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Sexual Aspects of Women with Turner's Syndrome

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Objective: *The Phenotypical characteristics of women with Turner's Syndrome (TS) are well documented but information on their psychosocial communication is considerably poorer.* Design: *The purpose of the present study was to assess the aspects of sexual life in 176 women with TS older than 18 years in Poland and to compare them with Polish women in general as well as with TS women in western European countries.* Setting: *Sexual attraction, initiation of sexual activity, age of sexual initiation, sensation of orgasm, reasons for not initiating sexual activity, marital status and marriage stability were analysed.* Methods: *Direct questioning method.* Results: *81,8% of TS women feel sexual attraction, 29,5% initiate sexual activity, mean age of sexual initiation is approximately 22,7 + 0,5 years, and 69,2% have orgasms. 18.2% of TS women had stable marriages. Women with TS differ from healthy Polish women is general in having a lesser interest in males, less frequent sexual activity, later initiation of sexual activity and a less frequent orgasm rate. The most frequent reason for reduced sexual activity is lack of a regular partner. Fewer women get married but their marriages are more stable. TS women differ from TS women in western European countries in less frequent sexual activity, later sexual initiation but greater orgastic capacity. They show a greater interest in males, more get married and their marriages are characterised by greater stability.* Conclusion: *1. In spite of significant hormonal abnormalities, sexual activity in women with Turner's Syndrome is not completely avoided. 2. The quality of sexual life of the studied women with TS is differentiated in comparison to women from the general population and TS women from other countries and depends on the analysed parameter.*

KEY WORDS: Turner's Syndrome; sexual activity.

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INTRODUCTION

Turner's Syndrome (TS) takes its name from the author H. Turner who in women 1938 described the disease nowadays called by his name. This syndrome occurs only in women and is characterised by abnormalities concerning the number and structure of sex chromosomes, gonadal dysgenesia and somatic disorders of which the most important is short stature. A low concentration of ovarian steroids in serum and a high concentration of gonadotrophins in women above the age of 14 are ascertained in hormonal examinations as being typical for this syndrome (1). Gonads appear to have cyclical hormonal activity only in a small number of women with TS and its manifestation is maintained menstrual rhythm and even fertility (2). Problems with psychosocial communication occur very often. While a phenotypical characteristic of TS is properly documented, information about psychosocial communication of these women is considerably poorer. TS occur in approximately one act of 25000 women (1,2). It can be stated that in Poland there are about 8000 such women, including 5000 above the age of 18.

The above-mentioned data became a basis for taking up inquiry studies of women with TS. And these were to answer the following questions:

1. Do women with TS differ from healthy women concerning sexual life, and to what degree?
2. Do Polish women with TS differ in their sexual activity from women with the same disease living in other European Countries?

Studies beyond the cognitive aspect may have large practical significance. Information given by women with TS about the reason contributing to lower the quality of their lives may become an important indictor for doctors regarding farther treatment (3,4).

METHODS

This study comprised 176 women with TS (mean age 25,0 + 0,6 years,— mean + SEM), from throughout Poland and gave their consent to participation in the studies. Information about the possibility to be examined was transmitted by press, radio and television (5). Examinations were conducted from 1 March 1995 to 30 June 1997 in consultation centre for women with TS and thereafter to 31 October 2002 in the Out-patient Clinic for Women with Turner's Syndrome in Bytom. Turner's Syndrome was diagnosed in every examined person by investigating the karyotype with cytogenetic and/or molecular examination. Data for such analysis was collected by the inquiry method in direct conversa-

tion with each examined women, whose history was taken always by the same person.

Questions concerned:

1. A feeling or lack of sexual attraction towards men,
2. Beginning or not having sexual activity,
3. Age of sexual initiation,
4. Occurrence or lack of orgasm concerning women who had begun sexual activity,
5. Reasons for not initiating sexual activity,
6. Civil state,
7. Marriage stability.

The obtained data was correlated to parallel data from published research concerning women with TS in other countries and Polish women in general (3,6).

RESULTS

The inquiry results are presented in Figures 1–2 and in Tables 1–4. As for Fig. 1 (a), only about 16,5% of women did not feel sexual attraction towards men. (3 answers—1,7%—were undecided). These results are more approximated to the data from the Polish general population where this percentage equals 5%—Fig. 1 (b) (6) and they differ markedly in comparison to the examined population of women with TS in other countries where up to 64%—Fig. 1 (c) of those women did not feel sexual attraction towards men (7).

