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# Perceived Social Capital of Women with Turner Syndrome

Stephanie Jasmine Cragg  
*University of Windsor*

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**Perceived Social Capital of Women with Turner Syndrome**

By

**Stephanie Cragg**

A Thesis  
Submitted to the Faculty of Graduate Studies  
through the Department of Psychology  
in Partial Fulfillment of the Requirements for  
the Degree of Master of Arts  
at the University of Windsor

Windsor, Ontario, Canada

2018

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**Perceived Social Capital of Women with Turner Syndrome**

by

**Stephanie Cragg**

APPROVED BY:

---

D. Hernandez Jozefowicz  
School of Social Work

---

R. Menna  
Department of Psychology

---

K. Lafreniere, Advisor  
Department of Psychology

September 17, 2018

## DECLARATION OF ORIGINALITY

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## ABSTRACT

This research study was conducted to answer the question: do women with Turner Syndrome have lower levels of social capital in a variety of areas compared to women of the same age range not diagnosed with Turner Syndrome, and does this affect their wellness and life satisfaction? A mixed-methods research design was utilized to examine the perceived social capital of a sample of women aged 18-30 diagnosed with Turner Syndrome. Two potential outcomes of social capital: wellness and life satisfaction, were also examined. Psychological capital was also examined to determine whether it was a mediating variable between the measures of social capital and outcome measures of wellness and life satisfaction. In total, 35 participants completed the survey. Eleven participants reported being diagnosed with Turner Syndrome, and 24 participants were in the comparison group of women not diagnosed with Turner Syndrome. Results revealed no significant differences between women diagnosed with Turner Syndrome and the comparison group in the areas of social capital at work, social capital at school, or online and offline social capital, indicating that women diagnosed with Turner Syndrome felt that they had the same amount of social resources available to them in those situations as women who were not diagnosed with Turner Syndrome. Psychological capital was found to be a mediating variable between the Social Capital Indexes and the outcome variables of satisfaction with life and wellness. While quantitative results indicated that women diagnosed with Turner Syndrome receive and utilize comparable numbers of social resources as women not diagnosed with Turner Syndrome, qualitative results indicate distinct nuances within the social experiences of each group.

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## Perceived Social Capital of Women with Turner Syndrome

**CHAPTER I: Introduction****Introduction to Social Capital**

Social capital is an essential resource in such areas as education, employment, health, and family and personal relationships. This study focused on an examination of the perceptions of social capital among women diagnosed with a rare genetic disorder called Turner Syndrome. There has been a lack of focus in the literature on the social and psychological effects of Turner Syndrome, and social capital of women with Turner Syndrome has not been subject to evaluation.

The term ‘social capital’ describes a form of resources that are not often concrete or visible, but that have very real effects (Pavey, 2006). A variety of definitions of social capital exist in the literature. A classic definition of social capital is: resources resulting from having a robust network of acquaintances (Bourdieu, 1985). Social capital is also defined as “the ability of actors to secure benefits by virtue of membership in social networks or other social structures” (Portes, 1998, p. 6). The commonality of these definitions is that social capital is an investment in various social relationships that can result in positive effects for the individual who has made these investments (Devine & Parr, 2008).

The concept of social capital is based on two types of resources: the advantage held by a group member, which can be human, cultural, physical, symbolic, or can take additional forms, and the relationships among group members that allows their admittance to the advantage (Devine & Parr, 2008). Newton (1997) conceptualized social capital in relation to three fundamentals: norms and values, networks, and consequences, all of which are based on a relationship of exchange and trust.

There are various types of social capital which produce differing effects (Allan, Smyth, I'Anson, & Mott, 2009). Bonding social capital is defined as the connections between individuals who share goals and other features, and results in promoting solidarity among individuals (Allan et al., 2009). Bridging social capital occurs when individuals from differing groups collaborate, and can result in greater relations among the various groups (Anthias, 2007). Linking social capital is considered by some to be the most profitable form of social capital (Woolcock, 1998), and is formed when individuals with differing amounts of power unite (Allan et al., 2009).

### **Social Capital and Disability**

Social capital is an essential component to study in individuals with disabilities such as Turner Syndrome. One criticism of social capital theory is that it does not focus on individuals who may experience difficulties developing social capital within their community very easily, also known as the “dark side of social networks” (Chenoweth & Stehlik, 2004, p. 65). This may pose issues when examining social capital in relation to disability, as research findings related to social capital may not be generalizable to individuals with disabilities, as their experiences are not commonly included in such research. Social capital theory is individualistic and based on a deficit model of disability, where individuals are responsible for developing their own social capital (Pavey, 2006). Social capital theory reflects the belief that providing opportunities for individuals with and without disabilities to interact may create greater awareness of mutual resources and how such individuals can assist each other (Devine & Parr, 2008). Chenoweth and Stehlik (2004) stated that there are five social factors which affect the social capital of individuals with disabilities and their families: a lack of emotional and financial resources for individuals with disabilities and their families; social isolation from the community due to

stigma; the frequent experiences of rejection that individuals with disabilities may face within their communities; the invisible assistance, often voluntary, that individuals with disabilities and their families engage in within the community such as committee and organizational memberships; and the strong bonds that exist within and among groups of individuals with disabilities.

Research has demonstrated that individuals diagnosed with a disability report lower levels of social capital (Mithen, Aitken, Ziersch, & Kavanagh, 2015). Devine and Parr (2008) interviewed eight youth at an inclusive summer camp for children with and without disabilities. The participants ranged in age from 12-16, and four of the eight participants identified as being diagnosed with a disability such as Asperger syndrome, cerebral palsy, and spinal muscular atrophy. The authors found that campers who were not diagnosed with a disability perceived that they were providing social capital within the summer camp, but were unable to determine how they would receive social capital from campers diagnosed with a disability. In contrast, the campers diagnosed with a disability were able to state how they provided social capital to the group and benefited from the social capital of other group members. Furthermore, campers without a disability were more likely to refer to differences between themselves and the campers with disabilities, as well as express more discomfort regarding such differences.

### **Social Capital and Education**

Social capital has been found in a variety of studies to provide benefits in the area of education. Winch (2002) views the economics of education as involving individual and social factors which can lead to individual and social benefits; such social capital ideas are becoming more pronounced within the educational system. Wu, Palinkas, and He (2010) utilized ecological theory to determine how social capital within family, peers, school, and community affected the

academic achievement of 772 migrant Chinese children. They found that greater levels of social capital within family and school relationships resulted in greater academic achievement. This finding was also corroborated by a study conducted by Yuan and Ngai (2016), in which they surveyed 1153 university students in Shanghai, China and discovered that family social capital was positively correlated with academic achievement.

Social capital can also be built through educational initiatives, and can foster more open viewpoints of situations. A study conducted by Allan et al. (2009) discussed a workshop in which two groups of students aged 10-12 and one group of students aged 12-14 were invited to discuss their perspectives of diversity, particularly of disability. The students were of varying ethnicities and abilities, and during the discussion the students moved from 'othering' and pitying individuals with disabilities to appreciating their need for independence and how all students benefit from inclusive environments. By allowing the youth to have an open discussion on the topic of disability, the conference appeared to have increased the existing bonding social capital of the participants, and fostered both bridging social capital and linking social capital through fostering new connections amongst the participants and through allowing the children to take charge of the conversation and educate the adults at the conference (Allan et al., 2009).

### **Social Capital and Employment**

Social capital has been shown through a variety of studies to have a significant effect on employment benefits and employment opportunities. Strömngren, Erikson, Bergman, and Delive (2016) surveyed 477 healthcare professionals and found a positive relationship between social capital and job satisfaction, as well as work engagement. Phillips, Robison, and Kosciulek (2014) presented various hiring scenarios to 139 American undergraduate business students, and found a positive correlation between direct and indirect social capital and starting wage. When

the scenario involved a strong direct relationship between the participant and the individual in the scenario, the individual would receive a higher hourly wage, resulting in \$1,500.00 more per year. A strong indirect relationship between the participant and the individual in the scenario resulted in the individual receiving \$800.00 more per year.

Due to the difficulties that individuals with disabilities frequently experience with finding employment, such individuals may pursue entrepreneurship as a means of employment; this could result in public sector or volunteer organizations working with individuals with disabilities placing more emphasis on encouraging entrepreneurship (Pavey, 2006). This can be concerning, as Pavey (2006) states that individuals with learning disabilities may not be as likely to learn skills while in school such as leadership and business management which are necessary when pursuing entrepreneurship. As a result, individuals with disabilities may be at a significant disadvantage when engaging in entrepreneurship, and may not obtain as many of the benefits which can be found from entrepreneurship. Research has demonstrated that entrepreneurial benefits in the areas of human capital can be obtained through work experience and educational experience, and social capital can be obtained through increased business contacts and networking (Honig, 2001). Additionally, some form of entrepreneurship, such as independently selling homemade products on platforms such as Etsy, may not provide as many opportunities for social capital as initiatives such as starting a lawn-care or cleaning service, which may require more frequent interactions with customers and a more long-term client base.

### **Social Capital and Families**

It has only been fairly recently that family relationships have been considered as social capital, as family relationships can aid in physical and psychological well-being and promote resilience (Furstenberg & Hughes, 1995). Widmer, Kempf-Constantin, Robert-Tissot, Lanzi, and



Carminati (2008) utilized a social network method to compare 24 individuals diagnosed with an intellectual disability, 24 individuals diagnosed with both an intellectual disability and a psychiatric diagnosis, and a comparison group of 24 individuals. The authors found that family social capital was strongly affected by the diagnosis of an intellectual disability. Compared to the comparison group, individuals from the two disability groups reported fewer supportive family members and were more likely to include support workers and other medical professionals as family members (Widmer et al., 2008). The authors concluded that individuals diagnosed with an intellectual disability do not receive the amount of bridging or bonding social capital from family members that individuals who do not have an intellectual disability do (Widmer et al., 2008).

### **Social Capital and Psychological Capital**

Psychological capital is a concept separate from social capital, in which a greater focus is placed on an individual's psychological makeup, as opposed to their resources and connections (Heled, Somech, & Waters, 2015). This is often neglected in the areas of social and human capital (Luthans, Youssef, & Avolio, 2007). The term psychological capital arose from positive psychology and is considered as a state of an individual that is stable but may experience growth and change over time (Luthans, Avey, Avolio, Norman, & Combs, 2006; Luthans, Norman, Avolio, & Avey, 2008). Avey, Luthans, and Jensen (2009) state that there are four core concepts of psychological capital: optimism, hope, self-efficacy, and resilience.

Psychological capital has been studied extensively in the area of employment. Research findings have demonstrated that Psychological Capital can create a positive impact on employee attitudes, behaviours, and work performance, and can reduce unwanted employee attitudes and behaviours (Luthans, Avolio, Avey, & Norman, 2007). Psychological capital has also proven to have a mediating effect in employee teams, with Heled et al. (2015) studying 395 participants in

82 management teams within the education system and discovering psychological capital acting as a mediator between the team's learning environment and their job satisfaction, as well as mediating between the team's learning processes and their citizenship behaviours within the organizational environment. The authors stated that teams demonstrating high psychological capital are more likely to display positive coping strategies within their daily life, which serves to strengthen the team, foster a positive team atmosphere, and encourage positive relationships among team members, thereby encouraging the team members to go above and beyond in their tasks. However, psychological capital has not been significantly researched in relation to other life domains. It is hypothesized that psychological capital may have a similar mediating effect between social capital and outcomes such as wellness and life satisfaction.

### **Social Capital, Wellness, and Life Satisfaction**

Wellness is defined as improving quality of life through creating equilibrium amongst the physical, mental, and spiritual components of well-being (Adams, Bezner, & Steinhardt, 1997). The concept emerged from the medical field as a more active and holistic alternative to the traditional, more passive viewpoint of health as an individual simply being absent of illness (Dunn, 1977). Wellness is considered to be a highly personalized concept, with a focus on using personal strengths to increase the individual's potential within their environments (Adams, 1995; Dunn, 1977). Researchers have noted a lack of examination of wellness, and it is theorized that this may be due to the broadness and the extreme personalization of the concept (Harari, Waehler, & Rogers, 2005).

Social capital, in relation to material resources, has been found to have a significant effect on well-being. A cross-sectional study of 530 participants over the age of 18 from two suburban areas of Adelaide, Australia conducted by Ziersch (2005) found that the participants who

reported greater access to social capital also were financially robust; these participants also reported better physical and mental health. This demonstrates the need to focus on increasing the social capital of individuals who may have lesser access to material resources, such as individuals with disabilities, which could in turn improve their mental and physical well-being.

Social capital has also been linked to physical and mental well-being in older adults. A six-year longitudinal study of 3,606 Australian individuals aged 45 and older was conducted by Yiengprugsawan, Welsh, and Kendig, (2017). The authors evaluated three components of social capital: connectedness, trust, and participation, as well as participant transitions between levels of the components during the years participants were evaluated. Results indicated that low trust experienced throughout the duration of the study was significantly correlated with deficient mental and physical functioning, as well as poor self-perceptions of health. Transitioning into low trust as well as transitioning into and out of low levels of social connectedness were also found to be indicative of poor self-perceptions of health (Yiengprugsawan et al., 2017). This research demonstrates the importance of forming and maintaining strong social capital throughout the lifespan.

Life satisfaction is defined as the process of an individual using personal criteria to assess quality of life. (Shin & Johnson, 1978). Satisfaction with life is assessed by the degree of similarity between the individual's actual and idealized lives, with greater similarity indicating greater life satisfaction (Pavot & Diener, 1993). While there may be general agreement regarding various components of life satisfaction, such as health and romantic relationships, the weights assigned to these components can vary based on the individual (Diener, Emmons, Larsen, & Griffin, 1985). Thus, an evaluation of overall life satisfaction is recommended rather than focusing on specific areas of satisfaction (Pavot & Diener, 1993). Research has indicated

that satisfaction forms a concept distinct from well-being, as perceptions of quality of life are frequently a result of current experiences and situations, whereas perceptions of life satisfaction are more long-term (Pavot & Diener, 1993). However, some merging of the concepts of life satisfaction and emotional well-being exists, as both are a result of personal evaluation (Pavot & Diener, 1993).

Social capital, well-being, and life satisfaction have been found to be affected by social media. Social media and devices such as smartphones can encourage relationships through engagement in communication (contacting family and friends), friending (adding individuals to your social media pages), and self-disclosure (discussing personal information and experiences) (Chen & Li, 2017). Usage of cellular devices is positively correlated with social capital as it allows for constant connections, as well as initiation of social activities (Campbell & Kwak, 2010; Wei & Lo, 2006). Additionally, cellular devices can encourage the sustainment of weaker social relationships through sending occasional messages and emails (Chen & Li, 2017).

Bonding and bridging social capital have been found to be enhanced through social media by synching contact information with social media sites, and by encouraging relationships with individuals who may know family and acquaintances (Chen & Li, 2017). Bridging and bonding social capital can also both be increased through using social media for communication, and the number of friends on social media sites was found to increase social capital and life satisfaction, and decrease loneliness in a study of college students (Burke, Marlow, & Lento, 2010). Research has also demonstrated a positive relationship between self-disclosure on social media and social capital, as social media allows a forum in which individuals can share their thoughts and feelings (Chen & Li, 2017). Social media may be an excellent resource to increase social capital for

individuals with disabilities, who may not know others with the same diagnosis. The ability to build such social capital could also result in increased life satisfaction and feelings of wellness.

### **Turner Syndrome**

Turner Syndrome is a rare genetic disorder which was discovered by Dr. Henry Turner in 1938 (Charney & Smillie, 1987). Turner Syndrome is a disorder which affects only women, and approximately one in every 2,500 women is born with Turner Syndrome (Deal, 2008; Rovet, 1993). The cause of Turner Syndrome is the result of a completely or partially missing X-chromosome, and it affects the body's ability to absorb growth hormone, and to produce the hormones estrogen and progesterone (Deal, 2008). Turner Syndrome can be diagnosed throughout the lifespan, with approximately one-third of the diagnoses occurring in utero or shortly after birth, one-third of diagnoses occurring in early childhood, and one-third of diagnoses occurring in adolescence or later (Charney & Smillie, 1987).

### **Physical and Psychological Effects of Turner Syndrome**

The most noticeable physical characteristic of women diagnosed with Turner Syndrome is short stature (Deal, 2008). The average adult height of women with Turner Syndrome is approximately 4'7 or 4'8", but final height can often be enhanced through growth hormone therapy initiated at a young age (Charney & Smillie, 1987; Orten, 1990). Additional challenges often faced by women diagnosed with Turner Syndrome include infertility, hearing loss, nonverbal learning disabilities, heart abnormalities such as aortic dissection and hypertension, and difficulties with spatial sense (Charney & Smillie, 1987; Pinto, 2008; Wide Boman, Bryman, & Möller, 2004). Individuals with Turner Syndrome also display a lower production of sex hormones; adolescents with Turner Syndrome frequently require hormone replacement therapy in order to initiate the characteristics of puberty, and as a result many women diagnosed with

Turner Syndrome often appear younger than their actual age (Orten, 1990; Rolstad, Möller, Bryman, & Wide Boman, 2007). Turner Syndrome is considered a medical condition which requires longitudinal medical and psychological interventions by the medical community (Christopoulos, Deligeoroglou, Laggari, Christogiorgos, & Creatsas, 2007).

