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Full Length Research Paper

A qualitative study of femininity and motherhood for outpatients with turner syndrome and variants in a public health sector, in southeast Brazil

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Approximately one in every 2.500 live-born female is a TS carrier. The most important clinical signs noted are: stunted growth, broadened shoulders, low hairline, absent secondary sexual characteristics, primary amenorrhea and, in all cases, infertility. This article aims to analyze the perceptions of femininity and motherhood for outpatients with TS and variants. To interpret meanings of these phenomena experienced by women, clinical-qualitative method was applied through semi-directed psychological interviews performed with 13 patients. After fluctuating readings of the interviews was conducted content analysis whose discussion was based on psychodynamic concepts, bringing the following results: feelings of uselessness and fears of reduced fecundity, vitality, strength and sexual desire were reported; the phenomenon of menstruation holds a central place in the mental functioning of the women studied, since it is related to their perceptions of how their femininity is constituted; but the meaning of femininity for them did not seem to be closely associated with the ideas of motherhood and reproduction; they gave priority to other desires and social meanings, such as studying, working and achieving social autonomy, and the possibility of adopting children. These results can guide the public services of health in the attendance the patients with TS and variants.

Keywords: Turner syndrome, infertility, sexuality, qualitative research, women's mental health.

INTRODUCTION

This article has the objective of discussing, from a psychological point of view, the meanings of the perceptions and experiences of femininity and motherhood as reported by TS carriers at the outpatient service of the Gynecology Outpatient Service at the Women's Hospital Prof. Dr. José Aristodemo Pinotti - Women's Integral Health Care Centre (CAISM), a tertiary hospital of the State University of Campinas, in South-eastern Brazil. Extracted from the doctoral research entitled "Experiences of the infertility phenomenon by patients suffering from Turner Syndrome or variants: a clinical-qualitative study" **(**Chvatal et al, 2005), approved by the University of Campinas, approved by Committee of Ethics in Research: Protocol 270/2002. We begin with the conviction that, in virtually all cases, women suffer from psychological difficulties related to this condition.

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Approximately one in every 2.500 live-born female is a

TS carrier. Prenatal ultrasound examinations often reveal severe alterations such as cystic hygroma and hydropsy, as well as occasional renal and cardiac anomalies. Due to the severity of these conditions, 95% of all embryos are aborted spontaneously and survivors show minor phenotypic anomalies. Postnatal clinical examinations show normal children except for the low birth weight, which, later on, generally leads to stunted growth, this usually being the only visible sign of TS during childhood. With the onset of puberty, differences from the general population become more evident, through the absence or underdevelopment of secondary sexual characteristics, including scarce pubic and axillaries hair, small or absent breasts, short stature and typical childlike physical characteristics. Delayed menarche or menstrual irregularities are the major problems cited by these patients (Davenport, 2010).

At some study centers growth hormones and estrogens are regularly prescribed for young patients as treatment for stunted growth and deficiencies in adult feminine characteristics. Irreversible infertility is present in almost all TS patients, except for the recent option for *in vitro* fertilization, which is available only in large cities and thus to only a small percentage of these women. Some cases require surgical vaginal correction and mammary prosthesis, but major interventions are rare and standard protocols are based on follow-ups, according to the possibilities of carriers and institutions (Velasco, 2006; Kanaka-Gantenbein, 2006).

According to (Ross et al., 2000) typically, specific deficits in visual-spatial/perceptual abilities, nonverbal memory function, motor function, executive function, and intentional abilities occur in TS children and adults of varying races and socioeconomic status. TS-associated psychosocial difficulties occur in the areas of maturity and social skills. Morgan (2007) says that the psychosocial impact of Turner syndrome may be substantial for young girls and women. These effects may be caused by (in decreasing order of patient importance) infertility; short stature; and impaired development of sexual characteristics, most importantly lack of libido.