In Fig. 2 (a) it is presented that only 29,5% of examined with TS took up sexual activity, in comparison with 58% of women with TS in other European Countries (8)—Fig. 2 (b). In the Polish general population up to 92% of women sexually active (6)—Fig. 2 (c).

As is revealed in Table 1, the average age of sexual initiation was about 22,7 + 0,5 years. In comparison with examined women from other countries, where it equalled 19,5 years (9), it was 3 years later. In the Polish general population 70% of women begin sexual activity before the age of 20 (6). Data referring to the experience of orgasm are presented in Table 2. About 69,2% of women experience orgasm. In the Polish general population this percentage equals 92% (6). Reasons for not initiating sexual activity are set out in Table 3. What attracts attention in the first place are lack of a partner, young age, religion and feelings towards the disease itself. In the Polish general population the reasons successively were absence of such a need, lack of a stable relationship and religious beliefs (6). Results from data presented in Table 4. show that only a small percentage of women get married—18,2% however at the 100% stability of these

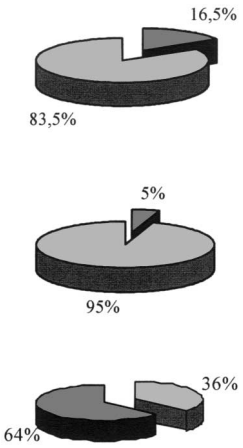

Fig. 1. Sexual attraction towards men (in yellow): (a) in examined women with Turner's Syndrome, (b) in Polish women (Z Lew-Starowicz 2002), (c) in women with Turner's Syndrome from Western European countries (JC Job, F Laudier 1991).

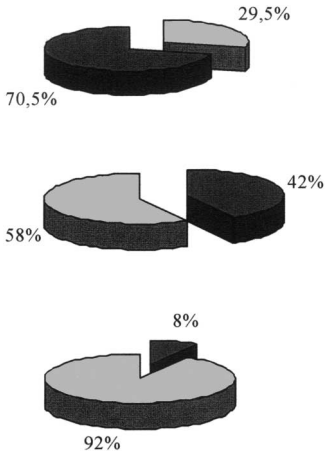

Fig. 2. Initiation of sexual activity (in yellow): (a) in examined women with Turner's Syndrome, (b) in women with Turner's Syndrome from Western European countries (JE Toublanc 1997), (c) in Polish women (Z Lew-Starowicz).

Table 1. Age of Sexual Initiation of Women with Turner's Syndrome (The average age of sexual initiation was approximately 22,7 years.)

Age of Sexual Initiation (years)	Number of Examined Patients	Percentage (%)
Under 20	12	23,1
20–25	28	53,8
Above 25	10	19,2
Lack of information	2	3,9
Total	52	100,0

Table 2. Orgasm Sensation in Women with Turner's Syndrome

Has the Patient Ever had an Orgasm Sensation?	Number of Studied Patients	Percentage (%)
Yes	36	69,2
No	16	30,8
Total	52	100,0

Table 3. Reasons for Lack of Sexual Activity in 124 Women with Turner's Syndrome (Explanation: A part of the examined patients gave more than one reason.)

No.	Reason of Sexual Activity Lack	Number of Examined Patients	Percentage (%)
1.	Lack of partner	45	36,3
2.	Young age	40	32,3
3.	Religious beliefs	24	19,4
4.	Lack of appropriate partner	22	17,7
5.	Feeling of being ill	14	11,3
6.	Lack in interest in men	5	4,0
7.	''All''	2	1,6
8.	Other	10	8,1
9.	No information	3	2,4
10.	Do not know	2	1,6

Table 4. Civil State of Women with Turner's Syndrome

Civil State	The Number of Persons	Percentage (%)
Married	32	18,2
Single	144	81,8
Total	176	100,0

marriages is significantly great. In the Polish population et large these percentages equal: 63% and 84% (6), respectively. In other counties only 10% of women with TS (10) or 17% (8) got married. Data regarding the marriage stability of women with TS in other countries was unavailable.

DISCUSSION

At the outset of discussion of the results drawn from the analysis it should be emphasised that the data was taken from as great a number as 176 women. In the other data, which we analysed, it was not possible to gather such a large group of patients. The most abundant data available are the examinations of Toublanc et al. (8), conducted in three centres (one in Rouen and two in Paris), where they received only 105 answers from 213 questionnaires sent to patients. Abundance of the rest is smaller. Notably, the examined women completed the questionnaires unaided, which may impeded direct comparison of the responses: a conclusion relating to the divergent results, should be approached with circumspection.