Girls and women diagnosed with Turner Syndrome often present with various karyotypes. Approximately 53 percent of individuals diagnosed with Turner Syndrome experience a completely missing X-chromosome, while the remainder experience a partial deletion of an X-chromosome or a mosaic karyotype, which is a combination of cells with both X-chromosomes and cells with a completely or partially missing X-chromosome (Ross, 1990). The complete deletion of the X-chromosome is considered to be the most severe form of Turner Syndrome, and often presents with more significant physical and medical characteristics (Ross, 1990). The various karyotypes associated with Turner Syndrome also appear to have an effect on the self-perceptions of women diagnosed with the disorder. Lagrou et al. (2006) compared 30 women between the ages of 18 and 23 diagnosed with Turner Syndrome to a comparison sample of 44 age-matched female social work and nursing students and found comparable scores between both groups in the areas of physical appearance, overall self-worth, athletic ability and intellectual ability. The authors discovered that women diagnosed with Turner Syndrome scored themselves lower than the comparison group in the areas of romantic relationships, social acceptance, and sense of humour. In addition, participants diagnosed with the 45, X karyotype of Turner Syndrome displayed lower scores on romantic relationships, close friendships, and sense of humour than participants with alternative karyotypes (Lagrou et al., 2006). Turner syndrome has also been found to have an impact on perceptions of body image and self-esteem. A study of 24 women between the ages of 18 and 30 diagnosed with Turner Syndrome and a comparison

sample of 63 women without Turner Syndrome conducted by Cragg and Lafreniere (2010) found that women diagnosed with Turner Syndrome reported lower levels of body image, in addition to lower levels of general, appearance, and social self-esteem.

Women diagnosed with Turner Syndrome also frequently demonstrate abnormalities in the socio-cognitive areas of emotion recognition and eye gaze; with deficits noted in the processing of fearful expressions, attributing emotional states to others, and eye gaze assessment which demonstrate numerous similarities to Autism (Burnett, Reutens, & Wood, 2010). One study which compared facial cue recognition amongst 17 girls with Turner Syndrome and 16 short-stature individuals between the ages of nine and 17 found that girls with Turner Syndrome received lower scores on facial affect recognition than the girls with short stature (McCauley, Kay, Ito, & Treder (1987). An in-depth analysis revealed that the participants with Turner Syndrome experienced greater difficulty with facial affect recognition in pictures of low-ambiguity male and female faces, as well as high-ambiguity female faces (McCauley et al., 1987). These differences remained when spatial performance was controlled for, indicating that spatial ability and facial affect discrimination may be independent of each other but related through the right hemisphere (McCauley et al., 1987).

A survey of 49 women diagnosed with Turner Syndrome conducted by Bannink, Raat, Mulder, and De Muinck Keizer-Schrama (2006) revealed that women diagnosed with Turner Syndrome reported greater Health-Related Quality of Life when compared to the average population. However, lower Health-Related Quality of Life in the area of social functioning was observed in the women diagnosed with Turner Syndrome who reported feelings of insecurity regarding their physical appearance. The authors theorized that the overall high Health-Related Quality of Life in women diagnosed with Turner Syndrome could be due to medical

interventions such as growth hormone and hormone replacement therapies which have become more widely available. Participants were asked additional questions regarding any limitations that they perceived in their lives due to their diagnosis of Turner Syndrome (Bannink et al., 2006). Thirty-five participants reported no limitations, while ten participants reported experiencing limitations. Three participants reported experiencing limitations with relationships, four participants reported experiencing limitations with employment, four participants reported experiencing insecurity regarding their physical appearance, and one participant reported experiencing both physical insecurity and limitations in relationships (Bannink et al., 2006).

### **Turner Syndrome and Social Relationships**

Individuals with short stature often have difficulties forming social relationships with same-aged peers, frequently due to the perception that they are younger than their actual age (Orten, 1990). For many adolescent females with Turner Syndrome, the fact that they may not be displaying the signs of puberty at the same time as other classmates may also influence social relationships, and may result in being left out of social conversations regarding crushes and dating (Christopoulos et al., 2007; Nakamura, 2005). Additionally, Money and Mittenhal (1970) stated that the short stature and pubertal delays which are prominent features of Turner Syndrome create the appearance of a more infantile individual, which can indirectly affect social development. Women and girls diagnosed with Turner Syndrome have been shown to be more likely to display personalities that are more compliant, less assertive, and display greater tolerance for personal adversity (Money & Mittenhal, 1970). These personality factors could have a significant effect on creating and maintaining social relationships.

Skuse (1987) conducted a meta-analysis of studies focusing on individuals diagnosed with various conditions associated with short stature and found that girls with Turner Syndrome



reported behaviours such as unassertiveness and relationship difficulties with peers, which could result in social problems. These findings may be a result of the nonverbal learning disability that is diagnosed in many girls and women with Turner Syndrome. Such a diagnosis could affect their development of social skills, and result in difficulties in social interactions. Another study which supports this finding was conducted by Rovet (1993), who studied girls with Turner Syndrome and found that participants reported lower levels of social competence, as well as greater instances of behavioural concerns and hyperactivity. Haverkamp, Dörholt, Ranke, and Noeker (2000) surveyed and interviewed 54 German women diagnosed with Turner Syndrome, and discovered that 38% of the women with Turner Syndrome reported experiencing difficulties with peers, lower self-esteem, and greater feelings of social isolation. Additionally, 21 of the participants reported experiencing pervasive stress due to their experienced difficulties in social relationships.

A survey of 48 adult women with gonadal dysgenesis, an alternate medical term which Turner Syndrome falls under, revealed that 29 of the participants reported varied and pleasing social relationships; however, when questioned further, 20 of the participants reported social relationships exclusively with female coworkers (Aran et al., 1992). The authors theorized that the discrepancy between the perceived and factual social relationships reported by participants could be a result of social desirability; participants may be hesitant to admit experiencing difficulties in social relationships, and therefore may engage in over-reporting of positive social experiences. An additional theory is that women with Turner Syndrome may be compensating for difficulties in romantic relationships by placing a greater focus on social relationships (Aran et al., 1992).

The rarity and lack of education of the diagnosis within the general population can also affect social relationships. The participants interviewed by Kagan-Krieger (1998) stated that they could not separate feelings of isolation from their diagnosis of Turner Syndrome. Due to the lack of education about Turner Syndrome within the general population, disclosure is a significant issue for many girls and women with Turner Syndrome. One of the women interviewed by Kagan-Krieger (1998), Dawn, stated that she finds it difficult to disclose her diagnosis to others, and as a result feels like her friends and peers do not have a complete understanding of her. She further commented "But I find when I'm with TS people I just feel a commonality that . . . obviously I don't feel elsewhere, and maybe that's something that's been missing in my relationships." (Kagan-Krieger, 1998, p. 131). This sense of isolation and being misunderstood can create a sense of vulnerability, and an increased desire to forge meaningful relationships, as interpersonal relationships are frequently viewed as essential to development in women (Kagan-Krieger, 1998).

Numerous studies of girls and women diagnosed with Turner Syndrome have noted deficits in various aspects of social functioning, and such social difficulties frequently endure in adulthood (Burnett et al., 2010). Girls diagnosed with Turner Syndrome frequently report a smaller quantity of friends, greater social difficulties, participating in fewer social interactions and activities, and also greater withdrawal from social interactions than peers who have not been diagnosed with Turner Syndrome (Lagrou et al., 1998; Siegel, Clopper, & Stabler, 1998). An additional study on 103 Canadian girls with Turner Syndrome between the ages of seven and 13 revealed that while there were no significant differences between the quantity of friends reported by the girls with Turner Syndrome and the comparison group, girls with Turner Syndrome stated

that they spent less time with their friends and had a less positive relationship with their friends than girls in the control group (Rovet & Ireland, 1994).

A study conducted by Lesniak-Karpiak, Mazzocco, and Ross (2003) evaluated behavioural displays of anxiety of children and young adults with Turner Syndrome and Fragile X Syndrome during simulated conversations with a stranger and compared them with a control group of similarly-aged participants. Fragile X Syndrome is often a result of an X-chromosome mutation at the location Xq27.3, and is diagnosed in both male and female populations with a frequent co-morbid diagnosis of severe mental impairment as well (Lesniak-Karpiak, Mazzocco, & Ross, 2003; Verkerk et al., 1991). Participants engaged in a scenario of interacting with a new neighbour with a research staff member with whom they had no prior interactions. Staff members were instructed to avoid initiating conversations, to engage in minimal responses, and to use a neutral response tone (Lesniak-Karpiak et al., 2003). Results revealed that age had a significant effect on social interactions, with younger participants engaging in greater fidgeting behaviours, increased eye contact avoidance, and lesser conversation engagement (Lesniak-Karpiak et al., 2003). The authors also found that while levels of social anxiety were not significantly different between the three groups, parents of participants with Turner Syndrome and Fragile X Syndrome stated that their children were experiencing greater social issues than those in the comparison group.

Determining the source of social deficits frequently observed in individuals with Turner Syndrome has been extremely difficult (Hong, Dunkin, & Reiss, 2011). One theory as to the source of the social deficits noted in Turner Syndrome focuses on the sex hormone deficit observed in individuals with Turner Syndrome, as estrogen has been found to be an essential component of social conduct, as noted in animal studies such as those conducted by Phan,

Lancaster, Armstrong, MacLusky, and Choleris (2011). In order to further evaluate social skills of girls with Turner Syndrome, a study was conducted on 42 girls with Turner Syndrome aged three to 12, prior to the initiation of estrogen therapy (Hong et al., 2011). The girls diagnosed with Turner Syndrome revealed deficits in social competence when compared to a control group of 32 similar-aged peers, and had clinically significant mean social responsiveness scores. The authors also discovered mild-to-moderate clinically significant results amongst girls with Turner Syndrome in the areas of social reasoning and autistic traits. The sole domain in which girls with Turner Syndrome scored on par with their peers was social motivation, revealing that girls diagnosed with Turner Syndrome desire social interactions while experiencing diminished social functioning (Hong et al., 2011). Additionally, the various differences observed amongst groups remained when the authors controlled for verbal intelligence, indicating that the social deficits observed in individuals with Turner Syndrome appear to represent a more specific neurocognitive factor, as opposed to resulting from a general cognitive deficit.

An additional report by Hong, Kent, and Kesler (2009) further delved into the association between the particular neurocognitive profile observable in a significant number of women with Turner Syndrome and social functioning. The authors discussed the recent surge of research on the cognitive aspects of Turner Syndrome, which supports the theory of a cognitive profile which is specific to girls and women diagnosed with Turner Syndrome. As stated earlier, individuals with Turner Syndrome frequently display deficits in processing eye gaze, facial and emotional recognition, and mental flexibility, as well as an increase in impulsivity (Hong et al., 2009). Such impairments could affect social functioning in a variety of ways. Visual perception difficulties could reduce the ability to interpret nonverbal cues in social situations, while spatial challenges associated with reasoning and pattern recognition could impact the ability to determine the

connection between behaviours and consequences in social situations (Hong et al., 2009).

Furthermore, mental inflexibility can result in a lack of perception of when to switch topics or an inability to cope with changing social situations, as well as affecting the ability to acknowledge another person's perspective (Hong et al., 2009). Finally, impulsivity can manifest itself in social situations and conversations and negatively affect social relationships (Hong et al., 2009). An alternative theory involves the connection between the hormonal deficiencies associated with Turner Syndrome and social deficits (Schmidt et al., 2006). Such hormone deficits could impact the areas of the brain associated with emotion regulation and social behaviour, resulting in social anxiety and depression.

### **Turner Syndrome and Family Relationships**

A diagnosis of Turner Syndrome and the additional medical and psychological effects frequently associated with it can have a significant effect on family relationships. Suzigan and colleagues (2011) included an evaluation of the perception of mothers of their daughter's social skills when compared to their child's sister who did not have a diagnosis of Turner Syndrome. The mothers disclosed experiencing more family issues with their daughters diagnosed with Turner Syndrome than with their daughters who did not have a diagnosis. Additionally, the mothers reported a more positive relationship with their daughter not diagnosed with Turner Syndrome than with their daughter who had received the diagnosis (Suzigan et al., 2011).

Family relationships and interactions frequently impact coping abilities. Haverkamp et al. (2000) discovered that women with Turner Syndrome who reported coping deficits referred to parents and caregivers as negating or minimizing issues of Turner Syndrome, as well as perceiving increased parental overprotectiveness. The authors reported that women with Turner Syndrome who scored higher in resiliency described parents and caregivers as extremely

supportive of their autonomy. These participants also reported overall life satisfaction which corresponded with peers without Turner Syndrome. Additionally, Lagrou et al. (1998) noted a negative correlation between social self-esteem of girls with Turner Syndrome and family investment in their children with Turner Syndrome, with girls reporting low social self-esteem while receiving high personal investment from family members. The authors also noted that the participants diagnosed with Turner Syndrome more often sought solace within their family while also avoiding disagreements with peers.

Family relationships during childhood can have a significant impact on adult development and relationships. Kagan-Krieger (1998) conducted a series of interviews focusing on the impact of Turner Syndrome and the life experiences of three women diagnosed with Turner Syndrome. One of the participants, Jane, discussed the impact of her family relationships on her adult development, particularly what she perceived as her mother's lack of understanding and support regarding the issues that she faced associated with her Turner Syndrome diagnosis. As a result, Jane felt unable to disclose and confide in her mother regarding the issues she was experiencing. Additionally, a study of 36 Brazilian women diagnosed with Turner Syndrome revealed that only 47 percent of participants stated that they had a positive relationship with their family (Suzigan et al., 2004). Such impacts can have lifelong effects, and may impact the ability to form social relationships and social capital.

### **Turner Syndrome and Education**

Turner Syndrome and the various comorbid diagnoses associated with it have also been found to impact the educational experiences of the girls and women diagnosed. Rovet (1992) stated that girls and women diagnosed with Turner Syndrome experience higher incidence rates of learning disabilities, particularly nonverbal learning disabilities which typically present as

significantly lower than average scores on arithmetic scales and high scores on verbal intelligence scales (Kagan-Krieger, 1998). Such learning disabilities frequently result in educational challenges, and such educational challenges have been linked with deficits in the areas of self-esteem, peer relationships, and employment if not treated efficiently (Kagan-Krieger, 1998). Additionally, in the study conducted by Lagrou et al. (1998) on 31 girls between the ages of three to 16 diagnosed with Turner Syndrome, questionnaires completed by parents and older participants revealed that the participants diagnosed with Turner Syndrome invested more effort in their schoolwork than their siblings without Turner Syndrome, while attaining less adequate results. Such challenges can emerge during the transition to post-secondary education (Ross, Zinn, & McCauley, 2000). Ross et al. (2000) hypothesized that women with Turner Syndrome experience difficulties navigating post-secondary education due to such factors as the more rapid pacing of courses, and the lack of structure to aide in forming a social identity and social relationships.

A study of 240 American women 25 years of age and older diagnosed with Turner Syndrome who were participating in the National Institutes of Health's National Institute of Child Health and Human Development study on women with Turner Syndrome between 2001 and 2010 revealed that over 70 percent of participants had obtained a college degree or greater; significantly higher than the general population rate of 30 percent (Gould, Bakalov, Tankersley, & Bondy, 2013). The authors also discovered that the women in their study diagnosed with Turner Syndrome had received an average of 15.4 years of formal education. An additional study conducted by Aran et al. (1992) in which the adult participants had been followed by the study's multidisciplinary team from childhood revealed that over 50 percent of the 48 women surveyed had obtained a post-secondary degree. An additional study conducted by Lagrou et al. (2006)

revealed that the 30 participants diagnosed with Turner Syndrome who were surveyed as members of the Belgian Study Group for Paediatric Endocrinology displayed extremely high educational attainment; 53 percent of participants had obtained a diploma of higher secondary education, and 33 percent obtained a post-secondary degree. Ten percent obtained a lower secondary diploma and one participant had been enrolled in special education courses (Lagrou et al., 2006). Furthermore, a study conducted by Pavlidis, McCauley, and Sybert (1995) evaluated 64 women with Turner Syndrome obtained from the Turner Syndrome Society of the United States and 16 women from a medical clinic formed to study the progression of Turner Syndrome in adult women. The authors found that 70 per cent of the women with Turner Syndrome surveyed had completed four or more years of postsecondary education.

Research findings have been discrepant regarding the correlation between Turner Syndrome, height and educational or employment status. Haverkamp et al. (2000) found that participants diagnosed with Turner Syndrome who obtained greater educational qualifications were of greater average height than participants who obtained lesser educational qualifications; with average heights of 154 cm (5' 1") and 147 cm (4' 10") respectively. Contradictory findings were noted in a study conducted by Downey, Ehrhardt, Gruen, Bell, and Morishima (1989) in which they found that a diagnosis of Turner Syndrome appeared to be negatively correlated with academic and employment success. The authors noted that women diagnosed with Turner Syndrome reported lower academic and employment attainment than a control group of women diagnosed with constitutional short stature. Alternatively, Gould et al. (2013) did not find any correlation between height and academic or employment success amongst the participants diagnosed with Turner Syndrome. A study conducted by Orten and Orten (1992) found that the sample of women diagnosed with Turner Syndrome had obtained analogous academic and



employment results as similar individuals in the general population. These studies appear to demonstrate that women with Turner Syndrome are as varied as women in the general population; some women with Turner Syndrome experience challenges within the educational and employment systems, while other women experience high levels of success (Kagan-Krieger, 1998).

### **Turner Syndrome and Employment**

Women diagnosed with Turner Syndrome were found to be employed at a greater rate than the general population in the study conducted by Gould et al. (2013); with employment rates of 80.4 percent and 70 percent respectively. The authors also discovered that the most frequent careers reported by women with Turner Syndrome were healthcare, legal, community, and social services. Women diagnosed with Turner Syndrome were significantly less likely to report careers in the areas of food preparation/serving or office/administration (Gould et al., 2013). Additionally, in the study conducted by Aran et al. (1992), all participants were employed in occupations corresponding to their educational achievement; 17 participants were employed in office work, 12 were employed in academia, and eight were employed in educational settings (Aran et al., 1992). An additional study conducted by Pavlidis et al. (1995) found that 86 percent of the women with Turner Syndrome surveyed were employed, with 52 percent of the women employed in professional roles. Furthermore, Suzigan and colleagues (2004) found that 75 percent of the women with Turner Syndrome surveyed reported having positive relationships with their employers, colleagues, and teachers. In a study comparing 52 Brazilian women with Turner Syndrome to their sisters who did not have the diagnosis, 29 of the women with Turner Syndrome reported being employed, compared to six of the siblings (Suzigan et al., 2011).