A review of the literature from a psychosocial perspective found that short stature could increase the risk of psychological and social difficulties. However, there is no consensus in the literature on the stature to be alone or combined with other factors, responsible for part of emotional and social problems found in ST. Infertility can be considered a factor of great emotional impact, can cause depression and interfere with sexuality and self-esteem. Also been reported in patients with ST, low self-esteem, more negative self-image and a greater tendency to social isolation. This study also indicated that female gender identity in patients with ST was considered normal, but the loving relationship difficulties are more frequent compared with the population as a whole. The family relationship and the interaction of ST with parents were also considered very important for a healthy psychological development (Suzigan et al., 2005). Another study found that women with TS may use more psychosocial mechanisms considered neurotic and immature than the psychosocial mechanisms considered more mature to handle the complications of the disease (Chvatal et al., 2009).

Vanderley et al., (2004) suggest that the best results from psychotherapeutic follow-up for TS girls and women are obtained from support groups. Psychosocial support should always involve both patients and their families. Moreover, as of the moment of diagnosis, maximum information about TS should be provided to all those involved. It is also important to encourage social activities with same-age non-TS persons, in order to help patients in their emotional maturation. Families should receive guidance as to the best ways to deal with TS girls. They should always be treated in consonance with their actual chronological age, rather than with their physical appearance, thus avoiding overprotection and improving their ability to carry out tasks that are clearly possible for them.

Unfortunately, there is no clue as to the existence of contact or support groups for TS girls or women in Brazil or other Latin-American countries.

SUBJECTS AND METHOD

This study had a clinical-qualitative design. Thus, it adopted a humanistic model, in seeking to scientifically interpret the meanings that individual's life experiences acquire, considering these persons natural settings. Hence, the present work had an exploratory, non-experimental character. If one wants to explain the infertility scientifically, this is a matter for researchers of gynecological diseases and so on. But if one wishes to understand what infertility means for the patient's life, this is a matter for qualitative researchers. These can be psychologists, psychoanalysts, sociologists, anthropologists or nurses. But it is extremely useful for physicians themselves to make use of qualitative methods. Through their professional experience, they bring in clinical and existentialist attitudes that enable them to perform both valuable data collection and authoritative interpretation of the results (Turato, 2010).

Qualitative researchers study things in their natural settings, in an attempt to interpret phenomena in terms of the meanings people place on them. Such methods have their own characteristics relating to sample composition, data analysis and the possible generalizations from the results (Denzin et al., 2005). The specific strategy utilized in the present research was the so-called clinical-qualitative method. This is considered to be a particularization and refinement of the generic qualitative methods of human sciences, which here was applied to a healthcare setting (Turato, 2010).

The data collection instrument was the so-called semi-

Table 1. Bio-socio-demographic data on the patients with TS or a variant interviewed at the gynecology outpatient clinic service

No	Age	Marital status	Height/weight	Secondary sexual characteristics
P1	30	Married	150 cm / 67 kg	Hypodevelopment
P2	31	Married	155 cm / 49 kg	Hypodevelopment
P3	31	Single	163 cm / 65 kg	Mild hypodevelopment
P4	22	Married	142 cm /45 kg	Hypodevelopment
P5	45	Married	149 cm / 73 kg	Hypodevelopment
P6	24	Married	158 cm / 32 kg	Mild hypodevelopment
P7	28	Married	154 cm / 65 kg	Mild hypodevelopment
P8	33	Married	145 cm / 42 kg	Hypodevelopment
P9	18	Single	135 cm / 31 kg	Hypodevelopment
P10	21	Single	161 cm / 69 kg	Mild hypodevelopment
P11	36	Single	146 cm / 65 kg	Hypodevelopment
P12	27	Single	150 cm / 40 kg	Hypodevelopment
P13	26	Single	144 cm / 57 kg	Hypodevelopment

directed interview with open-ended questions (Fontanella et al, 2006). This approach had the aim of ensuring that the matter was discussed with the interviewees in depth. It has been proved to be appropriate for qualitative research within the field of healthcare, as shown in the literature (de Figueiredo et al., 2001; Fontanella et al., 2002; Campos et al., 2003). The sampling method utilized for qualitative research does not require statistical representativeness in relation to the subject population, i.e., it does not require the use of randomized studies. The procedure involves intentionally seeking out individuals who possess information on the matter to be focused on and the characteristic of articulateness. This produces data with the aim of reformulating, deflecting, complementing and/or clarifying initial hypotheses, as is desirable in any scientific construction (Turato, 2005).

