




'I'm still a woman': A qualitative study on sexuality in heterosexual women with Turner Syndrome

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Abstract

Aim and objectives: The aim of this study was to describe and understand how heterosexual women with Turner Syndrome experience sexuality.

Background: Turner Syndrome is a genetic condition that is the result of one of the X chromosomes missing or partially missing, and it affects women of all ages. Turner Syndrome may lead to psychological, relational and sex life disorders.

Design: This is a qualitative study, and the COREQ checklist was employed to report on the current study.

Methods: The study was conducted in a region of southern Spain. Convenience and snowball sampling were used to recruit 18 women, aged 22–51 years, who had been diagnosed with Turner Syndrome. Participants' experiences were explored through semi-structured interviews between January and May 2021. Thematic analysis was used for data analysis.

Results: Three main themes and eight sub-themes emerge from the data analysis: (1) Sexuality linked to corporeality, with the sub-themes: 'Discovering that your body is different', 'Social stigma limits one's sex life' and 'Fear of penetration suppresses sexual desire'. (2) Adapting one's sexuality to Turner Syndrome, with the sub-themes: 'Feeling like a woman' and 'Suffering from and adapting to comorbidities'. (3) When infertility overshadows sexuality, with the sub-themes: 'Prolonging childhood by ignoring sexuality', 'Fertility treatment: always a possibility' and 'Lack of specialised professional knowledge'.

Conclusion: Heterosexual women with Turner Syndrome suffer from sexual problems, delayed diagnosis and treatment, and lack of information. Unawareness and relational problems may also lead to scarce and late sexual relations, jealousy and a fear of being left. The women with Turner Syndrome refer to little self-exploration or masturbation as well as a fear of penetration.

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Relevance to clinical practice: Understanding the experiences of sexuality in heterosexual women with Turner Syndrome is a challenge for clinical nurses, who could provide quality care to these women in contextualised services.

KEYWORDS

qualitative research, sexuality, turner syndrome, women's health

1 | INTRODUCTION

X chromosome monosomies are the most frequent genetic abnormalities in humans and account for 2% of all pregnancies (Álvarez-Nava & Lanes, 2018). Turner Syndrome (TS) is a genetic disorder caused by the partial or total loss of the second X chromosome, affecting multiple organs and body systems in women at any age (Haltrich, 2019; Jones et al., 2018; Swauger et al., 2021). With a prevalence between 1:2000 and 1:2500 live-born females (Apperley et al., 2018; Zhang et al., 2021), most studies on TS show how the 45,X karyotype is present in 60/100,000 live-born women (Berglund et al., 2019). As well as physical and reproductive problems, and multiple comorbidities, TS causes severe psychological, relational and sex life disorders, that have hardly been studied from the perspective of the women themselves (Gravholt et al., 2017).

2 | BACKGROUND

Turner Syndrome can be diagnosed at all ages (Apperley et al., 2018); early prenatal diagnosis of 45,X karyotypes is based on slow intrauterine growth, and cardiac, renal and lymphatic malformations (Gravholt et al., 2017). The diagnosis in paediatrics is made in the context of slowed growth and a short stature. Girls with TS are underweight and have an arched palate, low-set ears, a webbed neck and wide breasts with spaced nipples (Shankar & Bäckeljauw, 2018). Patients often present with strabismus, a straight nose, a large pinna, a prominent thorax and shortened limbs, along with hearing, ophthalmological and dermatological problems (Paolucci & Bamba, 2017). TS is associated with cardiovascular (Andersen et al., 2018), renal, endocrine and autoimmune problems (Aly & Kruszka, 2022), premature ovarian failure and subsequent oestrogen deficiency (Viuff & Gravholt, 2022). Although their IQ is usually normal, females with TS have an increased risk of receiving a diagnosis of neurodevelopmental or psychiatric disorder (Björölin et al., 2021). Women with TS suffer from deficits in visual-spatial perception and task management (Hutaff-Lee et al., 2019), inattention and hyperactivity (Chadwick et al., 2014), as well as increased prevalence of anxiety, depression and low self-esteem (Liedmeier et al., 2020). TS also has a negative impact on the development of relational skills and social communication (Wolstencroft & Skuse, 2019).

Most women with TS present with premature ovarian failure, delayed puberty, secondary amenorrhoea and sexual and reproductive health problems. 90–95% of affected women develop

What does this paper contribute to the wider global clinical community?

- TS involves physical, psychological and relational problems, alongside a set of comorbidities that directly affect women's sexuality.
- Overprotective parents and healthcare providers' lack of specialised knowledge causes girls and women with TS to be insecure when it comes to social, affective and sexual relationships.
- Nurses can explore the experiences of women with TS in a clinic, provide sex education or make referrals to sexuality specialists.

a comorbidity pattern similar to postmenopausal women (Viuff et al., 2020), characterised by a lack of secondary sexual characteristics, primary amenorrhoea and infertility (Gravholt et al., 2017). These patients require oestrogen replacement for regular menstruation and promoting breast growth (Idkowiak et al., 2022). Infertility is also a major concern (Schleedoorn et al., 2019); most are unable to have children and resort to assisted reproductive techniques (Deligeorgiou et al., 2016), and suffer high-risk pregnancies, foetal movement problems and premature delivery (Bouet et al., 2016).