Employment status of women with Turner Syndrome was further examined by Næss, Bahr, and Gravholt (2010). The authors found that women with Turner Syndrome were more likely to be employed full-time and less likely to be employed part-time or self-employed than participants in the control sample. Additionally, the participants with Turner Syndrome were most likely to be employed as kindergarten teachers, and were less likely to be employed in administrative or economic positions (Næss et al., 2010). When asked more specific questions regarding their position requirements, women diagnosed with Turner Syndrome stated that they were less likely to be required to make rapid and complex decisions or require additional employment training or education than control participants (Næss et al., 2010). An additional study conducted by Ross et al. (2000) revealed that a significant number of women with Turner Syndrome reported experiencing employment challenges with such tasks as multitasking, managing significant job details such as managing finances, and interpersonal requirements, affecting their success in complex roles.

Aran et al. (1992) theorized that the high educational and employment statistics reported by women with Turner Syndrome could be a result of a compensation mechanism. The authors stated that previous research has demonstrated that individuals diagnosed with physical abnormalities which do not impact intellectual functioning may compensate for any physical challenges through achieving in the areas of academics and employment as a method of improving social standing. As a result, women with Turner Syndrome may throw themselves into succeeding in their educational and employment pursuits, to the neglect of areas which may be more challenging, such as social and romantic relationships.

### **Turner Syndrome and Romantic Relationships**

Researchers have noted a dearth of research on the effects of infertility on the self-perceptions of women diagnosed with Turner Syndrome in relation to their value in romantic relationships (Clauson, Hollins Martin, & Watt, 2012). Due to the significant frequency of infertility in women and girls diagnosed with Turner Syndrome, infertility status is commonly known at the time of diagnosis (Clauson et al., 2012). It has been theorized that the knowledge of infertility status could affect the attachment and engagement within romantic relationships with partners (Clauson et al., 2012). Additionally, Haverkamp et al. (2000) observed that participants with more significant presentation of the physical characteristics of Turner Syndrome reported experiencing fewer heterosexual romantic relationships and activities. Similarly, Næss et al., (2010) stated that there appeared to be a positive correlation between the age of initiation of Growth Hormone and Hormone Replacement therapies and age of first sexual experience.

Research has revealed that women diagnosed with Turner Syndrome, when compared to the average population, frequently achieve sexual and relationship markers such as age of first sexual encounter at a later age, and that women with Turner Syndrome also report a lesser number of sexual partners than similarly-aged peers (Rolstad et al., 2007). Gould et al. (2013) stated that only 46 percent of the women diagnosed with Turner Syndrome reported being currently or previously involved in a marriage, compared to 78 percent in the general American female population. As a further example, of the 48 participants diagnosed with Turner Syndrome surveyed by Aran et al. (1992), only 14 participants were married; 27 participants were single; the other seven participants did not provide reliable data for the question. An additional study revealed that women with Turner Syndrome were more likely to live with their parents or to live independently than live with a partner (Næss et al., 2010). Furthermore, significantly fewer

women with Turner Syndrome were in romantic relationships compared with their siblings without a diagnosis; with nine women in romantic relationships compared to 29 respectively (Suzigan et al., 2011).

When asked if their life would be different if they had not been diagnosed with Turner Syndrome, the majority of women interviewed by Wide Boman, Bryman, Halling, & Möller (2001) agreed. A number of women felt that they would more likely be married and raising a family if they had not been diagnosed with Turner Syndrome, and one participant stated that while she would have liked to have a spouse and children, she had consciously chosen to be single due to her diagnosis (Wide Boman et al., 2001). However, while women with Turner Syndrome are less likely than the general population to be engaged in romantic and sexual relationships, research has demonstrated that the majority of women with Turner Syndrome that are married or cohabitating with partners express moderate to extreme satisfaction with their sexual relationship with their partner (Pavlidis et al., 1995). Such research demonstrates that romantic relationships remain a significant barrier for women with Turner Syndrome.

An additional study of 176 Polish women diagnosed with Turner Syndrome conducted by Lew-Starowicz, Jeż, Irzyniec, Kabzińska, and Boćkowska (2003) compared romantic and sexual relationship statistics of participants to previously obtained statistics of Polish women without Turner Syndrome, as well as women with Turner Syndrome from other Western European countries. The data revealed that Polish women with Turner Syndrome reported lower interest in men and less frequent sexual activity, as well as initial involvement in sexual relationships at a later age than women in the general Polish population. The women with Turner Syndrome also reported fewer marriages, but those who were married displayed greater marital stability than the general Polish population (Lew-Starowicz et al., 2003). However, when compared to women

with Turner Syndrome in other Western European countries, the Polish women interviewed continued to display later initiation of sexual relationships and lesser frequency of sexual activities but displayed greater romantic interest in men and had a higher rate of marriage with greater marital stability (Lew-Starowicz et al., 2003). When asked about reasons for their lack of initiation of sexual activity, the most frequent responses by the Polish women diagnosed with Turner Syndrome were the lack of a partner, their youth, their religious values, and their perception of their health and disability (Lew-Starowicz et al., 2003).

The interview respondents obtained by Kagan-Krieger (1998) also discussed the impact of Turner Syndrome on their experiences in romantic relationships. One of the participants, Jane, stated that she was interested in having a heterosexual romantic relationship, but expressed hesitancy at initiating any relationships. She disclosed:

I am afraid that if I ever did get into it, which I can't see myself doing right now, but if I ever got into being involved with someone to that extent, that he would turn away. And that if he turned away from me, I don't know if I could stand that. That's the major hurdle I have right now is relationships, or getting into one. (Kagan-Krieger, 1998, p. 130).

Infertility was a significant issue for the women interviewed by Kagan-Krieger (1998). Jane stated her perception that fertility is an essential aspect of womanhood, and that men would not be interested in a romantic relationship with her due to her infertility. Another participant, Eileen, revealed that disclosing her Turner Syndrome diagnosis and her resulting infertility resulted in significant feelings of insecurity when she was dating her future husband. She stated:

Yeah, I took the risk. Probably, thought I'd jump in there now rather than get too attached and then find out he can't cope with it or it's too hard and that was really important for

him right at that point. I felt like a big weight was off my shoulders after telling him.  
(Kagan-Krieger, 1998, p. 132).

As demonstrated throughout the studies mentioned, romantic relationships are significantly impacted for women with Turner Syndrome. Infertility and its impact remain a significant hurdle when contemplating or engaging in romantic relationships.

### **Turner Syndrome and Social Capital**

A review of the literature revealed a strong lack of research in the area of social capital in relation to Turner Syndrome, as the majority of past research has involved examining the medical effects of Turner Syndrome. Furthermore, due to the rareness of Turner Syndrome, many women diagnosed with the disorder may experience social isolation as they are often not aware of others in their community who are living with the same diagnosis. This may particularly occur in small cities and rural communities, where women are not able to take advantage of the social capital provided by the initiatives of such organizations as the Turner Syndrome Society of Canada. As a result of challenges currently facing the Turner Syndrome community, research on the perceptions of available social capital amongst women diagnosed with Turner Syndrome is paramount for this population.

The Turner Syndrome Society of Canada has chapters located throughout Canada, but all chapters are located in larger cities, such as Toronto, Ottawa, and Vancouver, with some smaller groups in such locations as Calgary, London, and Thunder Bay (Turner Syndrome Society of Canada, 2015b). The chapters and groups host social events and information days throughout the year, and the chapters alternate hosting the annual conference of the Turner Syndrome Society of Canada (Turner Syndrome Society of Canada, 2015b). Many individuals living in smaller communities may not be able to afford the expense of traveling to attend such initiatives. In

order to counteract this difficulty, the Turner Syndrome Society of Canada maintains a database of membership information which includes member locations, in order to link individuals in the same geographic area (Turner Syndrome Society of Canada, 2015b). Online support groups have also been initiated through social networking sites such as Facebook, and the online discussion platform Inspire (Turner Syndrome Society of Canada, 2015a). Such support groups have been formed without the aide of literature on the social capital of women with Turner Syndrome.

### **The Present Study**

Further research on the social and psychological effects of Turner Syndrome is essential, as there is a significant gap in the literature. Additionally, increasing social capital is necessary in order to enhance the educational, relationship, and employment experiences of women diagnosed with Turner Syndrome, and their participation in such domains. The present research study addresses this gap in the literature, and provides greater information on whether women with Turner Syndrome do report lower perception of social capital. Such research is strongly needed, as studies have indicated that girls and women diagnosed with Turner Syndrome report difficulties with self-esteem and social relationships (Cragg & Lafreniere, 2010; Wide Boman, Bryman, & Möller, 2004). Such difficulties could have an effect on social capital, and this link needs to be examined further.

### **Research Questions and Hypotheses**

This research study intends to answer the question: do women with Turner Syndrome have lower levels of social capital in a variety of areas compared to women of the same age range not diagnosed with Turner Syndrome, and does this affect their wellness and life satisfaction? A mixed-methods research design was utilized to examine the perceived social capital of a sample of women aged 18-30 diagnosed with Turner Syndrome. It was hypothesized

that women diagnosed with Turner Syndrome would report significantly lower levels of social capital compared to a control group of women in the same age range who have not been diagnosed with Turner Syndrome. Two potential outcomes of social capital: wellness and life satisfaction, were also assessed. It was hypothesized that individuals reporting as low in social capital would also display lower levels of wellness and life satisfaction. Psychological capital was also examined to determine whether it was a mediating variable between the measures of social capital and outcome measures of wellness and life satisfaction.

## **CHAPTER II: Methodology**

### **Participants**

Eleven women between the ages of 18 and 30 diagnosed with Turner Syndrome were obtained from the Turner Syndrome Society of Canada and various online Turner Syndrome support groups. As a comparison, 20 women in the same age range were obtained through the University of Windsor's psychology department participant pool. Only women participated in this study as Turner Syndrome is solely diagnosed in women. The age range was chosen in order to control for any discrepancies in medical interventions such as growth hormone injections and hormone therapy which could affect self-perceptions and the perceptions of others, and as a result could affect perceptions of social capital. These medical interventions were not available to older women with Turner Syndrome. In order to increase the diversity and quantity of the Turner Syndrome participants, participants were recruited in-person at the annual Turner Syndrome Society of Canada national conference in Edmonton, Alberta, as well as a luncheon held by the Toronto chapter of the Turner Syndrome Society of Canada. Snowball sampling techniques were utilized with this population by informing participants in-person and in the



consent form that they were allowed to share the study web-link and email address of the researcher with female acquaintances who may be interested in participating in the study.

Comparison group participants also included a sample of four community members to make the control sample more diverse and more representative of the general population, resulting in greater generalizability of study findings. Community members were recruited through advertisements in the community section of the website Kijiji, where many research studies are posted. Snowball sampling was also utilized through informing community members in the consent form that they were allowed to share the study web-link and email address of the researcher with female acquaintances who might be interested in participating in the study.

In order to attempt to increase the sample size of participants diagnosed with Turner Syndrome, data collection was undertaken for three months. Administrators of Turner Syndrome Support groups on Facebook were contacted through direct message and were sent a brief explanation of the study and a copy of the letter of permission for research to take place on site to sign. Permission was received from the sites of the Vancouver Chapter of the BC Turner Syndrome Network, the Turner Syndrome and Friends of Calgary and Supporting Area, Official TSSC - Toronto Chapter Group Turner Syndrome and Friends of Edmonton and Surrounding Areas, Turner Syndrome Canada, Turners Syndrome of southern Ontario, and the Turner Syndrome Society of Canada. Follow-up messages were also sent to Turner Syndrome support groups on Facebook who did not reply to the initial informational message. The Turner Syndrome Society of the United States was also contacted by email and phone to seek their participation in the study. In-person recruitment was also conducted at the Turner Syndrome Society of Canada's annual conference held in Edmonton, Alberta, and at a luncheon held by the Toronto chapter of the Turner Syndrome Society of Canada. Snowball sampling and online post

sharing was also utilized in order to obtain more participants. Despite these efforts, the desired sample size of 100 participants with Turner Syndrome was not achieved, and as a result the recruitment of the comparison group was scaled down accordingly to better match the number of participants diagnosed with Turner Syndrome.

## **Measures**

Demographic information of participants was collected, including age, ethnicity, country of residence, educational and employment status, height, weight, and information regarding the diagnosis of Turner Syndrome. Demographic information was used to control for and compare various demographic variables, such as ethnicity and educational attainment.

Quantitative measurement instruments included the Internet Social Capital Scale (Williams, 2006), an adapted version of the Psychological Capital Questionnaire (Luthans, Youssef, & Avolio, 2007, adapted by Bauman, 2014), and the Social Capital Indexes (Strömberg, Eriksson, Bergman, & Dellve, 2016). The Internet Social Capital Questionnaire (Williams, 2006) examines comparisons across bridging and bonding social capital, as well as online and offline social capital. The measure consists of two parallel scales measuring online and offline social capital, with each parallel scale including two subscales consisting of ten questions rated on a 5-point Likert scale which evaluates bridging and bonding social capital. Several items in the bonding social capital scale were adapted from the ISEL social support measure (Cohen & Hoberman, 1983). The Internet Social Capital Scale demonstrates high reliability, with alpha levels for the full online and offline bridging and bonding scales were .90, and .89 respectively (Williams, 2006). Convergent validity of the scale was also found to be high during initial testing of the measure (Williams, 2006). The scale includes such questions as: “Interacting with people online/offline makes me feel like part of a larger community.” As online

communication has become increasingly prominent, and women with Turner Syndrome increasingly rely on online support groups if they are not aware of any other women with Turner Syndrome in their geographic location and do not live near a chapter of a Turner Syndrome Society, The Internet Social Capital Questionnaire will explicitly evaluate the social capital individuals receive online in comparison to social capital received within their community.

The Psychological Capital Questionnaire (Luthans et al., 2007) places a focus on psychological and social capital in the workplace, and measures four factors: efficacy, optimism, hope, and resilience. Each factor has six questions that correspond to it which are rated using a 6-point Likert scale ranging from strongly disagree to strongly agree. The Psychological Capital Questionnaire was adapted to experiences in education by Bauman (2014). The questionnaire utilizes such questions as: “If you should find yourself in a jam at school, you could think of many ways to get out of it.” The Psychological Capital Questionnaire revealed high reliability in initial testing of three student samples and one adult sample, with Cronbach’s alphas ranging from .88 to .89 for the total questionnaire (Luthans et al., 2007). The four subscales also demonstrated high internal consistencies amongst the four samples, with alpha levels for efficacy ranging from .75 to .85, alpha levels for hope ranging from .72 to .80, alpha levels for optimism ranging from .69 to .79, and alpha levels for resilience ranging from .66 to .72 (Luthans et al., 2007). Psychological capital was assessed in this study in order to determine whether it plays a mediating role between social capital and the outcome measures of life satisfaction and overall wellness. The revised Psychological Capital Questionnaire was utilized in this study as it explicitly measures concepts and examples of social and psychological capital within the education system. Permission to use the measure was obtained by the original authors and can be viewed in Appendix A.

The Social Capital Indexes (Strömghren et al., 2016) also focuses on the workplace, and consists of ten questions utilizing a 5-point Likert scale consisting of the following response options: To a very large extent, To a large extent, Somewhat, To a small extent, To a very small extent. The scale measures four subscales: reciprocity, trust regarding management, mutual trust amongst employees, and recognition (Strömghren et al., 2016). Scores on the 5-point Likert scale are recalculated to a scale ranging from 0–100 points (Strömghren et al., 2016). Items measuring trust regarding management, mutual trust between employees, and recognition were taken from The Copenhagen Psychosocial Questionnaire (COPSOQ II, Pejtersen, Kristensen, Borg, & Bjorner, 2010), while the items measuring reciprocity were taken from the Modern Work Life Questionnaire (Oxenstierna, Widmark, Finnholm, & Elofsson, 2008). Social capital is calculated as the sum of the scores in each subscale (Strömghren et al., 2016). The Social Capital Indexes demonstrates high reliability, with a Cronbach's alpha of 0.73 (Strömghren et al., 2016). The questionnaire utilizes such questions as: "Is your work recognized and appreciated by the management?" The Social Capital Indexes was utilized in this study as it explicitly evaluates areas of social capital within the workplace.

As the questionnaires utilized are unidimensional and do not focus on all sources of social capital, the qualitative research component involved a series of open-ended questions which examined participant perceptions of social capital in the additional areas of family, social, and romantic relationships and provided a broader picture of participant perceptions of social capital from a variety of sources in their lives. Participants were also asked about recent stressful life and health events that may have impacted their social relationships, as well as their perception of their level of femininity compared to others and if they felt that this perception had an impact on their social relationships. Pilot testing of the open-ended questions was conducted

with a small sample of women diagnosed with Turner Syndrome to ensure the clarity of the open-ended questions. A copy of all measures is included in Appendix B.

Two potential outcomes of social capital were measured and evaluated: well-being and life satisfaction. Well-being was measured through the Perceived Wellness Survey (Adams, 2005; Adams, Bezner, & Steinhardt, 1997). The Perceived Wellness Survey consists of 36 questions measuring six life dimensions: psychological, emotional, social, physical, spiritual, and intellectual (Adams et al., 1997). Each dimension is measured on a 6-point Likert-scale ranging from 1 (very strongly disagree) to 6 (very strongly agree) (Adams et al., 1997). Items in the emotional dimension were adapted from the State Self-Esteem Scale (Heatheron & Polivy, 1991). Items in the physical dimension were adapted from the Medical Outcomes Survey-36 (Ware & Sherbourne, 1992). Items in the psychological dimension were adapted from the Life Orientation Test (Scheier & Carver, 1985). Items in the social dimension were adapted from the Perceived Social Support Friends and Family Scale (Procidano & Heller, 1983) and the Perceived Social Support Scale (Blumenthal et al., 1987). Items in the spiritual dimension were adapted from the Existential Well-Being Scale (Paloutzian & Ellison, 1982). The questionnaire utilizes such questions as “I am always optimistic about my future”. A total wellness score is obtained by dividing the average of the total scores of each subscale by the square root of the variance of the six subscales, plus a constant value of 1.25, to prevent a denominator of zero from occurring (Harari, Waehler, & Rogers, 2005). The Perceived Wellness Survey has demonstrated good reliability, with alpha levels over a 2–4-week period ranging from .73 to .81 for the wellness composite score within student ( $N = 54$ ) and corporate ( $N = 19$ ) samples (Adams et al., 1997). The complete scale also demonstrates good internal consistency, with a mean alpha level of .91 (Adams et al., 1997). The Perceived Wellness Survey was utilized in this study as it

covers a wide variety of life domains, and also allows for analysis of satisfaction in each domain as well as overall wellness.