The study sample consisted of 13 patients with Turner syndrome and variants. The sample was closed at this number by utilizing the saturation criterion. Thus, it was considered that the incorporation of additional interviews would make little significant contribution with regard to the objectives initially considered for this study. The transcriptions from the interviews formed the corpus for the study and were subjected to qualitative content analysis. Free-floating readings of the interviewees' responses had been made, so that the researchers would be able to familiarize themselves with the material. After applying the categorization strategy, the categories for this study were selected.

Qualitative analysis of a text does not infer categories from the frequencies of the analysis units (or from other mathematical approaches). Inductive reasoning stemming from identifying the phenomena associated with the interviewees' responses is utilized. The phenomena thus identified can then be interpreted so as to generate concepts capable of generalization to other settings (Campos et al., 2009). The topics thus delineated in the present study were discussed and interpreted according to psychodynamic concepts that are customarily applied within the discipline of medical psychology. The method adopted follows the traditional medical curriculum, in which the teaching of such discipline comprehends a theoretical framework that encloses an interdisciplinary approach in medicine, in which there is a work among psychologists, psychoanalysts and health professionals in order to both qualitatively understand and manage medical matters, such as difficulties in doctor-patient relationship and psychosomatic disorders (Dias et al., 2006).

The interviews were conducted among outpatient service of the Gynecology Outpatient Service at the Women's Integral Health Care Centre, a tertiary hospital of the State University of Campinas, in South-eastern Brazil. With the help of the nursing team, a strategy was devised to ensure privacy for the interviewee, so as to establish an empathic, cordial and confidential relationship between subject and researcher. Each interview began with the following question: "*Could you tell me what this problem meant for you?*" The following criteria for selecting patients were established, such that patients were only included if they presented:

- Confirmed diagnosis syndrome Turner and variants in semiannual or annual monitoring in the outpatient gynecology;
- Clinical, emotional and intellectual conditions that made them capable of undergoing a clinical-psychological research interview;
- Agreement to their participation, expressed through a statement declaring there free and informed consent, in accordance with the approval for the study granted by the Ethics Committee of the Institution.

The following criteria were not used for patient inclusion/exclusion: age, origin, marital status, family composition, educational level, socioeconomic status and religion. Nevertheless, in order to deal properly with possible bias, the variations in these factors were taken into account in interpreting the results.

RESULTS

We have chosen to merge the patients' statements and the respective discussion into a single section, for two reasons: 1) the peculiarities of the clinical-qualitative method, which draws interpretations as the interviews are held, and, 2) the methodological rigor of the construction of knowledge in the Human Sciences, because presentations produced separately can easily weaken the final text.

In addition, the emic perspective of qualitative research demands interpretations based on the way the members of a group see their psycho-cultural world (Essén et al., 2011).

The phenomenon of menstruation holds a central place in the mental functioning of the women studied, since it is related to their perceptions of how their femininity is constituted. They also showed feelings of uselessness and fears of reduced fecundity, vitality, strength and sexual desire. But the meaning of femininity for them did not seem to be closely associated with the ideas of motherhood and reproduction. TS patients gave higher priority to other desires and social meanings, such as studying, working and achieving social autonomy. In addition, some of the interviewees referred to the possibility of adopting children.

