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Major opinion about motherhood among women with Turner syndrome

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ABSTRACT

Objectives: Turner syndrome (TS) is associated with ovarian dysgenesis leading to infertility in most of the cases. There are some options for fertility preservation (FP) in patients with sufficient follicle numbers. The most recently studied are oocyte and ovarian tissue preservation. Due to premature ovarian failure among TS girls, the procedure should be performed as early as possible.
The aim of this study is to gain the opinions of women with TS about motherhood based on the web-survey.

Material and methods: The survey, hosted on SurveyMonkey.com, targeted women over 18 years with TS. It comprised 16 single-choice questions, ensuring anonymity and consent for data usage.

Results: The answers of a total of 152 women were analyzed. When asked if they had discussed motherhood options with their physicians, 72/152 of the participants responded negatively. Asked about the desire of maternity, 85/152 expressed a desire to have children. 5/152 had biological children from spontaneous pregnancies, 5/152 had biological children through oocyte donation, 1/152 through embryo donation, and 12/152 had adopted children. 75/150 respondents answered yes to the question of whether they desired to use ovarian tissues if they had been preserved during adolescence.

Conclusions: The findings suggest that a significant number of women with TS who aspire to become mothers would be inclined to use preserved cells if this option were available. This underscores the necessity for further exploration of FP techniques for individuals with TS.
Keywords: Turner syndrome; fertility; fertility preservation; motherhood; pregnancy; opinion

INTRODUCTION

Turner syndrome (TS) is diagnosed in one of every 2500 live-born females [1]. The diagnosis is made in individuals with a total or partial absence of the X chromosome [2]. Besides the characteristic phenotype, TS is associated with multiple conditions, including ovarian dysgenesis and premature ovarian failure, leading to infertility in most cases [3]. Follicular depletion begins in fetal life due to accelerated apoptosis caused by the haploinsufficiency of multiple genes located on the X chromosome [4, 5]. Patients with mosaic karyotypes are more likely to experience spontaneous menarche. However, this occurs in only 20% of patients with sufficient ovarian reserve [6].

Markers such as anti-Müllerian hormone (AMH), follicle-stimulating hormone (FSH), luteinizing hormone (LH), and ovarian ultrasonography may help predict the odds of spontaneous menstruation among patients with TS [6–8]. However, a patient's probability of maintaining regular ovulatory cycles remains difficult to estimate. Spontaneous pregnancy occurs in approximately 5% of patients with TS [9–11].

Adoption, surrogacy, and oocyte donation are options for women with TS who have insufficient ovarian reserve but wish to have children [12]. The inability to have biological children remains the main concern in this population [13]. There are some options for fertility preservation (FP) in patients with sufficient follicle numbers [14]. Oocyte preservation is a

well-established infertility treatment method used in women with conditions leading to premature menopause or who want to postpone pregnancy [15]. There are described cases of successful procedures in post-pubertal girls at risk of premature ovarian failure [16]. However, it can only be performed in patients with spontaneous menstruation [17]. Ovarian tissue cryopreservation (OTC), which may help maintain the reproductive and hormonal functions of the ovary, has become part of the care of patients prior to highly gonadotoxic treatment [18]. Although numerous pregnancies have been achieved using this method, there are no data on successful procedures in patients with TS [19]. There is an ongoing debate about the OTC in patients with TS. Researchers from various centers are conducting studies to determine the safety and effectiveness of the procedure. Recent years have provided data regarding the presence of follicles in collected tissues and factors that could help predict their density [20–23].

Guidelines published by Oktay and Bedoschi suggest how to counsel and manage young women with TS in terms of FP. After determining the ovarian reserve, a different approach is suggested for prepubertal and postpubertal girls with TS. In prepubertal patients, AMH levels should be assessed in series to delay OTC until the ovarian reserve starts depleting. In postpubertal girls with persistent ovarian reserve, OTC or oocyte retrieval should be processed irrespective of AMH levels [24].

Due to the young age of premature ovarian failure, patients involved in FP cannot be completely conscious of their own body and reproductive needs. The Delphi study of Schleedoorn et al. [25] of 55 experts showed that infertility leads to psychological harm and that FP should be offered to patients after proper psychological and cardiac screening. Regardless of their age, all patients should be involved in the decision-making process.

Here, based on a web-based international survey, we aimed to gain the opinions of women with TS about motherhood.

