

Meanings of Sexuality for Adolescents with Down Syndrome

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Abstract

The sexuality of young people with Down syndrome is still seen with discrimination, prejudice, stigma and fear. This study aimed to identify the meanings attributed by adolescents with Down syndrome to their own sexuality. The sample consisted of 15 adolescents with Down syndrome in the age group 15 - 24. Data collection was based on semi-structured interviews in five non-governmental organizations, in the city of Recife, Pernambuco. The results indicated that the participants were satisfied with their body image, without any kind of restriction or inhibition. For these participants dating is synonymous with a committed relationship, at the same time as the sexuality was seen as manifestations of intimacy, body touches and dialogue. In a general context, adolescents with Down syndrome expressed their sexuality in the same way as most adolescents without Down syndrome.

Keywords: Sexuality; Youth; Down Syndrome; Perception

Abbreviations

DS: Down Syndrome; UN: United Nations organizations

Introduction

Most people are used to imagining sexuality as a synonym for genitality, that is, as a reality involving only the genitals or as a simple physical expression, such as the sexual act [1]. Sexuality is not reduced to the sexual impulses and desires of each individual, but comprises the subjects in their biological, psychological, sexual and emotional aspects [2].

Sexuality is a basic foundation of human development, it is the core of the whole process of development as a person, the formation of his identity [3]. It is a social and historical construction, so it gains differentiated contours in different spaces and times, according to its specificities, as in Down syndrome (DS) [4]. It has its own characters, narratives, scenarios and poetics, forming a valuable field of knowledge, from which it is possible to identify sexual practices, desires and behaviors [5].

It is still quite ingrained, among family members, professionals and educators, the myth that the sexuality of young people with DS is inherently problematic and even pathological [6]. However, the development of sexuality in people with disabilities does not differ qualitatively from so-called "normal" ones, observing the same needs, emotions and experiences [7].

Aspects related to the unfolding sexuality of young people with Down syndrome bring concerns to parents and society, in general, translated by repressive and discriminatory attitudes, considering them, by their sexual innocence, eternal children, which consequently hinders the development. fullness of the individual [8]. This conception is constantly transmitted to these young people, which makes them learn early not to recognize the evolutionary process regarding their sexuality [9].

The lack of information on the subject can lead young people with DS to vulnerability and susceptibility behaviors, due to lack of guidance [10]. These behaviors can be reflected in the desire to manage their sexual manifestations, affect decision making, potentiate low self-esteem and need affirmation towards peers [7].

Given the above, knowing and clarifying the myths and misconceptions about the sexuality of young people with Down syndrome is an important task, as these beliefs can affect everyone, since based on them encourage the relationships of discrimination that occur in this population [11]. In addition, the more opportunities young people with Down syndrome have to explore and understand their own sexuality, the greater responsibilities may result from these opportunities [12].

The subject of sexuality has been hotly debated from the perspective of educators and parents. However, regarding this portion of the population and, especially under the eyes of young people with Down syndrome, it is still limited. In summary, we consider it imperative for social inclusion to listen to young people with Down syndrome about sexuality. In this context, we emphasize the importance of knowing the perception of these young people, in the current study, about their affectivity, their sexuality, aiming to identify the meanings attributed by young people with Down syndrome to their own affective-sexual individuality.

Materials and Methods

Participants

The sample selection criteria were young men and women with Down syndrome, who presented mild or moderate cognitive deficit, for better understanding of the interview. The sample consisted of 15 young people with Down syndrome who were between 15 and 24 years old at the time of the interview, 9 males and 6 females. This was selected by convenience, in which the researcher, through the initial diagnosis made by the professionals of the institutions that worked with these young people, previously identified the research subjects and selected those who could better understand the information needs of the study [13]. the sample size defined by data saturation.

Instruments

To draw the social and demographic profile of the studied population, information regarding age, gender, education, with whom they live and family income were collected, which were collected from parents or guardians of the youth at the time of the interview. To obtain the speeches of the young, the researcher elaborated a semi-structured interview script. The interviews were recorded and then transcribed in full for analysis of the collected data.

Data collection

The study was qualitative, with phenomenological approach. Phenomenology proposes to describe the phenomenon, not to explain it or to seek causal relations. It turns to the very things as they manifest themselves, to understand the meanings of lived experiences [14].

The collection was performed in July and August/2016, in three non-governmental institutions, which worked with young people with Down syndrome in the city of Recife-PE, Brazil.

