subjective and the observers' contributions to these would be important to consider in future research.

Clinical and Research Implications

The current study was the first to explore first impressions of women with TS, and has used an ecologically valid method that involved observers evaluating spontaneous social performance. The results are important to consider, as negative first impressions, regardless of their validity and accuracy, can create barriers to successful

social interactions (Harris & Garris, 2008). This is especially the case for people who may already be facing significant social challenges, as avoidance and rejection by peers inevitably decrease opportunities for socialisation and for practising social skills further (Boman et al., 2004). Additionally, studies have shown that those who are already shy and withdrawn become even more so when excluded by peers, and social rejection has been associated with more psychological problems and worse outcomes (Mulvey, Boswell, & Zheng, 2017; Oh et al., 2008; Rubin, Burgess, Kennedy, & Stewart, 2003), as well as with bullying and teasing (Rubin, Bukowski, & Parker, 2006).

As the findings of this study suggest, social problems in TS appear to be a bidirectional issue rather than an individual social impairment, as despite the social skills deficits of the individual, societal responses also contribute to the relational difficulties this population experiences. Milton (2013) suggested that social problems should be treated as a relational impairment and interventions should be comprehensive and target both the individual and the systems around them.

On the individual level, the social expression of women with TS (i.e. facial expressions, prosody, gestures) has not been extensively investigated and it would be beneficial for future research to explore this further. A better understanding of the dynamic social expression of girls and women with TS may be used for designing targeted interventions and social skills trainings, which could include compensatory strategies with the aim of improving social performance and social consequences.

Additionally, the current study found that the First Impressions Assessment Scale for Observers (Sasson et al., 2017) had good internal consistency and inter-item

reliability. Given that social competence is often determined by social success, perhaps this method of using the HiSoC task to explore first impressions could be employed in the future as a peer observation paradigm for assessing social competence. It would be compelling for future studies to investigate this further and to compare the First Impression Assessment Scale scores to empirically validated measures of social skills, so as to evaluate its validity as a possible social competence measure.

It would also be beneficial to consider the actions that can be employed on a systemic level, which could help shift negative assumptions and judgments of women with TS. Future interventions should focus on education and raising peer awareness of TS, with the aim of encouraging acceptance of difference, reducing stigma and promoting social integration. For instance, anti-stigma programmes and brief online trainings have been designed for ASD and have been found to improve peer attitudes, acceptance of people with ASD and knowledge of ASD (Gillespie-Lynch et al., 2015; Staniland & Byrne, 2013). Such programmes can be incorporated in schools, universities and the community.

Increasing awareness for parents, teachers and professionals working with women with TS would also be important, as they could encourage social interactions with typically developing peers from an early age. Although first impressions often persist and can be difficult to revise, increased contact and familiarity with groups different than one's own can reduce prejudice and discrimination, and decrease barriers to social integration (Mann & Ferguson, 2017; Pettigrew & Tropp, 2008). Teachers can play an important role in the systemic interventions with girls with TS, as they can support the development and maintenance of positive peer relationships in schools, as well as aid children to develop better social competence (Kemple & Hartle,

1997). Teacher trainings and programmes can assist educators to better understand the social needs and difficulties of children, including those with specific conditions such as ASD or TS (Leblanc, Richardson, & Burns, 2009). This can facilitate teachers to promote positive social interactions and peer acceptance, as well as help reduce bullying and social exclusion in schools (Audley-Piotrowski, Singer, & Patterson, 2015). It has been suggested that programmes that aim to both increase knowledge and decrease stigma yield the most benefits, and promote more meaningful interactions between people from diverse groups (Gardiner & Iarocci, 2014; Morrison et al., 2019). Similar interventions can be designed and promoted in relation to TS.

Conclusion

The current study found that observers formed significantly less favourable first impressions of the personal characteristics of women with TS, than those of TD controls. This was also related to reduced observer intentions to engage with the women with TS in further social interaction. Observers were not aware of the clinical status of the video participants, and the TS label was not mentioned. Therefore, observer responses were not driven by preconceived stereotypes or stigma related to the condition. Nevertheless, the findings do seem to suggest that negative perceptions can be formed quickly and that any divergence from the norm can inadvertently be negatively perceived and can have significant social consequences. Further research is needed to better understand the social problems that can be experienced by women with TS, both from the individual perspective (e.g. difficulties with social performance), as well as the systemic perspective (e.g. first impressions and societal barriers). It would also be critical to employ this more holistic approach to the assessment and treatment of social difficulties in TS.

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Part 3: Critical Appraisal

Overview

In this critical appraisal I share my reflections on the research process as a whole, and consider some of the methodological dilemmas and challenges that I encountered whilst designing and conducting this study. I then reflect on my findings and discuss their broader implications in relation to systemic theories and approaches.

Methodological Dilemmas and Challenges

Researchers are frequently faced with multiple methodological dilemmas when designing and conducting their studies. One common issue is the trade-off between scientific rigor (i.e. choice of optimal or gold standard designs and methods) and the realistic constraints of conducting a research project (i.e. practical limitations, limited resources and time constraints) (Barker, Pistrang, & Elliott, 2002). I also encountered this dilemma at various stages of my research, which required problem-solving and quick but also ethical decision-making.

This study involved multiple levels of recruitment for three separate groups of participants (i.e. women with Turner syndrome (TS), typically developing (TD) controls and observers) and the use of different research methods. This was demanding, as apart from advertising the study, recruiting the participants and collecting the data, it also involved learning how to film and edit the video clips and how to create an online survey with complex logic. Several unexpected situations also caused delays and required additional work or revision of what I had already done. Some of the methodological dilemmas and challenges that were faced during this process are discussed further below.

Changes to Information Governance

I received approval from the UCL Research Ethics Committee and the UCL Data Protection Office in September 2017, and soon after that recruitment was commenced. At that time, all study material and procedures had been designed in accordance to the Data Protection Act (DPA; 1998). In May 2018, the new EU General Data Protection Regulation (GDPR) came into effect and replaced the DPA. The shift to GDPR brought with it increased responsibilities for universities and for the scientific research community, with some of the introduced changes sparking debates and confusion as to the implications of the GDPR for scientific activities (Dove, 2018).

Following the introduction of the GDPR, I did implement the required adjustments to my project. But I also wondered whether the changes that were introduced overcomplicated the research procedures, and whether this in fact hindered rather than supported the research process. One example is that consent forms following the GDPR had to be lengthy and cover every possible situation. Although I understand and agree with the importance of informed consent, which is one of the central tenets of good research, I couldn't help but wonder whether extremely long forms would in fact work against truly informed consent. For instance, overly lengthy forms may result in the participants not reading the form properly or not understanding and engaging with all the details that are involved (Corneli et al., 2017). Overcomplicated consent processes can also be a deterrent to those who may otherwise have wanted to take part in research (British Psychological Society, 2014). This I suppose can be a common challenge in research, where optimal methodology comes with benefits and costs, and a researcher needs to make an ethical, as well as practical, decision, whilst also ensuring that legal obligations are followed.

