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ADOLESCENTES CEGAS: PERCEPÇÕES SOBRE A SUA SEXUALIDADE BLIND ADOLESCENTS: PERCEPTIONS ABOUT THEIR SEXUALITY ADOLESCENTES CIEGAS: PERCEPCIONES SOBRE SU SEXUALIDAD

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RESUMO

Introdução: Devido às transformações ocorridas na adolescência, as indefinições que a acompanham, somada à deficiência visual, justifica-se um estudo sobre a vivência da sexualidade deste cluster da população.

Objetivos: Identificar as percepções das adolescentes com deficiência visual acerca da sua sexualidade.

Métodos:Estudo exploratório de natureza qualitativa. Foram entrevistadas cinco (5) adolescentes de um Centro de Apoio Pedagógico do Brasil. As questões procuraram obter conhecimento e sobre as causa da sua deficiência visual, composição e orientações familiares, experiência afetivo-sexual, nível de conhecimento acerca de assuntos relacionados com a sexualidade, dentre eles, sobre os métodos contraceptivos e as doenças sexualmente transmissíveis.

Resultados: As participantes denotam desconhecimento sobre métodos contraceptivos e DSTs, verificando-se contudo que que apenas detêm informações superficiais.

Conclusões: Os resultados permitiram apurar que as adolescentes deficientes visuais apresentam as mesmas características de desenvolvimento da sexualidade das demais meninas, embora possuam características próprias. Considera-se que para gerar uma cultura de promoção da saúde é imprescindível que o conhecimento se faça de forma acessível para este grupo populacional.

Palavras chave: sexualidade; adolescência; deficientes visuais; enfermagem

ABSTRACT

Introduction: Due to the transformations that occurred in adolescence, the vagueness that accompanies it and the visual impairment, justifies a study on the experience of sexuality in this population cluster.

Objectives: To identify the perceptions of visually impaired adolescents about their sexuality.

Methods: Exploratory qualitative study. Five (5) adolescents from a Pedagogical Support Center in Brazil were interviewed. The questions sought to obtain knowledge and the causes of their visual impairment, family composition and guidance, affective-sexual experience, level of knowledge about issues related to sexuality, among them, about contraceptive methods and sexually transmitted diseases.

Results: The participants denote lack of knowledge about contraceptive methods and STDs, however, it appears that they only have superficial information.

Conclusions: The results showed that visually impaired adolescents have the same characteristics of sexual development as other girls, although they have their own characteristics. It is considered that in order to generate a health promotion culture, it is essential that knowledge is made accessible to this population group.

Keywords: sexuality; adolescence; visually impaired; nursing

RESUMEN

Introducción: Debido a las transformaciones que ocurrieron en la adolescencia, la vaguedad que la acompaña, sumada a la discapacidad visual, justifica un estudio sobre la experiencia de la sexualidad en este cluster de la población.

Objetivos: Identificar las percepciones de los adolescentes con discapacidad visual sobre su sexualidad.

Métodos: Estudio exploratorio cualitativo. Se an entrevistado cinco (5) adolescentes de un Centro de Apoyo Pedagógico en Brasil. Las preguntas buscaban obtener conocimiento y las causas de su discapacidad visual, composición y orientación familiar, experiencia afectivo-sexual, nivel de conocimiento sobre temas relacionados con la sexualidad, entre ellos, sobre métodos anticonceptivos y enfermedades de transmisión sexual.

Resultados: Los participantes denotan la falta de conocimiento sobre los métodos anticonceptivos y las ETS, sin embargo, parece que solo tienen información superficial.

Conclusiones: Los resultados mostraron que las adolescentes con discapacidad visual tienen las mismas características de desarrollo sexual que otras niñas, aunque tienen sus propias características. Se considera que para generar una cultura de promoción de la salud, es esencial que el conocimiento sea accesible para este grupo de población.

Palabras Clave: sexualidad; adolescencia; discapacidad visual; enfermería

INTRODUCTION

People with disabilities adolescence is a topic scarcely addressed in the literature. However, the vast majority of individuals with disabilities reach puberty, with the consequent sexual maturation, like other adolescents without disabilities. Yet, according to common sense, people with disabilities apparently do not live this stage of their development, because the physical changes would not correspond to the psychosocial ones, which is debatable. For instance, the normal pattern of the physiological, psychological and social development of the female human being happens regardless of the degree of visual acuity.

In the context of adolescence, physiological changes, sexuality, family, society and visual impairment are factors that constitute the process of personal and professional growth in the search for identity, autonomy and independence. If the development process that the child already has, within normal standards of experience, to reach maturity is complex, how will the visually impaired adolescent experience?

