

THE PERCEPTION OF PERSONS WITH INTELLECTUAL DISABILITIES ON SEXUALITY

A PERCEPÇÃO DE PESSOAS COM DEFICIÊNCIA INTELECTUAL SOBRE A SEXUALIDADE

LA PERCEPCIÓN DE LAS PERSONAS CON DEFICIENCIA INTELECTUAL ACERCA DE LA SEXUALIDADE

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ABSTRACT: The sexuality of people with intellectual disabilities is still a taboo, but it is understood by occupational therapy as a fundamental stage in life. Objective: To describe the perception of people with intellectual disabilities about sexuality. Method: a descriptive exploratory study of qualitative nature was carried out with eight students - aged between 13 and 42 years, from an institution for people with disabilities. A semi-structured interview was used to investigate the perception of sexuality and collect sociodemographic data; Thematic-categorical content analysis was used for data evaluation. Results: content analysis made it possible to establish two thematic categories: experiences in affective relationships and knowledge acquired about sexuality. Perceptions about sexuality are infantilized and families find it difficult to provide sex education. Conclusions: the study points out the necessity to create strategies to better teach sexuality and reproductive health for this population, also as a way of protecting these people.

KEYWORDS: Sexuality. Intellectual disability. Occupational therapy.

RESUMO: *A sexualidade de pessoas com deficiência intelectual ainda é um tabu, mas é entendida pela terapia ocupacional como etapa fundamental para a vida. Objetivo: descrever a percepção de pessoas com deficiência intelectual sobre a sexualidade. Método: estudo exploratório descritivo, de natureza qualitativa, realizado com oito alunos de uma instituição para pessoas com deficiências, com idade entre 13 e 42 anos. Utilizou-se uma entrevista semiestruturada para investigar a percepção sobre a sexualidade e coletar dados sociodemográficos; para a avaliação dos dados utilizou-se a análise de conteúdo temático-categorial. Resultados: a análise de conteúdo possibilitou estabelecer duas categorias temáticas: experiências em relacionamento afetivo; e conhecimento adquirido sobre sexualidade. As percepções sobre a sexualidade são infantilizadas e as famílias tem dificuldades em prover educação sexual. Conclusões: o estudo aponta a necessidade da*

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criação de estratégias de educação em saúde sexual e reprodutiva para esta população, inclusive como forma de proteção dessas pessoas.

PALAVRAS-CHAVE: *Sexualidade. Deficiência intelectual. Terapia ocupacional.*

RESUMEN: *La sexualidad de las personas con discapacidad intelectual sigue siendo un tabú, pero la terapia ocupacional la entiende como una etapa fundamental de la vida. Objetivo: describir la percepción de las personas con discapacidad intelectual sobre la sexualidad. Método: estudio exploratorio descriptivo, de carácter cualitativo, realizado con ocho estudiantes de una institución para personas con discapacidad, con edades comprendidas entre 13 y 42 años. Se utilizó una entrevista semiestructurada para investigar la percepción de la sexualidad y recolectar datos sociodemográficos; para la evaluación de los datos se utilizó el análisis de contenido temático-categorico. Resultados: el análisis de contenido permitió establecer dos categorías temáticas: experiencias en las relaciones afectivas; y conocimientos adquiridos sobre la sexualidad. Las percepciones sobre la sexualidad están infantilizadas y las familias tienen dificultades para brindar educación sexual. Conclusiones: el estudio señala la necesidad de crear estrategias de educación en sexualidad y salud reproductiva para esta población, incluso como una forma de proteger a estas personas.*

PALABRAS CLAVE: *Sexualidad. Discapacidad intelectual. Terapia ocupacional.*

Introduction

Disability can be part of the human condition. Some aspects related to people with disabilities are still little discussed, both in Brazil and internationally, such as, for example, the awakening of genital sexuality, widely recognized as a characteristic of human adolescence (MAIA, 2016). The development of sexuality is a fundamental stage of the human being. Everyone, including those with disabilities, is entitled to the healthy exercise of sexuality, which is an integral part of everyone's personality. It is a basic need and an aspect of the human being that cannot be separated from the other dimensions of life. It influences thoughts, feelings, actions, interactions, both in physical and mental health (GUEX; TASCETTO, 2014).

In general, sexuality is still a taboo in our society. For this reason, dealing with the sex education of children and students can also be difficult for many parents and educators. Anguish and difficulty increase when it comes to the sexuality of people with some type of disability, especially the intellectual (GUEX; TASCETTO, 2014). However, according to the Declaration of Sexual Rights (WORLD ASSOCIATION FOR SEXUAL HEALTH, 2014), regarding the right to equality and non-discrimination,

Everyone has the right to enjoy sexual rights [...], without distinction of any kind, be it race, ethnicity, color, sex, language, religion, political or other opinion, social or regional origin, place of residence, characteristics, birth, disability, age, nationality, marital or family status, sexual orientation, gender identity and expression, health status, economic, social or other situation (our translation).

Therefore, sex education should also be for everyone.