Life satisfaction was measured with the Satisfaction with Life Scale (Diener, Emmons, Larsen, & Griffin, 1985). The Satisfaction with Life Scale consists of five questions focusing on overall satisfaction with life (Diener et al., 1985). Scores on this measure are calculated on a 7-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree) (Diener et al., 1985). Scores range from 5 to 35, with scores ranging from 5-19 indicating various degrees of overall dissatisfaction with life, a score of 20 represents neutral life satisfaction, and scores of 21-35 indicating various degrees of overall satisfaction with life (Pavot & Diener, 1993). Diener et al. (1985) evaluated the measure with 176 undergraduate students at the University of Illinois, testing 76 of the students with the same measure two months later. The authors revealed a 2-month test-retest coefficient alpha level of .87 and a 2-month test-retest stability coefficient alpha level of .82. The scale includes such questions as: "If I could live my life over, I would change almost nothing". The Satisfaction with Life Scale was utilized in this survey as it is a brief measure which captures a reliable measurement of overall life satisfaction.

### **Procedure**

Prior to advertising the study, approval from the Research Ethics Board of the University of Windsor was obtained. Once the approval was confirmed, advertisements for the study were placed on the websites and in the newsletters of the Turner Syndrome Society of Canada, as well as on various online support groups for individuals with Turner Syndrome. Permission for the advertisements was obtained from the acting Executive Director of the Turner Syndrome Society of Canada, as well as the moderators of the online support groups. All individuals contacted were informed that the study had obtained ethics clearance from the University of Windsor's Research

Ethics Board. The study was also advertised through the University of Windsor's Psychology Participant Pool, as well as through the community volunteer section of Kijiji. In-person advertising and administration of the study also occurred at social events held by the Toronto chapter of the Turner Syndrome Society of Canada with permission from the President of the Toronto chapter, as well as the national conference held by the Turner Syndrome Society of Canada.

Participants obtained through the websites of the Turner Syndrome Societies of Canada, Turner Syndrome online support groups, the Kijiji advertisement, and the University of Windsor's Psychology Participant Pool completed an online version of the survey through the University of Windsor's online survey system, Qualtrics. Prior to completing the survey, participants viewed a copy of the consent form. Participants checked a box to confirm consent, and were encouraged to print a copy of the consent form for their records. Participants were informed in the consent form that any questions regarding the consent form or the survey could be answered by emailing the researcher, and the researcher's contact information was provided in the consent form. After reading the consent form, participants who selected 'yes' to consent were taken to the survey, while participants who selected 'no' to consent were taken to an exit page. It was anticipated that the survey would take approximately one hour to complete. Participants were informed that they had the option of withdrawing from the study at any point prior to completing the survey. After completing the survey, participants from the Turner Syndrome Society of Canada, the online support groups, and Kijiji were sent to a separate page to enter their contact information for a chance to win one of four \$20 Amazon gift cards. Participants from the Participant Pool were taken to a separate webpage where they entered their name and email address in order to receive bonus points for their participation.

Participants obtained through that Turner Syndrome Society of Canada's annual conference and the luncheon held by the Toronto chapter of the Turner Syndrome Society of Canada were given the option of completing the online or a physical copy of the survey. Participants who chose to complete a physical copy of the survey received a copy of the consent form prior to receiving a copy of the survey and were instructed to read the form and keep the copy for their records. As the researcher administered the survey and consent forms in person, participants were able to ask the researcher any questions regarding the consent form or study. After completing the survey, participants were provided with a separate page to enter their contact information for a chance to win one of the four \$20 Amazon gift cards. In order to maintain participant confidentiality, participants were given a large envelope to place their survey in or could place their survey in a box, depending on which method was easiest to implement at the venue. Participants were also provided with a separate envelope or box to place their contact information form in.

Participants were informed that they had the option of completing the online version of the survey if they did not feel that they had the time to complete the survey in the presence of the researcher. If participants chose this option, they were provided with a business card with the name and web-link of the survey on it, as well as the researcher's email address. The business card also included a QR code for participants to scan with their mobile phones in order to complete the survey on their mobile devices.

The consent form also informed participants of the anticipated date of the release of the summary of the results, and also provided a web-link to view the posted results. Additionally, a summary of the results were posted on the websites of the Turner Syndrome Society of Canada, as well as on the various online Turner Syndrome support groups which advertised the study.



### CHAPTER III: Results

#### Participant Background Characteristics

Eleven participants diagnosed with Turner Syndrome and 24 participants from the comparison group were included in the study, resulting in a total of 35 participants. Twenty-nine of the participants reported that they were currently living in Canada, and six participants reported that they currently lived in the United States. Approximately one-third of participants identified themselves as English Canadian. Participants ranged in age from 18-30, with a mean age of 23. For participants diagnosed with Turner Syndrome, the age at which they received their diagnosis ranged from prenatal to age 25. Participants diagnosed with Turner Syndrome reported an average height of 59.45 inches, while participants in the comparison group reported an average height of 65.58 inches. When asked about their weight, participants diagnosed with Turner Syndrome reported an average weight of 136.27 pounds, while participants in the comparison group reported an average weight of 164.22 pounds.

When asked about their level of education, approximately 46 percent ( $n = 16$ ) of participants reported that their highest level of education was some university. Eighty percent of participants ( $n = 28$ ) reported that they were currently enrolled as a student, with 62.9 percent of participants ( $n = 22$ ) reporting being full-time students. The majority of students were enrolled in their third year of studies ( $n = 11$ ). Further information regarding participant demographics can be found in Table 1.

Table 1

*Descriptive Statistics for Participants*

Variable	Turner Syndrome group (n = 11)	Comparison group (n = 24)
Age in years		
<i>M</i>	27.00	21.58
<i>SD</i>	3.23	2.86
Range	22-30	18-27
Location		
Canada (%)	5 (45.5)	24 (100)
United States (%)	6 (54.5)	0 (0)
Height (inches)		
<i>M</i>	59.45	65.58
<i>SD</i>	2.66	3.35
Range	56-65	60-72
Weight (pounds)		
<i>M</i>	136.27	164.22
<i>SD</i>	35.21	56.28
Range	95-205	110-350
Ethnicity		
Scandinavian (%)	1 (9.1)	0 (0.0)
British (%)	2 (18.2)	1 (4.2)
English Canadian (%)	3 (27.3)	8 (33.3)
W. European (%)	1 (9.1)	2 (8.3)
E. European (%)	1 (9.1)	1 (4.2)
S. European (%)	2 (18.2)	2 (8.3)
Far Eastern (%)	0 (0.0)	3 (12.5)
Middle Eastern (%)	0 (0.0)	2 (8.3)
Latin American (%)	0 (0.0)	1 (4.2)
Other (%)	1 (9.1)	4 (16.7)
Highest level of education		
High school (%)	0 (0.0)	6 (25.0)
Some college (%)	3 (27.3)	0 (0.0)
Some university (%)	3 (27.3)	13 (54.2)
College graduate (%)	1 (9.1)	2 (8.3)
University (%)	1 (9.1)	2 (8.3)

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Master's degree or other similar degree (%)	3 (27.3)	1 (4.2)
Student status		
Yes (%)	5 (45.5)	23 (95.8)
No (%)	5 (45.5)	1 (4.2)
Enrollment		
Full-time (%)	4 (36.4)	18 (75.0)
Part-time (%)	1 (9.1)	5 (20.8)
Year of Study		
1st year (%)	0 (0.0)	3 (12.5)
2nd year (%)	0 (0.0)	6 (25.0)
3rd year (%)	1 (9.1)	10 (41.7)
4th year (%)	2 (18.2)	3 (12.5)
Other (%)	2 (18.2)	1 (4.2)

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### **Data Cleaning**

In total, 38 participants were recorded as completing the survey. Three participants in the Turner Syndrome group were filtered out of the analysis, as they were over the age limit specified for the study. The final number of participants left in the study were 11 participants in the Turner Syndrome group and 24 participants in the comparison group. Of the participants in the comparison group, 20 participants were from the University of Windsor's Psychology Participant Pool, and four were from the greater Windsor community.

A missing values analysis conducted on the final sample ( $N = 35$ ) revealed a missing value percentage of 2.9 for items in the Internet Social Capital Scale and the Perceived Wellness Scale. The subscale of Offline Bridging Social Capital for the Internet Social Capital Scale had a missing value percentage of 5.7. In total, 31 cases had complete data, while four cases were missing data for some items. For cases which had less than 10% of their data missing, multiple imputation was utilized to estimate missing values. A Little's MCAR test was conducted on the missing data to determine if the data was missing at random. The test was nonsignificant, resulting in a  $\chi^2 = .000$  ( $df = 454$ ;  $p = 1.0$ ) indicating that the missing data was missing at random.

### **Quantitative Results**

As Turner Syndrome is such a rare disorder, the desired number of 100 participants was not obtained. Analyses were based on statistical tests suitable for small sample sizes, including independent samples  $t$ -tests to compare the scores of the Turner Syndrome group and the comparison group on the various forms of social capital, and the outcome measures of well-being and life satisfaction. The reliability of the measures was assessed prior to running the  $t$ -

tests. As with all statistical tests, the assumptions of linearity, normality of data, homogeneity of variance, and independence of variables were also assessed (Field, 2014).

### **Reliability and normality**

To evaluate the internal reliability of the measure used, Cronbach's alpha coefficients were calculated for each measure. The reliability for all measures was reasonably strong, with alpha coefficients ranging from .83 for the Offline Bonding subscale of the Internet Social Capital Scale to .94 for the online Bridging subscale of the Internet Social Capital Scale. Skewness and Kurtosis values were calculated in SPSS version 24 to establish the normality of the data. None of the quantitative survey measures were found to be outside of the acceptable range of -2 to 2 for skewness, or the acceptable range of -3 to 3 for kurtosis, indicating that the assumption of normality was not violated. The descriptive statistics for each measure are shown below in Table 2.

Table 2

*Descriptive Statistics for Quantitative Measures*

<b>Measure</b>	<b><i>M</i></b>	<b><i>SD</i></b>	<b>Skewness</b>	<b>Kurtosis</b>	<b><i>A</i></b>
<b>SCI</b>	724.00	124.2	-.57	1.30	.86
<b>ISCS_ONBON</b>	22.06	8.80	.54	-.71	.90
<b>ISCS_ONBR</b>	29.97	9.42	-.30	-.51	.94
<b>ISCS_OFFBON</b>	40.45	6.28	-.19	-.74	.83
<b>ISCS_OFFBR</b>	39.26	8.39	.26	.45	.93
<b>PCQ</b>	94.37	15.88	-.71	1.22	.91
<b>SWLS</b>	19.56	5.87	-.69	-.20	.89
<b>PWS</b>	123.34	19.31	-.89	1.22	.91

*Note:* SCI = Social Capital Indexes; ISCS\_ONBON = Internet Social Capital Scale Online Bonding subscale; ISCS\_ONBR = Internet Social Capital Scale Online Bridging subscale; ISCS\_OFFBON = Internet Social Capital Scale Offline Bonding subscale; ISCS\_OFFBR = Internet Social Capital Scale Offline Bridging subscale; PCQ = Psychological Capital Questionnaire; SWLS = Satisfaction with Life Scale; PSW = Perceived Wellness Survey.

### **Outliers**

To determine the existence of univariate outliers, z-scores were calculated through SPSS version 24 for scores on the quantitative scales of the questionnaire being examined. All cases with z-scores greater than -3.29 or +3.29, or three standard deviations above the mean, were considered to be outliers, as according to a normal distribution less than one percent of scores would be expected to be greater than those values (Field, 2014). This more lenient value was chosen due to the small sample size in each groups. An analysis of the z-scores revealed that no outliers were present in the data.

### **Homogeneity of variance**

Homogeneity of variance was tested through Levene's test of Equality of Error Variances. The results of the test were non-significant for all measures at  $p < .05$ , which indicates that the assumption of homogeneity of variance was not violated. Therefore equal variance between the Turner Syndrome sample and comparison sample can be assumed.

### **Hypothesis testing**

Independent sample *t*-tests were conducted to examine if there were any differences between the perceived availability of social capital to women with and without Turner Syndrome in the areas of employment, online and offline social networks, and education. Findings from the *t*-tests are shown in Table 3. It was hypothesized that women diagnosed with Turner Syndrome would report lower levels of social support in all areas. The independent sample *t*-tests for all areas were found to be non-significant at the  $p < .05$  range. The Levene's test of Equality of Error Variance was nonsignificant, indicating that equal variance between groups can be assumed, despite the fact that there were more individuals in the comparison group than in the Turner Syndrome group.

In order to determine whether there were any significant differences between women with and without Turner Syndrome in the outcome factors of life satisfaction and wellness, independent sample *t*-tests were performed. It was hypothesized that women diagnosed with Turner Syndrome would report lower levels of wellness and life satisfaction. The independent sample *t*-tests for both outcome variables were found to be non-significant. As no significant differences were found between the Turner Syndrome group and the comparison group on the quantitative measures, subsequent analyses were performed on the entire participant sample to evaluate the hypotheses regarding the relationship between the social capital variables measured and the outcome variables of life satisfaction and wellness, as well as to evaluate any significant mediating effects of psychological capital on the relationship between the social capital measures and the outcome measures.



Table 3

*Means, Standard Deviations, and t-statistics for Women with and Without Turner Syndrome*

Measure	$M_{Turner}$	$SD_{Turner}$	$M_{Comp.}$	$SD_{Comp}$	95% CI	$t$	$Df$
1. SCI	709.09	148.15	730.83	114.51	-114.83, 71.34	-.46	33
2. ISCS_ONBON	25.55	7.22	20.46	9.13	-1.28, 11.45	1.62	33
3. ISCS_ONBR	33.00	9.62	28.58	9.19	-2.49, 11.32	1.30	33
4. ISCS_OFFBON	41.82	6.32	39.82	6.29	-2.67, 6.62	.87	33
5. ISCS_OFFBR	42.38	7.48	37.83	8.54	-1.55, 10.65	1.52	33
6. PCQ	92.99	16.45	95.00	15.93	-13.92, 9.91	-.34	33
7. SWSL	19.80	4.45	19.45	6.51	-4.06, 4.76	.16	33
8. PWS	120.24	16.04	124.76	20.80	-18.95, 9.91	-.64	33

*Note:* SCI = Social Capital Indexes; ISCS\_ONBON = Internet Social Capital Scale Online Bonding subscale; ISCS\_ONBR = Internet Social Capital Scale Online Bridging subscale; ISCS\_OFFBON = Internet Social Capital Scale Offline Bonding subscale; ISCS\_OFFBR = Internet Social Capital Scale Offline Bridging subscale; PCQ = Psychological Capital Questionnaire; SWSL = Satisfaction with Life Scale; PWS = Perceived Wellness Survey; \* =  $p < .05$ ; \*\* =  $p < .01$ ;  $n$  for comparison group = 24;  $n$  for Turner Syndrome group = 11.

In order to determine whether there were any significant correlations between any of the measures, Pearson correlations were calculated between all pairs of quantitative survey measures. The Social Capital Indexes was found to be moderately positively correlated with the Perceived Wellness Survey  $r(35) = .47, p < .01$ . These results support a relationship between social capital and the outcome variable of wellbeing. The Offline Bonding subscale of the Internet Social Capital Scale was found to be moderately positively correlated with the Satisfaction with Life Scale,  $r(35) = .60, p < .01$  supporting a relationship between social capital and the outcome variable of satisfaction with life. The adapted form of the Psychological Capital Questionnaire was moderately positively correlated with the outcome variable of the Perceived Wellness Survey  $r(35) = .61, p < .01$ , indicating a relationship between the potentially mediating variable of psychological capital and the outcome variable of wellness. The outcome variables of the Satisfaction with Life Scale and the Perceived Wellness Survey were also found to be strongly positively correlated,  $r(35) = .77, p < .01$ .

The Social Capital Indexes were found to be moderately positively correlated with the Satisfaction with Life Survey,  $r(35) = .34, p < .05$ , indicating a relationship between social capital and the outcome variable of satisfaction with life. The Offline Bonding subscale of the Internet Social Capital Scales was found to be moderately positively correlated with the Perceived Wellness Survey  $r(35) = .51, p < .05$ , indicating a relationship between social capital and the outcome variable of wellness. The adapted version of the Psychological Capital Questionnaire was found to be moderately positively correlated with the outcome variable of the Satisfaction with Life Survey,  $r(35) = .41, p < .05$ . Further information on the correlations is provided in Table 4.

Table 4

*Table of Pearson Correlation Values Between Survey Measures*

	1	2	3	4	5	6	7	8
1. SCI	–	.03	.20	.45**	.44**	.33	.34*	.47**
2. ISCS_ONBON		–	.46**	-.02	.10	.09	.32	.09
3. ISCS_ONBR			–	-.11	.42*	-.20	-.18	-.28
4. ISCS_OFFBON				–	.34*	.19	.60**	.51*
5. ISCS_OFFBR					–	-.16	-.08	-.13
6. PCQ						–	.41*	.61**
7. SWSL							–	.77**
8. PWS								–

 $p < .05$  \* $p < .001$  \*\*

*Note:* SCI = Social Capital Indexes; ISCS\_ONBON = Internet Social Capital Scale Online Bonding subscale; ISCS\_ONBR = Internet Social Capital Scale Online Bridging subscale; ISCS\_OFFBON = Internet Social Capital Scale Offline Bonding subscale; ISCS\_OFFBR = Internet Social Capital Scale Offline Bridging subscale; PCQ = Psychological Capital Questionnaire; SWSL = Satisfaction with Life Scale; PWS = Perceived Wellness Survey.