In the current study, Part A (i.e. recruitment and data collection from women with TS and TD controls) was completed prior to GDPR coming into effect. Part B (i.e. recruitment and data collection from observers) was conducted post GDPR. It thus required a re-designing of the information sheet and consent forms, in order to comply with the change in legislation. It also led to a series of conversations with information governance officers to ensure that I was storing my confidential data in the best way possible, and that the procedures for the online part of my study were the most secure. This process was necessary but also felt challenging at times, as it seemed that the transition to GDPR had led to some confusion between professionals. However, with the help of my supervisors and perseverance, Part B of the study was also completed in line with data governance regulations.

Recruitment and Data Collection

Sample generalisability. A main aim of research recruitment is to obtain a sample of participants that is as representative of the target population as possible, so that the findings can be generalisable (Barker et al., 2002). More stringent inclusion criteria result in a sample that is more homogeneous, which in turn can increase the power of a study to detect effects more precisely and reduce statistical noise. Nevertheless, this can also reduce generalisability, as a homogenous sample would be less representative of more heterogeneous populations (Barker et al., 2002). In the case of TS, women with TS often show great variability in symptomatology and large individual differences in terms of physical characteristics, as well as social and emotional difficulties (Gravholt, 2009). Consequently, we decided that it would be important to have broad inclusion criteria for participation in Part A of the study (i.e. the recruitment of TS and TD video participants), to ensure that the sample of women

with TS would better represent the variability that is found in the TS population. For example, we did not exclude participants with TS who also had traits of ASD, as firstly the TS population has higher rates of ASD (Creswell & Skuse, 1999), and secondly it is not yet clear to what extent social skills difficulties in TS are distinct from those in ASD (Skuse, 2009). If we were to exclude women with TS girls with ASD traits, that would make our sample much less representative of the TS population.

Despite these efforts, it must be acknowledged that the current TS sample might still not be fully generalisable to the entire population of women with TS. This is because the sample did not include women with more severe TS symptoms and physical differences, and additionally the sample was quite small (N=12). This study included multiple levels of recruitment and a lot of practical and technical demands (e.g. filming the video participants, editing the videos and creating a survey). As my time was constrained due to other demands such as clinical placements and other academic assignments, I did not have the flexibility to prolong the recruitment of the video participants. As such, I had to make the decision to stop when 12 participants with TS were recruited, so that I could start the recruitment of the control video participants and move on to the next stage of the study.

Additionally, I was interested in looking at social difficulties and first impressions during late adolescence and early adulthood, because it is a life stage that can often present with additional social pressures for young women with TS (Jež et al., 2018). However, having a specific age range also means that the results might not be generalisable to individuals with TS in other age groups, who may experience different demands in their social environment or who may have found different ways of coping with social pressures. For instance, older women with TS exist in a different

social environment to adolescent girls with TS and may also have had more time to learn and practice their social skills (Suzigan, de Paiva E Silva, Guerra-Júnior, Marini, & Maciel-Guerra, 2011).

It is also worth keeping in mind that participants who choose to get involved in research studies may differ from those who decline to take part, in terms of their motivation, interests and personality (Barker et al., 2002). In the case of women with TS, those who agreed to take part in the current study and to be filmed for it, may have been more socially confident and competent than those who declined. The results of the current study are an important first step in understanding observer impressions of women with TS. However, future research should investigate first impressions and social relationships in TS further, for example with different age groups across the lifespan and different severity of symptoms.

In terms of the control group for Part A of the study, and the observer participants for Part B, again the inclusion criteria were designed to be broad for similar reasons. The observer sample was large (N= 204) and the study had high statistical power, which supports the generalisability of the findings and the probability of detecting an effect that is true. Nevertheless, the majority of controls and observers were recruited through a limited pool of universities, and as such may not be fully representative of the social circles that women with TS find themselves in. Recruitment from schools was attempted, but it proved too challenging, as even though a large number of schools was invited to take part, none responded. Therefore, in order to facilitate recruitment and to be able to obtain the required sample in the time that was available, I had to focus on recruiting through universities and social media.

Observer participant characteristics. The observers in this study were asked to rate the video participants in the stimuli on various dimensions. When considering the results, it is a limitation that no information was obtained regarding observer characteristics. Rater pre-existing world views and attitudes, personality characteristics or even their emotional state might impact on their ratings and bias the results (Isquith, Roth, & Gioia, 2013). The reason such information was not collected was because the online survey was already lengthy, and the addition of extra questions and measures could have overburdened the participants. Respondent burden can lead to a greater chance of participants dropping out of the study, or not being attentive when completing the survey, which would affect data quality (Diehr, Chen, Patrick, Feng, & Yasui, 2005). Additionally, again due to time constraints and the fact that this was a thesis project, additional measures would have required the use of more complex statistical techniques, which would in turn necessitate more time and training.

Internet-Mediated Research (IMR)

Technological advances over the years and the explosion of online platforms and programmes have contributed to changes in how people communicate with each other (Brignall III & Van Valey, 2005). Many social exchanges now occur online and social media and social networking sites are thriving (O’Keeffe, Clarke-Pearson, & Council on Communications and Media, 2011). This has created new opportunities for psychological research. For example, experimenters can now use online platforms (e.g. social media sites) to increase accessibility to their research and recruit larger and more diverse samples of people in a more efficient, quick and low-cost way than before (Nosek, Banaji, & Greenwald, 2002). Researchers can also directly study online social phenomena by observing online behaviour and communications (Kraut et al., 2004).

Additionally, the use of online survey software to collect data can save time and lead to datasets with fewer errors (Kraut et al., 2004). This is because the data is not entered by a human, but rather the software automatically records participant responses, which can then be exported as a complete dataset (Kraut et al., 2004). Such software can also be used to design surveys with complex logic and experimental manipulations, as well as collect metadata such as completion time and date.

IMR does not lead to more risks than traditional offline research, it just gives rise to different ethical considerations and methodological dilemmas that are specific to the online nature of the risks (Kraut et al., 2004). These mainly arise due to the researcher having less control over the process, and being less able to monitor the recruitment and data collection, due to the lack of face-to-face contact with the participants (Nosek et al., 2002). Part B of the current study involved IMR, as observers were recruited online and participated in an online survey. In order to mitigate the aforementioned risks and to manage the methodological dilemmas that came up in relation to the online part of my study, I followed the IMR guidelines (British Psychological Society, 2017) and the advice of my supervisors.

A common issue in IMR relates to the challenge of establishing that participants have carefully read the study information and then properly engaged with the consent process (Nosek et al., 2002). IMR also complicates how researchers can determine whether a participant wishes to withdraw from a study. For instance, if someone exits the survey before completing it, it can be difficult to judge whether this means they changed their mind and withdrew their consent or whether they would be happy for their partial data to be used (Kraut et al., 2004). IMR guidelines (British Psychological Society, 2017) suggest that valid consent for online recruitment can be

assumed, as long as an information sheet is provided and the participant completes the survey. Therefore, at the start of my survey I included an information page and a downloadable information sheet, which was followed by a consent page with clear consent statements and a tick box for participants to select 'I consent'. If a participant clicked 'I do not consent', they were taken to an exit page and could not return to the survey. Partial responses in the online survey were excluded from the analysis, as it was deemed safer to assume that participants that did not finish the survey wished to withdraw their consent (British Psychological Society, 2017).