We chose to work only with visually impaired female adolescents. This choice was due to some reasons, such as: the overprotection received by girls is greater than that boys receive. This is because of the repressed education that still prevails. As a child, she is encouraged to have good manners and control over her will; women find it more difficult to address issues related to sexuality.

The present study was carried out as an integral part of the Federal University of Ceará Integrated Eye Health Project which emerged in 1993 and has since developed research with the visually impaired in all age groups. In relation to research and materials on sexuality produced by the Project, we can cite the article entitled Behavioral contraceptive methods: educational technology for the visually impaired (Pagliuca & Rodrigues, 1999). This article reports that the study's contributions were: to give the visually impaired the opportunity to grope a life-size female hemipelves, as the anatomy and physiology of Organs external organs was explained. It also used embossed drawings of the vaginal canal, the uterus, the fallopian tubes and the ovaries. These drawings were made on special paper to give an idea of the organ's location. The design allowed the visually impaired to identify the path taken by the egg until it reached the uterus.

To facilitate the understanding of those interested, the male reproductive system was approached verbally and explored through the groping of a full-size penile prototype. In this, the urethral orifice, the glans, the scrotum and the penis could be identified. The internal structures were also designed in embossed drawings. Through touch, they identified testicles, epididymis, vas deferens, seminal vesicles, prostate, bladder and urethra (Pagliuca & Rodrigues, 1999).

In this same study, the behavioral methods of the table, basal body temperature and ovulation or Billings were also addressed. The table method was based on the tactile exploration of a calendar created to facilitate the calculation of the fertile period. For this, a calendar with 30 days of the month was used, with digital reading in which small squares of velcro were used for each day. This calendar consisted of a fixed part, made with the roughest part of the velcro, and another movable part, used to identify the day when menstruation occurred and the day when the person is likely to ovulate. In this way, the fertile period can be identified. For the basal temperature method, a thermometer is required in which you can make a digital reading or inform the temperature with a speakerphone. In this case, it puts the visually impaired woman at a disadvantage, because she depends on a psychic to read the thermometer. In view of the difficulties exposed in relation to the use of this method, there was no interest in the visually impaired. As for the ovulation method, it was exposed through the tactile exploration of egg white to simulate cervical mucus (Pagliuca & Rodrigues, 1999).

We can also quote the publication entitled: Barrier contraceptive methods and IUDs: Educational technology for the visually impaired ["*Métodos contraceptivos de barreira e DIU: Tecnologia educativa para deficientes visuais*"]. The article embodies the study that offered the blind an educational material composed of an instruction manual, a VHS tape and materials to be explored by touch. The manual contains instructions in Braille and clarifies that the material would be for individual use, self-instructional and could be heard as many times as necessary, with the necessary interruptions. Among the materials explored by touch were the anatomical structures of the male and female reproductive system, in addition to vaginal spermicide with applicator, diaphragm, male condom and a prosthesis in the shape of a penis, female condom and IUD. The text of the recording guided the tactile exploration of the material while instructing on its use (Pagliuca, 1999).

We also mentioned the creation of an educational game about the contraindications and side effects of oral contraceptives. This material consists of a game composed of two geometric pieces where the circles that represent the contraindications and the triangles the side effects. The aim of this game is to induce the blind to group the pieces according to their shape and then read the pieces and, at the same time, the circle (contraindication) and triangle (side effect) relationship. In the identification of the material, ink and braille were used to enable reading by the seer and the blind.

Also for guidance, a manual on breast cancer prevention for the blind has been produced. This manual explained to the visually impaired the anatomy of the breast, the constitution of the breast tissue, the breast self-examination and the normal and abnormal patterns that could be found in this self-examination.

Although we are developing research and materials in the field of sexual health for the visually impaired, the material available for guidance and health education in schools is presented, predominantly, in the form printed in ink. Thus, access for the visually impaired is almost impossible. Hence the importance of the relationship between patient versus health professionals and teachers through appropriate communication channels.



Knowing the state of the art and reflecting on the sexuality of visually impaired adolescents can contribute to the understanding of these issues. At the same time, greater knowledge of this theme by health professionals can be reflected in a better approach, both with family members and adolescents, favoring the fulfillment of their rights, including sexual ones.

In this context, the guiding question of the study was defined: *What perceptions do visually impaired adolescents express about their sexuality?*

Accordingly, this study objective was to identify the perceptions of visually impaired adolescents about their sexuality.