A mediation regression analysis was utilized through PROCESS Macro v.3.1 for SPSS and SAS (Hayes, 2018) to evaluate the hypothesis that Psychological Capital would have a mediating effect variable between the various measures of social capital and the outcome measures of wellness and life satisfaction. As a result of the small sample size and the fact that the sample is under-powered, a more lenient 90% confidence interval was selected, as well as 1,000 bootstrap samples for the percentile bootstrap confidence intervals. Results indicated that Psychological Capital had a significant complete indirect mediating effect between the Social Capital Indexes and the Satisfaction with Life Scale,  $b = .11$ , BCa CI [0.01, 0.26]. A diagram modeling the mediation relationship can be viewed in Figure 1.

A significant complete indirect mediating effect of Psychological Capital was also noted between the Social Capital Indexes and the Perceived Wellness Survey,  $b = 0.17$ , Ba CI [0.03, 0.37]. A diagram modelling the mediation relationship can be viewed in Figure 2. These results provide partial support for the hypothesis that Psychological Capital would mediate the relations between Social Capital and the outcome measures. The mediation analyses of Psychological Capital for all subscales of the Internet Social Capital Scale were found to be non-significant at the  $p < .05$  range for the outcomes of satisfaction with life and wellbeing.

Figure 1

Model of social capital as a predictor of satisfaction with life, mediated by psychological capital

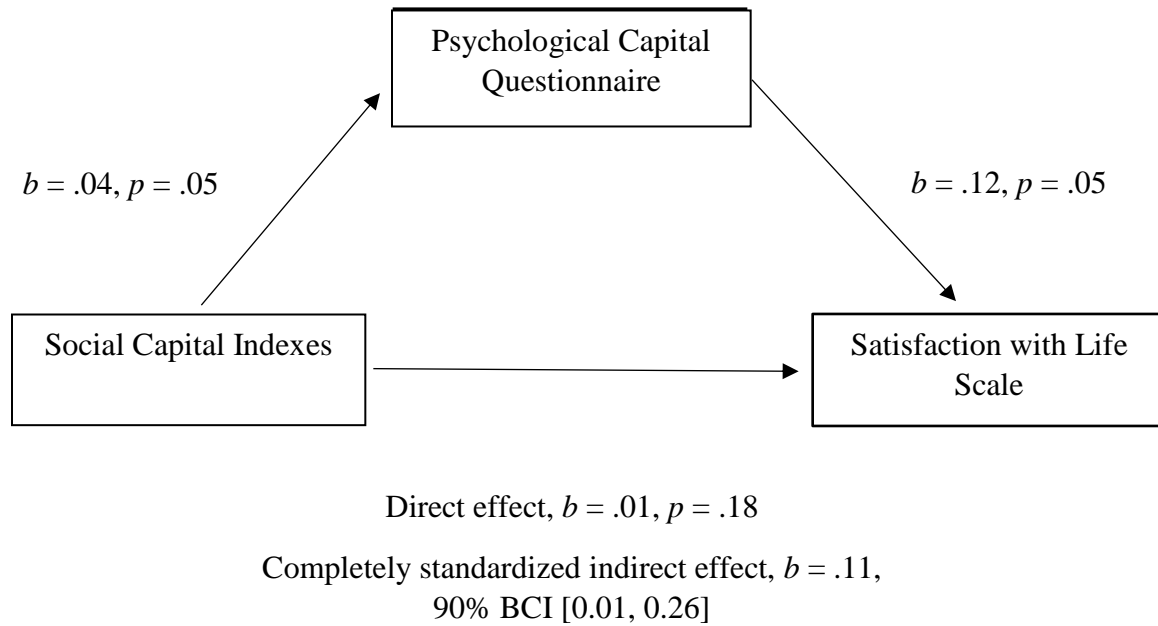
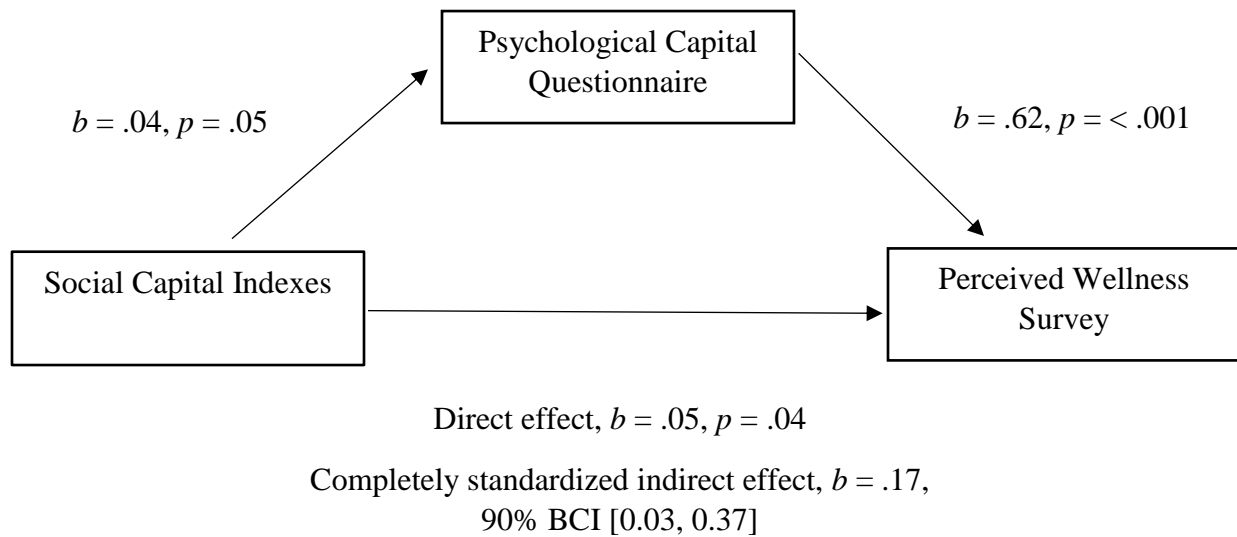


Figure 2

Model of social capital as a predictor of wellness, mediated by psychological capital



## Qualitative Results

Participants were asked nine open-ended questions relating to the support received from their social network, family, and their significant other, as well as perceived impact of recent stressful life and health events. Participants were also asked their perceptions of their level of femininity when compared to others. Qualitative data obtained from the open-ended questions underwent a content analysis which led to the extraction of relevant themes. Responses were entered into Microsoft Excel, and numbers were assigned to the themes that emerged. The numbers were entered in a separate column, and responses were colour coded if they related to more than one theme. A copy of the themes and number of participants categorized into each theme for both groups can be found in Table 5.

To determine whether there were any significant differences between the groups in their forms of support or in the themes that both groups shared, chi-square statistics were calculated from the frequencies of the participants represented in each theme and form of support. Two themes in the area of family support were found to be significant. The relationship between the groups and emotional support when achieving goals was significant,  $\chi^2 (1, N = 32) = 4.23, p = < .05$ , indicating that women in the Turner Syndrome group received significantly less emotional support from family members than women in the comparison group. The relationship between the groups and receiving intermittent or lack of support when achieving goals was also significant,  $\chi^2 (1, N = 32) = 4.31, p = < .05$ , indicating that women in the Turner Syndrome group received significantly more intermittent support or no support from family members than women in the comparison group. One theme in the area of support from significant others was found to be close to significance. Women in the Turner Syndrome group reported receiving more

emotional support from their significant others than women in the comparison group  $\chi^2$ , (1, N = 30) = 3.20,  $p = < .08$ . A copy of all of the chi-square statistics can be viewed in Table 6.



Table 5

*Qualitative Data Themes and Frequency Table*

Question	TS Group Themes and Frequencies	Comparison Group Themes and Frequencies
How does your social network assist you in achieving your goals?	Emotional support (n = 7) Concrete support (n = 3) Social networks who were not or were infrequently supportive (n = 3)	Emotional support (n = 10) Social media as a form of support (n = 4) Support through online videos and tutorials (n = 2) Concrete support (n = 4) Social networks who were not or were infrequently supportive (n = 7)
How does your social network assist you in facing any challenges that you have experienced?	Emotional support and advice (n = 5) Providing encouragement and reassurance (n = 1) Concrete support (n = 1) Listening (n = 2) lack of or intermittent support from their social network (n = 3)	Emotional support and advice (n = 9) Providing encouragement and reassurance (n = 5) Concrete support (n = 2) Social media support (n = 2) Listening (n = 2) Not receiving support from their social network (n = 4)
How does your family assist you in achieving your goals?	Emotional support and encouragement (n = 4) Financial and concrete support (n = 3) Advice and guidance (n = 2) Intermittent or lack of support from family members (n = 4)	Emotional support and encouragement (n = 17) Financial and concrete support (n = 7) Intermittent or lack of support from family members (n = 2)
How does your family assist you in facing any challenges that you have experienced?	Encouragement and guidance (n = 3) Concrete support (n = 3) Listening (n = 2) Intermittent or lack of support (n = 3)	Support with decision making (n = 6) Encouragement and guidance (n = 6) Listening (n = 4) Emotional support (n = 3) Concrete support (n = 3) Intermittent or lack of support (n = 3)

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How does your significant other assist you in achieving your goals?	Encouragement and motivation (n = 2) Emotional support and acceptance (n = 2) Academic support (n = 2)	Encouragement and motivation (n = 9) Academic support (n = 3) Emotional support and acceptance (n = 2)
How does your significant other assist you in facing any challenges that you have experienced?	Emotional support (n = 4) Concrete support (n = 2)	Providing advice and discussion (n = 4) Listening (n = 3) Providing emotional support (n = 3) Providing encouragement and motivation (n = 2)
Have you recently experienced any stressful life events which you believe have impacted your social relationships?	Work stress (n = 3) Relationship issues (n = 2)	Relationship issues (n = 3) Academic stress (n = 3) Family issues (n = 2)
Have you recently experienced any health issues which you believe have impacted your social relationships?	Physical illness (n = 1) Infertility (n = 2)	Stomach issues (n = 3) Physical illness (n = 2)
What are your perceptions of your level of femininity compared to others? Do you feel that these perceptions have impacted your social relationships?	Infertility and femininity (n = 2) Fashion and femininity (n = 1)	Identifying as feminine (n = 5) Fashion and femininity (n = 5) Low femininity (n = 4)

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Table 6

*Qualitative Data Chi Square Statistics*

<b>Supports and Themes</b>	<b>TS Group (n)</b>	<b>Comparison Group (n)</b>	$\chi^2$	<i>df</i>	<i>p</i>
<b>Social network-achieving goals</b>	7	15	0.01	1	0.918
Emotional support	3	10	1.66	1	0.197
Concrete support	3	4	0.56	1	0.454
Social networks who were not or were infrequently supportive	7	7	0.01	1	0.918
<b>Social network-facing challenges</b>	7	17	0.19	1	0.660
Emotional support and advice	5	9	0.23	1	0.631
Providing encouragement and reassurance	1	5	0.73	1	0.393
Concrete support	1	2	0.01	1	0.935
Listening	2	2	0.75	1	0.387
Lack of or intermittent support from their social network	3	4	0.56	1	0.454
<b>Family relationships-achieving goals</b>	6	17	1.01	1	0.314
Emotional support and encouragement	4	17	4.23	1	0.040*
Financial and concrete support	3	7	0.01	1	0.918
Intermittent or lack of support from family members	4	2	4.31	1	0.038*
<b>Family relationships-facing challenges</b>	7	19	1.21	1	0.272
Encouragement and guidance	3	6	0.03	1	0.874
Concrete support	3	3	1.21	1	0.272
Listening	2	4	0.02	1	0.901
Intermittent or lack of support	3	3	1.21	1	0.272
<b>Significant others-achieving goals</b>	5	12	0.00	1	0.959
<b>Currently in a relationship</b>	6	13	0.15	1	0.694
Encouragement and motivation	2	9	0.97	1	0.324
Emotional support and acceptance	2	2	0.97	1	0.324
Academic support	2	3	0.34	1	0.322
<b>Significant others-facing challenges</b>	6	12	0.24	1	0.626
Emotional support	4	3	3.20	1	0.073
<b>Stressful life events</b>	6	9	1.70	1	0.193
Relationship issues	2	3	0.35	1	0.555

<b>Stressful health events</b>	4	6	0.52	1	0.472
Physical illness	1	2	0.00	1	0.935
<b>Perceptions of femininity</b>					
<b>No impact on femininity</b>	6	11	0.41	1	0.520
Fashion	1	5	0.65	1	0.423

$p < .05$  \*

### **Social network support**

Ten participants diagnosed with Turner Syndrome answered the questions “Does your social network assist you in achieving your goals?” and “Does your social network assist you in facing any challenges that you have experienced?” Seventy percent of participants (n = 7) stated that they received assistance from their social network to achieve their goals. Three main themes emerged from the data: emotional support, concrete support, and social networks who were not or were infrequently supportive. Of the eight participants, seven participants stated that they received emotional support from their social networks. One participant stated “My family is very supportive and always there for me. Because of their support I feel like I can do whatever I want to do”. Another participant referenced her wide social network, stating “...they have helped me by supporting me and teaching me. Family, friends, staff and teachers have been there for me.” One participant also mentioned receiving support from individuals in the Turner Syndrome community, stating “Yes, because I have people who support me emotionally. Mostly it is TS people”.

Three participants discussed obtaining concrete support towards their goals from individuals in their social network. One participant discussed receiving employment support, stating “I am always able to go to my friends and tell them when I have a job interview, etc. They are also very good about telling me when positions come up that I would be good for”. Another participant discussed receiving support for their educational courses and research from their friends. Finally, one participant discussed receiving financial support from their spouse and parents as they were pursuing their education.

One participant discussed obtaining all three main forms of support indicated in the themes from their social network. She stated:

My social network has absolutely assisted me in achieving my goals. For example, I'm currently in graduate school and I would not be able to do so without the support of my friends and family. My family has supported me emotionally and financially throughout my education. My spouse has supported me financially while working on my doctorate, my mother paid for part of my student loans, my father has sent me gift cards that can be used to purchase food and gas throughout my education. My friends have also been supportive by providing me with emotional [support] through phone calls and messages during times of stress and generally. Many of my friends in school have also provided me with informational support regarding course materials, research, and my learning institution/department.

Three participants stated that they received either no support or infrequent support from their social networks. Two participants stated that the level of support that they received depended on the person they spoke with for assistance, with one participant stating "...some people don't take the time to listen and understand my goals which has hindered me a bit." One participant disclosed receiving a lack of support from their family, stating: "I used to live at home and although my family is wonderful, they discouraged me from trying new things and taking on new challenges. Currently, the social network I associate with is either not close enough to discuss this type of issue with, or not overly ambitious, and judge my ambitions."

Twenty-two participants in the comparison group answered the same questions about their social networks. Sixty-eight percent of participants (n = 15) stated that they received assistance from their social network. Six main themes emerged from the data: emotional support, social media as a form of support, support through online videos and tutorials, concrete support, and social networks who were not or were infrequently supportive. Ten participants stated that

they received emotional support from their social networks. One participant stated “I have a few great friends and an amazing boyfriend and a wonderful family that support me and help me when I am overwhelmed. They are my face to face social network and I wouldn’t want it any other way.” Another participant discussed the many ways in which her support network assists them, stating:

My social network has assisted me in achieving my goals because I have received support from friends and family in many ways, whether it be financial or emotional. They have always been there to help me through challenges and assist me with advice. As well, it is important for my mental health to have social interactions that are fun and to take some time to relax when I am not at school.

Four participants discussed social media as a form of support. Two participants stated that they found social media to be a positive form of social support, while two participants described social media as unsupportive or detrimental. The participants who found social media to be supportive described the benefits of the inspirational quotes and various educational tutorials which can be found online. One participant stated

...if used the right way it can be very inspiring and uplifting. For example, meaningful and inspiring quotes have helped my confidence grow and even videos on how to work on your inner self have helped me very much. Another way social networking has helped me is cooking videos on Facebook. There are many ways social networking was beneficial to me.

Of the two participants who described social media as unsupportive or detrimental, one participant stated “I personally believe that social media does not help me currently reach my goals. It is just a resource to getting in contact with fellow students to connect about homework,

assignments, class notes, etc.”. The second participant discussed the negative aspects of social media, disclosing “Social media has ruined the world in my opinion. It has weakened my trust and has me noticing in myself that I end up overthinking and worrying.”

Four participants discussed the concrete support provided by their social network. Two participants discussed the concrete support provided by their parents, including allowing them to live at home and paying for university. Two participants disclosed that their social networks provided them with contacts and information to help them succeed at work and at school, with one participant writing “...my social network has helped me to achieve my goals such as through having connections to people to help me academically or help me get a job.”

Seven participants stated that their social networks were either intermittently supportive or non-supportive. Three participants stated that their social networks often served as a distraction, with one participant stating “...they make me focus on things that are not necessarily beneficial to my future or my goals”. One participant discussed the harmful behaviours that some members of her social network engage in, stating “Hurtful words can be discouraging and kill my spirit when I am excited about a goal path. Also some people are still pretty sexist about what roles men and women should fill.” Another participant revealed that she does not share her goals with her social network, writing “I don't have a large social network. I prefer to be closed off. My friend group is limited to one or two people and they're not nearby. I don't share my goals with them.”