Turner Syndrome patients have also been classified as intersex, the state of being born with biological sex characteristics that vary from what is typically thought of as exclusively male or female (Griffiths, 2018). The lack of ovarian development negatively influences the sexuality of women with TS (Garrido & Castelo-Branco, 2016; Liedmeier et al., 2020). While these problems can arise at any age, they are crucial during puberty, when alongside physical changes, social and sexual relationships are shaped (Kosteria & Kanaka-Gantenbein, 2018). Sexuality is a central aspect of being human that encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction (WHO, 2006). Sexuality is influenced by biological, psychological, social or cultural factors; it goes beyond intercourse/penetration and encompasses fantasies, desires, masturbation and interpersonal relationships. Sexual identity is the name/meaning that individuals assign to themselves based on sexual aspects of their lives (Savin-Williams, 2011), and may also be affected. Disorders of sexual development such as genital dissatisfaction and sex-neutral sexual/

body characteristics may have a negative impact on the way these women view their bodies (de Vries et al., 2019). Women with TS have lower body, social and appearance-related self-esteem (Cragg & Lafreniere, 2010). In addition, girls/women gradually begin to comprehend the long-term implications of the condition, including their diminished fertility potential (Colindres et al., 2016). Treatment of TS includes puberty induction for age-appropriate women (Carel et al., 2006). Women with TS are less likely to be sexually active, with arousal dysfunction being their main symptom (Ros et al., 2013). Sexuality disorders extend into adulthood; women with TS report a lack of confidence regarding their sexuality, tend to live alone and have fewer partners (Fjermestad et al., 2016).

Understanding the changes associated with TS and its impact on women's sexuality is key to maintaining their quality of life. While epidemiological (Viuff et al., 2020), clinical (Gravholt et al., 2017) or psychological (Hutaff-Lee et al., 2019) studies have been conducted, there is a need to incorporate the experiences and perspectives of those affected (Prakash et al., 2019). Although experiences of women with TS on social interaction (Wolstencroft & Skuse, 2019), physical activity (Thompson et al., 2020) or impact on family life (Nisbet et al., 2022) have been studied, little is known about their sexuality and quality of life. By understanding how women with TS experience their sexuality, we can better address their needs and demands. Therefore, the aim of this study was to describe and understand how heterosexual women with TS experience sexuality.

3 | MATERIALS AND METHODS

3.1 | Design

A qualitative descriptive study allowed us to describe little-known experiences (Sandelowski, 2000), such as sexuality in women with TS, identifying the fundamental elements of the phenomenon through low-inference interpretation and reporting the participants' experiences. This manuscript has been prepared in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines (Tong et al., 2007; Data S1).

3.2 | Participants and recruitment

Purposive and snowball sampling were used to recruit potential participants from the data registry of the 'Andalusian Association of Patients with TS'. Inclusion criteria were to be a woman diagnosed with TS, heterosexual, Spanish-speaking, 18 years of age or older and to have signed informed consent. Women who did not meet all of these criteria were excluded from the study. A total of 30 women with TS were selected for initial telephone contact and 14 did not participate for various reasons (four did not answer the phone, seven refused to discuss the topic and three said that they did not have time for an interview). A total of 18 participants were interviewed (Table 1).

TABLE 1 Demographic characteristics of interviewees (n = 18).

Participant	Age	Menstruation	Marital status	Children	Profession	Sexual relations
WTS1	37	Yes	Single	No	Nurse	No
WTS2	42	Yes	Single	No	Educator	Yes
WTS3	34	Yes	Partner	Yes	Housewife	Yes
WTS4	46	Yes	Partner	No	Administrative role	Yes
WTS5	51	No	Single	No	Retired	Yes
WTS6	22	Yes	Single	No	Social worker	No
WTS7	46	No	Single	No	Administrative role	No
WTS8	29	Yes	Partner	Pregnant	Primary school teacher	Yes
WTS9	28	No	Single	No	Primary school teacher	No
WTS10	37	No	Single	No	Administrative role	No
WTS11	30	Yes	Single	No	Shop assistant	No
WTS12	51	No	Married	No	Teacher	Yes
WTS13	41	Yes	Single	No	Housewife	No
WTS14	22	Yes	Single	No	Student	Yes
WTS15	48	No	Single	No	Teacher	No
WTS16	33	Yes	Married	Yes	Farmer	Yes
WTS17	30	Yes	Partner	Yes	Cleaner	Yes
WTS 18	37	Yes	Married	Yes	Nurse assistant	Yes

Abbreviation: WTS, Woman Turner Syndrome.

TABLE 2 Interview guide.

Stage	Subject	Content/example questions
Introduction	Motives, reasons	To understand the experiences of women with TS in relation to their sexuality
	Ethical issues	To inform about the voluntary nature of participation, recording, consent, the possibility to withdraw, confidentiality
Beginning	Introductory question	Tell me about your experience of sexuality as someone with TS
Development	Conversation guide	What does sexuality mean to you in your life and how does it affect your quality of life?
		How does TS affect your relationships with family, friends, co-workers and other social relationships?
		How does TS affect the way you perceive your body, how you look for a partner or your life with your partner?
		What is your experience in relation to sexual and reproductive health?
Closing	Final question	Is there anything else you would like to add?
	Appreciation	Thank them for participating, remind them that their account will be of great use and that they can contact us

Abbreviation: TS, Turner syndrome.