Occupational therapy is dedicated to Occupational Performance and the daily activities of individuals (AOTA, 2014), which are arranged in eight occupational areas of the Occupational Therapy Domains and Processes: Basic Activities of Daily Living; Instrumental Activities of Daily Living; Sleep and Rest; Education; Job; Play; Leisure and Social Participation. These activities are related to human needs for self-care, entertainment and social participation, and because they are carried out according to cultural values, they provide structure and meaning to people's lives.

Thus, understanding the healthy exercise of sexuality as fundamental to human life, this research aims to describe the perception of people with intellectual disabilities about sexuality.

Materials and Method

It is characterized by a field, exploratory, descriptive and qualitative nature. This research works with the universe of meanings, motives, aspirations, beliefs, values and attitudes, through the lived and shared reality. The universe of human reproduction is the object of qualitative research that can hardly be translated into numbers and quantitative indicators (MINAYO, 2009).

The research was carried out in an institution that aims to treat, promote well-being and the development of people with disabilities, whether physical or intellectual, located in the interior of Minas Gerais, which at the time of the research served 400 people, children, teenagers and adults, daily. It has professionals in the clinical (pediatrician, neurologist, physiotherapist, psychologist, speech therapist, nutritionist, nurse, social worker and occupational therapist) and pedagogical area. The choice of this institution was due to the population served and because this location is an internship field for the Occupational Therapy Course of a Federal University, this research being carried out for the conclusion of a course by one of the authors.

Eight people with intellectual disabilities, aged between 13 and 42 years, participated in this work, whose name was changed here according to the participant's choice to preserve

their identities, invited to participate according to the following inclusion criteria: (a) have a diagnosis intellectual disability, given by the medical professional, registered in the institution's medical record; (b) having comprehensible speech conditions, indicated by the speech therapist of the service; (c) be 12 years of age or older; and (d) accepting to participate in the research, through the consent form and having authorization from a legal guardian through the Informed Consent Form. Participants were given autonomy to choose the fictitious names they would like to be called by, maintaining anonymity as recommended by Resolution 466/2012.

For data collection, an interview script was elaborated, which dealt with how the person with intellectual disability perceives and experiences their sexuality; affection; dating; contraceptive methods; how the family addresses these issues. A pilot study was carried out, through which the questions were adequate to meet the objectives of the work. The interviews were recorded in mp3 and the observations recorded in a field journal, involving aspects of the institution's environment and relational aspects about the participants. Each interview was conducted only once, with an individual approach, conducted by the researchers in a private room at the institution, in November 2018 and lasted approximately 15 minutes. The interviews were transcribed by the researchers after their end, with double verification of the content. Before the beginning of the interview, the explanation about the research and signing of the Terms of Consent was explained.

The population was composed by the intentional non-probabilistic sampling method, submitted to the willingness of cooperation by the participants and their guardians. The collection took place through the speech therapist, guiding which individuals were capable (in terms of speech) of answering the questions of this research. The parents or guardians of the participants were approached by the researchers to authorize their participation in the study through the informed consent form (ICF). In cases of consent, the researchers provided guidance on completing the ICF and made this document available, ensuring a copy for the participants. After this authorization, people with intellectual disabilities, over 12 years old, who attended the institution were invited to participate in the research, answering the interview and signing the consent form. The objectives of the study were clarified, as well as its benefits and risks for those responsible and the participants.

The narratives obtained from the interviews were evaluated through thematic content analysis adapted for qualitative research (BARDIN, 2010). This modality requires, initially, a comprehensive and exhaustive reading of the set of selected material. Here, we seek to obtain an overview; apprehend the particularities of the set of material to be analyzed; develop initial

assumptions that will serve as a parameter for the analysis and interpretation of the material; choose forms of initial classification; determine the theoretical concepts that will guide the analysis (BARDIN, 2010).

In the second stage, an exploration of the material is carried out. In this stage, we try to distribute excerpts, phrases or fragments of each text of analysis by the scheme and initial classification; do a reading dialoguing with the parts of the analysis text, in each class; identify through inferences, the nuclei of meaning pointed out by the parts of the texts in each class of the classification scheme; dialogue with the nuclei of meaning with the initial assumptions and, if necessary, make other assumptions. Then, the different cores of meaning present in the various classes of the classification scheme are analyzed; the parts of the text are grouped by themes found; an essay is elaborated by theme. As a final step, an interpretative synthesis is constructed through an essay that can dialogue with the data found in the research, the objectives of the study and with the theoretical framework found in the literature (BARDIN, 2010). From the analysis of the content of the interviews, it was possible to establish two thematic categories: experiences in affective relationships; and acquired knowledge about sexuality.

The development of this study followed all the ethical norms guiding the work involving human beings, the Declaration of Helsinki (1964, last revision in 2000), the specific legislation of Brazil and the International Convention on Human Rights, being approved by the Ethics Committee in Research by the Federal University of Triângulo Mineiro - UFTM, opinion CAAE 51665615.4.0000.5154.

Results and Discussion

Ten people who met the inclusion criteria of the research were selected, but only eight participated because two users were not at the institution on the day the data collection was scheduled. Four female and four male people were interviewed. The interviewees' age ranged from 13 to 42 years. All participants had been diagnosed with some intellectual disability by the medical service professional, and this information was obtained from the users' medical records. The characterization of the participants was shown in table 1.

