

The experience of sexuality by visually impaired adolescents*

A VIVÊNCIA DA SEXUALIDADE POR ADOLESCENTES PORTADORAS DE DEFICIÊNCIA VISUAL

LA VIVENCIA DE LA SEXUALIDAD POR ADOLESCENTES PORTADORES DE DEFICIENCIA VISUAL

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ABSTRACT

The combination between transformations in adolescence, the indefiniteness they are accompanied by and the visual impairment justifies a study about the sexual experience of female, visually impaired adolescents included in society and in the school community. Five adolescents were interviewed at a Pedagogical Support Center. Questions attempted to find out their knowledge and understanding about the cause of their visual impairment, family composition and orientations, affective-sexual experience, level of knowledge about sexuality-related issues, including contraceptive methods and sexually transmitted diseases. Results revealed that these adolescents display the same sexuality development characteristics of their age group, though they have particular characteristics. It was observed there is a lack of knowledge regarding contraceptive methods and sexually transmitted diseases, of which the adolescents have superficial information. Making knowledge on the referred issues accessible to this population is indispensable.

KEY WORDS

Sexuality.
Adolescent.
Visually impaired persons.
Nursing.

RESUMO

Devido às transformações ocorridas na adolescência, as indefinições que a acompanham, somadas à deficiência visual, justifica-se um estudo sobre a vivência da sexualidade das adolescentes portadoras de deficiência visual inseridas na sociedade e na comunidade escolar. Foram entrevistadas cinco adolescentes em um Centro de Apoio Pedagógico, com questões que buscaram o conhecimento e a compreensão sobre as causas da sua deficiência visual, composição e orientações familiares, experiência afetivo-sexual e o nível de conhecimento acerca de assuntos relacionados à sexualidade, dentre eles métodos contraceptivos e doenças sexualmente transmissíveis. Os resultados mostram que estas adolescentes apresentam as mesmas características de desenvolvimento da sexualidade da sua faixa etária, embora possuam características individuais. Percebeu-se o desconhecimento sobre métodos contraceptivos e doenças sexualmente transmissíveis com informações superficiais. Torna-se imprescindível que o conhecimento se faça de forma acessível para esta população.

DESCRIPTORIOS

Sexualidade.
Adolescente.
Portadores de deficiência visual.
Enfermagem.

RESUMEN

En razón de las transformaciones sufridas durante la adolescencia, las indefiniciones que a acompañan, sumándose la deficiencia visual, se justifica un estudio sobre la experiencia de la sexualidad de las adolescentes afectadas por deficiencia visual insertas en la sociedad y en la comunidad escolar. Fueron entrevistadas cinco adolescentes en un Centro de Apoyo Pedagógico con preguntas que buscaron el conocimiento y comprensión de la causa de su deficiencia visual, composición y orientaciones familiares, experiencia afectivo-sexual, nivel de conocimientos acerca de asuntos relacionados con la sexualidad, sin excluir métodos anticonceptivos y enfermedades de transmisión sexual. Los resultados muestran que estas adolescentes presentan las mismas características de desarrollo de la sexualidad de su faja etaria, sin embargo poseen características particulares. Se percibió el desconocimiento respecto de métodos anticonceptivos y enfermedades de transmisión sexual, temas acerca de los cuales estaban superficialmente informadas. Es imprescindible que el conocimiento se transmita de modo accesible para esta población.

DESCRIPTORIOS

Sexualidad.
Adolescente.
Personas con daño visual.
Enfermería.

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INTRODUCTION

Little attention has been paid to the illness experience of disabled people in literature. Nevertheless, the large majority of these people reach puberty and, hence, sexual maturity, just like so-called normal adolescents. According to common sense, disabled people apparently do not experience this phase in their development, as physical changes would not correspond to psychosocial changes.

In the context of adolescence, physiological changes, sexuality, family, society and visual impairment are constituent factors of the personal and professional growth process in the search for identity, autonomy and independence. As the development process of children is already complex within normal standards to reach maturity, what will the experience of visually impaired adolescents be like?

We will try to answer this question and decided to work with female visually impaired adolescents only. This choice was due to some reasons, such as: girls are more overprotected than boys; as children, women are stimulated to behave well and control their desires; women experience more difficulty to address sexuality-related issues.