MATERIAL AND METHODS

The survey/questionnaire study was designed by physicians (an endocrinologist and a pediatric resident) in collaboration with a young woman with TS. The questionnaire was hosted on SurveyMonkey.com. One of the authors (WK) shared the questionnaire's link via Messenger, an instant messaging platform, with women who had self-identified as having TS

within an online forum dedicated to women with TS on Facebook. The sampling method employed was convenience sampling. Respondents were contacted directly through the Messenger platform and were given the opportunity to discuss any questions or concerns they had about the questionnaire with the author.

Two versions of the questionnaire were made available: one for women with TS in Poland and another for international respondents. The initial version of the Polish questionnaire underwent a translation process, which involved forward translation by two independent bilingual experts, followed by back translation. The survey's debut on the Polish forum was considered a pilot study, during which participants had the opportunity to provide feedback on the clarity and relevance of the questionnaire items.

Data from Polish participants were collected between November 5, 2022, and December 14, 2022, while data from the international group were gathered from January 8, 2023, to April 30, 2023. The questionnaire was administered to women with TS aged 18 and above. Out of the 860 messages sent globally, 292 recipients read the messages, resulting in a response rate of 53%.

The questionnaire comprised 14 single-choice questions (Q2–Q5, Q7–Q16), with an 'Other' option provided for 4 questions, and 2 open-ended questions (Q1, Q6). The survey addressed reproductive care, inquiring about spontaneous menstruation and the timing of maternity consultations. Participants were asked about their desire for children and the use of preserved ovarian tissues if available. Respondents were also queried regarding ovarian tissue or oocyte cryopreservation. Lastly, women were surveyed about pregnancy contraindications, including heart defects and hypertension. The responses of participants who did not provide information on their age or approximate age at diagnosis were deemed unreliable and consequently excluded from the analysis.

Chi-square analyses were performed using STATISTICA 13.3 to examine correlations between karyotype and willingness for motherhood and between age at diagnosis and willingness for motherhood. A p value < 0.05 was considered significant.

The survey was conducted in accordance with ethical guidelines. According to the ethics committee of the Medical University of Silesia, formal approval was not required due to the anonymous and non-invasive nature of the study (reference no. PCN/CBN/0022/KB/126/21).

Participation was voluntary, and participants provided implied consent by submitting the questionnaire anonymously. The authors' contact information was available for potential feedback, and the questionnaire could be completed only once per IP address.

RESULTS

The answers of a total of 152 women were analyzed. The patients’ current ages, countries, ages at the time of TS diagnosis, and karyotypes are presented in Tables 1 and 2.

Reproductive Care (Q5, Q6, Q8)

A total of 24 (15.7%) of the respondents menstruated spontaneously. When asked if they had discussed motherhood options with their physicians, 72 (47.4%) of the participants responded negatively, 22 (14.5%) answered that they had such conversations before 18 years of age, 23 (15.1%) had such conversations after 18 years of age, and 35 (23.0%) had such conversations after becoming interested in the topic. The distribution of the answers is shown in Figure 1.

Motherhood willingness (Q9, Q10, Q11)

Twenty individuals (13.2%) within the participant group did not express a desire to become a parent, while 85 (55.9%) expressed a wish to have children. Among the respondents, 5 (3.3%) had biological children from spontaneous pregnancies, 5 (3.3%) had biological children through oocyte donation, 1 (0.7%) through embryo donation, and 12 (7.9%) had adopted children. Additionally, 10 (6.6%) respondents remained undecided. Fourteen respondents (9.2%) provided open-ended answers under the category 'Other,' which did not align with the predefined options. The distribution of the answers is shown in Figure 2.

A total of 150 respondents answered the question of whether they desired to use ovarian tissues if they had been preserved during adolescence. Of them, 75 (50.0%) stated yes, 39 (26.0%) stated no, and 36 (24.0%) were undecided. The distribution of the answers is shown in Figure 3. None of the respondents had their oocytes or ovarian tissues preserved prior to this survey.

Pregnancy Risk (Q12, Q13, Q14, Q15)

A total of 121 (79.6%) participants were aware of the risks associated with pregnancy. Thirty-two (21.1%) answered positively regarding having contraindications for pregnancy, while 66 (43.4%) did not know if they had any contraindications.

Out of the total respondents, 78 (51.3%) were under cardiological care. Forty-four (28.9%) had heart defects, and 45 (29.6%) had arterial hypertension.

Statistical Correlations

There was no correlation between karyotype and willingness for motherhood (chi-square > 0.05), and no correlation was observed between the age at diagnosis and willingness for motherhood (chi-square > 0.05).