Another challenge in IMR that derives from the absence of direct contact with the researcher is that it can be difficult for researchers to verify that the participants do indeed meet the required demographic criteria for taking part, and to monitor the context and the conditions under which participation occurred (Kraut et al., 2004). In controlled settings where a participant completes a task in the presence of the researcher, it is easy to firstly verify the identity of the participant and secondly ensure a setting with limited distractions. In IMR though, other methods need to be used in order to minimise the risks to data integrity associated with this issue (British Psychological Society, 2017).

In order to prevent wrongful participation in the current study, if a potential participant indicated they did not meet the age criterion, they were directed to an exit page and were unable to re-enter the survey. Repeat participation was prevented by the programme so as to ensure that the data was not compromised. Furthermore, the inclusion criteria were kept broad and the study was advertised on platforms that would attract participants that were more likely to meet those criteria. The collection of a large sample also meant that small deviations or noise would be less impactful and

meaningful effects could be detected. Finally, having no control over the conditions in which the survey was completed was perhaps more ecologically valid in the case of the present study. This is because young people make social judgments about others online all the time (O’Keeffe et al., 2011), and studying how these occur without us intervening in the setting may have led to more realistic conditions for first impression formation.

Lastly, with online research there can be additional threats to privacy and confidentiality, as third providers run the online platforms that collect and store the data, and the researcher has less control over them (Nosek et al., 2002). To mitigate these risks in my study, I used online platforms that had been approved by the ethics and data protection committees and was explicit in the information sheets about how the data would be used. For instance, the video clips of my video participants constitute personal data because the participants could be identified from the clips. The information sheet explained that they would be filmed and those clips would be shared with observers of a similar age in an online survey, therefore participants were aware of what they were consenting to. No other identifiable information about the video participants was shared with the observers. Moreover, I ensured that observers would not be able to download, save or share the stimuli in the survey, and that they would not be able to access the survey more than once.

In order to safeguard the information of the observers further, I also ensured that the software would not track their IP addresses. Observers who wished to be included in the prize draw or be given course credit had the option to give their name and email, however these were not included in the analysed dataset, which was anonymised. The current study was considered low risk; therefore, it was deemed

sufficient to attempt to minimise the IMR risks through the aforementioned methods that are also recommended by IMR guidelines (British Psychological Society, 2017) and through the collection of a large enough sample.

Reflections on the Results

The findings of my study were disagreeable in many ways, as they revealed what many women with TS may already be fearing. That is, typically developing observers judged women with TS in this study more negatively and appeared to be more reluctant to interact with them in social situations. Discovering these results was unpleasant. As a clinician, I often work with people who have experienced the painful and harmful effects of stigma and discrimination, and who have suffered as a result of social exclusion and bullying. On a personal level, I have myself experienced fears about others' judgments of me and I want to make a good impression in my social interactions. After all, as humans we are inherently social beings and most of us place great importance on our social relationships.

As researchers and psychologists, we have a social responsibility and moral duty to consider the consequences of our findings and to ensure that the benefits of new knowledge would outweigh the costs (British Psychological Society, 2014). With this in mind, I was faced with a scientific dilemma as to the potential advantages and risks of reporting my findings. Such dilemmas must have been faced by other researchers who have used a similar paradigm to assess social performance and first impressions, such as in the autism or psychosis literature (Gibson, Penn, Prinstein, Perkins, & Belger, 2010; Sasson et al., 2017). I had to consider the implications of my research and how to best present the findings in any publications that may arise from

this work, so as to reduce harm to participants and readers. I was aware that even though the participants with TS had consented to taking part, hearing the results could be distressing for them and could have an impact on their self-esteem. Moreover, it may also have an impact on other women with TS and their families who may come across this work, or professionals and researchers involved with the TS community.

On the other hand, this research was the first to investigate observer impressions of women with TS. As such, it may constitute an important step towards filling some of the gaps in our knowledge about social relationship difficulties in TS, and may also validate the experiences of women with TS who have struggled in their social relationships. After all, in order to be able to create any positive change we firstly need to have a better understanding of what contributes to the creation and maintenance of problems. Therefore, I understood that it was important not to shy away from reporting unpleasant results, but at the same time I aimed to ensure that these were reported in a sensitive and thoughtful manner, always keeping in mind that women with TS would be reading the published reports. Additionally, I wanted to emphasise that despite the negative results, it is important not to become pessimistic or blind to the fact that many girls and women with TS are functioning well in their social environments, report good life satisfaction and have many strengths and protective factors that need to also be acknowledged (Gould, Bakalov, Tankersley, & Bondy, 2013; McCauley, Feuillan, Kushner, & Ross, 2001).

From the Individual to the System

The findings of this study are in line with systemic theories and models, that emphasise how the different systems around an individual often contribute to the creation and maintenance of problems (Bronfenbrenner, 1979). One example is the

Ecological Systems Theory (Bronfenbrenner, 1979) which describes four main layers of context and systems that influence an individual; these include: the microsystem (i.e. immediate environment such as family and peers), the mesosystem (i.e. interaction between the different agents of the microsystem, such as parent and teacher interactions), the exosystem (i.e. neighbourhood, social services, workplace), and the macrosystem (i.e. culture, politics, history, societal beliefs and more). All these, along with the personal characteristics of the individual, interact and affect one another in various ways over time and impact on wellbeing. Social relationships are after all transactional, as people can evoke certain reactions from their environment, which in turn can have an impact on them (Sameroff, 2009).

The social model of disability (Oliver, 1983) supports these ideas, as it suggests that disabilities are not a result of the impairment or difference of an individual, but they are in fact caused by societal barriers and attitudes towards those with differences. This model is often applied in relation to physical and sensory disabilities (Graby, 2015), but there have been recent calls in the UK for this to also be implemented in relation to those with neurodiversities, such as autism (Woods, 2017).

Such theories posit that solutions to problems are not only personal to the individual, but rather they need to be relational and collective, taking into consideration how interventions can be applied to different parts of the system in order to effect lasting change (White & Epston, 1990). As psychologists, we are used to working with the distressed individual or those in their immediate social environment (e.g. parents, partners), however, mental health and social problems are also determined by wider systems. The philosophy behind community psychology

approaches is also based on this idea, and aims to improve wellbeing by encouraging interventions that help shift societal causes of distress (Parker, 1999).

A focus on systemic issues is not meant to undermine the importance of individual support and interventions for people who suffer with social skills difficulties, as these can be helpful for developing better social competence and increasing confidence in social relationships (Wolstencroft et al., 2018). However, problem saturated stories that focus on individual deficits can feel blaming, stigmatising and disempowering for those who may already have a great deal to grapple with in terms of their medical or psychological conditions (White & Epston, 1990). There is evidence in the literature that demonstrates that individuals with neurodiversities, or those who differ from the norm in terms of their physical appearance or mental and psychological difficulties, are perceived more negatively by others and are often teased, bullied or excluded (Mulvey, Boswell, & Zheng, 2017; Sasson et al., 2017). Given the impact the actions and attitudes of others can have on the social experiences of a person, it would be unreasonable to put the burden to adapt and change fully on the individual, without considering the effect of contextual factors (Woods, 2017).