This research was carried out in the Integrated Project on Eye Health at the Federal University of Ceará, which emerged in 1993 and has been developing research with visually impaired people since then. With regard to research and news items produced in the project, initially, the paper entitled behavioral contraceptive methods: educative technology for visually impaired people can be mentioned⁽¹⁾. This study allowed visually impaired people to grope a female hemipelvis of natural size while receiving explanations about the anatomy and physiology of external organs.

In the same research, high-relief drawings were used, made on special paper to pass an idea about the location of these organs, demonstrating the vaginal channel, uterus, Fallopian tubes and ovaries. The drawing allowed visually impaired people to identify the course followed by the egg until reaching the uterus. For the sake of a better understanding for anyone interested, the male reproductive apparatus was verbally discussed and explored by groping a penis prototype of natural size, on which the meatus, glans, scrotum and penis could be identified. Internal structures were also drawn in high relief. Through touch, they identified the testicles, epididymis, deferent duct, seminal vesicle, prostate, bladder and urethra⁽¹⁾.

The same study also addressed the behavioral methods using rhythm, baseline body temperature and ovulation or Billings. The rhythm method was shown through tactile exploration of a calendar created to facilitate the calculation of the fertile period. Therefore, a thirty-day calendar was used with digital reading, using small velcro

squares for each day. This calendar comprised a fixed part, made with the roughest part of the velcro, and a mobile part used to identify the day menstruation occurred and the day the person would probably ovulate. This permits the identification of the fertile period. For the baseline temperature method, a thermometer that allows digital reading or informs the temperature aloud is needed. This puts visually impaired women at a disadvantage, as they depend on a seeing person to read the thermometer. In view of the difficulties to use the method, the visually impaired people did not demonstrate any interest. The ovulation method was exposed through tactile exploration of egg white to simulate the cervical mucus⁽¹⁾.

About the use of these methods, we can also mention the paper entitled Barrier contraception methods and IUD: educative technology for visually impaired people. This study offered the blind educative material, include an instruction manual, a cassette-tape and material for tactile exploration. As the instruction manual in Braille informed, the material was intended for individual, self-instruction use and could be heard as many times as needed, with the necessary interruptions. The material for tactile exploration

included the anatomical structures of the male and female reproductive system, like in the abovementioned study, besides vaginal spermicide with an applicator, diaphragm, male condom and a prosthesis in the form of a penis, female condom and IUD. The recording informed about the tactile exploration of the material and at the same time gave instructions on its use⁽²⁾.

An educative game about the contraindications and collateral effects. It comprised two geometrical pieces in which the circles

represent the contraindications and the triangles the collateral effects. The mission was to group the pieces by form and then read the pieces and, at the same, the relation between circle (contraindication) and triangle (collateral effect). In the identification of the material, paint and Braille were used to permit reading by seeing and blind people. As yet another orientation activity, a manual on breast cancer prevention for blind people was included. This manual explained the anatomy of the breast, the constitution of breast tissue, breast self-exam and possible normality and abnormality standards during this self-exam.

Although we are developing research and material on sexual health for the visually impaired, the material available for health orientation and education in schools is mainly presented in ink print form. This makes access for visually impaired people almost unviable. That shows the importance of the patient versus health professional and teacher relation through adequate communication channels.

Knowing the state of the art of reflections about the health of visually impaired adolescents can contribute to the understanding of these issues. At the same time, greater

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knowledge on the theme by health professionals can reflect in a better approach of family members as well as adolescents, favoring compliance with their rights, which includes the sexual.

When considering the role of nurses as health educators, we include the visually impaired in this context, as well as the possibility of decreasing conflicts and concerns accompanying these people and helping them to exercise a sexuality free from prejudice and misunderstanding⁽³⁾.

In the search for this possibility, this research aimed to identify the opinion of visually impaired adolescents on their sexuality.

METHOD

A descriptive and exploratory study was carried out. This type of study is adequate for descriptive investigation to the extent that it involves observation, description and classification⁽⁴⁾. The research was carried out at a Pedagogical Support Center (CAP) for blind and visually impaired people. The purpose of CAP is to offer appropriate resources for visually impaired students registered in the state education network to develop activities related to reading, research and curriculum reinforcement. Attached to this center is a school for people with special needs, including visually, mentally and hearing impaired people.