3.3 | Data collection

Data collection included 16 in-depth interviews with women diagnosed with TS between January and May 2021. The researcher contacted participants who met the inclusion criteria by telephone, explained the objectives, answered queries, assessed eligibility and requested their voluntary participation in the study. The COVID-19 epidemic prevented face-to-face interviews, which were conducted via Google Meet instead. Researchers adapted to the schedule and situation chosen by the participants; most of them connected to the Internet while alone in a private room at home. The interviews were done privately and individually following a guide (Table 2). The interview guide included questions about sexuality in women with TS, and was developed by RAR (school teacher, diagnosed with TS), IMFM (sexologist, qualitative health researcher) and MDRF (clinical psychologist, extensive experience in qualitative research). The interviews began with questions about life in general: 'Tell me about your experience of sexuality as someone with TS', followed by specific questions about sexuality: How important is penetration in your sex life as a woman with TS? We ended with the question: Is there anything else you would like to add? The pilot study tested the interview guide with two participants, resulting in minimal changes to the questions. Focal groups were not used for data collection, as the women were very shy and found it difficult to talk about their sexuality. Prior to the interview, the participants were informed about the study, asked to provide informed consent, and socio-demographic data were collected. Each woman was interviewed only once for an average of 48 min. Interviews were carried out by RAR and MMJL (Master's Degree and PhD), audio-recorded and transcribed verbatim by GGH and MIVM. The researchers are experienced in conducting in-depth interviews in the context of qualitative research. The interviewers had not been involved in the patients' care at any point prior to the study. Data collection ended when the researchers felt

they had reached data saturation. After the interviews, the participants had the opportunity to check the transcripts.

3.4 | Data analysis

Thematic analysis was carried out following the steps described by Braun and Clarke (2021). Phase 1. Data familiarisation: all of the transcripts were read to gain a general understanding, then re-read by writing notes using the memo function of ATLAS.ti. Phase 2. Systematic data coding: transcripts were coded using ATLAS.ti software (open coding, live coding). Phase 3. Generation of initial themes from codes and data: well-established codes were grouped into themes with shared patterns of meaning, connected by a central concept or idea. Phase 4. Review and development of themes, ensuring consistency with codes and quotes. ATLAS.ti was used in this phase to create networks and a conceptual map. Phase 5. Refining, defining and naming themes. Phase 6. Report writing by selecting explanatory examples (quotes) (Figure 1) The analysis was linked back to the research question and the bibliography. The analysis was carried out by three researchers (JGM, IMFM and MMJL). In the coding process, codes that did not reach 66% consensus were eliminated (phase 2). The themes were provisionally named by three coders (phase 3), then refined and validated by the whole team (phases 5 and 6).

3.5 | Rigour

The quality criteria of Lincoln and Guba (1985) were adopted to assess the quality of the study. Credibility: the participants and researchers were familiarised with the context of the study to ensure a safe setting in which valuable data could be obtained. One of the

researchers is a nurse affected by TS. Three researchers (nurse, psychologist and sexologist) were involved in the coding, analysis and interpretation of the data. Transferability: the researchers described the experiences and context of the study in detail. Confirmability: the interview transcripts were reviewed by the main researcher and verified by the participants. Regular research team discussions were held about the details of the study. Dependability: audit trails were

kept, including original recordings as verbatim transcripts, and interpretations were reviewed by two qualitative research experts external to the study. Reflexivity: the researchers examined their own values and pre-understanding of the study's phenomenon before describing the results.

3.6 | Ethical considerations

The study was carried out in accordance with the ethical standards of the Declaration of Helsinki. Approval was obtained from the Ethics and Research Committee of the Department of Nursing, Physiotherapy and Medicine, University of Almería (EFM 116/2021). The data were coded in a way that protected the participants' identity and integrity. Prior informed consent was obtained from all of the participants in the study.

4 | RESULTS

Socio-demographic data and factors associated with the study's participants are presented in [Table 1](#). The women with TS had a mean age of 36.8 years (SD=8.9), almost 62% of them were single, 50.5% had had sexual intercourse, only 27.7% had managed to have a child and one was pregnant. The informants had different experiences and preferences regarding their sexual activities, relationships, social lives and in terms of their communication with healthcare professionals. As such, three themes emerged from the inductive analysis of the data ([Table 3](#)).

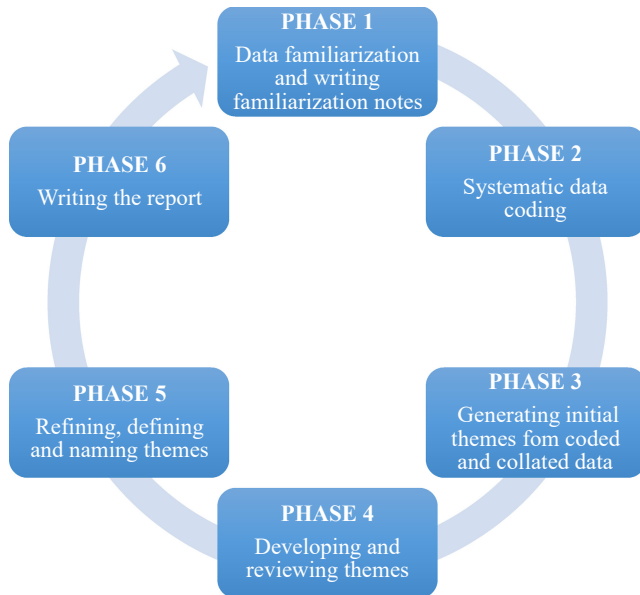


FIGURE 1 Six-step thematic analysis procedure (Braun & Clarke, 2021). [Colour figure can be viewed at [wileyonlinelibrary.com](#)]