1. METHODS

1.1 Study type

This is an exploratory study. This type of study is suitable for descriptive research as it is observed, described and classified (Polit, Beck & Hungle, 2004). The research was carried out in a Pedagogical Support Center (CAP) for the blind / visually impaired in Brazil. The CAP aims to offer appropriate resources to visually impaired students enrolled in the state school system, for the development of activities related to reading, research and curriculum development. Attached to this Center is a school that receives people with special needs, including the visually, mental and hearing impaired.

The sample consisted of five (5) female adolescents, with visual impairment, aged between 12 and 17 years old.

1.2 Participants

The sample consisted of five (5) female adolescents, with visual impairment, aged between 12 and 17 years old. To define the number of participants, we adopted data saturation, which will depend on the understanding of the phenomenon studied, regardless of the number of respondents.

1.3 Data collection instrument

As a data collection technique, we use semi-structured interviews. This part of a pre-established order by the interviewer, containing closed and direct questions. In addition it may include some open questions, in which the interviewer have some freedom on pursuing (Gauthier, Cabral & Santos, 1998).

The basic interview script comprised questions aimed at gaining knowledge and understanding of the following aspects: cause of visual impairment, level of education, family composition and guidance, affective-sexual experience.

The interviews were conducted individually in support rooms or educational resources existing in the selected schools. After clarification and agreement by the adolescents and their parents, to participate in the research, the interviews were recorded and filmed.

After the interviews were concluded, we proceeded to clarify the doubts presented by the adolescents. We also provided additional information that complemented the responses issued by the adolescents, demonstrating the educational role of the study.

The information obtained through the interviews was submitted to Bardin's content analysis technique (1979).

1.4 Ethical procedures

As required, the study was approved by the Ethics and Research Committee of the Federal University of Ceará (COMEPE-UFC) to respect the ethical-legal precepts (autonomy, non-maleficence, beneficence and justice) recommended in resolution 196/96 on research involving human beings of the National Health Council-Ministry of Health (Brazil, 1997).

Two Terms of Free and Informed Consent were drawn up, one given to the adolescent and the other to the parents and / or guardians of the adolescents. In addition to the authorization of the parents / guardians, we read the consent form, out loud, in the presence of the interviewees so that they could freely agree and sign.

2. RESULTS AND DISCUSSION

We interviewed five teenagers between the ages of 12 and 17. Of these, only one had low vision, while the others were totally blind. None of the interviewed adolescents reported having sexual experience, but all of them expressed their desire and interest in talking about sexuality, exposing their doubts, fears and desires.

In order not to identify the research participants, we decided to replace their names with types of flowers¹. More than grace, flowers leave perfume in the hands of those who pick flowers. This was a very pleasant way to be able to live with those disabled teenagers visual. In addition, the beauty, purity and fragility typical of flowers were also observed in the young women interviewed.

¹ Names of the participants in order of appearance: Violet — Violeta; Rose — Rosa; Orchid — Orquídea; Daisy — Margarida; Tulip — Tulipa.

2.1. Family life

In the questions addressed in this part of the interview, we intend to know the parental guidelines on sexuality and other relevant aspects of the adolescents' family life, including: criteria for knowing who the teenager considers to be the person in charge of the family, with whom they talk about issues related to sexuality and what are the contents and forms of sexual orientation received and which will be analyzed below.

In this group, only two (2) of the adolescents live with married parents. In order to assume the leadership of the family, the main criteria are: to be the financial provider of the group's needs, to be the one who orders and determines tasks for the other family members or to be the person who provides emotional guidance and support to the other members of the family group.

... I defer to my father, because It must be what he says. Do not try to change it. (Violet).

...It is my mother. She is very attached to me and I am very attached to her, everything that happens she tells me, everything that happens to me I tell her, there is nothing to keep hiding, because I am more like my mother. I think she has a lot of understanding with me, she knows how to talk well, without fighting, I think that's it (Rosa).

However, the teenager does not always seek guidance for her sex life with the person in charge of the family. Girls who talk about the topic with someone in the family do so with married sisters. Only one of them reported talking openly about sexuality with her mother. The other adolescents reported that they talk about this topic with friends from the street and from school.

I talk about these things with my mother. So, I already asked when I could have my first boyfriend. She said she has nothing against it, but, as every mother says, you have to be very careful with these things. So, like, when they call to have intercourse, these things, it is better not to happen too soon, but later, with time, when you get to know the person better. So that's what she asks me to be careful about (Orchid).

