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CASE REPORT

Sexuality and Down syndrome

B. Garvía Peñuelas

Centre Mèdic Down, Fundació Catalana Síndrome de Down, Barcelona, Spain

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Abstract

Introduction: The emotional sphere and its relationships with sexual identity and awareness of disability in a person with Down syndrome (DS).

Case report: 25-year-old woman with DS who has a psychotic episode with delusions when a tubal ligation is being considered. The condition arises due to a conflict between sexuality and identity.

Discussion: People with Down's syndrome can undergo unharmonious development or remain anchored in previous evolutionary stages. This situation, together with difficulties to symbolise, can lead to psychotic mental disorders, as in this case.

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Resumen

Introducción: La vida afectiva y sexual y su relación con la identidad y la conciencia de la discapacidad, en una persona con síndrome de Down (SD).

Caso clínico: Mujer de 25 años con SD que inicia un episodio psicótico con ideación delirante en el momento en que se plantea la realización de una ligadura de trompas. La enfermedad surge por el conflicto entre sexualidad e identidad.

Discusión: Las personas con SD pueden tener una evolución disarmónica o quedar fijadas en etapas evolutivas anteriores. Esta situación, junto con sus dificultades para simbolizar, puede llevar a desorganizaciones mentales de tipo psicótico, como en el caso que se expone

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Introduction

The emotional and sexual life of people with Down syndrome (DS) is the object of a series of myths, prejudices and ghosts that cause society a certain degree of concern. Among the myths are those that refer to mental age (they are children and do not understand sexuality) or the idea that their sexuality is different. It is perceived as more exaggerated —“they cannot control their impulses” —or more inhibited —“they are not interested in the subject”. However, sexuality in people with DS is human sexuality, not a special type of sexuality.

Sexuality and affection are two dimensions of a person's personality that affect behaviour; they are biological and emotional functions. Sexuality goes beyond genitality. It is present in all essential elements of human life, from individual identity, to a life project, the exercise of rights and compliance with duties and participation in social life. A decent life is linked to conditions that allow a responsible exercise of sexuality¹.

A basic concept that it is necessary to keep in mind is, when speaking of sexuality, the concept of identity. “Sexuality is related to identity and desire. That is why the expression of sexuality in people with DS depends on the force and form of their identity which, furthermore, depends on the position society assigns them and its expectations with regards to them” (Denis Vaginay)². Due to the fear of consequences (pregnancy) concern is more related to contraception than to a way of providing sex education that will ensure satisfactory sexual-emotional relationship³.

The case we are going to analyse is an example of psychotic depression in a woman with DS which is the consequence of an identity conflict (trisomy) and her sexuality (sterilisation). Her difficulties to symbolise and her very precarious understanding of sexuality triggered the crisis.

Case report

25 year old woman with DS and good learning, expression and comprehension levels. With a happy and loving character, she had good personal and social relationships with considerable autonomy.

At the time of consultation she had a clinical condition of one year's evolution, characterised by anxiety, awareness of her disability, long periods of time sitting on her bed, sleep alterations, fear, lack of attention to personal care and cleanliness and onset of rigid wandering (with closed fists and rigid legs). Furthermore, she starts to have aggressive behaviour towards her mother and does not want to wash, care for her appearance or sleep in her room. She starts to have delusions about her sexuality and pregnancy: there is a woman under her bed who wishes to harm her. This is the mother of a character on TV that the patient is in love with. She presents marked rejection of her father and she stops going to her workshop because others laugh at her. Any movement takes for ever because she moves very slowly and with her legs completely rigid.

Her parents associate her condition with the fact that at her workshop, after a psychological assessment, she is

downgraded to a lower level and separated from the mates she had always had. She went from earning a weekly salary to collecting a sum that was merely symbolic. Furthermore, all her mates undergo a Fallopian tube ligation, which was also programmed for the patient, but which was not performed because she falls ill with depression. The patient explains that people with DS have an extra chromosome, but that they are not “stupid” although they do have limitations. She rebels at being as she is and wants to attend University. She is obsessed with the operation: it is good to have the operation because then she will be like her mates who keep a higher level job.

The psychiatrist who attends to her diagnoses a psychotic episode with delusional and relational ideation all related to the projected surgery. He prescribes haloperidol and Meleril and advises psychotherapy.

The patient says: “When I have my operation I will be OK, because the operation will be my salvation”. She responds well to treatment, agrees to wash her teeth (has not been doing so for months) and to sleep in her bed. She rejoins her workshop, but does not want to see her friends and insists that she will be OK when she has the operation. She agrees to shower and also decreases aggressiveness and rejection of her father. In the last year, since the onset of the condition, the patient has put on 14 kg. She speaks of the boy in the TV serial as if he were real and when he is mentioned: “Well, but I want to make love and the operation will be my salvation”.