Theme	Sub-theme	Units of meaning
Sexuality linked to corporeality	Discovering that your body is different	Symptoms, physical changes, capabilities, height, weight, limitations in daily life
	Social stigma limits one's sex life	Social and work prejudice, limitations, self-image, self-esteem, respect, bullying
	Fear of penetration suppresses sexual desire	Anxiety, fear of talking about it, fear or sexual intercourse, loss of sexual desire
Adapting one's sexuality to TS	Feeling like a woman	Intersexuality, orgasm, discovering your body, sexual identity, sex education
	Suffering from and adapting to comorbidities	Short, alopecia, strabismus, hearing impairment, no secondary sexual characteristics, infections, genital dryness
When infertility overshadows sexuality	Prolonging childhood by ignoring sexuality	Maternal control, staying at home, insecurity, overprotected, fear of being left, jealousy
	Fertility treatment: always a possibility	Egg donation, waiting list, psychological problems, communication, sexuality is not spoken about
	Lack of specialised professional knowledge	Lack of knowledge, need for protocols, trivialising comorbidities, lack of sex education

TABLE 3 Themes, sub-themes and units of meaning.

Abbreviation: TS, Turner syndrome.

4.1 | Sexuality linked to corporeality

This theme describes how participants discovered they had TS, a condition linked to profound changes in women's physical and psychological characteristics. The participants insisted on the need for early diagnosis, as delays set back hormone replacement therapy and increase comorbidities. In addition to physical problems, there are also social, family and work-related issues. The women in our study discovered their sexuality with a different type of body; body image disorders can lead to low self-esteem, relational problems, social rejection, stigma or bullying.

4.1.1 | Discovering that your body is different

The majority of women with TS show typical signs of short stature, webbed neck, large breasts and signs of late puberty. Our participants were progressively aware from childhood that their bodies, notably their secondary sexual characteristics, differed from other girls, which is why it is now understood that TS is not diagnosed early enough. As one participant explained, this situation resulted in severe consequences for her physical, mental and sexual development.

I didn't know I had TS until two years ago. I knew that I had stopped growing, that I had a strange physical appearance, different to other girls, ...but that's all. I don't think that the doctors looked hard enough detect it. (WTS1)

In line with our sample, early detection favours the sexual and reproductive development of girls with TS, allowing hormonal treatments to be started earlier and thus attenuating the consequences. Early treatment with growth hormone helps them to grow taller, and later treatment with oestrogen contributes to pubertal development resulting in physical, psychological and relational improvements. The participants recalled long treatments with pills (oestrogens) or growth hormone injections. From a young age, they were used to blood tests or anthropometric assessments, but they were not fully aware of their TS.

I was lucky, I was diagnosed with TS when I was 1 year old and I started treatment with growth hormones early, but it's not common. My mother would inject me every day into my thigh, into my arm, ... They talked to me about my height, about having children, but nothing about sexuality. I have practically lived a normal life, but I didn't become fully aware of TS until I was older... (WTS7)

The impact of a TS diagnosis on girls and families is variable, with a tendency to avoid disclosing it to others. Girls might require special consideration during the transition to adulthood. During this period,

growth hormone treatment is completed, and sexual development is induced. As one participant stated, this has later repercussions on psychosocial development, finding a partner and having a fulfilling sex life.

Yes, adolescence is difficult, you can imagine with all the hormone treatments, fears, complexes. You are constantly anxious about your studies, your professional life... but above all, you think about whether you are ready for sex, a partner, children... (WTS9)

4.1.2 | Social stigma limits one's sex life

Most of our participants reported that they have suffered from social prejudice, and some of them were bullied at school because of their physical appearance and limitations. These women are stigmatised, have severe body image disorders and generally very low self-esteem. TS, together with other comorbidities, can have negative consequences on their relationships, sex lives and their search for a romantic partner. This is one participant's account:

There are social prejudices that hurt you, based on your physical appearance, height, obesity..., they don't think that I have a genetic problem, they think that I eat too much. They see a fat person, not a patient with TS, they don't understand, and they look at you differently, ... it's really hard (WTS2)

Participants associated part of their low self-esteem with negative experiences concerning their sexuality. They consider themselves to be friendly, affectionate people, and seek a type of sexuality linked to the concept of love, having a romantic partner and making life plans. However, they stated a feeling of social rejection that restricts them, and that is not easy to deal with or overcome:

My self-esteem is low, it's awful. I don't feel valued, guys don't see the good in me, only my flaws. I haven't felt listened to, cared for, looked at, desired, just ignored ... as if we didn't have needs for sex and affection. I haven't been taught how to cope with this (WTS10)

In addition to physical problems, our participants spoke of the difficulties in task solving, visual-spatial perception, reading comprehension, facial recognition and motor coordination. The participants are afraid of rejection in the workplace, and they often hide their condition in job interviews. On a relational level, they do not understand when their colleagues use irony, double entendres or make jokes. These limitations not only restrict their performance at work but also affect them in social and interpersonal terms. This can lead to insecurity and a lack of confidence, which are essential for making contacts, finding a partner and having a full sex life. This is how one participant put it:

At work I am slower than the rest, I find it hard to understand, to focus, I'm not a good listener, I find it hard to know what's going on. TS is a disability that makes life difficult, we can't relate to others, it's hard to find a partner. What can I say about sexuality?! (WTS5)

4.1.3 | Fear of penetration suppresses sexual desire

The women from our study have spoken about the difficulty to relate to others, as they are sometimes insecure and anxious, which negatively affects their sex lives. They are afraid to explore themselves, to touch themselves and to enjoy their hidden sexuality. As one participant states, it is difficult to get started but then everything is normal:

We are shy and more insecure when it comes to exploring ourselves, touching ourselves, getting to know ourselves, it's like breaking a taboo. But it's not a problem, we have orgasms, and we like it, ... I'm assuming the pleasure is the same as for the rest of the girls. (WTS18)

Our participants have told us that they do not think their orgasms are different, they even know women who are multi-orgasmic. Once they have overcome their initial fears, they enjoy sex like any other woman, only expressing differences when it comes to having sex for a longer period of time:

It happens to many of us that, after an orgasm, our genitals are very sensitive. Then ... we find it difficult to keep going during sex, we feel discomfort and irritation. But it can also happen to girls who don't have TS... (WTS17)

As one participant said, from puberty onwards, they experienced their sexuality under a cloak of silence. Parents and professionals referred to comorbidities, menstruation and infertility but never alluded to sexual desire, masturbation, affection, sex play or sexual intercourse.