Seventy percent (n = 7) of participants diagnosed with Turner Syndrome stated that their social networks assisted them in facing challenges. Four main themes arose from the data: emotional support and advice, providing encouragement and reassurance, concrete support, and listening. Five participants stated that their social network provided them with emotional support



and advice, with one participant saying “they help me push through the problem.” Two participants answered that their social networks assist them by listening, with one participant writing “...they are great listeners and my weird/quirky nature is something they embrace. This has helped build confidence.” Two participants also discussed receiving emotional support from their social networks, and one participant discussed receiving support from speaking with other women diagnosed with Turner Syndrome.

One participant discussed receiving emotional support, concrete support, and encouragement at various times from their social network:

My social network assists me with challenges that I've experienced. My family has provided instrumental support (i.e., ride and money), informational support, and emotional support when it comes to issues related to my education and health from a young age. For example, when I received my diagnosis of TS, my mother immediately joined a national support group and shared all of the information about my new diagnosis with me. She also supported my request for a second [opinion]with my cardiologist when I was only 16. While my friends have not provided me with instrumental support, they have provided me with informational support and emotional support. I know that if I needed it my friends and family would continue to do this in the future. When I've encountered challenges to my health (e.g., TS and my cardiac conditions), my friends supported me through my anxiety and concern as I came to terms with my new diagnoses. Many of my friends have also supported me through my academic challenges by providing me with information I need to overcome the challenge and my reading my work to ensure its in the best shape possible before its submitted. There are many other

examples, but I would not be able to fit them all here. The individuals in my life are instrumental in helping me overcome barriers I've faced throughout my life.

One participant reiterated that she receives intermittent support from her social network when facing challenges. Two participants stated that they did not approach their social networks for assistance when facing challenges. One participant stated that she prefers to handle challenges on her own, writing “This is mainly because when I come across a challenge, I usually prefer to tackle it alone. It's nothing to do with my social network.” The second participant stated that she does not seek assistance from her social network because she does not want to bother them.

Seventy-seven percent of participants in the comparison group ( $n = 17$ ) stated that they receive support from their social network when facing challenges. Six main themes arose from the data: emotional support and advice, providing encouragement and reassurance, concrete support, social media support, listening, and not receiving support from their social network. Nine participants stated that they receive emotional support from their social networks when facing challenges. One participant wrote “My social network has always been there and given me anything I needed when I was facing challenges. They have assisted me with advice, love, and support to help me through hard times. My friends are also always there to cheer me up when I need it.” Another participant mentioned “...my social network has offered me advice, support and comfort when I have faced family problems.”

Five participants discussed receiving encouragement and reassurance from their social networks when facing challenges. One participant wrote “My boyfriend and my parents always try and calm me when I am in a difficult situation, especially when I am stressing about work or school.” Another participant stated “...they have helped me in times of challenges by reassuring

me that everything is going to be okay.” Two participants discussed receiving concrete support from their social networks when experiencing challenges. Such support included funding for tuition and academic materials, as well as funding for academic tutoring.

Two participants discussed social media as a form of support when facing challenges. Both participants did not feel that social media was a helpful support system, with one participant stating “When faced with challenges I usually turn to more experienced adults such as my parents or grandparents or even older family friends. Social media has just served as a form of entertainment and in some cases can be helpful, however, never has it helped me through my rough times.” The second participant wrote that she tries to limit posting on her social media about any challenges that she may be facing.

Listening was an important form of social support that was mentioned by two participants in the comparison group. One participant wrote “Words of encouragement have been helpful. Also sometimes it is nice just to have a shoulder to cry on. I like being listened to.” Four participants stated that they do not receive support from their social network when facing challenges. Two participants disclosed that when facing challenges they preferred to seek advice from elsewhere, such as family members or other trusted adults.

### **Family support**

Ten participants diagnosed with Turner Syndrome answered the questions “Does your family assist you in achieving your goals?” and “Does your family assist you in facing any challenges that you have experienced?” Sixty percent of participants diagnosed with Turner Syndrome (n = 6) stated that their families did assist them in achieving their goals. Four main themes arose from the data: emotional support and encouragement, financial and concrete support, advice and guidance, and inconsistent or lack of support. Four participants stated that

their family provided emotional support and encouragement, with one participant writing "...my family has definitely assisted me with achieving my goals. They never let the diagnosis [define] me and always made me feel like I was able to accomplish things."

Three participants discussed receiving financial and concrete support from their family. One participant wrote "I don't drive, so if I have a job interview, or something else like that, they are always there to drive me and make sure I get to it." Other participants wrote about receiving financial support from their family in the form of assisting with educational expenses and co-signing financial documents. Two participants disclosed that they received advice and guidance from their family members in the form of advice when facing a job interview or feedback on school assignments.

Two participants reported receiving intermittent support from their family members, and two participants reported that they do not seek out support in achieving goals from family members. One participant who reported receiving intermittent support from their family wrote "...often times it seems I have to come to them AFTER reaching/making progress towards my goal. Otherwise they can discourage me from trying new/challenging things." Of the participants who stated that they do not receive support from their family members, one participant stated that she prefers to be independent when working towards goals. The second participant experienced more negative interactions with her family, stating "My closest family turns me away because I have different needs to learn or ways to achieve my goals."

Twenty-two participants from the comparison group answered the same questions about their family support. Three main themes arose from the data: emotional support and encouragement, financial and concrete support, and intermittent or lack of support from family members. Seventy-seven percent of participants (n = 17) stated that they frequently received

support from family members in achieving their goals. Thirteen participants reported receiving emotional support and encouragement from their family members to achieve their goals. One participant described the impact that her female family members have had on her, stating “My mother and grandparents have embodied the kind of woman I hope to become one day. They are continuously looking out for me, supporting me in all that I do and continuing to push me to step outside my comfort zone.” Some participants described their family supporting them during times of failure. One participant wrote “...my family assists me in achieving my goals by always motivating me to continue on, despite any failures or setbacks that may arise in the process. They will help me by giving me advice and words of wisdom from their experiences.”

Seven participants reported their family providing financial and concrete forms of support to help them achieve their goals. Participants described receiving money for education, being allowed to live with their parents, and being driven by their parents to various locations. One participant wrote “...my parents have been there every step of the way-paid for everything-saved money for my future life.” However, three of the participants reported that while they received financial and concrete support from their family, they experienced a lack of emotional support. One participant wrote “My parents gave me an RESP to get some post secondary education. They would drive me anywhere I needed to achieve my goals. But they have hindered my goals by fostering an environment that demanded adherence to biblical doctrine rather than exploration of self.” Another participant disclosed “My family has been supportive of me in achieving my goals, been of financial aid and understanding. but also certain members have hindered my ability to meet emotional goals for mental well-being by making our relationship very difficult.” Finally, a participant stated that while her family allows her to live with them and has encouraged her education they do not display any interest in what she is doing in school.

Two participants reported intermittent or lack of support from family members in achieving their goals. One participant revealed that while she receives support from some family members, she does not receive support from the majority of her family. This participant wrote "...Most of my family members say discouraging words and are negative and skeptical of everything I wish to accomplish. Also they have hindered me financially by taking money and not repaying me, even though they borrowed it years ago..." The second participant reported that she does not receive support from her family as her family does not support what she wants to be.

When asked if their family assisted them in facing challenges, seventy percent of participants diagnosed with Turner Syndrome ( $n = 7$ ) stated that they received support from their family. Four main themes arose from the data: encouragement and guidance, concrete support, listening, and intermittent or lack of support. Three participants discussed receiving encouragement and guidance from their family, with one participant writing "...My family is always there for me. They are so encouraging. I was never [allowed] to not do things because of my diagnosis." Another participant revealed that her family guides her when making decisions and provides emotional support. Two participants stated that their family helps them by listening to them, with one participant stating "...they are a very caring family and always ready to listen if I have a bad day."

Three participants reported receiving concrete support from their family members. One participant wrote that her stepfather helps her with learning things. Another participant revealed that a member of her family usually attends medical appointments with her. Finally, a participant discussed the many forms of support that her family provides her, writing:

My family absolutely assists me in facing challenges. My parents have provided me with down payments so that I can afford to purchase a car or rent a house. They've provided me with words of encouragement when I am under pressure or experience stress. They've provided me with information (usually health-related) to overcome barriers when they are able to.

Three participants reported receiving intermittent or lack of support from family members in facing challenges. One participant repeated that some of her family members do not take the time to listen and understand her goals or the challenges she is facing. The second participant stated that she prefers to be independent when facing challenges. The third participant stated that her family tells her to "...just get over it..."

When asked if their family assisted them when facing challenges, eighty-six percent of the comparison group (n = 19) reported that their family did assist them. Six main themes arose from the data: support with decision making, encouragement and guidance, listening, emotional support, concrete support, and intermittent or lack of support. Six participants stated that their family assisted them when making decisions. One participant stated "...my family is the go to when facing an issue. This is because they give the possible solutions that I may want to take into consideration and relate the situation to something they have experienced to make me feel like I am not lonely." Another participant mentioned that her family assisted her with her outlook on challenges, and wrote "...when I face challenges in my life I rely on my family to assist me in making the right/best decision and when I am struggling mentally, I rely on them to help me to see [the] positive side of the challenge."

Six participants wrote that they received encouragement and guidance from their family members. One participant stated that she has discussions with her family when facing challenges

and her family will offer advice. Another participant disclosed “My family assists me in any challenges by always being there for me when I need them. They are there to comfort and support me and to help me through hard times.” Four participants stated that their family members assisted them with challenges by listening, with one participant stating “...my family supports me when I’m facing challenges. They are always there to listen, share their opinions and set a positive example.” Three participants stated that their family provided emotional support. One participant stated that her family supports her decisions and is always available for emotional support, while another participant disclosed “...my family assists me in facing any challenges I have experienced. They are always there for me to talk to them when I need them, even though it isn't often. I find I am able to deal with my problems alone or with minimal support, but they are always available if I do need them.” Three participants stated that their family provided them with concrete support, including money, paying for academic tutors, and providing employment opportunities. One participant revealed “My dad has been a listening ear and has helped provide job opportunities such as babysitting his kids from his second marriage so that I have a source of income when I needed it.”

Three participants stated that their family provided intermittent or no support when they were experiencing challenges. One participant reported receiving intermittent support from her family, writing “My parents usually listen when I get upset. However, they sometimes treat me like my feelings are irrational and that I'm not logical, even though I am being serious. It means that I feel belittled.” Another participant reported that her family does not support her when experiencing challenges, and in fact often caused her to feel worse about her experiences. The third participant reported receiving no support from her family, and that she was solely responsible for financing her living expenses and education.



### **Support from significant others**

Nine participants diagnosed with Turner Syndrome answered the questions “Does your significant other assist you in achieving your goals?” and “Does your significant other assist you in facing any challenges that you have experienced?” Sixty-seven percent of the participants reported being in a relationship ( $n = 6$ ), while three of the participants reported that they were not currently in a relationship. Of the participants currently in a relationship, eighty-three percent ( $n = 5$ ) reported that their significant other assisted them in achieving their goals. Three main themes arose from the data: encouragement and motivation, emotional support and acceptance, and academic support. Two participants reported receiving encouragement and motivation from their significant other. One participant revealed that her significant other encouraged her to continue pursuing her college education, while another participant wrote “...my husband does definitely help me achiev[e] my goals. He doesn’t really know what he wants to do so he always encourages me to do my dreams.”

Two participants reported that their significant others assisted them in facing challenges through providing emotional support and acceptance. One participant stated that her significant other assisted her by listening, while the second participant stated that her spouse grounds her when she feels stressed. Two participants also wrote that their significant others provided academic support to them as well. One participant revealed that her significant other helped her learn her material for school, and the second participant wrote “...He has supported me financially throughout my postgraduate schooling. He often reviews my work to make sure it's in good shape before I submit it to my advisor. If I am stressed or busy, he will try to pick up the slack at home so I have less on my plate...” One participant reported not receiving support from

her significant other, writing “Not overtly. They are very different from me and sometimes have different goals which clash with mine, or are just not very supportive.”

Twenty-two participants from the comparison group answered the question regarding the support they received from their significant others in achieving their goals, and 21 participants from the comparison group answered the question regarding if their significant other assisted them in facing challenges. Fifty-five percent of the participants reported being in a relationship ( $n = 13$ ), while nine of the participants reported that they were not currently in a relationship. Of the participants currently in a relationship, ninety-two percent ( $n = 12$ ) reported that their significant other assisted them in achieving their goals. Three main themes arose from the data: encouragement and motivation, academic support, and emotional support and acceptance. Nine participants stated that they received encouragement and motivation from their significant others, with one participant stating “My significant other is extremely supportive. He continues to always be there for me, he pushes me to step outside my comfort zone and he encourages me in all that I do.” Another participant wrote “My boyfriend always encourages me and makes me feel like the best version of myself. He is also there for support in achieving my goals if I ever need anything.” Additionally, one participant stated that her significant other provides her with advice and motivation in order to help her focus and stay on track with her goals.

Three participants stated that their significant others provided academic support through such methods as helping to provide a good environment for studying and by reminding them to avoid procrastinating. Two participants stated that their significant other provided them with emotional support and acceptance to help them achieve their goals through listening and providing advice. One participant stated that her significant other provided intermittent support, writing:

He encourages me to finish school, find work, and lose weight. He has hindered me by not being financially or emotionally stable enough to pursue marriage earlier in our relationship. Marriage is my main goal. He's been engaged to me for a year and a half and we still aren't able to start planning our wedding because of his instability.

When asked if their significant other assisted them in facing challenges, one hundred percent of participants diagnosed with Turner Syndrome who were currently in a relationship (n = 6) stated that they received support from their significant others. Two main themes emerged from the data: emotional support and concrete support. Four participants stated that their significant other provided them with emotional support through holding their hand and being there for them when they are experiencing challenges, One participant wrote “He provides emotional support when there is nothing I can do to overcome the challenge.” Two participants stated that their significant other provided concrete support when they experienced challenges. Such concrete support included attending medical appointments, and researching various topics associated with the challenge. One participant disclosed that her significant other widened her social network, writing “He has brought a new group of friends into our lives, helping with social networking challenges. He relocated to another province for me, eliminating a long-distance relationship challenge.”

Of the 21 participants in the comparison group who answered the question regarding if their significant other assisted them in facing challenges, thirteen reported currently being in a relationship. Ninety-two percent of participants currently in a relationship (n = 12) reported that their significant other provided support when they were facing challenges. Four main themes arose from the data: providing advice and discussion, listening, providing emotional support, and providing encouragement and motivation. Four participants disclosed that their significant others

supported them when facing challenges by giving advice and discussing the challenge with them. One participant wrote "...He also helps me by giving me anything I need, even if it is just good advice. I feel like I always have someone to talk to knowing that he is there." Another participant stated that she has always been able to lean on and vent to her significant other.

Three participants stated that their significant other supported them by listening to them. One participant wrote "When faced with challenges my significant other is the first person I go to. He is always there to listen and never fails to make me laugh in challenging situations. He continues to support me each and every day." Another participant described some of the challenges she faced in getting her significant other to listen, but stated that they were always supportive in the end. The participant revealed:

He is able to give me a reality check when I need one so I can stop having a pity party for myself. Sometimes it can be difficult to have a serious conversation with [him] but when he realizes that it is something that makes me upset he is all ears and sits down and listens and comforts me and assures me that if I keep working hard and prepare myself I will get where I need to go.

Three participants stated that their significant other supported them by providing emotional support. One participant disclosed "He is always optimistic and he knows exactly what I need." Two participants stated that their significant others provided them with encouragement and motivation when facing challenges. One participant wrote "...he is always there to motivate me and walk with me through challenges." The second participant described the calming effect that her significant other has on her, stating "...he is always there to help me through challenges. He calms me down when I am upset and makes me feel better."

### **Stressful life and health events**

Nine participants diagnosed with Turner Syndrome answered the question “Have you recently experienced any stressful life events which you believe have impacted your social relationships?”, and ten participants diagnosed with Turner Syndrome answered the question “Have you recently experienced any health issues which you believe have impacted your social relationships?” Of the participant who responded, sixty-seven percent ( $n = 6$ ) reported experiencing stressful life events, and two main themes emerged: work stress and relationship issues. Three participants mentioned issues that they had experienced that were related to work. One participant disclosed experiencing a lack of respect and fulfillment at work, while another participant wrote “...my husband is in the military so all [the] moves are very stressful and affect social relationships.” Two participants reported experiencing issues with various relationships in their lives, with one participant disclosing “I feel like bullying and experiencing the end of many friendships has shaped my friendships later in life.” Individual participants also mentioned the death of an immediate family member, studying for school, and family illness as events which had impacted their social relationships.

Twenty-two participants in the comparison group replied to the questions regarding stressful life events and recent health concerns. When asked about stressful life events, forty-one percent ( $n = 9$ ) reported experiencing a recent stressful life event. Three main themes arose from the data: relationship issues, academic stress, and family issues. Three participants reported stressful experiences with various relationships in their lives. One participant discussed a stressful roommate situation which has resulted in her being required to do more chores than the other roommates and not feeling comfortable with having friends over to the house. Another participant wrote about a recent friendship breakup, stating “I went through a friendship

"breakup" just recently due to a miscommunication. This miscommunication was due to built up tension and anger that has been going on for months. It was pretty severe to the point where our friends circle has been split." Finally, another participant discussed a breakup with a boyfriend which was continuing to be fought through the court system. Three participants discussed academic stress in their lives, referencing the adjustment to university taking up a lot of their social time, as well as stress associated with studying for exams. One participant discussed the stress associated with appealing a grade, writing:

Stressful events that have impacted my social relationships was when I appealed a grade due to family and health issues I struggled with. I didn't tell anyone about this, and because I was sad/embarrassed about this, I became "MIA" as I studied for my re-do exam. Due to the shame, embarrassment and concentration to my studies, I didn't talk to most of the people who are part of my social network for close to three and a half weeks. I drifted away from my friends and I had to gain their trust back as in their eyes I kind of abandoned them as they did not know what I was going through during the month I was "MIA". I missed out on social events and had to catch up on everything I had missed. I felt like I missed out on their lives.