The research population comprised female visually impaired adolescents between 10 and 20 years old. To define the number of participants, we adopted data saturation, depending on the understanding of the study phenomenon. As a data collection technique, we use semistructured interviews, starting with an order pre-established by the interviewer, with closed and direct questions and also including open questions, in which the interviewer has a certain degree of freedom⁽⁵⁾. The basic interview script comprised questions focused on knowledge and understanding about the following aspects: cause of the visual impairment, education level, family composition and orientations, affective-sexual experience.

As agreed upon, interviews were held individually in support or pedagogical resource rooms that existed at these schools. After the research participants received clarifications and agreed to participate, the interviews were recorded and filmed. After concluding this step, the adolescents received clarifications regarding their doubts. Additional information complemented the adolescents' answers, demonstrating the study's educative role. Information was submitted to content analysis⁽⁶⁾.

As required, the study was approved by the Research Ethics Committee at the Federal University of Ceará, No 167/06, in compliance with ethical-legal guidelines (autonomy, non-maleficence, beneficence and justice) recommended in Resolution No 196/96 on research involving human beings, issued by the Ministry of Health – National Health Council⁽⁷⁾. Two Free and Informed Consent Terms

were elaborated: one for the adolescent, in Braille, and another for the parents and/or people responsible for the adolescents. Besides the parents/responsible people's authorization, we read the consent term together with the interviewees in order to get their agreement and signature. Reading aloud was optional and done with participants who chose this option.

RESULTS AND DISCUSSION

We interviewed five adolescents between 12 and 17 years of age. Only one of them had low vision, while the others were totally blind. None of the interviewed adolescents reported any sexual experience, but they all manifested the desire and interest in talking about sexuality, their doubts, fears and desires.

To avoid identifying the participants, we decided to replace their names by types of flowers as, besides their grace, flowers leave perfume on the hands of those who pick them, considered similar to the contact with these visually impaired adolescents. Moreover, the beauty, purity and frailty typical of flowers were also observed in the young interviewees.

Family life

In this part of the interviewees, parental orientations were addressed in terms of sexuality and other relevant aspects of the adolescents' family life. Besides, attempts were made to know whom they consider the family leader, whom they talk with about sexuality issues and the contents and forms of sexual orientations they received. Next, these aspects will be analyzed.

In this group, only two adolescents live with married parents. To assume family leadership, the main criteria are: being the financial provider of group needs, being the person in charge and maintaining tasks for other family members or being the person offering guidance and emotional support to other family members.

[...] I think my father because that's what he says. Don't try to change, that's it (Violet).

[...] It's my mother. She is very close to me and I am very close to her, she tells me everything that happens, I tell her everything that happens to me, there's nothing to hide, because I'm just like my mother. I think she's very understanding towards me, she knows how to talk well, without fighting, I think that's it (Rosa).

It is not always, however, that adolescent girls turn to the person leading their family for advice on their sexual life. Girls who talk about the theme with a family member do this with married sisters. Only one of them mentioned talking openly about sexuality with her mother. The other adolescents reported that they talk about this theme with friends from the neighborhood and school.

I talk about these things with my mother. Like, I've already asked when I could have my first boyfriend. She said she

doesn't have anything against it, no, but, like all mothers say, you have to take great care with these things. Like, kind of, when they ask you to have intercourse, those things, not so early, but later, after a while, when you know the person better. So that's what she asks me to take care (Orquídea).

One very important aspect of adolescence refers to the sexual education the family provides. That education has not allowed adolescent girls – including sighted ones – to assume their affective-sexual relations responsibly. In general, information is restricted to sexuality connected with the genitals, as parents still face difficulties to talk about the theme.

Parents feel profound difficulties regarding their adolescent daughters' sexuality. Thus, they end up transferring their educative role to third parties and, hence, reproduce disciplinary forms of control and perpetuate a cycle for many generations. Often, however, the parents' difficulties to discuss sexuality issues with their daughters derive from the way they experience this situation themselves. In this context, most parents attribute the task of providing their children with sexual advice to the school which, in turn, is not always prepared for it⁽⁸⁾.

Despite the missing or limited information on the theme, adolescent girls start being sexually active, even without understanding very well what is happening to them. Consequently, unexpected results occur often, such as an unplanned pregnancy.

According to the adolescents' statements, most of them do not clearly understand the sexual advice they receive from their parents. As observed throughout the interviews, this happens because advice is given indirectly. Thus, in line with the adolescents' understanding, their parents do not address these issues at home.