You don't talk about sexuality, you don't ask about it. ... It took me years to use tampons, alone, scared, in the bathroom, little by little, ... and they didn't tell me anything. Sexuality is as if it didn't exist, they are more afraid of it than us (WTS14)

Our participants stated that they are afraid of change, of what someone else will think of them, of not being accepted as a romantic partner, of falling in love and not having it reciprocated and, above all, of initiating sexual relations. Affection, touching and foreplay are progressively incorporated into their relationships, slowly breaking down barriers, but they are afraid of penetration and intercourse.

I used to panic about sexual intercourse, especially penetration. I suffered from anxiety, panicked, I'd sweat just

thinking about it. Would his penis go in? Would it be painful? What would my partner say? Would he notice that I was different? Would it be satisfying? Would he like it? Would he leave me if he didn't like it?... (WTS8)

For some of the participants, the first experience of full sexual intercourse comes later than usual, accompanied by the fear of their partner leaving them. Although some patients have overcome this situation, others are left with a permanent block in their sex life. Even if they have sexual desire, it is repressed by fear, making them feel even stranger and more misunderstood.

I've never done it (intercourse), I'm terrified that it won't go in (penis), that it will hurt me, that it will hurt him ... I already suffered with vaginally administered tablets, when I put in my first tampon ... I know it's strange that I haven't done it at my age (coitus), ...sometimes I want it, but fear outweighs the desire (WTS6)

Other participants have overcome the fear phase and consummated the relationship, but insecurity and being afraid of not doing it right prevents them from enjoying it until they have been with their partner for a long time. As one participant said, fear and not knowing kill desire.

I still remember, my partner was trying but I didn't want to, ... so, little by little, being really careful. And yes, in the end we did it (coitus). When we finished, I felt strange, dirty, tainted, and I asked myself, did I do it right? (WTS12)

Our participants referred to the importance of being in contact with other women in the same situation. TS patient associations play an important role as it is a context in which the women get to know each other, feel understood and talk about their problems, including sexuality, without fear:

I contacted other girls in the association (TS), and yes, it was an important source of support for me. I started to ask about menstruation, relationships with boys, desire, how to overcome shame... They understand me (WTS18)

If they were able to overcome these impediments, the women with TS from our study generally did not report problems regarding sexual desire, and after hormone treatment they described their sexual relations as satisfactory, with no problems concerning pleasure or reaching orgasm. One of our participants expressed the following:

Our sexual relations improved with the treatment (hormones)... we were young, there was desire, excitement, everything was normal. But you need trust, you need time with your partner, if the relationship is stable, he knows you, he knows how to wait, he gives you your time... (WTS12)

The participants also described how the use of vaginal lubricants facilitates full sexual intercourse.

They might have problems with penetration, yes ... but they get better by extending foreplay, using lubricants, ... Your partner has to understand (WTS3)

4.2 | Adapting one's sexuality to TS

Many women with TS can come across as shy; many do not have a partner, do not explore their bodies and do not even have sexual relations. Insecurity can make them dependent on or jealous of other people, which evidently has repercussions on their relationships with their partners. Sex education, together with social, family and professional support, are key to confronting these issues.

4.2.1 | Feeling like a woman

Women with TS face a limited and delayed development of secondary sexual characteristics, characterised by small breasts and genitalia, as well as vaginal dryness. This can lead them to feel insecure and not sexually attractive, which increases their fear of sexual intercourse and penetration. They are women whose bodies do not fit into the anatomical and sexual norms of the male/female binary system, which can cause misinterpretations on a social level. As one participant states, although they are sometimes seen as intersex, they know they are fully women; they have sexual desire, they have a vagina and they do not doubt their gender.

I've never had sexual intercourse out of fear that it will hurt, but I'm a woman, I have a vagina and that's what it's for! I feel like a woman, there's no doubt about it, I completely identify with the female gender... (WTS6)

For our participants, understanding themselves and being understood by others does not mean categorising them in a gender that does not represent them. They feel like women just as other women do. As one woman with TS said, she does not understand or accept why they are categorised as intersex as they are born genetically female and their sexual organs are female.

We are not intersex, we are women! Our reproductive capacity may be stunted, it may not work at all or we may not have children. However, the space, the hole, it's there, it's there for sex and reproduction, ... if you can't do it, you don't stop being a woman (WTS2)

It is important that these women learn to get to know their bodies, to explore them, to relate to others and to themselves, in order to feel confident and avoid emotional dependence. Many do not know their own bodies as they are too embarrassed to touch themselves. As one

woman said, she identifies fully with the female body/sex, but nobody has explained it to her.