Two participants referenced stress associated with family relationships. One participant wrote that she had become the primary caregiver of her grandparents when they fell ill. Another participant described a conflicted relationship with her mother, writing "Going through a difficult relationship with my mom has affected me and in turn made me a little less myself or talkative around friends." A singular participant discussed body image issues hampering her social relationships and stated that this was due to not feeling comfortable wearing revealing clothing.

Of the ten participants diagnosed with Turner Syndrome who answered the question regarding experiencing recent health issues, forty percent ( $n = 4$ ) reported experiencing health issues. Two main themes emerged from the data: physical illness and infertility. One participant disclosed an additional diagnosis of Charcot Marie Tooth Muscular Dystrophy, writing "...My short stature, and my abnormal walking gate has caused bullying for me in the past which hasn't been easy when trying to make friends. I find it difficult to trust people's opinion of me." Another participant wrote about experiencing frequent fatigue, stating "...I do find that the fatigue related to my diagnoses and medications hinders my social relationships a bit. It's often difficult for me to find the energy to be in social situations and sometimes it affects my mood. This can be difficult to explain to others as outwardly I appear healthy and young." Two participants wrote that infertility had a major impact on their social relationships, with one participant disclosing:

The current biggest health issue that impacts my relationship with my husband is the fact that I cannot have kids. As sad as it is my husband actually is very supportive and we are trying to adopt. Having the future so unknown with my health also has affected our relationship. It has affected the types of jobs my husband chooses to [accept] so that he can stay with me as much as possible not knowing if and when I'll be sick.

Of the 22 participants in the comparison group who responded to the question regarding health issues impacting social relationships, twenty-seven percent ( $n = 6$ ) reported experiencing recent health concerns. Two main themes arose from the data: stomach issues and physical illness. Three participants reported experiencing various stomach issues, including IBS and lactose and gluten intolerance. One participant wrote:

I suffer from IBS and as a result, there are times when I have to miss out on dinners, parties or get togethers because I am in so much pain -- pain that cannot be relieved from medication, can only be relieved from me laying down. At times, the pain can come on suddenly, and at times has caused me to cancel last minute. Some people in my social network don't understand how much pain I am in and they think that I am just brushing off a get together.

Two participants discussed various physical illnesses impacting their social relationships. One participant wrote that she had been away from social settings for a period of time due to going through surgeries, and another participant stated that back pain impacted her social experiences.

### **Perceptions of femininity**

Ten participants diagnosed with Turner Syndrome answered the question “What are your perceptions of your level of femininity compared to others? Do you feel that these perceptions have impacted your social relationships?” Sixty percent of participants (n = 6) stated that their perceptions of their femininity did not impact their social relationships. Two main themes emerged from the data of participants who reported that their perceptions of femininity had an impact on their social relationships: infertility and femininity and fashion and femininity. Two participants stated that they occasionally felt less feminine than their peers due to experiencing infertility, with one participant disclosing:

I sometimes feel less feminine than other women. Not being able to have my own biological children does make me feel less womanly and like a lesser romantic partner than women that are able to have their own children naturally. This has come up in my romantic relationships in the past. For example, one man who I disclosed my diagnosis of



TS to immediately asked me if I was a woman. I immediately responded of course and never saw him again.

One participant stated that her femininity was impacted by the types of clothing accessible to her, writing “I often think of fashion when it comes to femininity. Due to my Charcot Marie Tooth I am unable to wear high heel shoes. When it comes to dressing up I have never felt 100% that I look as nice as other woman around me.”

Twenty-three participants in the comparison group completed the question regarding their perceptions of their femininity. Forty-eight percent of participants (n = 11) stated that their perceptions of their femininity did not impact their social relationships. Three main themes arose from the data: Identifying as feminine, fashion and femininity, and low femininity. Five participants identified as feminine, with one participant writing “I am feminine and I am strong and independent. I think it helped me attract people like-minded.” Fashion was also described as strongly linked to femininity, with five participants mentioning fashion when discussing their perceptions of femininity. One participant wrote “I'm not very feminine. I don't wear makeup and I don't dress up. My heart is tender and feelings are dainty but I am physically bigger and stronger than a lot of women. I have to wear men's shoes instead of nice lady shoes. I think it affects my ability to attract a mate, yes.” Another participant stated “I am a pretty feminine girl. However, I do dress pretty casual and go more for the comfort rather than the style. Some people judge me for this, so my perceptions of my femininity have affected a very small percent of social relationships.”

Four participants disclosed that they perceived themselves as having a low level of femininity when compared to others. One participant believed that her level of femininity affected her romantic relationships, writing “I would say I have a low level of femininity

compared to others. These perceptions sometimes influence my social relationships because, for example, as a heterosexual female, I sometimes feel that I might not attract the opposite sex because I am not very feminine.” Another participant disclosed:

I identify as female but I am definitely more suited to traditional male roles. I’m very business oriented. I don't care to wear make up. Dresses don't interest me, though I wear them for work. I don't cry often and sometimes I feel heartless compared to most women. I think I’m feminine in some ways. I like kids. I care about the broken-hearted. I want to be inclusive of people in group settings. Sometimes I wish people wouldn't create these boxes of femininity and masculinity. Why can we not engage in both? Getting socially sanctioned for things that should not matter is dumb. I'm involved in religious communities. A lot of what I do is seen as unacceptable for women. I am a natural leader and speaker yet there is still that mindset that women should be silent or at the very least quieter than men. Women are not supposed to lead in these circles, but I can't help it - it's who I am. This affects my social standing in these communities. At the heart of it people fear change and it is their baggage, not mine. I have learned to be willing to walk away.

#### **CHAPTER IV: Discussion**

The focus of this study was to determine whether women with Turner Syndrome have lower levels of social capital in a variety of areas compared to women of the same age range not diagnosed with Turner Syndrome, and if their levels of social capital affected their wellness and life satisfaction. It was hypothesized that women diagnosed with Turner Syndrome would report significantly lower levels of social capital compared to a control group of women in the same age range who had not been diagnosed with Turner Syndrome. Results from independent samples *t*-tests indicated that there were no

significant differences between the women diagnosed with Turner Syndrome and the comparison group in their perceived levels of social capital in the areas of employment, education, or online and offline social experiences. Two potential outcomes of social capital: wellness and life satisfaction, were also assessed. It was hypothesized that individuals reporting as low in social capital would also display lower levels of wellness and life satisfaction. Results from independent samples *t*-tests indicated that there were no significant differences between the women diagnosed with Turner Syndrome and the comparison group in their perceived levels of social capital in the areas of wellness or life satisfaction, a positive result indicating that over all, women diagnosed with Turner Syndrome feel that they have the same amount of social resources available to them at work, school, and in their online and offline social networks as women who do not have a diagnosis of Turner Syndrome. Nonetheless, the interpretations of the study results must be treated with caution given the low sample size, which resulted in a lack of statistical power with respect to the quantitative findings.

These results may be due to the fact that organizations such as the Turner Syndrome Society of Canada frequently have seminars focusing on workplace interactions, as well as on advocating for yourself in the workplace. Additionally, many Turner Syndrome organizations place a significant focus on providing resources and information in the area of education. Individuals diagnosed with Turner Syndrome and their families are frequently informed about the links between Turner Syndrome and various learning disabilities, such as non-verbal learning disability (Rovet, 1992), as well as classroom accommodations and study habits that can assist individuals diagnosed with Turner Syndrome who experience difficulties with nonverbal communication or with

spatial reasoning. These results may also be supported through a study conducted by Cragg and Lafreniere (2010) where women diagnosed with Turner Syndrome reported slightly higher scores on performance self-esteem than the comparison group, indicating that women diagnosed with Turner Syndrome felt confident that they could accomplish tasks as successfully as anyone else performing the same tasks.

Aran et al. (1992) theorized that focusing on achievement in such areas as employment and education may be a coping method for individuals with physical discrepancies. The authors stated that individuals with physical discrepancies that do not impact their intelligence may compensate for their disadvantage by improving their educational and vocational position. As a result, such individuals may work extremely hard to build social and psychological capital at their places of education and employment. Additionally, Aran et al. (1992) suggested that women diagnosed with Turner Syndrome may compensate for the difficulties of finding a romantic relationship that are often experienced by women with Turner Syndrome by focusing on and building their other social relationships.

The findings that women diagnosed with Turner Syndrome reported similar levels of online and offline social capital may be due to the fact that there is a strong online social support system available for women with Turner Syndrome. Social media sites such as Facebook have numerous groups which were created to support women and girls diagnosed with Turner Syndrome and their families. These support groups allow individuals to connect with a wide social network to ask questions and share experiences. Additionally, individuals diagnosed with Turner Syndrome frequently use such support groups to connect with individuals living near their geographic area. This can frequently

turn into in-person friendships and can increase their social network. Furthermore, Schramer and Lafreniere (2018) surveyed individuals diagnosed with Turner Syndrome who were members of online support groups, and found that participants reported feeling membership and influence over their online communities, as well as a sense of need fulfillment and emotional connection.

Psychological capital was also examined to determine whether it was a mediating variable between the measures of social capital and outcome measures of wellness and life satisfaction. Psychological capital was found to be a mediator between the Social Capital Indexes, which measures perceived social capital at work, and the outcome variables of satisfaction with life and perceived wellness. These results align with the study on employee teams by Heled et al. (2015) which found that psychological capital had a mediating effect between the team's learning environment and their job satisfaction. As psychological capital in this study was measured focusing on the area of education, it is hypothesized that high levels of psychological capital may increase educational success, which could translate to greater success in finding employment which aligns with personal interests, as well as success at managing the relationships and tasks within their employment. Such success and access to social and psychological capital could translate to other areas of life, resulting in increased satisfaction with life and wellness perceptions.

An additional theory was posited by Suzigan et al. (2011) regarding the discrepancy between the self-reported social perceptions of women diagnosed with Turner Syndrome and their mothers' perceptions. The mothers of the women diagnosed with Turner Syndrome were more likely to describe negative social events and described

them as more significant, while their daughters diagnosed with Turner Syndrome were more likely to downplay the events, or to omit them altogether. Suzigan et al. (2011) discussed several theories which could explain such results, including social desirability bias. Participants may have wanted to appear more socially adept to the researchers, and as a result may have downplayed their negative social interaction experiences (Suzigan et al., 2011). The authors also theorized that the participants diagnosed with Turner Syndrome may not have noticed their negative social interactions, may have knowledge of appropriate social skills in theory but may experience difficulty in implementing them, or may have genuinely felt that the negative social interactions they reported were not significantly impactful on them to discourage seeking out social relationships or produce negative feelings regarding their social lives (Suzigan et al., 2011).

Open-ended questions were utilized in order to evaluate perceptions of social capital in social relationships, family, relationships, and romantic relationships, as well as to discuss recent impactful life events and perceptions of femininity. Several common themes of support were noted within both groups across forms of social supports, including emotional support, concrete support, encouragement and advice, and listening. No significant differences were found between the women diagnosed with Turner Syndrome and the comparison group in their perceptions of the level of support they received from their social networks when achieving goals or facing challenges. These results may be supported by the results from the online and offline subscales of the Internet Social Capital Scale, and may be due to the fact that all members of the Turner Syndrome group were recruited from Turner Syndrome support organizations, and online

support groups, which may have strengthened their social networks and the social resources available to them.

When asked about the support family members provided in achieving goals and facing challenges, comparison group participants reported receiving significantly more emotional support when achieving goals, while women in the Turner Syndrome group reported experiencing significantly more intermittent or a lack of support from family members when achieving goals. This may be due to the fact that Turner Syndrome support organizations frequently provide resources and seminars for parents on how to foster independence in their daughters who have been diagnosed with Turner Syndrome. However, these supports are often geared towards parents of young children and adolescents, and not parents of adult children. As a result, parents may not be as knowledgeable about how to support an adult daughter diagnosed with Turner Syndrome. This may be supported by the research findings of Suzigan et al. (2011), which revealed that the mothers of women diagnosed with Turner Syndrome who were surveyed disclosed experiencing more family issues and a less positive relationship with their daughters diagnosed with Turner Syndrome compared to their daughters who did not have Turner Syndrome.

A surprising result of the qualitative questions was the discovery that a greater percentage of women diagnosed with Turner Syndrome reported being in a romantic relationship than the women in the comparison group. This contradicts the findings of such researchers as Pavlidis et al. (1995) and Suzigan et al. (2011), who found that fewer women diagnosed with Turner Syndrome reported being in a romantic relationship than women in comparison groups. It is possible that some individuals diagnosed with Turner

Syndrome who were not in a relationship may have declined to answer the relationship-related questions. Results demonstrated that while more women in the comparison group than the Turner Syndrome group reported receiving support from their significant others, more women in the Turner Syndrome group reported receiving emotional support from their significant others when facing challenges. This may be related to the findings of Cragg and Lafreniere (2010), who reported women diagnosed with Turner Syndrome reported slightly higher scores on performance self-esteem than women in the comparison group, indicating their confidence that they could accomplish tasks as successfully as anyone else. As a result, women diagnosed with Turner Syndrome may feel that they are adequately able to accomplish their goals independently, and therefore may place more value on significant others who provide support during challenging moments, and may be more likely to seek out and stay in relationships with such individuals.

When asked about recent stressful life and health events, significantly more women diagnosed with Turner Syndrome reported experiencing such events compared to women in the comparison group. Stressful health events in the women diagnosed with Turner Syndrome may be due to the various health concerns frequently associated with Turner Syndrome, including infertility, hearing loss, and heart abnormalities such as aortic dissection and hypertension (Charney & Smillie, 1987; Pinto, 2008; Wide Boman, Bryman, & Möller, 2004). When asked about their perceptions of their femininity, women with Turner Syndrome were more likely to mention infertility as an impact on their perceptions of their femininity, and reported feeling less feminine than their peers due to this diagnosis. Women in the comparison group reported a wider degree of



perceived femininity, and were more likely to describe themselves as feminine or moderately feminine. Women in the comparison group expressed feeling less feminine as a result of not enjoying stereotypically feminine beauty standards such as makeup or wearing feminine clothing like dresses or skirts, or for being more outspoken than is stereotypically desired from females. One participant disclosed feeling less feminine due to a diagnosis of Polycystic Ovarian Syndrome. Some participants felt that their perceived lack of femininity negatively affected their desirability to the opposite sex. These results support the research findings of Schmidt et al. (2006), which found a link between infertility and psychosocial functioning in a group of women who had been diagnosed with Turner Syndrome or Premature Ovarian Failure.

These results indicate that stereotypical views of femininity produce harm not only in women diagnosed with Turner Syndrome, but in typically-developing women as well. This could be explained by Harrison's (2003) Media Theory. The majority of women and female characters portrayed in the media are taller and thinner than the average woman, and are often hypersexualized and overly feminine. Additionally, while fashion, movies, and television have worked to become more diverse, such diversity is often demonstrated by including women of various weights and ethnicities. Diversity in height and ability still remains underrepresented. This disparity may have an extremely significant effect on all women, as a significant number of women do not see themselves represented in the media they consume.

Femininity also remains strongly linked to fertility in women. Difficulties with fertility, as experienced by individuals diagnosed with such disorders as Turner Syndrome, Premature Ovarian Failure, and Polycystic Ovarian Syndrome (PCOS), often

have social and psychological impacts. Schmidt et al. (2006) surveyed 100 women with Turner Syndrome, 100 women with premature ovarian failure, and 35 comparison women. The authors found many similarities between the women diagnosed with Turner Syndrome and women diagnosed with premature ovarian failure. Both groups reported significantly higher levels of social anxiety, shyness, and depression and lower levels of self-esteem than the comparison group (Schmidt et al., 2006). Maçik (2016) studied the effect of PCOS compared to other diagnoses that have an impact on feminine appearance, such as menopause and mastectomy, as well as a comparison group. The author found that women diagnosed with PCOS reported greater levels of crisis and anxiety compared to women in the other groups. Women diagnosed with PCOS also reported experiencing negative self-esteem and guilt.

A study by Pickens and Braun (2018) interviewed 21 single women from New Zealand between the ages of 23-35. The authors found that the women frequently described their relationship status as linked to overall views of heterosexuality and femininity. The women interviewed described feeling pressured to portray a desirable level of femininity, including maintaining feminine beauty standards, conforming to acceptable standards of feminine sexuality and avoiding unacceptable feminine sexuality standards, and feeling the need to obtain stereotypically feminine milestones such as marriage and children by a specific age (Pickens & Braun, 2018). Several of the women interviewed expressed criticism and resistance towards such views, and yet also described attempting to conform to them in some ways (Pickens & Braun, 2018). These results demonstrate the need to broaden what it means to be feminine.

## Limitations

Several limitations were noted in this study. One limitation is the small sample size of women diagnosed with Turner Syndrome. As a result, the sample size resulted in the study being underpowered, which may have affected the significance of the *t*-tests. Consequently, the findings may not be generalizable to the larger population of women diagnosed with Turner Syndrome.

Another limitation is the fact that participants in the Turner Syndrome group were recruited from Turner Syndrome support organizations and online support groups. Such participants are already receiving support, resources, and are sharing questions and concerns with others. As a result, such individuals may be more comfortable and willing to discuss their perceptions and experiences, and to participate in research studies. Additionally, those who continue to participate in such communities may do so due to receiving positive support and experiences, and therefore may be more likely to report positive experiences with their social networks.

The individuals who receive such supports may also have access to resources to which individuals who do not belong to any Turner Syndrome organizations may not have access. As a result, these women are able to utilize the information and advice that they receive from such resources in their everyday lives. Organizations such as the Turner Syndrome Society of Canada frequently provide conference sessions and brochures which focus on the topics of advocacy and supports in the areas of employment and education. It is possible that these resources assist them in building greater social resources in their lives, and this may be a reason why there were no significant differences between groups in the areas of education and employment.