Even when advice is given, in some cases, this takes the form of alerting the girls about pregnancy. Hence, parental advice is not directly oriented at that adolescent's specific issues. The advice is general, impersonal, diffuse and almost always deriving from the parents' lack of knowledge about the topics, or their constraint to address these themes with their daughters.

When I watch television, then she says: If your head does not think, then your belly has to pay, right? And I say: Then you become a mother, that's right. She gives me some hints, but really touching the issue, no she doesn't (Margarida).

[...] She used to tell me that I was too young to have sex. That if I were [...], despite being young, if I wanted to have sex it was good to use a condom always, so that I wouldn't get a kid and ruin my life. She kept on saying that. Gave me lots of advice (Rosa).

In the parents' advice to the girls, studying is put forward as a priority over dating and these two areas of life are even appointed as irreconcilable. According to the parents' advice, first they have to study and then date.

[...] She thinks that studying is better, because we regret it later. After you stop. She says that she regretted stopping. Then she supports me to continue (Tulipa).

[...] It would be better to study enough and then, later, when we are more mature and think about dating after we get a job. She doesn't want us to date early, no (Orquídea).

At birth, visually impaired people are inserted in a system of relations and social meanings that will serve as the background, the place where they will organize and structure their own identity. In this historical-cultural perspective, the family tends to imprint the idea on visually impaired people that they are incapable, unable, insecure and, hence, are *educated* to be helpless, dependent and even considered by some as asexual and uninteresting⁽⁹⁾.

In general, these contingencies prevent impaired people from developing and establishing a relation with themselves and other people that allows them to express themselves as sexual beings. Consequently, desire is even hidden, and pleasure and the erotic turn into experiences that only the so-called *normal people* can have⁽¹⁰⁾. These words were found in the statements ranked under the category discussed next.

Affective-sexual life

The goal of this part of the interview was to hear the adolescents on different topics related to their affective life and the way they deal with them. Their opinions and experiences regarding *going steady*, dating, sex and love are described and analyzed next.

None of the interviewed adolescents experienced *being with someone*, but all of them defined this practice and distinguished it from dating. The duration of the relationship, the *liking*, the level of commitment and seriousness, as well as confidence and sincerity define the limit between being with someone and dating.

[...] Being with someone is just that [...] you're with someone one day and do not know the person, there's no commitment whatsoever, you can be with someone just for a couple of hours or can just give a kiss and bye, now I don't think about doing that, just when I stop studying (Tulipa).

Dating is when it's something serious, with a commitment, with intimacy [...] dating seriously is like that, taking someone home, getting to know the parents, but I don't know if I'll ever date someone one day [...] (Rosa).

Dating is when you like the boy, being with someone is for a day, but I have to process that idea more, I'm still too young to do those things (Orquídea).

When moving from childhood to adult age, one peculiar aspect is physiological maturing, gaining the ability to procreate, or have children, which boys and girls acquire through the first ejaculation and the menarch, respectively⁽¹¹⁾. Thus, falling in love is generally a frequent consequence. For visually impaired adolescents, however, as

shown by the units of meaning apprehended in their statements, the dating does not actually occur.

The adolescents clearly distinguish between being with someone and dating. Being with someone is associated with a single moment, without commitment or bonding. Dating, on the other hand, reflects greater involvement, commitment, it becomes something more serious, associated with fidelity and intimacy. One of the interviewees demonstrated a trend towards denial when discussing the theme dating/being with someone, as shown in her statement.

A boyfriend, never! I don't even want to, I have never even been with someone, nor will I [...] (Violeta).

This position can be justified by the fact that visually impaired adolescents who cannot engage in the esthetic standards of society start to act like the stereotype they carry along, as asexual beings without desire, thus supporting other people's expectations about them⁽¹¹⁾.

As some young girls reported, they prefer to be with someone than to date, as the former grants greater freedom.

[...] Because it's less serious than dating. Dating, I don't know. You can be with someone, if you're not fond of the boy, then, if you are you can start to date him. But if you aren't you can break up, you see. Then, when I get involved, I'll think it's better to be with someone because of that. Because it doesn't tie you up so much (Tulipa).

According to the girls, being with someone might involve some moral risk: the risk of being the subject of other people's talk. When frequent, this behavior is reprehensible in their parents' viewpoint:

She thinks it's ridiculous this thing of being with someone, sometimes she even fought about this thing of being with someone, these young people are just being with someone (Violeta).