DISCUSSION

This study revealed that nearly half of the respondents never received counseling regarding their reproductive options. Based on recent studies, counseling should be offered regardless of the patient's age [26]. However, a prospective study conducted by Rodriguez-Wallberg et al. [23] demonstrated that undergoing FP at the onset of spontaneous puberty or at the expected start of puberty, especially in cases with a karyotype showing mosaicism, was associated with the best outcomes. Unfortunately, according to a study by Morgan et al. [27], only two-thirds of families had documented fertility counseling, and less than one-third of charts documented counseling specifically with patients. Even patients with a limited window of reproductive potential were infrequently referred to FP specialists. Similar conclusions can be drawn from a survey study based on answers from TS providers – nearly one-third of pediatric TS patients and their families are not provided with information about fertility implications [28].

The findings of this study indicate that out of the 152 respondents, only 12.9% of adult women with TS did not want to have children. Among the respondents, 108 (71%) expressed a desire to have or already had biological or adopted children. Among them, there were 5 women who were able to have children by spontaneous pregnancy. Studies involving larger

cohorts of women have shown that spontaneous pregnancies can occur in only approximately 5% of women with TS [9–11].

Half of the women with TS would use cells preserved during adolescence. This perspective may encourage physicians to help adolescent girls consider undergoing FP. These findings indicate that there is a significant need for further studies on FP among women with TS. However, the decision to undergo tissue collection must be made at a very young age, a process in which patients should participate regardless of maturity [18]. Moreover, the patient should not feel obligated to use preserved cells in the future when the final decision about having children is made.

Since oocyte cryopreservation and OTC are invasive procedures, proper health screenings, including gynecological, cardiac, and mental examinations, should be performed for every candidate due to the high risk of pregnancy complications. According to the latest guidelines for TS patient care, these examinations are recommended prior to laparoscopy [29]. Based on menstruation history, estradiol, FSH, LH, and AMH serum levels, and ovarian ultrasonography findings, the ovarian reserve should be established to avoid the removal of nonfunctional tissue. Before invasive procedures are performed, high-risk patients with cardiovascular events should be identified. Heart magnetic resonance imaging should be performed in every girl at an age sufficient to perform the procedure without anesthesia. The most recent guidelines by Gravholt recommend avoiding spontaneous conception when the aortic diameter is enlarged [3, 30]. It is noteworthy that 43.4% of the respondents in the study were unaware of any contraindications to pregnancy.

In addition to maternal risk, fetal complications should be considered. Women with TS may have chromosomal aberrations, and caesarean sections are performed significantly more frequently in women with TS than in unaffected women [31]. A Swedish study analyzing the pregnancy outcomes of 482 women with TS reported 124 pregnancies among 57 women with a mean birth rate of 54%. Miscarriages occurred less frequently in pregnancies with donated oocytes [10]. A study of a French TS patient population reported 52 pregnancies among 480 patients, resulting in 30 (57.7%) full-term live deliveries [10]. The study by Cauldwell et al. [32] showed that the number of spontaneous pregnancies in women with a 45,X karyotype was significantly lower than in women with a mosaic 45,X/46,XX karyotype. In their study, there were two cases of aortic disruption among 81 women. The cardiovascular outcomes are controversial. Grewal et al. [33] reported 68 pregnancies among 60 women with TS. Although

10 pregnancies were considered high risk for cardiovascular complications, no cardiovascular events were reported during 6 months postpartum. However, the aortic diameter assessment was performed only in 20 of the women. According to current recommendations, the diameter of the ascending aorta should be measured at 5–8 days postpartum and then again 15 days and 8 weeks postpartum [34].

To our knowledge, there is only one more study focusing on aspects of motherhood in women with TS. Falsy et al. [35] discuss the interest in routes of parenthood and factors influencing approaches among women with TS. One-quarter of the respondents were already parents, including 54.5% who had achieved pregnancy and 45.5% who had adopted. Of those who were not parents, 68.5% expressed a desire to become a parent. However, there is no discussion about FP.

The main strength of this study is its anonymous data collection design; despite the personal nature of the questions, the women felt free to answer frankly. The survey was short, and its questions were simple enough to avoid confusion among the respondents. The validity of the study group may be confirmed by the compliance of its findings with data in the literature about spontaneous puberty and the prevalence of heart defects among women with TS.