It's been hard to get to the point of knowing what I know now. Now I know my body and my sexual desire better, I have a partner, we talk about sex, about what we like, positions, sex play, lubricants...If they had explained those sorts of things to me, my sex life would have been a lot better (WTS11)

4.2.2 | Suffering from and adapting to comorbidities

Comorbidities associated with TS are perceived negatively by our study's participants, as they affect their body image and make them feel more insecure. Hypogonadism can be linked to a higher incidence of obesity; on a cutaneous level, they can suffer from haemangiomas, vitiligo, atopic dermatitis and a predisposition to keloid scars. Our participants referred to obesity and skin diseases contributing to their perceived unattractiveness, making it difficult for them to find a partner and making them more reluctant to have sex. As one participant said, despite the treatments, it is a very difficult obstacle for them to overcome.

Sex is important to me, but when you are short, fat and don't have boobs...you don't attract men, not like other women do. If on top of that you have dermatitis outbreaks...you feel ugly, you don't like your body and you don't think you are attractive to others. I have never felt good about myself! (WTS5)

This is compounded by social ignorance of the disease and its comorbidities. Obesity is generally blamed on overeating, thus blaming the women themselves, who feel stigmatised as a result. This was acknowledged by one participant.

No, I don't give explanations anymore, nobody believes that I'm overweight because of my TS. They look at me like I'm a pig. ...I feel awful (WTS9).

Comorbidities can have a negative effect on the self-image of women with TS. Strabismus, hearing impairment, pinna abnormalities, alopecia and psychomotor disorders make it difficult to find a partner. Our participants have a lack of secondary sexual characteristics and side effects of pubertal induction treatments. On a genital level, they suffer from many urinary infections, vaginal dryness, inflammation and vulvar irritation; all of which can have negative repercussions on their sex life.

Vaginal dryness led me to have sores on my vulva and redness all over. It held me back a lot, it made sex really uncomfortable and painful...How was I not going to turn down sex?! (WTS5)

4.3 | When infertility overshadows sexuality

Women affected by TS suffer from gonadal dysgenesis, multiple comorbidities and severe fertility problems. According to the women with TS this situation can lead mothers to overprotect their daughters, especially during puberty when they see them as incredibly vulnerable. Our participants perceived that, rather than being able to seek information about sexuality from professionals and healthcare providers, their mothers exercised strict control over their daughters' lives, convincing themselves that it was to keep them safe.

4.3.1 | Prolonging childhood by ignoring sexuality

Although the participants advocated the importance of social, professional and family support, they recognised that their parents (especially mothers) overprotected them, treating them like children despite already being women. Mothers can see their daughters with TS as weak and fear that they will be hurt, especially during adolescence. They hardly leave the house, they stay in the family home until they are much older, and they barely partake in leisure activities. The participants perceived that this could lead to increased emotional dependence and affect the development of their sexuality.

They wrap us up in cotton wool. My parents were always one step ahead and they turned me into an overprotected person. My mother sees me as weaker than my siblings, they don't realise that we don't learn like that. Talk about sexuality? Unthinkable! (WTS9).

Some women get used to this; if they face social rejection or bullying, they themselves ask for parental protection, and they do not want to go out. According to our participants, this situation limits their social relations and conditions their sexual life.

The "mummies" overprotect their girls ... it's difficult to deal with your mother when you have TS. My Mum didn't realise she was making me weak, my sexuality is always going to be there... (WTS11)

Girls have support from their families, but overprotective parenting leads to loss of self-esteem and insecurity when developing their sexuality or looking for a romantic partner. Participants want communication, to talk about everything, and this includes sexuality.

I have experienced sexuality as a taboo, in silence, ... having a boyfriend seemed wrong. It took me a long time to have a partner because I was overprotected; it made me feel insecure and fear the unknown. They can't wait forever to talk to us about menstruation, masturbation, penetration, partners, etc.... (WTS4)

According to our participants, early sexual relations are rare as women with TS tend to start later than other women. They have a hard time finding a partner, but when they do, they develop a bond, and their sex life stabilises. However, then the fear of being left begins to surface, jealousy sets in and this affects these women's lives.

Yes, I recognise that I am emotionally dependent, insecure and jealous. If I hear my partner mention the name of another girl, friend or work colleague, ... I get nervous, jealous, I can't help it, I'm really scared of him leaving me... (WTS8)

4.3.2 | Fertility treatment: Always a possibility

As is the case in our study, women with TS rarely fall pregnant naturally; despite assisted reproductive technologies, they find it very difficult to get pregnant and have children, which adversely affects their quality of life. The process of administering hormone treatments and reproductive techniques is long and complex; waiting lists are long, there is no certainty of full-term pregnancies and there is a high risk of miscarriage. As one participant said, they try their best because their dream is to have children.

I had progesterone and oestradiol treatment in a long, difficult process, but thanks to egg donation I have managed to get pregnant. I never thought I would be able to, ... it has made me so happy; my dream has always been to be a mother. (WTS8)

For one of the participants, living with this limitation can cause her to worry, but with the support of her partner, she can face not having children. For this reason, if the women do get pregnant, they hardly celebrate it, because they are aware of the risks and the high possibility that it will not be carried to term. Once again, the participants made few references to sexuality, which is overshadowed by reproductive problems.

When I was 16, they told me I couldn't have children; but they didn't tell me anything about sex, sexual desire, positions, pleasure, contraception... they didn't tell me anything about it. I have found everything out with my partner, we have always wanted to have children... and if you can't, it's not the be-all and end-all. (WTS4)

Parents often inform them of the high probability of not getting pregnant or carrying a pregnancy to term. Reactions vary, some participants accept it in adolescence, but when they find a partner in adulthood, they rethink the situation again.