Love is a feeling all of the interviewed adolescents value and consider fundamental to join a couple, it is an ambivalent feeling, it has one good side and another bad side. According to a study that involved visually impaired adolescents in the Netherlands, they have a romantic idea about relationships and have already felt in love, but interpersonal relations are linked with family contact, which makes it difficult to construct new relationships and experiences. This fact is unfavorable, as adequate knowledge about sexuality makes them have a better self-esteem and, a gender difference, male adolescents who reported sexual intercourse showed greater security and living with the family. Those living in institutions did not mention any sexual experience. Male and female adolescents confirmed the family's overprotection⁽¹²⁾.

I do not think a lot about love, no. I think it's an illusion. I've already loved a boy and that's why I'm thinking like that[...] I used to like him a lot but he did not correspond. I don't want to love anyone ever again [...] (Rosa).

[...] Love for me, that's [...] great, but it also has its bad side (Margarida).

When comparing love and sex, some interviewed adolescents perceive that love can exist without sex and that sex can exist without love. The latter is not their preferred option, however:

Then I can't tell. Honestly [...] I think that if you like the person, but you don't have sex, one day you'll have sex with that person. You have dated the boy for more than one year and you already need to have sex, I don't think it's like that. When the two are ready, then it's going to happen. And not too much in a hurry (Orquídea).

According to all of them, love should be associated with sex or make the sex better, although none of the interviewees already had an active sexual life.

I think that, to have sex, you need to like the other person. I think that's all. If not it's not the same thing. What I hear around here is that, when you have sex with a person you don't like, it's different from having sex with a person you like. I agree too. (Tulipa).

Sexual exercise starts at an increasingly young age. According to a study, at the age of 14, 34% of the adolescents had already started their sexual life. As none of the girls in the group under analysis had had this experience, one may infer that family protection in this population is more frequent and postpones this intercourse. As evidenced by a research with blind people, when schooling occurs in an environment restricted to this population, like the special school the adolescents in this study attend, this entails consequences. Limitations of the experience exchange are less autonomy and worse school performance. This raises discussion on the formal education system and affects sexual education⁽¹²⁾.

On the other hand, a study of Asian children and young people demonstrates that the constant presence of a caregiver, whether a relative or not, improves their quality of life and is related with the caregiver's education level⁽¹⁴⁾.

FINAL CONSIDERATIONS

The interviews allowed the researchers to examine different aspects in the lives of the young visually impaired girls who participated in the research. Regarding family life, as opposed to the traditional criterion that defined the family leader as the resource provider, that is not the only factor for these girls. As the statements demonstrated, their family leaders can also be those people whom they have blood bonds with, who are in charge or determine tasks, or who give advice and support to other family members.

Only one of these adolescents mentioned parental advice for affective-sexual life. This advice comprised diffuse warnings about the probable risks of sexual life. Silence about sexual issues still sets the tone in advice to the girls.

In the family context, the lack of dialogue between the interviewees and their parents was evidenced, so that the former turn to friends to clarify their curiosities and doubts.

Despite visually impaired people's sensory limitation, television was mentioned as a learning means, evidencing these people's adaptation skills: even when they cannot see images on the theme, they can absorb and apprehend the contents of the message. This confirms that the communication process involves a selection perception of content interpretation. People perceive, absorb and remember the contents in different ways.

In the researchers' opinion, institutions like families and schools need to participate more actively in the lives of visually impaired adolescents with a view to preparing them for sexual life. Visually impaired adolescents attempt to act very similarly to their sighted friends: they want to discover the world, get to know people, date. But the lack of vision raises barriers, as it interferes in their sense of physical in-

tegrity and in their body image of sexually acceptable people, as well as in their ability to choose a partner.

The affective-sexual life of visually impaired adolescents shows the same sexual development characteristics as other people. Blindness does not decrease sexual interest, but only distinguishes curiosity on the theme: they want to get to know their bodies and how they work. Young blind girls also attempt to define their identity and place in society. They want to discover their own sexuality and find adequate means to express their sexual impulses and experience affective relations.

Identifying the perceptions of visually impaired adolescents about their sexuality was gratifying and revealed that they lack information and knowledge about different issues inherent in sexuality. The experience with the adolescent girls granted rich contact through exchanges and moments of pleasure, through knowledge the academy rarely provides, and stimulated the researchers even more to take up their role as health providers and educators.

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Financial support from CNPq