The main weakness of this study is its poor validation. The questionnaire was designed by the authors. The Polish population answers were considered a pilot study for detecting potential problems. The data is representative only for developed countries due to the demographics of the respondents (the majority of whom are from Poland, the USA, and the UK, all of which are developed countries), the distribution of the questionnaire (access to the internet and social media is more common in developed countries), and healthcare considerations – FP involves advanced medical procedures that may not be available in developing countries. Also, reaching out through a specific online forum may introduce bias, as only those who are active on that forum may participate.

In conclusion, it is crucial to prioritize TS patients' perspectives in FP discussions and decisions. Further research into FP for TS patients is essential, with active involvement from adolescents, parents, and physicians. This study highlights the need for comprehensive FP counseling and support, emphasizing early and informed decision-making. It provides valuable data on patients’ perspectives, health risks, and FP strategy effectiveness, contributing significantly to the understanding and management of fertility issues in TS.

Clinically, these results can improve FP counseling, optimize intervention timing, manage health risks, and tailor reproductive health strategies, enhancing reproductive health and quality of life for TS patients.

Article information and declarations

Data availability statement

The data that support the findings of this study are available from the corresponding author (MW, mallgorzatawegiel@gmail.com), upon reasonable request.

Ethics statement

According to the ethics committee of the Medical University of Silesia, formal approval was not necessary due to the anonymous and non-invasive nature of the study (reference no. PCN/CBN/0022/KB/126/21).

Author contributions

MW and AG designed the study. MW, WK and AG designed the survey. WK distributed the survey. MW prepared the draft of the manuscript. AG provided supervision and editing of the manuscript.

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Conflict of interest

There is no conflict of interest that could be perceived as prejudicing the impartiality of the research reported.

Supplementary material

Questionnaire in English.

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Table 1. Country distribution among the 152 respondents

Country	Respondents (n = 152)
Poland	56 (36.8%)
United States of America	54 (35.5%)
Great Britain	12 (7.9%)
Australia and New Zeland	5 (3.3%)
Canada	4 (2.6%)
Ireland, Germany	3 (2.0%)
Cameroon, Iceland, South Africa, Slovenia, Brazil, Ecuador, Denmark, Sweden, Norway, Italy, Croatia, Puerto Rico, Egypt, Belgium, Austria	1 (0.7%)

Table 2. Current age, age of TS diagnosis, and karyotype distribution among the 152 respondents

Current age (years)	
18–24	17 (11.2%)
25–34	56 (36.8%)
35–44	38 (25.0%)
45–54	29 (19.1%)
55–64	7 (4.6%)
Age of diagnosis (years)	
during the pregnancy	11 (7.2%)
first year of life	29 (19.1%)
< 3 yo	5 (3.3%)
3–6 yo	13 (8.6%)
7–9 yo	16 (10.5%)
10–15 yo	43 (28.3%)
Karyotype	
45,X	64 (42.1%)
Mosaic 45,X/46,XX	22 (14.5%)
Mosaic 45,X/46,XY	8 (5.3%)
Other	10 (6.6%)
I do not know	25 (16.4%)
I do not remember	22 (14.5%)
No data	1 (0.7%)