### **Future Directions**

Future research should address the limitations of the current study. One future direction is to obtain a larger sample size of participants diagnosed with Turner Syndrome. A larger sample size would increase the effect sizes surrounding the results of the study, and could also allow the study results to be more generalizable. Sample size and diversity could be increased by forming greater connections with chapter leaders of the Turner Syndrome Societies of Canada and the United States through attending events and national conferences, as well as sharing and commenting on news and information on their social media. Further interactions on online Turner Syndrome support groups could also serve to increase the size and diversity of the sample.

Another suggestion for future studies is to conduct wider community recruitment in order to potentially obtain a greater number of participants diagnosed with Turner Syndrome who may not be members of any Turner Syndrome organizations or support groups. Such recruitment could be initiated by attending and presenting at local health fairs, and networking and advertising research with physicians and specialists who would be likely to serve patients diagnosed with Turner Syndrome, such as endocrinologists and metabolic specialists. This could further serve to create a more varied and generalizable sample. Additionally, data obtained from comparing individuals who are members of Turner Syndrome organizations or support groups to individuals who were not members could serve to elaborate on the benefits that such organizations and support groups provide, as well as areas in which they can continue to improve on.

A final future direction for similar research in the area of Turner Syndrome and social capital is to create quantitative measurement instruments to evaluate perceptions of

social capital in the areas of family relationships and romantic relationships. Such measurement instruments would provide more data on these areas, and could serve to verify the results obtained from the qualitative questions.

### **Implications**

The results of this study have many implications for organizations that support girls and women diagnosed with Turner Syndrome and their families. The results provide further information for Turner Syndrome societies and support groups on how to change or improve their existing programs to improve the social capital of women diagnosed with Turner Syndrome and add to the evidence-based knowledge available to Turner Syndrome support groups and organizations. Additionally, as little consideration has been placed on the social and emotional effects of Turner Syndrome, the current research investigation adds to the knowledge base, and addresses this gap in the literature.

The qualitative results reveal that a lower percentage of women who were diagnosed with Turner Syndrome who participated in the study reported receiving support from family members in achieving goals and facing challenges than women not diagnosed with Turner Syndrome. These results may indicate that more resources and supports are needed for parents of adult women with Turner Syndrome. While organizations such as the Turner Syndrome Society of Canada provide pamphlets and conference seminars for parents that focus on fostering their child's independence and providing support and advocacy for their child's education, none of the materials are geared towards parents of adult children. Turner Syndrome support organizations could address such concerns by creating informational brochures geared towards parents of adult children, and could also diversify the programming offered at their conferences and information days by creating seminars and workshops geared towards this demographic.

Qualitative results also indicated that a lower percentage of women who were diagnosed with Turner Syndrome who participated in the study reported receiving support from their significant others to achieve goals and face challenges than women not diagnosed with Turner Syndrome. These results are also telling, as the majority of resources available to individuals with a relationship to an individual diagnosed with Turner Syndrome focus on parents or caregivers. Additionally, there is a significant lack of seminars or information day workshops geared towards spouses or significant others in organizations such as the Turner Syndrome Society of Canada. As such, it can be quite rare to see spouses or significant others attend events such as the annual conference. Creating resources and supports geared towards spouses or significant others would serve to foster greater education and awareness of how to most effectively support their loved one who has been diagnosed with Turner Syndrome. Additionally, such initiatives could also create a support network for spouses and significant others where they could have the opportunity to share questions and concerns and connect through their shared experiences.

Finally, when discussing their perceptions of their level of femininity, several participants diagnosed with Turner Syndrome stated that their perceptions of femininity were connected to their fertility status and their clothing. These are two aspects which are strongly and stereotypically linked to femininity in the media. To address these perceptions, support organizations for girls and women diagnosed with Turner Syndrome could promote media such as television shows, movies, and magazines which demonstrate non-stereotypical portrayals of femininity. Additionally, finding age-appropriate clothing has frequently been a concern for women in the Turner Syndrome

community. Turner Syndrome support organizations could address this by advertising and promoting clothing lines which sell items for petite individuals of various body shapes. Workshops facilitated by fashion consultants or stylists could also be held in order to teach adolescents and women with Turner Syndrome how to dress for various body shapes, and to encourage more positive perceptions of their bodies. This in turn could improve confidence levels in girls and women with Turner Syndrome which could assist them in their social relationships and promote greater social resources.

In conclusion, the nonsignificant findings between groups on the quantitative measures of social capital, satisfaction with life, and wellness revealed that women diagnosed with Turner Syndrome felt that they had the same amount of social resources available to them in multiple situations. These findings indicate that the resources and supports provided by Turner Syndrome support organizations and groups may be having a positive effect. Additionally, when experiences were examined more deeply through the qualitative questions, individual differences were noted in the areas of family relationships, romantic relationships, and stressful life and health experiences. The negative impact of traditional and stereotypical views of femininity were also noted in both groups. The use of a mixed-methods design allowed for a much deeper and richer exploration of the concept of social capital in multiple life situations, and allowed for these results to be revealed. Future researchers are encouraged to consider utilizing more qualitative aspects when building their studies of underrepresented groups.

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## APPENDIX A

## Copyright Permission for the Psychological Capital Questionnaire

Stephanie Cragg



To whom it may concern,

This letter is to grant permission for Stephanie Cragg to use the following copyright material:

Instrument: ***Psychological Capital (PsyCap) Questionnaire (PCQ)***

Authors: ***Fred Luthans, Bruce J. Avolio & James B. Avey.***

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for his/her thesis/dissertation research.

Three sample items from this instrument may be reproduced for inclusion in a proposal, thesis, or dissertation.

The entire instrument may not be included or reproduced at any time in any other published material.

Sincerely,

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## APPENDIX B

## Measures

## Social Capital Indexes (Strömngren et al., 2016).

*Reciprocity*

(1) At my workplace we care for each other.

1	2	3	4	5
To a very small extent	To a small extent	Somewhat	To a large extent	To a very large extent

(2) At my workplace we treat each other with respect.

1	2	3	4	5
To a very small extent	To a small extent	Somewhat	To a large extent	To a very large extent

(3) At my workplace I feel safe and accepted.

1	2	3	4	5
To a very small extent	To a small extent	Somewhat	To a large extent	To a very large extent

*Trust regarding management*

(1) Can you trust the information that comes from the management?

1	2	3	4	5
To a very small extent	To a small extent	Somewhat	To a large extent	To a very large extent

(2) Does the management withhold important information from the employees?

1	2	3	4	5
To a very small extent	To a small extent	Somewhat	To a large extent	To a very large extent

*Mutual trust*

(1) Do the employees withhold information from the management?

1	2	3	4	5
To a very small extent	To a small extent	Somewhat	To a large extent	To a very large extent

(2) Do the employees in general trust each other?

1	2	3	4	5
To a very small extent	To a small extent	Somewhat	To a large extent	To a very large extent

*Recognition*

(1) Is your work recognized and appreciated by the management?

1	2	3	4	5
To a very small extent	To a small extent	Somewhat	To a large extent	To a very large extent

(2) Does the management at your workplace respect you?

1	2	3	4	5
To a very small extent	To a small extent	Somewhat	To a large extent	To a very large extent

(3) Are you treated fairly at your workplace?

1	2	3	4	5
To a very small extent	To a small extent	Somewhat	To a large extent	To a very large extent

## Internet Social Capital Scale (Williams, 2006)

When some people are online, they interact with others by exchanging emails, reading message boards, and participating in chat rooms. Now I would like to ask you some questions about how you interact with other people online.

## Bonding Subscale

There are several people online/offline I trust to help solve my problems.

1	2	3	4	5
not at all	a little bit	somewhat	very much	extremely

There is someone online/offline I can turn to for advice about making very important decisions.

1	2	3	4	5
not at all	a little bit	somewhat	very much	extremely

There is no one online/offline that I feel comfortable talking to about intimate personal problems. (reversed)

1	2	3	4	5
not at all	a little bit	somewhat	very much	extremely

When I feel lonely, there are several people online/offline I can talk to.

1	2	3	4	5
not at all	a little bit	somewhat	very much	extremely

If I needed an emergency loan of \$500, I know someone online/offline I can turn to.

1	2	3	4	5
not at all	a little bit	somewhat	very much	extremely

The people I interact with online/offline would put their reputation on the line for me.

1	2	3	4	5
not at all	a little bit	somewhat	very much	extremely



The people I interact with online/offline would be good job references for me.

1	2	3	4	5
not at all	a little bit	somewhat	very much	extremely

The people I interact with online/offline would share their last dollar with me.

1	2	3	4	5
not at all	a little bit	somewhat	very much	extremely

I do not know people online/offline well enough to get them to do anything important.  
(reversed)

1	2	3	4	5
not at all	a little bit	somewhat	very much	extremely

The people I interact with online/offline would help me fight an injustice.

1	2	3	4	5
not at all	a little bit	somewhat	very much	extremely

#### Bridging Subscale

Interacting with people online/offline makes me interested in things that happen outside of my town.

1	2	3	4	5
not at all	a little bit	somewhat	very much	extremely

Interacting with people online/offline makes me want to try new things.

1	2	3	4	5
not at all	a little bit	somewhat	very much	extremely

Interacting with people online/offline makes me interested in what people unlike me are thinking.

1	2	3	4	5
not at all	a little bit	somewhat	very much	extremely

Talking with people online/offline makes me curious about other places in the world.

1	2	3	4	5
not at all	a little bit	somewhat	very much	extremely

Interacting with people online/offline makes me feel like part of a larger community.

1	2	3	4	5
not at all	a little bit	somewhat	very much	extremely

Interacting with people online/offline makes me feel connected to the bigger picture.

1	2	3	4	5
not at all	a little bit	somewhat	very much	extremely

Interacting with people online/offline reminds me that everyone in the world is connected.

1	2	3	4	5
not at all	a little bit	somewhat	very much	extremely

I am willing to spend time to support general online/offline community activities.

1	2	3	4	5
not at all	a little bit	somewhat	very much	extremely

Interacting with people online/offline gives me new people to talk to.

1	2	3	4	5
not at all	a little bit	somewhat	very much	extremely

Online/Offline, I come in contact with new people all the time.

1	2	3	4	5
not at all	a little bit	somewhat	very much	extremely

Psychological Capital Questionnaire (Luthans, Youssef, & Avolio, 2007; adapted by Bauman, 2014)

Below are statements that describe how you may think about yourself right now. Use the following scales to indicate your level of agreement or disagreement with each statement.

(1 = Strongly disagree, 2 = disagree, 3 = somewhat disagree, 4 = somewhat agree, 5 = agree, 6 = strongly agree)

I feel confident analyzing a long-term problem to find a solution.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

I feel confident about my academic work when meeting with professors.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

I feel confident contributing to class discussions.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

When I am part of a group project, I feel confident helping determine what the group is going to do.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

I feel confident contacting campus personnel such as professors, professional staff members, and administrators if I encounter problems.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

I feel confident doing oral presentations in class.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

If I should find myself in a jam at school, I could think of many ways to get out of it.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

At the present time, I am energetically pursuing my academic goals.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

There are lots of ways around any problem.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

Right now I see myself as being pretty successful in college/university.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

I can think of many ways to reach my current academic goals.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

At this time, I am meeting the academic goals that I have set for myself.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

When I have a setback academically, I have trouble recovering from it, moving on. (R)

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

I usually manage difficulties one way or another at work.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

I can be “on my own,” so to speak, at school if I have to.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

I usually take stressful things in school in stride.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

I can get through difficult times in college/university because I've experienced difficulty before.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

I feel I can handle many things at a time in my classes.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

When things are uncertain for me, I usually expect the best.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

If something can go wrong for me at school, it will.(R)

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

I always look on the bright side of things regarding my college/university experience.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

I'm optimistic about what will happen to me in the future academically.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

In my college/university experiences, things never work out the way I want them to. (R)

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

I approach my college/university experience as if “every cloud has a silver lining.”

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

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## Satisfaction with Life Scale (Diener, Emmons, Larsen, &amp; Griffin, 1985)

Below are five statements with which you may agree or disagree. Using the 1 -7 scale below, indicate your agreement with each item by placing the appropriate number on the line preceding that item. Please be open and honest in your responding.

(1 = strongly disagree; 2 = disagree; 3 = slightly disagree; 4 = neither agree nor disagree; 5 = slightly agree; 6 = agree; 7 = strongly agree)

In most ways my life is close to my ideal.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Agree	Strongly Agree

The conditions of my life are excellent.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Agree	Strongly Agree

I am satisfied with my life.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Agree	Strongly Agree

So far I have gotten the important things I want in life.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Agree	Strongly Agree

If I could live my life over, I would change almost nothing.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Agree	Strongly Agree



## Perceived Wellness Survey (Adams, 2005; Adams, Bezner, &amp; Steinhardt, 1997)

The following statements are designed to provide information about your wellness perceptions. Please carefully and thoughtfully consider each statement, then select *one* response option with which you most agree.

**Psychological Dimension Items**

I am always optimistic about my future.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

I rarely count on good things happening to me.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

I always look on the bright side of things.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

In the past, I have expected the best.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

In the past, I hardly ever expected things to go my way.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

Things will not work out the way I want them to in the future.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

### Emotional Dimension Items

There have been times when I felt inferior to most of the people I knew.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

In general, I feel confident about my abilities.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

I sometimes think I am a worthless individual.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

I am uncertain about my ability to do things well in the future.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

I will always be secure with who I am.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

In the past, I have felt sure of myself among strangers.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

**Social Dimension Items**

Members of my family come to me for support.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

Sometimes I wonder if my family will really be there for me when I am in need.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

My friends know they can always confide in me and ask for advice.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

My family has been available to support me in the past.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

In the past, I have not always had friends with whom I can share my joy and sorrows.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

My friends will be there for me when I need help.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

**Physical Dimension Items**

My physical health has restricted me in the past.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

My body seems to resist physical illness very well.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

My physical health is excellent.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

Compared to people I know, my past physical health has been excellent.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

I expect always to be physically healthy.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

I expect my physical health to get worse.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

**Spiritual Dimension Items**

I believe there is a real purpose in life.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

Life does not hold much future promise for me.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

Sometimes I don't understand what life is all about.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

I feel a sense of mission about my future.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

I felt in the past that my life was meaningless.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

It seems that my life has always had purpose.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

### Intellectual Dimension Items

I will always seek out activities that challenge me to think and reason.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

I avoid activities which require me to concentrate.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

Generally, I feel pleased with the amount of intellectual stimulation I receive in my daily life.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

The amount of information that I process in a typical day is just about right for me (i.e., not [too much, not too little]).

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

In the past, I have generally found intellectual challenges to be vital to my overall well-being.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

My life has often seemed devoid of positive mental stimulation.

1	2	3	4	5	6
Very Strongly Disagree					Very Strongly Agree

Open-Ended Questions

Please take a moment to consider your social network. Does your social network assist you in achieving your goals? If yes, how? If no, how have they hindered you?

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Does your social network assist you in facing any challenges that you have experienced? If yes, how? If no, how have they hindered you?

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Please take a moment to consider your family members. Does your family assist you in achieving your goals? If yes, how? If no, how have they hindered you?

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Does your family assist you in facing any challenges that you have experienced? If yes, how? If no, how have they hindered you?

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Please take a moment to consider your romantic relationship. Does your significant other assist you in achieving your goals? If yes, how? If no, how have they hindered you?

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Does your significant other assist you in facing any challenges that you have experienced? If yes, how? If no, how have they hindered you?

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Have you recently experienced any stressful life events which you believe have impacted your social relationships? If yes, please describe the nature of these events, as well as how often and how severe they have been.

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Have you recently experienced any health issues which you believe have impacted your social relationships? If yes, please describe the nature of these issues, as well as how often and how severe they have been.

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What are your perceptions of your level of femininity compared to others? Do you feel that these perceptions have impacted your social relationships?

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## Demographics

1. Age: \_\_\_\_\_

2. Which ethnic or cultural group do you identify with?

- Central American (El Salvador, Honduras, etc.)
- Scandinavian (e.g., Denmark, Sweden)
- French Canadian
- English Canadian
- British (Scotland, Wales, England, N. Ireland)
- W. European (France, Germany, Holland, etc.)
- E. European (Russia, Poland, Baltic States, etc.)
- S. European (Italy, Spain, Portugal, Greece etc.)
- Far Eastern (Japan, China, India, Hong Kong, etc.)
- African (specify North, Central, or South) \_\_\_\_\_
- Caribbean
- Middle Eastern (Israel, Lebanon, Iran, Iraq, etc)
- Latin American
- Indigenous (e.g., First Nations, Metis, status/nonstatus Indian)
- Other (please specify) \_\_\_\_\_

3. What is the highest level of education you have obtained?
- Some elementary school or Elementary school graduate
  - Some high school
  - High school graduate
  - Some college
  - Some university
  - College graduate
  - University graduate
  - Master's degree or other similar degree
  - PhD/MD or other similar degree
4. Are you currently a student? (if you are not currently a student, please proceed to question 8)
- Yes
  - No
5. If you are a student, are you a:
- full-time student
  - part-time student
6. What is your year of study?
- 1st year
  - 2nd year
  - 3rd year
  - 4th year
  - Other (please specify) \_\_\_\_\_
7. What is your major? \_\_\_\_\_
8. What is your employment status?
- employed full time
  - employed part time

- not currently employed
- other (please specify) \_\_\_\_\_

7. What is your height? \_\_\_\_\_

8. What is your weight? \_\_\_\_\_

9. Where do you currently live?

- Canada
- United States
- Other: please specify \_\_\_\_\_

10. Have you been diagnosed with Turner's Syndrome? (If you have, please continue to the next question)

- yes
- no

11. If you have been diagnosed with Turner's Syndrome, at what age did you receive the diagnosis: \_\_\_\_\_

## VITA AUCTORIS

NAME: Stephanie Cragg

PLACE OF BIRTH: Windsor, ON

YEAR OF BIRTH: 1985

EDUCATION: Walkerville Collegiate Institute, Windsor, ON,  
2003

University of Windsor, BA., Windsor, ON, 2007

University of Windsor, MSW., Windsor, ON,  
2012