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Subjective Experiences of Women with Turner Syndrome and Their Communities: A Photovoice Project

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Research Summary

Background: Turner Syndrome (TS) is a genetic condition that is characterized by the complete or partial loss of the second sex chromosome in females. Its most significant characteristics include short stature, amenorrhea, and infertility (Deal, 2008). This study used an arts-based, participatory action research method, Photovoice, to explore the experiences of women with TS living in Canada and the US. In photovoice, community members take photographs, share these photographs with other community members to begin a dialog, and then share these photographs and narratives with individuals who can promote change within their community (e.g., Wang, 1999). As this places the voices of the community at the centre of the research, this work is in line with the approach to research suggested by those who ascribe to the social model of disability (e.g., Shakespeare, 2012). The social model of disability argues that a disability is not due to an individual's diagnosis but caused by the attitudes and systems in the environment where that person exists.

This project was guided by the following research questions:

Q1) How does a diagnosis of Turner Syndrome (TS) impact the life of women living with TS?

Q2) What role do face-to-face (FTF) and online communities for individuals affected by TS play in supporting, facilitating, or creating barriers to improving the lives of women with TS?

Methods: Two groups of women (age 18-62, $M = 37.111$, $SD = 12.859$) with TS participated in 90-minute introductory workshops and submitted photos and narratives to the online survey ($n_1 = 5$; $n_2 = 4$), 3-4-hour focus groups ($n_1 = 4$; $n_2 = 4$), and optional 30-60 minute interviews ($n = 7$). All aspects of the study were completed online using the web conference software Blackboard Collaborate Ultra. Participants submitted their photos and associated narratives through an online survey via Qualtrics.

Preliminary Results: As part of the focus group, participants were asked to identify any themes they noted from the photographs, narratives, and surrounding discussion. Themes noted in the first group included: 1) strength, resilience, and hope and 2) community and support. The second group identified the following themes from their images and discussion: 1) need for TS advocacy and education, 2) community and support, 3) strength, coping, and resilience, 4) importance of self-care (physical and emotional), and 5) creativity and self-expression.

Discussion: To the authors' knowledge, this is the first study that has used Photovoice to explore the experiences of women with TS. This process places the voices of participants at the centre of the work. As such, it has allowed for an in-depth and personal exploration of the impact a diagnosis has on the day-to-day experiences of these women. Additionally, it allowed for the exploration into topics not commonly discussed in the literature (e.g., community, resilience, and creativity). It also provided the opportunity for community members to discuss what can be done surrounding challenges faced by individuals with TS (e.g., advocacy and education). Finally, participants were also involved in the dissemination of the findings of this project through the creation of a photo book which will be sent to community leaders with the potential to share the findings more broadly with the community in the future.