Two categories emerged from these results: (1) biological and cultural aspects of femininity; (2) TS patients and their desire to be mothers. Reference to their overall condition as women was included only in order to contextualize the research problem. Moreover, the assertion of femininity was in reference to "womanliness" and not specific to sociological roles of the women interviewed. The approach used is not aimed at understanding the nature of gender inequality, but only of the subjects' life experiences.

DISCUSSION

Biological and cultural aspects of femininity

TS and its variants show specific characteristics that differentiate them from other genetic disorders. Many diseases and disorders show signs and symptoms that allow early diagnoses, but the women who participated in this study had only been diagnosed at puberty, in the wake of primary amenorrhea or early menopause. By the time these patients were between 16 and 20 years old, when menstruation should have manifested itself but had not (or they had had only a few menstrual cycles), they had been referred to medical services for examinations. Regarding the fact that several secondary female characteristics never appeared for her, the P5 said: *"My mother was worried about me because I was going to turn on 19 and I had never menstruated"*. Although menstruation is common to all women, it is a phenomenon related to the role that women occupy in society as well as to their female identity and their reproductive functions. For many, menstruation is a primordial experience of the female body.

It might be said that women are essentially hormonal beings. Research has shown that female physiology has changed greatly over the last two centuries (Berenstein, 2001). Menstruation is an important factor related to female identity for all women, including TS bearers. For this reason, some pubescent girls enjoy menstruating and their first menstruation represents a milestone in their lives (Martin, 2001) as can be noted in the following comment by their P6: *"At first I was worried and sad about not menstruating like my friends. I didn't know what was happening to me. In my hometown nobody likes to talk about it and I already knew that my classmates menstruated and I didn't!".*

From a psycho-sociological point of view, the phenomenon of menstruation can be understood as the recurrent and intrusive validation of a woman's reproductive capacity, the essence of her reproductive state (Giffin, 1991). In this regard, from the individual woman's point of view, the beginning of menstruation would seem to symbolize her passage from being a girl to being a woman (Bancroft, 1995**)**. This gives rise to a range of opportunities for both pregnancy and procreation. Menstruation also establishes a psychosocial differentiation between female and male identity, as illustrated in the following statement by P12:

"When we got the diagnosis, the doctor said I didn't have to menstruate and he just wanted to do hormone replacement. I got really worried and thought I'd have to giving up being a woman!" It might be inferred that the female identity of TS patients who have not yet experienced menstruation is impaired. It is as if periods would give them the status of being a woman. In this case, menstruation can be seen as a thermometer that confers certain intensity to one's femininity.

It is to be supposed that menstruation and pregnancy are closely related in the feminine psyches. Not only is menstruation an important aspect of a woman's life – it is also a mystery that she lives out and that gives her a feeling of belonging to and being close to Nature. It can then be conceived that the impossibility to menstruate, or the cessation of menstruation, stirs up in a woman's mind feelings of uselessness, and atavic fears of losing their fertility, vitality, power, heat, sexual desire and femininity (Bancroft, 1995).

Even today there are stereotypes about menstruation, such as the widespread belief that, at menopause, a woman loses interest in sex. In fact, she merely ceases to be fertile. Despite that fact that menstruation is often seen as a bother or a state of impurity, it also consists of a language for a woman. It serves as a sign that her uterus, her body, is in a state of availability to bear children. A woman's body speaks through menstruation, saying, in a sense: I'm not pregnant right now, I'm healthy, I'm fertile.

One of the participants in our research illustrated this attitude in the following words: *"I take my hormones and now my menstruation comes regularly. So I can get pregnant, can't I?"* (P7).

Since stereotypes can construct forms of subjectivation, unconscious fears about a woman's own value was expressed by another patient when she said: *"I got worried when I found out I couldn't have any children"* (P2). If one of the stereotypes forms of seeing women is as wife and mother, those who do not fit into this role feel depreciated by society. One of our interviewees (P3) had the following to say in this regard: *"I started taking hormones and then menstruation began. Now, after a year, I've been having symptoms of menopause, and this makes me sad because I'm still young"*. This statement expresses both concern and sadness about not menstruating, even artificially, and it is plausible to think that this might indicate this woman's anxiety concerning an early end to her reproductive life.