TS — Turner syndrome

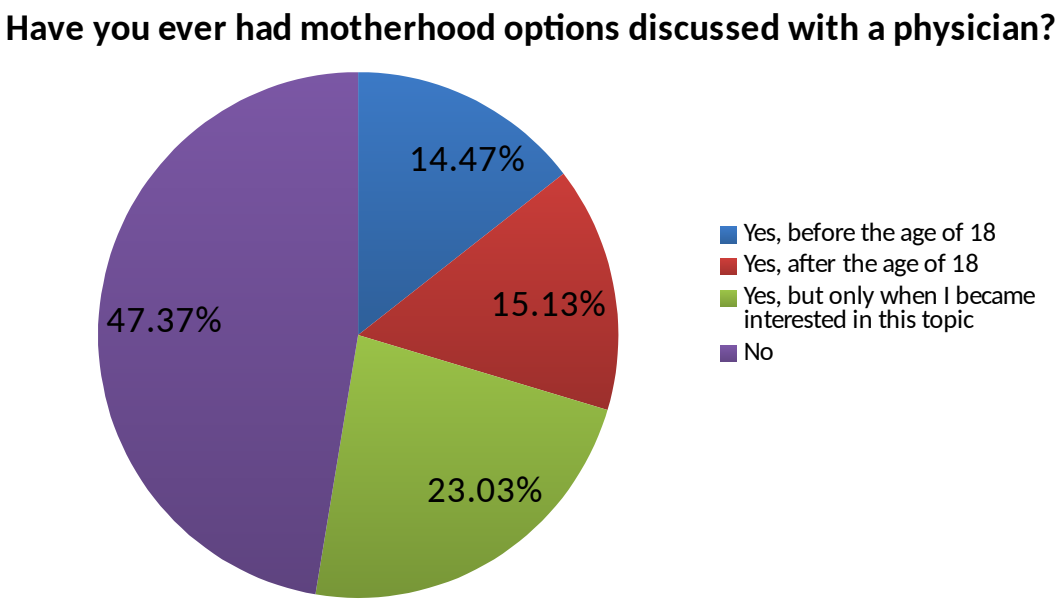

Figure 1. Pie chart showing the percentage distribution of responses to the question on discussion on motherhood options with a physician

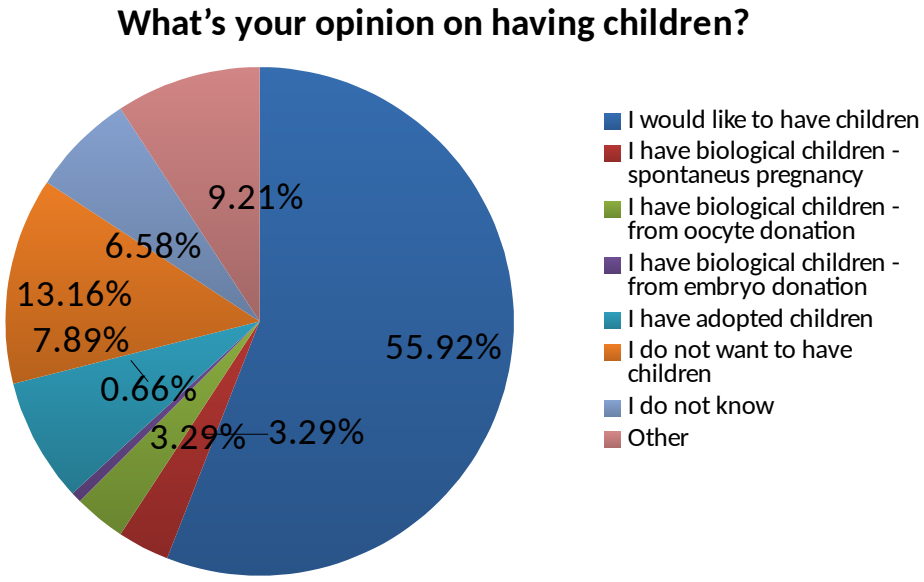

Figure 2. Pie chart showing the percentage distribution of responses to the question about motherhood willingness

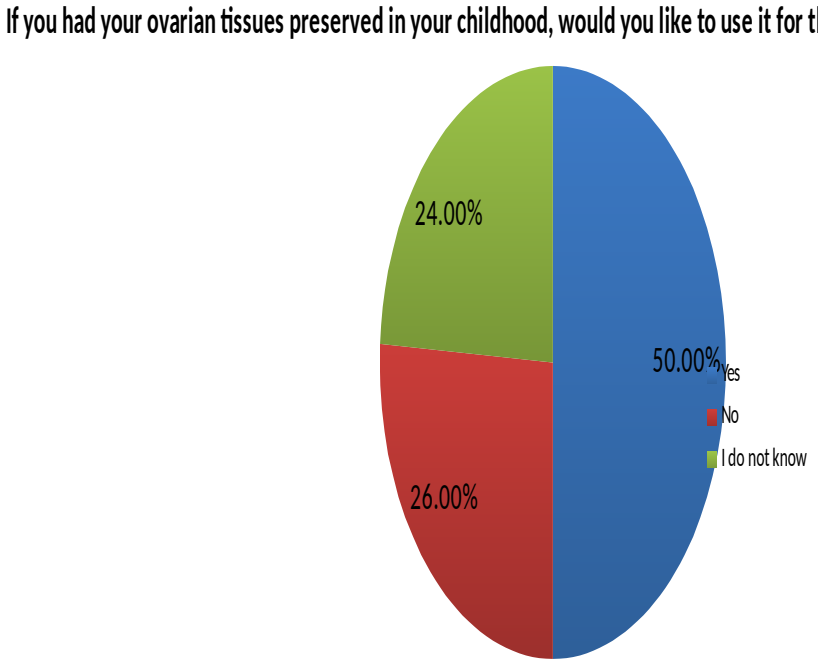

Figure 3. Pie chart showing the percentage distribution of responses to the question about willingness to use preserved ovarian tissues