In order to introduce change for girls and women with TS at the different levels of systems, we need to work together as a society to promote acceptance of difference, encourage inclusion and reduce stigma (Gillespie-Lynch et al., 2015). For instance, interventions at the meso-system could involve implementing anti-bullying initiatives and peer support programmes in schools. Studies have found that increasing knowledge of autism in neurotypical peers and disclosing the diagnostic status of an individual with autism have been associated with more positive first impressions of

those with autism (Matthews, Ly, & Goldberg, 2015; Sasson & Morrison, 2019). This suggests that education and raising awareness of the different conditions can help reduce some of the social barriers that are faced by people who tend to be perceived less favourably (Sasson & Morrison, 2019).

Another study showed that first impressions can also worsen following diagnostic disclosure, if a neurotypical rater has negative pre-existing attitudes and stigma towards people with autism (Morrison, DeBrabander, Faso, & Sasson, 2019). Stigma towards individuals suffering with mental or physical health conditions can have devastating consequences, including but not limited to discrimination, worse quality of life, negative self-perceptions and bullying (Corrigan & Watson, 2002). Morrison and colleagues (2019) suggest that the most effective interventions for shifting negative attitudes would be those that work on raising awareness and knowledge, combined with a focus on reducing stigma and misconceptions about a condition.

Additionally, providing training and working with staff teams in various systems, such as the educational and social care sectors, could support these efforts further. The evidence suggests that teacher trainings can help significantly improve teacher knowledge about autism, facilitate teachers to provide better support for students with autism and promote integration in the classroom (Leblanc, Richardson, & Burns, 2009). This systemic perspective can also be further incorporated into the assessment of social competence and social difficulties in clinical practice and research, for example, through the use of more sociometric measures to evaluate peer perceptions towards an individual with social impairments. Obtaining peer ratings at

the start and end of an intervention, may for example indicate improvements in social competence (Blandon, Calkins, & Keane, 2010).

Interventions in the exo-system could relate to working with the local community to raise awareness about certain issues and to strengthen community resilience and resources. The use of campaigns and social media can create more positive narratives and promote inclusion, by focusing on strengths and resources and through the use of positive language. A recent campaign run by the Turner Syndrome Support Society (TSSS) called ‘Missing an X’ aimed to raise awareness and celebrate difference and strengths of girls and women with TS. Women with TS are after all defined by so much more than their condition and the TSSS has created a valuable community of support. Lastly, interventions at the macro-system could involve changing policies in order to empower marginalised groups and reduce health inequalities (Nelson & Prilleltensky, 2010). For example, by designing ‘health-related stigma frameworks’ to support policy changes, that would reduce institutionalised stigma and discrimination, and improve access to services (Stangl et al., 2019).

Conclusion

Designing and conducting this research study was a challenging but also an exciting endeavour. Through this work, I learned the importance of flexibility and the ability to adapt to unexpected circumstances, all the while keeping in mind research ethics and guidelines when methodological dilemmas are encountered. I also learned to balance aiming for scientific rigor, whilst simultaneously taking into account the practical limitations of the work. Finally, this work further demonstrated the value of using systemic ideas to inform research and clinical practice.

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Appendices

Appendix A

UCL Research Ethics Committee Letter of Approval

UCL RESEARCH ETHICS COMMITTEE
ACADEMIC SERVICES



26th September 2017

Dr Will Mandy
Department of Clinical, Educational and Health Psychology
UCL

Dear Dr Mandy

Notification of Ethics Approval

Project ID/Title: 11837/001: The Social Skills Peer Observation Tool (SPOT). A new method of assessing social skills

I am pleased to confirm in my capacity as Joint Chair of the UCL Research Ethics Committee (REC) that your study has been approved by the UCL REC until **15th September 2019**. Ethical approval is not required for the subsequent data analysis or publication of the results.

Approval is also subject to the following conditions:

Notification of Amendments to the Research

You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form'

<http://ethics.grad.ucl.ac.uk/responsibilities.php>

Adverse Event Reporting – Serious and Non-Serious

It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Final Report

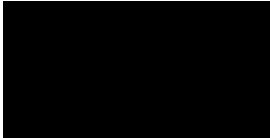
At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research: <http://www.ucl.ac.uk/srs/governance-and-committees/resgov/code-of-conduct-research>
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely



Dr Lynn Ang
Joint Chair, UCL Research Ethics Committee

Cc: Kalia Cleridou

Video Participant Information Sheet and Consent Form (TS version)

Study Information Sheet | Over 16s



Title of the Project: The Social Skills Peer Observation Tool (SPOT): A New Method of Assessing Social Skills

This study has been approved by the UCL Research Ethics Committee (Project ID Number): 11837/001

We would like to invite you to take part in a research study. Please take time to read the following information carefully before you decide whether or not to take part. Talk to others about the study if you wish or ask us if there is anything that is not clear or if you would like more information. Take as much time as you need to decide whether or not you wish to take part.

What is the purpose of this study?

We all act differently in social situations, and often the way we express ourselves affects what others think about us. Having good social skills is important for helping us form friendships, relationships and to communicate with each other. Some people may find social situations difficult, and may need some help to improve their social skills.

There are many ways to look at someone's social skills, but most of these are completed by adults (such as clinicians, parents or teachers). This study aims to develop a new way of evaluating people's social skills, using peers of a similar age who will observe someone taking part in a social task and then tell us what they think. It is important to be able to measure people's social skills accurately, so that we can find treatments and trainings that are more effective in helping people develop better social abilities.

Do I have to take part?

Taking part in the study is entirely voluntary. It is up to you to decide whether or not you wish to take part; choosing not to take part will not disadvantage you in any way. If you do decide to take part, you are still free to stop at any time without giving a reason.

What will happen if I take part?

If you agree to take part, you will be asked to sign a consent form and we may also ask your parents to sign one too. You and your parents will also be asked to provide your contact details and to complete two short questionnaires about your strengths and difficulties, and social skills. Then, you will be invited to take part in a task that involves a mock audition for a new reality TV show for young people your age. You will have to speak for 45 seconds to show the TV judges why they should select you for the show. This will be filmed with a video camera, and you will be given a T-shirt to wear.

What will happen next?

Once you have completed the questionnaires and the video task, the researcher will edit the videos to make sure they have the correct length and format. The researcher will send a copy of the video to you via email, so that you can have a look first and let us know if you are happy for us to share it with other participants as part of our questionnaire. If you change your mind and would like to withdraw from the study, you can let the researcher know and your video will not be shared. We might also ask you to tell us what it was like for you taking part in this study.

Once you agree for the video to be shared, all videos will be entered in an online survey, which will be completed by peers of a similar age to you. These peers will not be given copies of the videos and they will not be told any other information about you. Once they complete the survey they will not be able to access it again. The information you provide us with as part of the study will be held on a secure computer at UCL.

What are the possible disadvantages of taking part?

Some people may find it difficult or upsetting to be contacted to take part in the study or to complete some of the tasks. Some people may find being filmed uncomfortable or may find it upsetting for the videos to be shared. Our research team can talk to you either over the phone or via email and to advise where to get further help if you need it. Please contact us or visit your local GP or health care team if you have found being approached to take part in the study upsetting.

What are the benefits of joining the study?

Taking part in this study means you will be helping us understand social skills difficulties, and how to measure them. This will be helpful for evaluating treatments and trainings, to make sure they are effective.

Everyone taking part will be entered into a prize draw, to win an Amazon voucher of £50. You will also be able to keep the T-shirt we give you as part of the filming.

Will my involvement in the study be kept confidential?