The sexual sphere is one of the most important areas of a woman's life. It undeniably influences the quality of her life. Knowledge of this domain may become an important indicator for a doctor concerning direction in which he should proceed with his treatment and to what degree to use the data from native or other countries' research. Significant differences in the comparison of women with TS with healthy Polish women and with women with TS from other countries already appear in the data presented in Fig. 1. Job et al. (7) started that 64% of women with TS had no interest in males. In the Polish population examined it refereed to only 16,5% (Fig. 1). It is a lower indicator in comparison to women with TS from other countries. It is hard to define the reason for such a difference. Does it result from the fact that what we understand in the name of interest in a person of the opposite sex is different in compared groups from occurrence of sexual attraction towards men? However, the existence of such a significant difference is striking. As many as 70% of the female population examined by us did not take up sexual activity, as presented in Fig. 2. This data markedly differs the Polish population from other examined European populations where about 42% of women take up sexual activity (8). As is shown in Table 1 the sexual initiation most often occurs in within 20–25 years age group (53,8%), average 22,7 years. Sylven at al. (9) examining 22 middle-aged women with TS gathered information that sexual initiation of those women took place on average at the age of 19,5. However according to Toublanc (8) the average initiation age was 20,5 years. So the sexual debut of our group of women with TS was about 3 years later in comparison to women with TS from other countries. Perhaps the difference result from the fact that healthy women in

compared countries also begin sexual activity earlier. However there is lack of objective data in this domain. In the Polish general population around 70% of women begin sexual activity before the age of 20 (6). Among different, sometimes associated, causes of not taking up sexual life the main ones were: 36,6% lack of a partner, 32,3% young age, 19,4% religious reason, and 17,7%—lack of a proper partner (Table 3). Concerning 52 persons who led sexual activity, 69,2% experienced orgasm (Table 2). It testifies to only slightly less ability to feel orgasm in comparison to healthy Polish women (6), where 92% experience orgasm. Raboch et al. (11) revealed in women with gonadal dysgenesia, retardation of sexual development, smaller needs and sexual activity, more rare orgasm experience in comparison to 50 healthy women from a control group. However women who lived with a stable partner did not differ from healthy women. It was confirmed also in our observations that women with TS were astoundingly well adapted to their weak points.

Pavlidis et al. (12) found in 80 adult women from Denmark more conservative sexual attitudes, a negative image of their own bodies, lower activity, but greater sexual satisfaction in comparison to healthy women. Kondradsen and Nielsen (13) write that in Denmark two-thirds of patients live with a stable partner. As is presented in Table 4 only 18,2% of women were married which is a substantially lower number in comparison with Polish women—63% (7). Calo et al. (10) revealed that 90% from 48 women were unmarried and 38% lived with parents. In Toublanc's (8) examined group 17% of women are or were married and 10% lived in free relationships. This probably signals disorders in sexual identification of one's own and in emotional capacity. Hettmer et al. (14) led an inquiry and test study asking 25 patients about their sexual activity behaviour and orgasm capacity. Results were compared to women from the general population. In women with TS sexual development in prepuberty was normal and puberty was 4 years late. All women had proper feminine and heterosexual orientation. Women, who were lated administered hormonal substitutive therapy displayed losses in psychic and social attributes and also in sexual activity. A fact, which is worth emphasising, is that none of the marriages in our group broke up. In Poland in general the percentage of divorces equals 16 (3).

To sum up data from literature and the results of our observations it seems that women with TS differ from healthy women in the general Polish population in having lesser interest in males, less frequent sexual activity, later initiation of sexual life and a less frequent orgasm rate. The most frequent reason for reduced sexual activity is lack of a regular partner. Fewer women get married but their marriages are more stable. TS women differ from TS women in western European countries in less frequent sexual activity, later sexual initiation but greater orgastic capacity. They show greater interest in males, get married more often and their marriages are characterised by higher stability.

CONCLUSIONS

1. In spite of significant hormonal abnormalities, sexual activity in women with Turner's Syndrome is not completely avoided.
2. The quality of sexual life of the studied women with Turner's Syndrome is differentiated in comparison to women from the general population and women with Turner's Syndrome from other countries and depends on the analysed parameter.

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