Her maternal grandfather becomes seriously ill and her mother is considering going to care for him which would mean that she would have to be absent for some time. It is agreed that the patient will remain at home, with her father and siblings, for a month, while the mother is away. Little by little the patient starts to speak of real people. She explains that she is the friend of a boy (F) and that they kiss. When asked why she thinks the woman who is under her bed wants to harm her, she answers: “It is a problem of love, because I like her son” (see the guilt caused to the patient by her sexual desire). The patient improves markedly, although she continues to neglect her personal appearance. On this point, she explains that she does not groom herself so as not to be provocative, that she would like to be two years old and never grow older. She wants to cut her hair and wear trousers, like a boy, and she does not like taking a shower because she fears somebody —a man—might see her and do something to her. “What do you fear that he will do to you?” “Look at my legs or touch my legs. Some boys touch and kiss each other. I do not. If I am provocative, people hurt me.” “If you are provocative, they can touch and kiss you.” “Yes, that's right.” Her mother explains in front of her, how she likes kissing F.

Treatment continues and the patient starts to bathe by herself and sleep with a soft doll. When asked what she knows about making love, she answers that she knows nothing and that, also, she suffers from a cold. There are a girl and a boy who kiss each other on the mouth and that scares her (she is the girl). “And are you scared of becoming pregnant?” “Yes, that's right.” “Is that why the operation will be salvation?” “Yes, that's right.” A short time later she starts to walk correctly and says: “Today I have washed my arse”. And points to her genitals. The confusion is explained and

she answers: "OK my vagina". "My mother is leaving at the end of the month and I am not afraid." "You walk well and you have not had the operation." She answers: "At times I walk well. Sometimes I sway forwards and backwards and like doing this" (substitution for masturbation): Treatment is interrupted due to the holidays. She returns after having spent a good summer: she is agreeable, grooms herself more and says her doll is called Ruby. "She is beautiful, lovely. I play at being a parent with her. F is the father and I am the mother." When asked if she has thought of having a child with F. when she kisses him, she answers that she has. "Now that you are better maybe you can talk about that subject that had made you so fearful." "Yes, they were going to cut something in my stomach." "What?" "I do not know. A baby or my legs (pregnancy and castration fantasies), and I was very scared." "Maybe what they were going to cut was the possibility of having a baby." "Yes, and I was scared. I shall never do it again."

Discussion

Freud⁴ explains that small children elaborate their theories on sexuality under the sole influence of instinctive sexual components. One of these theories explains that children grow in their mothers' bellies. The ignorance of the existence of the vagina, leads them to think that birth is through the guts (the baby is expelled as if it were an excrement or deposition). How do babies get into their mothers' bellies? Another children's sexual theory is that babies are engendered by a kiss⁴. Freud says this theory is exclusively female. Later, at 10 or 11 years of age, children have their first revelations on sexual intercourse (the patient has not reached this degree of evolution).

The patient's condition is triggered by the influence of this oral pregnancy fantasy (due to kissing F. she has got pregnant) and also due to the ingestion of food (she has put on 14 kg like a pregnant person.) This causes her enormous guilt (I will not do it any more.) As she has kissed, they are going to operate on her and take away her baby. Guilt triggered the delusions. Furthermore her friends underwent the operation and are cleverer (they have changed their jobs for others that pay better). She wants to be clever and to be clever she has something that is redundant (remember

how she explains that DS consists in having an extra chromosome). The announcement of the operation seems to have caused a short-circuit of all her fantasies and triggered psychotic decompensation. On one hand, the operation is a punishment, and on the other, it is salvation because they are going to remove the baby that does not let her move around and, at the same time, she can become clever like her operated friends and go to the workshop with them. The operation is the decompensating element.

The patient says that she knows nothing about sexuality. She is excited and confused. She has oral fantasies and genital excitement. She says she has a cold. As she has a cold she cannot kiss and this clams her down. That is why she does not wash her teeth either. The delusion grows surrounding the guilt.

The patient is detaching herself from her mother but becoming independent and growing scares her. She is scared of becoming a woman. That is why she wants to be two years old, because being a woman implies sexual desire and that desire can lead to pregnancy and operations. In her fantasy she has boyfriends, flirts, but she cannot metabolise all this and suffers decompensation.

This case is an example of how the impossibility of symbolically elaborating sexuality—even in a girl with a good intellectual level—can cause mental disorganisation and disease.

It is important to work with identity and sexuality in patients with intellectual disabilities to help them to integrate functions, building on those that are in a more advanced state of progress, understanding the patient's real needs and the moment of their psycho physiological evolution.

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