Yes. We will follow best ethical and legal practice and all information about you will be handled in confidence. All information will be collected and stored in accordance with the Data Protection Act 1998. Only authorised members of the research team will have access to your personal details. The information you provide us with will not be used or made available for any purpose other than for research and improvements in health care. Your name or any other personal details will not be in any report or publication. Any research data generated and made available to others for further research will have your personal identity removed.

The software and online platforms that will be used for sharing the online survey and video recordings have appropriate security policies and have been approved by the UCL Data Protection office.

Can I know the results obtained from the study?

A summary of the study's findings can be emailed to those who are interested. Please let the researcher know if you would like that.

What will happen if I want to withdraw from the study?

You can withdraw from the study at any point, without having to give a reason. If you decide to withdraw, we will stop collecting data from you. However, data that has already been collected up to the point of your withdrawal will remain in the study.

Further information

If you would like any further information about this study, please contact the researchers directly:

Email: kalia.cleridou.10@ucl.ac.uk
w.mandy@ucl.ac.uk

Thank you for your interest in this study!

Title of the Project: The Social Skills Peer Observation Tool (SPOT): A New Method of Assessing Social Skills

This study has been approved by the UCL Research Ethics Committee (Project ID Number): 11837/001

Thank you for your interest in taking part in this research. Before you agree to take part, please read the Information Sheet and/or listen to an explanation about the research. If you have any questions, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

To take part in this study, you need to:

- Be female
- Be between the ages of 16 to 25
- Have no significant hearing or visual impairments
- Have not received social skills training

If you meet all the above criteria, please complete the statements below.

Please read the statements carefully and initial the boxes if you agree.

Statements	Initial Boxes
<p>1 I confirm that I have read and understood the information about taking part in this study. I have had the time to consider the information, ask questions and have received satisfactory answers to my questions.</p>	
<p>2 I understand that taking part in the study is voluntary and that I am free to withdraw at any time without giving any reason.</p>	
<p>3 I understand that my participation will be video recorded and I consent to the use of this material as part of the project. I understand that I will have the chance to review the video and consent to its release, and that I am free to withdraw my consent for its use at any point.</p>	
<p>4 I consent to the processing of my personal information for the purposes of this research study. I understand that such information will be treated as strictly confidential and will be handled in accordance with the provisions of the Data Protection Act 1998.</p>	
<p>5 I understand that the information collected about me, after it has been fully anonymised, can be shared with other researchers and may be</p>	

published as a report. Confidentiality and anonymity will be maintained and it will not be possible to identify me from any publications.

6 I agree to take part in this study

Contact Details | Please complete in block capitals

Name of Participant

Date of Birth

Gender

Ethnicity

DD	/	MM	/	YY		
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Telephone

Mobile

--	--

Email address

Address

Signature

Date

	DD	/	MM	/	YY
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Preferred Mode of Contact: Phone

Email

Researcher's Signature (Do not complete)

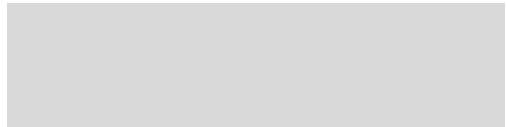
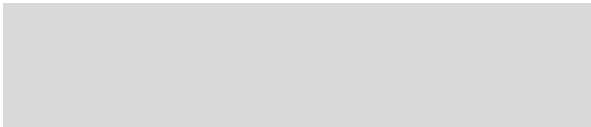
Name of Researcher

Participant Identification Number



Signature

Date



Appendix C

Information Sheet and Consent Form for Parents of Video Participants

Study Information Sheet | Parent/Guardian



Title of the Project: The Social Skills Peer Observation Tool (SPOT): A New Method of Assessing Social Skills

This study has been approved by the UCL Research Ethics Committee (Project ID Number): 11837/001

We would like to invite your child to take part in a research study. Please take time to read the following information carefully before you decide whether or not your child can take part. Talk to others about the study if you wish or ask us if there is anything that is not clear or if you would like more information.

What is the purpose of this study?

We all have different ways of expressing ourselves in social situations, and often our expressive style contributes to how others perceive us. Social skills are therefore important for helping us form friendships, relationships and to communicate with each other. Some people may find social situations difficult, and may need some help to improve their social skills.

There are various ways to measure someone's social skills, but many of these are completed by adults (such as clinicians, parents or teachers). This study aims to develop a new way of evaluating people's social skills, using peers of a similar age who will evaluate someone after observing them take part in a social task. It is important to be able to assess people's social skills accurately, so that we can explore whether treatments and trainings are effective in helping people develop better social competence.

Do I have to take part?

Your child's participation in the study is entirely voluntary. It is up to both of you to decide whether or not your child will take part; choosing not to take part will not disadvantage you/your child in any way. If you do decide that your child can take part, your child is still free to withdraw at any time without giving a reason.

What will happen if I take part?

If you agree that your child can take part, you will be asked to sign a consent form and we will also ask your child to sign one too. You will both also be asked to provide your contact details and to complete two short questionnaires about your child's strengths and difficulties, and social competence. Then, your child will be invited to take part in a task that involves a mock audition for a new reality TV show for young people their age. They will have to speak for 45 seconds to show the TV judges why they should select them for the show. This will be filmed with a video camera, and they will be given a T-shirt to wear.

What will happen next?

Once your child has completed the questionnaires and the video task, the researcher will edit the videos to make sure they have the correct length and format. The researcher will send a copy of the video to you/your child via email, so that you can both have a look first and let us know if you consent for us to share it with other participants as part of our questionnaire. If you/your child change your mind and would like to withdraw from the study, you can let the researcher know and the video will not be shared.

Once you/your child agree for the video to be shared, all videos will be entered in an online survey, which will be completed by peers of a similar age to your child. These peers will not be given copies of the videos and they will not be given any other information about your child. Once they complete the survey they will not be able to access it again. The information your child provides us with as part of the study will be held on a secure computer at UCL.

What are the possible disadvantages of taking part?

Some people may find it difficult or distressing to be contacted to take part in the study or to complete some of the tasks we ask for. Some people may find being filmed uncomfortable or may find it distressing for the videos to be shared. Our research team will be available to talk to you/your child either over the phone or via email and to advise where to get further help if needed. Please do not hesitate to contact us or arrange to see your local GP or health care team if you have found being approached to take part in the study upsetting.

What are the benefits of joining the study?

Taking part in this study means that your child will be contributing to our understanding of social skills difficulties, and to the development of new ways to assess them. This will be helpful for evaluating treatments and trainings, to make sure they are effective.

Everyone taking part will be entered into a prize draw, to win an Amazon voucher of £50. Your child will also be able to keep the T-shirt we give them as part of the filming.

Will my involvement in the study be kept confidential?

Yes. We will follow best ethical and legal practice and all information about you/your child will be handled in confidence. All information will be collected and stored in accordance with the Data Protection Act 1998. Only authorised members of the research team will have access to your personal details. The information you/your child provide us with will not be used or made available for any purpose other than for research and improvements in health care. Any personal identifiers will not be in any report or publication. Any research data generated and made available to others for further research will have your child's personal identity removed.

For the purpose of this study, the software and online platforms that are used for sharing the online survey and for handling the video recordings have appropriate security policies and have been approved by the UCL Data Protection office.