Data analysis

Participants were given fictitious names of gems in order to remain anonymous. The reading of the transcript was performed several times, trying to identify meaning connections that made up the proper meanings of the experience that was being investigated. From

these readings, we identified the central themes that emerged and related to the objectives of the study. Then, data categorization was performed, in which each theme received an appointment, and the transcripts of each theme were grouped.

The last stage was composed by the interpretation of the data, which turned to the theoretical frameworks, pertinent to the investigation and they provided background and significant perspectives for the study. In all the steps described above, the epoche was practiced, that is, the analyzes and interpretations were made with the temporary suspension of the researcher's values and beliefs.

Ethical considerations

This study followed the legal ethical aspects, with the signing of the consent form by young people and informed consent by the parents or guardians. It was approved by the Research Ethics Committee of the University of Pernambuco-UPE with CAAE: 52305515.2.0000.5207.

Results and Discussion

The results will be presented from the analysis of the transcribed interviews, which made it possible to identify the perceptions of young people with Down syndrome about their sexuality, followed by fragments of the participants' reports.

Body perception

In this category participants were asked if they liked their body and which part they preferred. Each person sees their body in a unique way, from their culture, learning, life experiences, limitations, not unlike young people with Down syndrome.

In their process of development and construction of sexuality young people seek to know their body, but are not always satisfied with its image. However, the young people in this study were satisfied with their body image, demonstrating that they are aware of their body parts and have preferences for specific parts, as shown in the following statements.

"I like my body because I was born that way ... because my face gets attention". (Morion, 19 years old, male, high school).

"My body is beautiful ... I like my chest better because the heart is beautiful and in honor of my mother". (Jasper, 17 years old, male, elementary school).

"I'm beautiful ... I like my neck". (Quartz, 15 years old, male, elementary school).

"My body is skin ... I like my leg because I walk a lot". (Berilo, 17, male, elementary school).

"Because I can move bones, arms, feet ... I like the belly, because it's dry". (Onyx, 16 years old, male, elementary school).

The body is understood, then, as a semantic vector that evidences the relationship of the subject/actor with the world, making the idea that human existence, before anything else, is corporeal. Being a reference through which human beings communicate and express themselves, where human motricity shows that the recognition of one's own body and its differentiation with objects in the environment, influences the determination of people's behavior [15].

Body satisfaction and self-perception are paramount in people's self-acceptance and can generate attitudes that interfere with the experience of their sexuality [16]. The standards of beauty set by society have an effect on the body perception of people with disabilities. They often have difficulty developing a healthy image of their bodies, especially compared to their non-disabled peers [17]. However, this was not staged by the youth of the present study, and high self-esteem was observed in all respondents, since all said they considered themselves beautiful.

People with disabilities can develop positive self-esteem if social mediation, family and social affective bonds are established primarily through feelings of love, affection and acceptance. An adequate sexual and bodily identity involves the ability of the individual to accept his condition, so that this must be accepted by society through the various forms of relationships that are provided to it [18].

Two young women were concerned about their hair and body throughout the interview by straightening their hair and massaging their hands with their hands. These attitudes were interpreted as characteristics of vanity, present in young people in general, as shown in the following statements:

- "I like my body, it's so soft, it's so beautiful... the part of my body that I like best is for us to walk... make movements... When I look in the mirror, I keep moving and looking my body, because I like to look a lot". (Emerald, 24 years old, female, high school).
- "He is soft, sensitive ... My hair, because I don't let anyone move ... only my hair is combed... I like my nails too". (Pearl, 23 years old, female, high school).

For many people, disability overcomes the sexual issue, as if the deficient body appeared before the sexual body and made it impossible to satisfy one's own sexuality. The body traits of the person with Down syndrome may represent a stigma to the point of damaging the individual's image of his own body, but if this belief that the aesthetic model is merely an imposition of social patterns is worked out, it may not have a negative impact on the lives of young people with Down syndrome.

Meanings about dating

Young people were asked about the meaning of dating for them. And in their opinion, it is a serious relationship, the establishment of a loving commitment, as shown in the following reports:

- "Dating is love". (Olivin, 22, male, elementary school).
- "Dating is kissing". (Jasper, 17 years old, male, elementary school).
- "Dating is passion". (Topaz, 22, male, high school).
- "It's take the hand, walk, talk, get together". (Turquoise, 19 years old, female, elementary school).
- "To date is to hold on and to kiss on the mouth". (Amethyst, 24 years old, female, elementary school).
- "There are two people who like to go out and kiss on the mouth". (Morion, 19 years old, male, high school).
- "Dating is a cupid thing, is going out, having dinner out, is pulling the chair for the lady, is kissing" (Onyx, 16 years old, male, elementary school).
- "Give each other affection, kiss, friendship". (Ruby, 24 years old, female, elementary school).