When my parents told me about the difficulty of becoming a mother, I took it well, but over the years, it's really hit me hard. Now I think ... it is what it is, I know that

there are options in the future, but maybe in that future I won't want to be a mother... (WTS6)

The participants have also stated that when they announce their pregnancy, it is welcomed with a mixture of joy and deep concern, as miscarriages are very frequent and pose a severe problem. Although they do not initially associate miscarriage with TS, they do start to wonder.

I had two miscarriages at around two months, one when I was 24 and the other when I was 31. After the first miscarriage I didn't think about TS, but I did after the second one. It affected me and my relationship a great deal, ... you lose a baby that you have wanted and been trying to have for such a long time. We thought the first miscarriage was bad luck, being a first-time mother and all but the second time I thought, why did it happen again? (WTS2)

4.3.3 | Lack of specialised professional knowledge

The majority of participants considered that there was a lack of professional knowledge about TS, symptomatology, treatment, etc. They were often unaware of the clinical picture, side effects and associated comorbidities. In their opinion, a protocol for the comprehensive follow-up of all these women is needed.

When I go to the doctor, he doesn't listen to me, I try to tell him my problem but he doesn't understand me. Nor did he inform me clearly about potential comorbidities, ... and even less so about sexuality. There is a huge knowledge gap, and we need proper professional information (WTS8)

Uncertainty only increases when it comes to considering childbirth; most pregnancies are achieved through egg donation and, after long processes of treatment and follow-ups, the women cherish their pregnancies and are afraid of losing their babies. Our participants believed that professionals do not take into account their specific TS condition in order to adapt their interventions as needed.

I am pregnant through egg donation and I feel very vulnerable because of the risks of TS. I would like to have a caesarean section to avoid complications, but they don't give me a choice, ... as if I didn't have the disease. They consider it a low-risk pregnancy, but I'm afraid of labour, the potential for hypertension, the heart... it's taken a lot to get here and it could get complicated! (WTS8)

Obstetric check-ups do not seem to take into account the increased risk posed by TS. Despite the patients' indications, specialists and family doctors do not consider specific follow-ups of comorbidities such as cardiological problems. This is another concern for the women in our study:

In a fertility treatment appointment, I asked the gynaecologist if I was going to be referred to a cardiologist for a check-up. He said, Do you have any heart problems? I said, "No, not right now, but I could do." They ignored what I was saying, and my GP didn't want to give me an appointment either... (WTS8)

In the participants' opinion, professionals have heard of TS but do not know how to manage it, what the guidelines for action are, and which comorbidities should be taken into account.

Professionals do not have a good understanding of the treatment and diagnosis. They know what TS is, but there aren't enough protocols for action and management of associated pathologies (WTS4).

Sexuality is hardly ever discussed at appointments; it seems to be left off the agenda. Instead, the participants need to seek the information they are lacking in patient associations, on websites, or by talking to a friend with TS.

When my mother asked about the risks of sexual intercourse (coitus), the doctor recommended that we read a book (WTS14).

The women with TS in our study stated the need for comprehensive monitoring from childhood by specialised multidisciplinary teams including psychologists, doctors, nurses and sexologists. Although they have counselling in the TS patient association, as one participant said, they need specific help, not general recommendations that do not yield positive results.

Yes, I was in therapy with a psychologist from the association. I did everything he told me, for a long time, but without results. Looking at yourself in the mirror, internalising everything, loving yourself, accepting yourself ..., it's something we have to learn on our own. We need other tools (WTS15)

5 | DISCUSSION

This study aimed to describe and understand experiences of sexuality in women with TS, a condition linked to profound physical, psychological, social and sexual changes. The variability of cases contributes to delaying and withholding a full diagnosis (Apperley et al., 2018; Swauger et al., 2021), which is of concern to women (Berglund et al., 2020; Nisbet et al., 2022). Concurring with Sutton et al. (2006), our participants call for a clear and early diagnosis, including sexual issues. This would enable women to become aware of TS, accelerate treatment and improve their quality of life (Liedmeier et al., 2020). The women have told us that they are aware of comorbidities associated with TS; this self-awareness is key to

facing the condition (Jež et al., 2018). Puberty and the transition to adulthood are critical periods for sexuality (Kosteria & Kanaka-Gantenbein, 2018). According to Sutton et al. (2005), women are worried about their sexuality, and stuck in a body that limits them. The negative perception they have of their body is related to a lack of acceptance and dissatisfaction (Machado et al., 2018). The women require early induction of puberty in order to develop secondary sexual characteristics, improve their self-esteem, social adjustment and sexual life (Carel et al., 2006).

We agree with Boman et al. (2001) that the sexual experiences of women with TS occur at a later stage in life because they are less active (Robbins et al., 2013). However, our results indicate the opposite is true in stable relationships. Our participants discover their sexuality in a different body, which is a challenge for social, work, romantic and sexual interactions (Suzigan et al., 2004). In line with Wolstencroft and Skuse (2019), our findings show the need for support, understanding and social skills training for these women (Wolstencroft et al., 2020). TS is associated with being older than average for one's first date, first kiss, first partner and first time having sexual intercourse (Cardona et al., 2020; Carel et al., 2006; Stockholm et al., 2012), which can be associated by the tendency for social withdrawal and a lack of social skills in those with the condition. The women are afraid to start having sexual intercourse; they do not lose their sexual desire, but their fear of intercourse impedes, hinders or reduces their sexual activity (Ros et al., 2013). We agree with Machado et al. (2018) that this can lead to disinterest in sex. Although our participants only allude to the use of vaginal lubricants, applying topical vaginal oestrogen or androgen supplementation also may be beneficial (Trolle et al., 2012).