Can I know the results obtained from the study?

A summary of the study's findings can be emailed to those who are interested. Please let the researcher know if you would like that.

What will happen if I want to withdraw from the study?

Your child can withdraw from the study at any point, without having to give a reason. If your child decides to withdraw, we will stop collecting data from them. However, data that has already been collected up to the point of withdrawal will remain in the study.

Further information

If you would like any further information about this study, please do not hesitate to contact the researchers directly:

Email: kalia.cleridou.10@ucl.ac.uk
w.mandy@ucl.ac.uk

Thank you for your interest in this study!

Title of the Project: The Social Skills Peer Observation Tool (SPOT): A New Method of Assessing Social Skills

This study has been approved by the UCL Research Ethics Committee (Project ID Number): 11837/001

Thank you for your interest in this research. Before you agree for your child to take part, please read the Information Sheet and/or listen to an explanation about the research. If you have any questions, please ask the researcher before you decide whether your child can join in. You will be given a copy of this Consent Form to keep and refer to at any time.

To take part in this study, your child needs to:

- Be female
- Be between the ages of 16 to 25
- Have no significant hearing or visual impairments
- Have not received social skills training

If your child meets all the above criteria, please proceed to the statements below.

Please read the statements carefully and initial the boxes if you agree.

Statements	Initial Boxes
<p>7 I am the parent or legal guardian of the child named below and have the authority to sign this Consent Form.</p>	
<p>8 I confirm that I have read and understood the information about my child taking part in this study. I have had the time to consider the information, ask questions and have received satisfactory answers to my questions.</p>	
<p>9 I understand that taking part in the study is voluntary and that my child is free to withdraw at any time without giving any reason.</p>	
<p>10 I understand that my child’s participation will be video recorded and I consent to the use of this material as part of the project. I understand that my child and I will have the chance to review the video and consent to its release, and that we are both free to withdraw our consent for its use at any point.</p>	
<p>11 I consent to the processing of my child’s personal information for the purposes of this research study. I understand that such information will be treated as strictly confidential and will be handled in accordance with the provisions of the Data Protection Act 1998.</p>	

- 12 I understand that the information collected about my child, after it has been fully anonymised, can be shared with other researchers and may be published as a report. Confidentiality and anonymity will be maintained and it will not be possible to identify my child from any publications.
- 13 I agree for my child to take part in this study

Contact Details | Please complete in block capitals

Child's Details

Name of Participant (Name of Child)

Date of Birth

Gender

Ethnicity

DD	/	MM	/	YY		
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Parent's Details

Name of Parent/Guardian

Email address

Telephone

Mobile

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Address

Signature

Date

	DD	/	MM	/	YY
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Preferred Mode of Contact:

Phone

Email

Researcher's Signature (Do not complete)

Name of Researcher

Participant (child) Identification
Number

Signature

Date

Appendix D

Information Sheet and Consent Page in the Online Survey



The Social Skills Peer Observation Tool (SPOT): **A New Method of Assessing Social Skills**

What is the purpose of this study?

This study aims to develop a new way of evaluating young women's social skills. It is important to be able to assess social skills accurately, so that we can explore whether treatments and trainings are effective in helping people develop better social competence.

What it involves

You will firstly be asked to provide some basic details about yourself. Then, you will be presented with various types of material that include extracts of young women talking about themselves as part of a mock audition for a new TV reality show. You will be asked to rate each one on various dimensions. For example, how likeable you found the person or whether you would start a conversation with them. The survey will take around 20-30 minutes to complete.

Important Information

- This study has been approved by the UCL Research Ethics Committee (Project ID Number): 11837/001. All data will be collected and stored in accordance with GDPR 2018.
- Your participation in the study is entirely voluntary and you can withdraw at any point.
- Everyone taking part will be entered into a prize draw, to win an Amazon voucher of £50.

Please read the [SPOT Information Sheet](#) which includes more information about the study.

If you would like to discuss this study further, or if you have any questions, please contact the researchers directly: kalia.cleridou.10@ucl.ac.uk | w.mandy@ucl.ac.uk

To take part in SPOT, you need to:

- Be between the ages of 16 to 30
- Have no significant hearing or visual impairments

If you meet all the above criteria, please proceed to the next page.



Title of the Project: The Social Skills Peer Observation Tool (SPOT): A New Method of Assessing Social Skills

This study has been approved by the UCL Research Ethics Committee (Project ID Number): 11837/001

We would like to invite you to take part in a research study. Please take time to read the following information carefully before you decide whether or not to take part. Talk to others about the study if you wish or ask us if there is anything that is not clear or if you would like more information.

What is the purpose of this study?

We all have different ways of expressing ourselves in social situations, and often our expressive style contributes to how others perceive us. Having good social skills is important for helping us form friendships, relationships and to communicate with each other. Some people may find social situations difficult, and may need some help to improve their social skills.

At the moment, there are various ways of evaluating someone's social skills, but those involving observation are mostly completed by adults (such as clinicians, parents or teachers). This study aims to develop a new way of measuring people's social skills, using peers of a similar age who will evaluate someone after observing them taking part in a social task. It is important to be able to assess people's social skills accurately, so that we can explore whether treatments and trainings are effective in helping people develop better social competence.

Do I have to take part?

Your participation in the study is entirely voluntary. It is up to you to decide whether or not you wish to take part; choosing not to take part will not disadvantage you in any way. If you do decide to take part, you are still free to withdraw at any time without giving a reason.

What will happen if I take part?

If you agree to take part, you will be asked to sign a consent form. You will then be sent a link to an online survey, which should take under half an hour to complete.

The survey will firstly ask you to provide some basic details about yourself. The survey will include short videos of young women engaging in a mock audition for a new TV reality show, and you will be asked to rate each video on various dimensions; for example, how likeable you found the person or whether you would start a conversation with them. The information you provide us with as part of the study will be held on a secure computer at UCL.

What are the possible disadvantages of taking part?

Some people may find it difficult or distressing to be contacted to take part in the study or to complete some of the questionnaires we give them. Our research team will be available to talk to you either over the phone or via email and to advise where to get further help if needed. Please do not hesitate to contact us or arrange to see your local GP or health care team if you have found being approached to take part in the study upsetting.

What are the benefits of joining the study?

Taking part in this study means you will be contributing to our understanding of social skills, and to the development of new ways to assess them. This will be helpful for evaluating treatments and trainings, to make sure they are effective.

Everyone taking part will be entered into a prize draw, to win an Amazon voucher of £50. You may also receive course credit for taking part, depending on the institution you are studying in.

Will my involvement in the study be kept confidential?

Yes. We will follow best ethical and legal practice and all information about you will be handled in confidence. All the information that we collect about you during the course of the research will be kept strictly confidential. You will not be able to be identified in any ensuing reports or publications.

Local Data Protection Privacy Notice

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk.

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice: [click here](#).

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The categories of personal data used will be as follows:

- Name (optional)
- Email address (optional)
- Age
- Gender
- Ethnicity
- Presence of social skills impairment/disorder

The lawful basis that would be used to process your personal data will be performance of a task in the public interest. The lawful basis used to process special category personal data will be for scientific and historical research or statistical purposes.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

For the purpose of this study, the software and online platforms that are used for the online survey have appropriate security policies and have been approved by the UCL Data Protection office.