According to this author [19] falling in love is the "nascent state of a collective movement for two", i.e. it is a process that happens between two people, in which a project is involved and the union of what was separated. It is the fusion of different people in the search for overcoming diversity. That is, one has to open to a different existence that provides no guarantees to realize.

The dating reported by young people consists of sharing all moments together to the possibility of a future with another, in which affection, respect and trust are present [20]. For this other author [21], the social norms governing the dating situation and dating behavior are in many dimensions, including individual, racial / ethnic, socioeconomic differences, historical landmarks, and cultural contexts, as shown in the following dialogues.

"Dating is a pleasant thing. One has to behave... help each other". (Esphenium, 18 years old, male, higher education).

"Take the hand, kiss, you have to have the right behavior". (Jade, 17 years old, female, high school).

"Knowing how to love, respect people, not flirt with other people". (Pearl, 23 years old, female, high school).

The tendency for relationships to develop with young people until they reach dating relationships is gradual. Initially, young people begin by having casual encounters, relationships that become somewhat formal and public, go through a phase of open relationships, which usually give rise to more intense relationships, and eventually reach a stage where they establish a relationship. one to one [22].

The desire to date, whether or not you have a disability, exists and manifests in every human being. Eroticism, desire, gender building, feelings of love, affective and sexual relationships are potentially existing expressions in everyone, including those with disabilities, such as young people with Down syndrome [23].

Meanings of the sexual act

In this category we present the perception of young people with Down syndrome with regard to the sexual act, as one of the components of human sexuality. Participants presented convergent ideas to perceive sexuality as a manifestation that involves intimacy and body touches, as shown in the following statements.

"It is kissing, taking the breasts ... taking the butt, the pitoca ... smoothing each other". (Berilo, 17, male, elementary school).

"Sex is dating, kissing, straightening, sleeping with your wife in bed". (Onyx, 16 years old, male, elementary school).

It is to touch each other and kiss ". (Ruby, 24 years old, female, elementary school).

From the discursive contributions expressed it is noted how clear the participants are regarding the sexual act, revealing that having Down syndrome is not an inhibiting factor of experiencing sexuality.

These testimonies contribute to disarticulate the decreolization of people with disabilities, which according to [24] ends up restricting or denying the access of people with disabilities to erotic practices, sexual experiences and love relationships. It is argued that the sexual repression exerted in the lives of people with disabilities has become one of the major factors for their social, emotional and psychological maladjustment [7].

The stigma that young people with Down syndrome are asexual beings is a mistaken idealization, whose origin, among other factors, would lie in the processes of infantilization and high protectionism that fall on them, most may not experience sexuality, but it is intrinsic as part of your being. Infantilization and social isolation, emphasizing sexual experiences for this segment of the population, prevent them from having a love and sexual life. Excessive protection of parents ends up becoming practices that curtail experiences, limiting their possibilities for development and, in this case, negatively inferring the sexual and affective dimension [8].

Protectionism leads young people not to experience their sexuality, to be deprived of information on the subject, or to obtain limited information [25]. As the statements below show, in which participants reported ignorance of the topic or television as their only source of information.

"I don't know, but I have to research". (Esphenium, 18 years old, male, higher education).

"Just saw it on tv". (Jade, 17 years old, female, high school).

"I've seen it on tv". (Citrus, 21, Male, Elementary School).

The deprivation of experience of sexuality, restriction of experiences and lack of access to knowledge, installs a framework of difficulties in the relationship with oneself and others, requiring more than a simple itinerary of teachings and learnings made in sexual education [26].

It's having sex or making love in bed". (Pearl, 23 years old, female, high school).

"Sex means making love". (Emerald, 24 years old, female, high school)

The analysis of the above discourses shows the perception that for the interviewees sex is not only a mechanical / penetrative activity restricted to physiological contexts, but also synonymous with love, ratifying a romantic view of the subject.

Demonstrations of tenderness, sympathy, and attraction express love and affection and reveal the nature of the individual as a sexual being [27]. Sexuality refers to the feelings, attitudes, and perceptions related to people's sexual and affective life; it implies the expression of values, emotions, affection, gender and also sexual practices. In this context, it is only possible to understand the development of people and the construction of their individual sexuality on the basis of the construction of broad sexuality, which culminates in the way one perceives, judges and guides oneself in the experience and development of people. people's sexual practices [28].