A very important part of adolescence concerns the family's sex education. This education has not made it possible for adolescents - including those who see - to assume their affective-sexual relationships responsibly. In general, the information is restricted to sexuality linked to the genitalia, because even today, parents still have difficulty talking about this topic.

Parents experience profound difficulties in the face of the sexuality of adolescent daughters, so they end up transferring the educational role to third parties, reproducing disciplinary forms of control and perpetuating this cycle for many generations.

Often the parents' difficulties in addressing sexuality issues with their daughters are due to the way they themselves experienced this situation. In this context, most parents assign the task of sexual orientation of their children to school, and school, in return, is not always prepared to fulfill this task (Brêtes & Silva, 2002).

Despite the inexistence or limited information on the subject, adolescents still start to engage in sexual practice, even without understanding very well what is happening to them. Consequently, unexpected results often occur, such as an unplanned pregnancy.

As shown by the responses of the adolescents, transcribed from the interview records, hereinafter referred to as "speeches" / "dialogues", most of them do not clearly perceive the sexual orientation transmitted by their parents. As we noted during the interviews, this is because the orientation happens indirectly. Thus, in the understanding of adolescents, parents do not address these issues directly.

Even when there is guidance, in some cases, it is done as a warning to girls against pregnancy. Therefore, parental guidance is not directed directly at the specific issues of "that" teenager. These are general, impersonal, diffuse guidelines that are often the result of the parents' lack of knowledge about the issues, or the embarrassment of approaching these issues with their daughters.

When I watch television, she says: If the head doesn't think, the belly pays, right? [refering to getting pregnant if careless] And I say: Yes mother, it is. She plays some hints for me, but even talking about the subject, she doesn't touch it (Daisy).

... She told me that I was too young to "have sex". That if I were ..., even though I was young, if I wanted to "have sex" it was good to always use a condom to avoid getting a child and not to ruin my life, she would say. She gave me a lot of advice (Rose).

In the guidelines of parents to girls, the study is placed as a priority in relation to dating and the two fields of life are even pointed out as irreconcilable things. According to all parental guidelines, they must first study and then date.

... She thinks studying is better [than dating], because then we regret it. If we stop studying [like her mother did]. She says she regretted having stopped. Then she supports me to continue (Tulipa).

... It was better to study hard for us to grow up and think about dating after we had a job. He doesn't want us to date early, no (Orchid).

At birth, the visually impaired is inserted in a system of relationships and social meanings which will be the foundation, the place where his own identity will be organized and structured.

In this historical-cultural perspective, the family tends to impress, visually impaired, the idea that they are incapable, awkward, insecure and thus "educated" to be helpless, dependent and even considered by some to be asexual and uninteresting. (Burns, 2000).



These contingencies, in general, prevent the disabled person from developing and from establishing a relationship with himself and with the other that allows him to express himself as a sexual being. Consequently, there is even a concealment of desire and pleasure and the erotic remain as experiences to be experienced only by the so-called "normal" (Vash, 1991). We can see this in the "lines" / "dialogues" of the category shown below.

2.2. The affective-sexual life

This part of the interview aims to get to know the adolescents' opinion on several issues related to their affective life and the way they deal with these feelings. Therefore, their opinions and experiences regarding to be "*staying with someone*" ("ficar"²), dating, sex and love are described and analyzed below.

None of the adolescents interviewed experienced the practice of just "*staying with someone*" ("*ficar*"), but all defined this practice and differentiated it from being in a relationship. The length of the relationship, "liking", the level of commitment and seriousness, as well as trust and sincerity, define the limit between "staying" and "dating".

... Staying is just ... you stay one day and you don't know the person, you have no commitment to anything, you can stay just for a few hours or you can just kiss and bye, now I don't think about doing that, only when finish my studies (Tulip).

Dating is when it is a serious thing, with commitment, that has intimacy [...] serious boyfriend anyway, to take home, to meet the parents, but I do not know if one day I will date someone [...]. (Rose).

Dating is when you like the boy, staying for a day, but I have to mature this idea in me, I'm still too young to do these things (Orchid).

In the transition from childhood to adulthood one of the peculiar aspects is the physiological maturation, the acquisition of the ability to procreate, or generate children, which boys and girls acquire with the first ejaculation and menarche, respectively (Bruns & Salzedas, 1999).

Thus, falling in love is, in general, a frequent result. When it comes to the visually impaired adolescent, however, as can be seen by the units of meaning, the "lines" / "dialogues" apprehended from theirs, the courtship is not actually taking place.