Can I know the results obtained from the study?

A summary of the study's findings can be emailed to those who are interested. Please let the researcher know if you would like that.

What will happen if I want to withdraw from the study?

You can withdraw from the study at any point, without having to give a reason. If you decide to withdraw, we will stop collecting data from you. However, data that has already been collected up to the point of your withdrawal will remain in the study.

What if something goes wrong?

Should you wish to raise a complaint regarding this study, you can contact the Supervisor for this research, Dr William Mandy (w.mandy@ucl.ac.uk).

Should you feel your complaint has not been handled to your satisfaction, you can also contact the Chair of the UCL Research Ethics Committee – ethics@ucl.ac.uk.

Further information

If you would like any further information about this study, please do not hesitate to contact the researchers directly:

Email: kalia.cleridou.10@ucl.ac.uk
w.mandy@ucl.ac.uk

Thank you for your interest in this study!

Consent

By clicking the “I consent” button below, you are confirming that:

- I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction.
- I understand that I will complete questionnaires online and I consent to the use of this material as part of the project.
- I understand that I will be able to withdraw my data up to 4 weeks after completing the online questionnaire.
- I understand that my personal information (name, email address, age, gender, ethnicity, social skills disorder status) will be used for the purposes explained to me. I understand that according to data protection legislation (GDPR 2018), ‘public task’ will be the lawful basis for processing.
- I understand that all personal information will remain confidential and that my data gathered in this study will be stored anonymously and securely. It will not be possible to identify me in any publications.
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason. I understand that if I decide to withdraw, any personal data I have provided up to that point will be included in the study unless I request for it to be deleted.
- I understand that my information may be subject to review by responsible individuals from the University for monitoring and audit purposes.

- I understand the direct/indirect benefits of participating.
- I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.
- I agree that my anonymised research data may be used by other researchers for future research. No one will be able to identify me when this data is shared.
- I understand that the information I have submitted will be published as a report and if I wish I can request a copy of it from the researchers.
- I hereby confirm that I understand the inclusion criteria as detailed in the Information Sheet.
- I hereby confirm that:
 - I understand the exclusion criteria as detailed in the Information Sheet; and
 - I do not fall under the exclusion criteria.
- I am aware of who I should contact if I wish to lodge a complaint.
- I voluntarily consent to take part in this study.

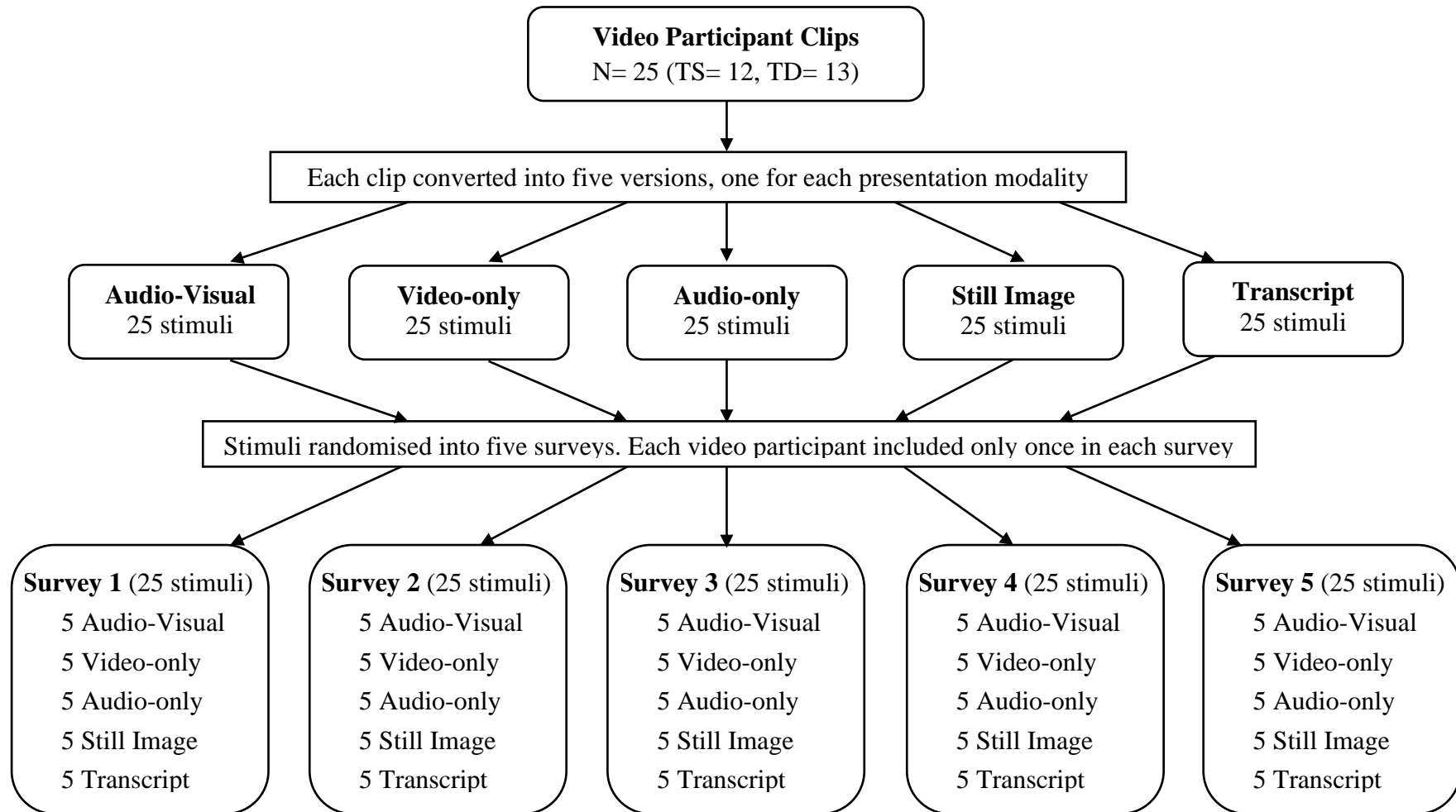
I consent

I do not consent



Appendix E

Flow Chart of the Stimuli and Survey Construction Process



Appendix F

Online Survey Instructions for Observer Participants

Survey Instructions

You will be presented with various types of material that include short 10 second extracts of young women talking about themselves. The young women in this survey have completed a videotaped task, pretending to take part in a mock audition for a new reality TV show.

You will be asked to give your FIRST IMPRESSIONS of each person on a number of traits, by giving a rating from strongly agree to strongly disagree.

You will have to form first impressions based on:

- Watching and listening to a video of a person
- Watching a silent video of a person
- Listening to a person speak
- Viewing a still photograph of a person
- Reading a quote of what a person has said

Please watch, listen, or read all the information provided before proceeding to give your first impression ratings. Try to respond as QUICKLY and HONESTLY as possible.

Please make sure to switch on the speaker/sound on your device, or plug in your headphones.