According Martin (2001) the lack of rites of passage leads them to believe they are useless, a feeling that can be attributed to a specifically patriarchal attitude which implies that a woman who cannot have children is no longer useful to society. Despite modern ways of looking at fertility, unconsciously we are still influenced by those archaic beliefs.

It is presumed that these patients' discourse can be seen as expressing unconscious archaic fears about their values. P2 put it this way: *"I was worried when I discovered I couldn't have children".* Menstruation is a type of language for women because it is a sign that they are ready to have children. Oscillating between feelings of distress and of hope, P11 said in this respect: *"I take the hormones the doctor prescribed and now my periods are coming regularly".* This comment was accompanied by suggestive mainly non-verbal language more specifically, a questioning look and an anxious tone of voice. The interviewee seemed to wonder why she could not get pregnant if she is taking her medication and menstruates. At a different point in the interview, this woman said she would like to get married and have a family, so she seems to see menstruation and pregnancy as closely linked.

TS patients and the desire to experience motherhood

Motherhood and family are social representations that correspond more closely to men's than to women's expectations. The substratum of the unconscious is a given, but the imagination is constructed at a much deeper level. Men and women are constructed by the system, just as the body is also produced by the system. But nowadays, women have begun to question these structures on a broad scale in the search for modes of social insertion that go beyond the domestic sphere, which has always involved taking care of the house, husbands and children (Vargas et al., 2010). We might illustrate this broader perspective with a statement made by P10, who said: *"I want to study. I'm finishing up my training as a primary school teacher and later I want to study psychology or maybe education".*

Through their knowledge and attitudes, women today are questioning older social structures that relegated them to the private world while men belonged to the public sphere. Today, public and private lives are concepts used for both genders, in the sense that, since the 1950s, psychosocial changes have brought about a crisis in organizing the symbolic references of modern society. As our P4 put it, *"I know that every young woman wants to have family and children, [...] but I was never too worried about this. I can adopt children if I want to".*

Maternal feelings are unconsciously taught and built up during childhood through women's contact and example in the family. With successive fixations, contact and example mark women's emotions in a process, and they structure gestures and ways of being and feeling (Vargas et al, 2010). Without great psychological damage, most TS patients are therefore able to substitute direct processes of motherhood for situations of mothering that consist of taking care of others regardless of blood ties. After all, for millennia women have learned to be caretakers for others. P10 stated it very simply: *"If I can't get pregnant, I can always adopt children. There are lots of children to be adopted".*

In today's post-modern world, each person is increasingly concerned with their own particularity. Outmoded models and long-established sexual roles are questioned and infinity of possible parameters is put in their place. Therefore, becoming pregnant or not, being a biological or an adoptive mother, setting up a family with or without children, studying and becoming professionally fulfilled, are all modalities that are open to TS patients within a broad range of new possibilities. P5 commented*: "I adopted my baby daughter and she's my pride and joy".*

The TS women interviewed for this study suggested, adoption can therefore be considered a feasible choice.

CONCLUSIONS

Considering the biological and psycho-cultural foundations of femininity, the absence of menstruation was an important factor that was brought to light in the patients' mental functioning, associated with perceptions of femininity. This is clearly due to the fact that the phenomenon was very important to the women in our sample.

The psychology meanings of femininity do not seem to be directly associated with motherhood, perhaps in view of recent historical changes in the cultural context surrounding the TS patients in our study. These women talked especially about their desire to study, work and

attain social autonomy. As expected from today's women in general, in many different cultures, and probably due to innate conditions of female psychology and/or to the influence of social-anthropological values, the women in our study expressed this same desire to experience motherhood. When faced with their infertility, the adoption of children was a possibility spontaneously considered by many of them. These results can guide the public services of health in the attendance the patients with TS and variants.

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