As the "lines" / "dialogues" transcribed / those of the interviews show, adolescents make a clear distinction between "staying" and "dating". Staying is associated with just one moment, with no commitment or bonding. Dating, on the other hand, reflects a greater involvement, a commitment, it becomes something more serious, associated with fidelity and intimacy.

One of the interviewees showed a tendency towards denial when we approached the topic of dating / staying, as explained in her answer.

Boyfriend, never! I don't even want to, nor have I ever "stayed", nor will I stay with anyone [...] (Violet).

This position can be justified by the fact that the visually impaired adolescent, unable to engage in the aesthetic standards advocated by society, starts to act as the stereotype that he carries, that is, as an asexual and without desire, supporting with this the expectations of others about you (Bruns & Salzedas, 1999).

Some young women reported that they prefer to "stay" with dating, as this practice allows greater freedom.

... because it's less serious than dating. Flirt, I don't know. You can "stay", if you don't like the boy, then if you do [like him], you can start dating him. But if you don't like it, you can finish it, got it. Then when I start a relationship I will find it better to stay because of that. Because it doesn't hold much (Tulip).

For girls, however, the practice of staying can involve a certain moral risk: the risk of being "spoken". This behavior, when it lasts or is frequent, is reprehensible, according to the view of their parents:

She thinks this "staying" situation is ridiculous, sometimes she even fought with this situation of "staying", these young people are just "staying" (Violeta).

Love is a feeling valued by all the teenagers interviewed and considered fundamental to bring a couple together. For most girls, love is an ambivalent feeling, it has a good side and a bad side.

I don't think much about love, no. I think it's an illusion. I already loved a guy and that's why I think so ... I liked him a lot, but he didn't respond. I never want to love anyone again ... (Rose).

... Love for me, it's ... all the best, it has its bad side too (Daisy).

In the relationship between love and sex, some adolescents interviewed realize that love can exist without sex and that sex can exist without love. However, this is not their preference:

Then I can't say. Honestly ... I think if you like the person, but you don't have sex, there are times when you will have sex with that person. You dated the boy more than a year and you already have sex? I don't think so. When the two are ready, it will happen. And not in too much of a hurry (Orchid).

² "ficar" direct translation is "staying": it happens when a couple don't really know each other and don't have a commitment, neither are in a relationship, and decide to engage in kissing, tender moments or intercourse, for a few hours or a day.

In the opinion of all of them, this feeling must be associated with sex or make sex better, although none of the interviewees has a sex life yet.

I think that to have sex a person has to like the other. I think that's all. Otherwise, it's not the same. I hear that out there that having sex with a person you don't like is different than having a person you like. I think that too (Tulip).

CONCLUSIONS

The interviews allowed to examine different parts of the lives of the young visually impaired people interviewed.

In relation to family life, as we could see, contrary to the traditional criterion that defined the family leader, as the material provider, it was possible to realize that this is not the only factor for these young women. As the "speeches" / "dialogues" showed, the leaders of their families may also be those with whom they have blood ties, who send or determine tasks or who provide guidance and support to others.

As for parental guidelines for the affective-sexual life of these adolescents, only one of them mentioned them. Such guidelines, however, consisted of diffuse warnings about the risks that sexual life can bring. As the "speeches" / "dialogues" show, the silence about sexual issues still gives the tone of the guidance to the girls. In the context of the family, the lack of dialogue between the interviewees and their parents was evident, and curiosities and doubts were often answered with friends.

Despite the sensory limitation of the visually impaired, television was mentioned in one of the "speeches" / "dialogues" selected as a means of learning and, in view of this attitude, we found the ability of the visually impaired to adapt. It is said that even if unable to see images on the subject, he is able to absorb and apprehend the contents of the messages. This reaffirms that the communication process involves a selective perception of content interpretation. People perceive, absorb and remember content in different ways.

In our view, institutions, such as the family and the school, need to participate more actively in the life of the visually impaired adolescent in order to educate her and provide her with the necessary instruments for a healthy and positive experience of sexual life. The visually impaired teenager seeks to act similarly to her friend who sees, she wants to discover the world, meet people and date. The lack of vision creates barriers, however, as it interferes with your sense of physical integrity and your body image as a sexually acceptable person, as well as your ability to choose your partner.

Identifying the perceptions of visually impaired adolescents about their sexuality was gratifying and allowed us to verify that they lack information and knowledge in relation to several issues that involve the healthy experience of sexuality. In addition, the experience with the adolescents allowed for a rich interaction with exchanges and pleasant moments of knowledge acquisition rarely provided by the academy and also stimulated the assumption of the role of educator and health provider.

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