Appendix G

Two-way ANOVA Results of the Main Effect of Group and Presentation Modality and Interaction Effects, Separately for each Item of the First Impressions Assessment Scale

	F	df	p ^a	η_p^2	Mean (SD)		Bonferroni Comparisons	Cohen's <i>d</i>
					TS	TD		
Awkward								
Group	204.52	(1, 203)	<.001**	.50				
Modality	48.38	(4, 200)	<.001**	.49				
Group X Modality	17.86	(4, 200)	<.001**	.26				
Post hoc tests								
Audio-Visual					1.32 (.64)	1.87 (.58)	<.001**	0.90
Video-only					1.44 (.64)	1.85 (.56)	<.001**	0.68
Audio-only					1.66 (.60)	2.01 (.49)	<.001**	0.64
Still Image					1.45 (.54)	1.82 (.51)	<.001**	0.70
Transcript					2.04 (.53)	2.00 (.56)	.366	0.07

Table X (continued)

	F	df	p ^a	η_p^2	Mean (SD)		Comparisons	<i>d</i>
					TS	TD		
Attractive								
Group	291.67	(1, 203)	<.001**	.59				
Modality	3.23	(4, 200)	.014	.06				
Group X Modality	16.66	(4, 200)	<.001**	.25				
Post hoc tests								
Audio-Visual					1.33 (.53)	1.88 (.49)	<.001**	1.08
Video-only					1.37 (.52)	1.85 (.52)	<.001**	0.92
Audio-only					1.47 (.50)	1.72 (.43)	<.001**	0.54
Still Image					1.46 (.53)	1.81 (.48)	<.001**	0.69
Transcript					1.63 (.55)	1.75 (.45)	.006 [◇]	0.24
Trustworthy								
Group	38.54	(1, 203)	<.001**	.16				
Modality	15.51	(4, 200)	<.001**	.24				
Group X Modality	1.69	(4, 200)	.153	.03				
Post hoc tests								
Audio-Visual					1.77 (.53)	1.90 (.50)	.008 [◇]	0.25
Video-only					1.78 (.47)	1.96 (.39)	<.001**	0.42
Audio-only					1.69 (.50)	1.77 (.43)	.063	0.17
Still Image					1.88 (.42)	1.94 (.44)	.065	0.14
Transcript					1.63 (.65)	1.76 (.49)	.023 [◇]	0.23

Table X (continued)

	F	df	p ^a	η_p^2	Mean (SD)		Comparisons	<i>d</i>
					TS	TD		
Dominant/Aggressive								
Group	16.05	(1, 203)	<.001**	.07				
Modality	34.82	(4, 200)	<.001**	.41				
Group X Modality	9.35	(4, 200)	<.001**	.16				
Post hoc tests								
Audio-Visual					2.04 (.66)	2.10 (.52)	.193	0.10
Video-only					2.11 (.62)	2.13 (.54)	.702	0.03
Audio-only					1.83 (.70)	1.89 (.60)	.223	0.09
Still Image					2.20 (.50)	2.14 (.53)	.092	0.12
Transcript					1.62 (.80)	1.96 (.58)	<.001**	0.49
Likeable								
Group	151.48	(1, 203)	<.001**	.43				
Modality	10.25	(4, 200)	<.001**	.17				
Group X Modality	5.96	(4, 200)	<.001**	.11				
Post hoc tests								
Audio-Visual					1.67 (.53)	2.04 (.45)	<.001**	0.75
Video-only					1.77 (.43)	2.07 (.45)	<.001**	0.68
Audio-only					1.68 (.51)	1.89 (.43)	<.001**	0.45
Still Image					1.89 (.40)	2.02 (.39)	<.001**	0.33
Transcript					1.73 (.63)	1.91 (.48)	.001*	0.32

Table X (continued)

	F	df	p ^a	η_p^2	Mean (SD)		Comparisons	<i>d</i>
					TS	TD		
Smart								
Group	36.14	(1, 203)	<.001**	.15				
Modality	4.44	(4, 200)	.002*	.08				
Group X Modality	3.96	(4, 200)	.004*	.07				
Post hoc tests								
Audio-Visual					1.68 (.61)	1.85 (.51)	<.001**	0.30
Video-only					1.68 (.56)	1.87 (.54)	<.001**	0.35
Audio-only					1.63 (.58)	1.74 (.53)	.004*	0.20
Still Image					1.74 (.55)	1.85 (.51)	.002*	0.21
Transcript					1.75 (.58)	1.73 (.51)	.557	0.04
Hang Out With								
Group	163.03	(1, 203)	<.001**	.45				
Modality	2.86	(4, 200)	.025	.05				
Group X Modality	12.59	(4, 200)	<.001**	.20				
Post hoc tests								
Audio-Visual					1.34 (.59)	1.80 (.54)	<.001**	0.81
Video-only					1.43 (.53)	1.80 (.49)	<.001**	0.72
Audio-only					1.42 (.56)	1.64 (.50)	<.001**	0.41
Still Image					1.54 (.55)	1.69 (.48)	<.001**	0.29
Transcript					1.55 (.63)	1.65 (.50)	.051	0.18

Table X (continued)

	F	df	p ^a	η_p^2	Mean (SD)		Comparisons	<i>d</i>
					TS	TD		
Live Near								
Group	27.07	(1, 203)	<.001**	.12				
Modality	8.72	(4, 200)	<.001**	.15				
Group X Modality	2.80	(4, 200)	.027	.05				
Post hoc tests								
Audio-Visual					2.21 (.66)	2.39 (.59)	<.001**	0.29
Video-only					2.31 (.57)	2.35 (.59)	.199	0.07
Audio-only					2.25 (.60)	2.29 (.58)	.196	0.07
Still Image					2.32 (.55)	2.41 (.58)	.006 [◇]	0.16
Transcript					2.21 (.65)	2.28 (.60)	.093	0.11
Sit Near								
Group	38.79	(1, 203)	<.001**	.16				
Modality	3.72	(4, 200)	.006	.07				
Group X Modality	5.48	(4, 200)	<.001**	.10				
Post hoc tests								
Audio-Visual					2.16 (.62)	2.39 (.53)	<.001**	0.40
Video-only					2.24 (.58)	2.35 (.57)	.001*	0.19
Audio-only					2.21 (.59)	2.29 (.59)	.048 [◇]	0.14
Still Image					2.31 (.55)	2.34 (.58)	.208	0.05
Transcript					2.19 (.65)	2.30 (.57)	.009 [◇]	0.18

Table X (continued)

	F	df	p ^a	η_p^2	Mean (SD)		Comparisons	d
					TS	TD		
Have Conversation								
Group	116.67	(1, 203)	<.001**	.37				
Modality	1.76	(4, 200)	.139	.03				
Group X Modality	4.88	(4, 200)	.001**	.09				
Post hoc tests								
Audio-Visual					1.53 (.61)	1.89 (.57)	<.001**	0.61
Video-only					1.61 (.54)	1.88 (.53)	<.001**	0.50
Audio-only					1.60 (.56)	1.76 (.50)	<.001**	0.30
Still Image					1.68 (.58)	1.82 (.56)	<.001**	0.25
Transcript					1.63 (.64)	1.77 (.54)	.002*	0.24

Note. Scores can range from 0 to 3, with higher scores indicating more positive impressions. df= degrees of freedom; η_p^2 = partial eta-squared; SD= standard deviation; TS= Turner Syndrome group; TD= Typically Developing group.

^a Bonferroni correction used to adjust the α to $\alpha_{Bonf}=.005$

[◇] p<.05 *p<.005. **p<.001