Women with TS are more likely to live alone, have fewer sexual partners and biological children (Fjermestad et al., 2016). Our participants do not doubt their sexual or gender identity; they feel feminine and heterosexual. Furthermore, if they have a partner, they become less afraid and their sexuality improves (Machado et al., 2018). However, this leads to jealousy and a fear of being left (Lin et al., 2019). Participants have told us that obesity, physical (Thompson et al., 2020), hearing, dermatological or gynaecological problems have a negative impact on their sexuality (Mediã et al., 2022). In general, they feel more comfortable in structured families with clear roles, which helps them trust their partners more (Fjermestad et al., 2016). Although conversations about sexuality in adolescence should be had with one's parents (Lin et al., 2019), participants stated that they were too overprotected to share with them. Infertility is another common concern; patients diagnosed in childhood/adolescence may receive hormone therapy (Gravholt et al., 2017), which leads to developing sexual characteristics and the possibility of pregnancy (Deligeoroglou et al., 2016). Women undergo lengthy hormone treatments to get pregnant, and assisted reproductive techniques have a negative impact on their quality of life and sexual performance (Idkowiak et al., 2022; Schleedoorn et al., 2019). They face high-risk pregnancies alongside their partners (Bouet et al., 2016), so uncertainty and a fear of miscarriage overshadow concerns about sexuality. According

to Sutton et al. (2005), one participant sees sex as a means to get pregnant, but if she does not get pregnant, she is reminded of her painful situation of infertility. We agree with Eroglu Filibeli et al. (2020) that there is a lack of training on TS for healthcare providers. Multidisciplinary teams (Colindres et al., 2016; Jivraj & Stillwell, 2021) are needed to respond to women's sexuality issues and concerns (Sutton et al., 2006).

5.1 | Limitations

Although the sample size is acceptable, our findings cannot be generalised for all girls and women with TS. Disparate groups were represented in this study. Given the wide age range of our participants, it is difficult to make comparisons. Participants were only hispanic women, so the sample is not representative of our multicultural society today. Most participants primarily associate sexuality with penetration. This implicit conceptualisation of sexuality seems to derive from the social, cultural and familial environment in which these women live, and may also be related to their reproductive problems. Given that female sexuality is much broader, this may have led to this study being biased. Aspects such as masturbation, desire or other sexual activities of women with TS should be further explored. Our sample only includes heterosexual women, so the results may not necessarily be representative of non-heterosexual and/or cisgender women with TS.

6 | CONCLUSIONS

Women with TS suffer from severe limitations in their sex life due to comorbidities and lengthy treatments. They discover their sexuality in the context of TS, and face delays in diagnosis and a lack of information. Physical appearance, corporeality and comorbidities have an impact on when girls/women initiate sexual activity/intercourse. Aware of this, the women interviewed demand early diagnosis and treatment for sexual and reproductive development. They find it difficult to relate socially, especially during puberty, when insecurity, lack of self-esteem and anxiety overshadow their sex life. Fear and unfamiliarity lead to later and less frequent sexual relations, jealousy and a fear of being left by the partner. Hormonal treatment mitigates problems related to sexual desire, arousal or orgasm, but the women still have a fear of exploring themselves, masturbation and penetration. Women with TS do not have sexual identity problems, they see themselves as women, as feminine, and refuse to be treated as intersex. They have social and family support, but their mothers are overprotective, which hinders their social and sexual development, and their search for a sexual partner. Infertility problems, present throughout their lives, overshadow their sexuality, which is ignored by family and healthcare providers. Women with TS call for multidisciplinary teams and specific programmes that address their reproductive and sexual problems.

7 | RELEVANCE TO CLINICAL PRACTICE

Sexual and reproductive health is important in comprehensive care programmes for women with TS. Families and professionals should communicate openly and honestly with patients. Specific programmes, multidisciplinary teams and qualified healthcare providers are needed for the care, psychological support and sexual counselling of women. A structured plan for the transition from girl-to-woman phase is crucial. Nurses are well positioned in clinical settings to talk about sexual and reproductive health for women with TS. Well-trained nurses can inform and advise girls/women with TS about sexual/relationship problems or refer them to other specialised professionals. Primary care nurses know their history and development, and as most of them are women, this can build trust and encourage discussion of sexuality-related problems. Together with a multidisciplinary team, they can play a pivotal role in the information, screening and care provided for sexual problems. Educating nurses at undergraduate and postgraduate level on the topic would contribute to ensuring holistic, person-centred care.

ACKNOWLEDGEMENTS

We would like to thank the women with TS who agreed to participate in this study. We are grateful to the Health Sciences Research Group of the University of Almería (CTS-451) for their help in developing this research. We are grateful to Isabelle Soliani for her advice and translation of this article.

FUNDING INFORMATION

The authors received financial support from the Research Group CTS-451, University of Almería.

CONFLICT OF INTEREST STATEMENT


We confirm that there is no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Granero-Molina, J., Román, R. A., del Mar Jiménez-Lasserrotte, M., Ruiz-Fernández, M. D., Ventura-Miranda, M. I., Granero-Heredia, G., & Fernández-Medina, I. M. (2023). 'I'm still a woman': A qualitative study on sexuality in heterosexual women with Turner Syndrome. *Journal of Clinical Nursing*, 32, 6634–6647. <https://doi.org/10.1111/jocn.16715>