Talking about sex

Respondents were asked if they would like them to talk to them about sex. The following statements show that two participants expressed their willingness to learn about the topic.

"I want to know everything". (Jasper, 17 years old, male, elementary school).

"I wanted them to talk about it". (Quartz, 15 years old, male, elementary school).

Rarely, adequate attention is paid to the sexuality of people with Down syndrome as a consequence of various preconceived beliefs and ideas. In short, it can then be seen that the biggest problem of sexuality for people with disabilities, despite their particularities and possible limitations, is not the disability itself, but the lack of information, prejudice and taboos of society [11].

For the authors [29]

Mentally handicapped people exhibit inappropriate sexual behavior, or are sexually inactive or inhibited, because they have not been given proper sexual education and guidance, or at least the opportunity to "learn in life" like others.

The guidance provided for the sexual behavior of young people with Down syndrome consists largely of prohibitions and repressions. Many parents oppose their sexual approach, arguing that this may trigger an interest in sex that might not have been naturally aroused.

The United Nations (UN) Convention on the Rights of Persons with Disabilities provides that "persons with mental disabilities have the same basic rights as other citizens" [30]. As such, individuals with disabilities have the same needs and rights as everyone else, whether they are social rights, labor rights, or the right to receive the same sexual approach as their peers [31].

The sexuality approach is an important way to prevent problems related to young people's sexual and reproductive health [32]. In this context, approaching the theme can contribute positively to young people with Down syndrome in several aspects, such as a positive acceptance of the sexed body, the construction of sexual identity and a non-discriminatory attitude towards different sexual expressions and orientations [33, 34]. When sexuality is openly and routinely discussed, conversations become easier to start, more comfortable to continue, and more effective and informative for all participants.

"I don't want to talk because I'm Down". (Morion, 19 years old, male, high school).

"It's a very private matter, only when I'm old". (Esphenium, 18 years old, male, higher education).

"Maybe I would talk about it because it's embarrassing". (Topaz, 22, male, high school).

"I wanted them to talk, not like that right away ... because it's too much, I can't explain ... I'd be ashamed to talk". (Ruby, 24 years old, female, elementary school).

The above statements seem to be loaded with taboos regarding sexuality, being expressed as something closed, shameful, that needs to be unveiled according to some laws and rules of society, in which young people with Down syndrome could not have access to information about their sexuality. theme. This framework given the sexuality, demonstrated by the participants suggests the implementation of the dialogue on the theme in the family context, unlike what some parents may have experienced in their youth.

As the degree of mental impairment may exist in the sexual development of young people with Down syndrome, differences in cognitive and adaptive abilities. As a consequence, they have greater difficulty in understanding the forms of manifestation of sexual behaviors [8].

These particularities point to the need for the young person with Down syndrome to be heard and receive guidance, as nothing that dialogue and mediated management do not solve. This can lead you to learn the conduct that the personal and social environment requires of them and then obtain conduct compatible with social demands [35].

This learning can be mediated through artistic expressions, expressive dance, theater, photos, pictures, among other resources that can help build their thoughts on their sexuality and sexual identity, thus helping them to be protagonists of their own history [36].

One of the limitations of the research was the dysarthria most young people had, some with a higher degree of phonetic difficulty for verbal communication. However, during the various stages of the study, the researcher entered this universe that was unveiled by a greater number of contact with these young people and their reports. Exploratory study and field research provided, through films and plays, the greatest understanding.

Respondents presented reduced speech, a characteristic of people with Down syndrome, and more specifically young people, however the theme addressed may also have influenced the speech production of participants, as it would influence any segment of the young population. Despite the difficulties faced and reported, this study was given the real opportunity for these young people to express their wishes and make their speech heard without compromising the quality of the data collected.

Conclusion

This study aimed to understand the perceptions of sexuality from the perspective of young people with Down syndrome. In reporting the manifestations of sexuality, such as dating, the body and the sexual act, young people with DS expressed bodily acceptance, that dating is considered a love relationship, the sexual act involves intimacy and body touches and would like to learn about sexuality. However, the study revealed that the perception of sexuality for young people with Down syndrome is scaled from the perspective of what society shows you to be sexuality.

The study also allowed the researcher to unveil pre-established ideas that young people with Down Syndrome are eternal children, considered asexual beings, who cannot experience their sexual and affective emotions. Moreover, the research showed that perceptions about sexuality are peculiar to each young person and that they are entitled to affection, dating, marriage, like any other young person, with clarification and responsibility. Thus, contributing to enrich their existence as being sexed, according to the competence of each.

Conflict of Interest

No conflict of interest.

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