Table 1 – Characterization of participants

| Name | Age | Diagnostic | Sex |
|-------|-----|-----------------|-----|
| Talia | 28 | Down's syndrome | F |

| | | | |
|-------------|----|-----------------------------|---|
| Michael | 40 | Down's syndrome | M |
| Ana Raio | 35 | Down's syndrome | F |
| Giovana | 42 | NPMDD* | F |
| Transformes | 17 | Moderate Mental Retardation | M |
| Bob esponja | 13 | Moderate Mental Retardation | M |
| Minnie | 16 | Cognitive Disability | F |
| Batman | 29 | NPMDD * | M |

* Neuropsychomotor Development Delay

Source: Devised by the authors (2018)

From the analysis of the narratives it was possible to establish two thematic categories: experiences in affective relationships; and knowledge acquired about sexuality.

In the category 'experiences in affective relationships', the experiences of those participants who have already had some type of romantic relationship, such as dating or engagement, were reported. This experience was lived by four people, three female and one male, who made references to holding hands, hugging, kissing on the cheek, kissing on the mouth, the desire to have children and get married.

Giovana reported that when the partner tried to have sex, she ended the relationship: "I'm ashamed. We kissed on the mouth, he wanted to have sex with me, and I ended it. Then he hooked with my friend" (our translation).

Some respondents reported that parents think their children are ugly to date or have an affective relationship, or justify to them that they are not of the right age to date. Some families infantilize their children to avoid this type of relationship. Those who never dated said that they know how to talk about the subject because this information was constructed through soap operas, films and observations between father and mother. Perhaps the fear of having sex is related to the parents' approach to dating, which are often repressive. It may also be due to the lack of information and education on sexuality, because, as they often behave in a childlike manner, their educators and caregivers believe that they will not develop sexually and will not feel sexual desire or attraction. In agreement with Jahoda and Pownall (2014), if parents recognize that their children are becoming more autonomous and have the potential to become sexually active, they can feel motivated to help and ensure that their children get enough information to stay insurance.

Taila, the only interviewee who was engaged, reported how this relationship went and why it ended. She said: “I was engaged. We held hands, hugged, kissed on the mouth. [...] I lived in São Paulo and he lived in Bahia. I never forgot him” (our translation).

For Bob Esponja to date is to kiss the cheek, but his mother says that he cannot do this kind of affection on other people and that dating is ugly. The participant is confused to answer whether dating is ugly or not, and reports that his sister should complete dating before he starts: “I already [dated]. My mom doesn't let me kiss her on the cheek, my mom says we can't. I must wait for Carol to date and then I can” (our translation).

The neglect of this issue that permeates our society today, in which dating, marriage, sexual activities are normal for people who have perfect bodies or have no intellectual disabilities, generates a progressive restlessness for those who have some disability, because access to television and social networks allow contact with the topic, thus providing curiosity, but not the healthy exercise of sexuality. In other words, it is reasonable to suggest that it is not only the lack of knowledge, but also the discomfort of young people with their developing sexuality may be linked to their confusion and shame about sexual feelings and anxiety about sexual expression. Therefore, the inability to develop a more balanced or positive view of their own sexuality can reduce young people's sense of management and control, making them more reluctant to seek the information they need or create the confidence to express their own desires for an intimate relationship (JAHODA; POWNALL, 2014).

It is observed that due to the lack of sexual education and information about affective relationships, participants do not exercise sexuality in a healthy way, an essential human occupation. This education could be used as a form of intervention for both participants, as well as for parents and educators, offering adequate guidance for people with intellectual disabilities so that they can exercise this activity of daily life in a healthy way, which is not limited to the sexual act, but it involves affections and relationships, natural for human life.

In the category 'knowledge acquired about sexuality', it was addressed how parents guide their children with intellectual disabilities about sexuality or other ways in which they acquire knowledge on the topic. Participants were asked whether their parents talked about dating and sexuality, whether they knew what dating is, how people date, many doubts were notable. Participants who have never had an affective relationship report that they have the idea that it is a relationship between two people, in which they can have a loving relationship with kisses on the cheek, hug and walk holding hands.

It is noticed that family members infantilize these individuals because they are people with intellectual disabilities. Many participants reported that they did not know what dating

was, they did not know what boyfriends did, that they felt wrong in talking about the subject of affectionate relationships. Some families said it was wrong to kiss on the cheek, kiss on the mouth, walk hand in hand, hug and have affectionate relationships, like Batman's: "I never dated. I don't know what is dating. My family says it's ugly. [Do you think it is ugly to date?] No. [Have you seen it in a soap opera, a movie?] Yes, it is kissing on the mouth, holding hands, hugging" (our translation).

Many factors can influence individuals in relation to their sexuality, for example, society, family values, religious beliefs and intellectual disabilities (MAIA, 2016). This construction and understanding of the subject of dating is interconnected in the way the family approaches this topic. However, some interviewees show knowledge about the topic and, even though the family says that dating is wrong, they disagree with the family's opinion, such as Minnie, who dated with the consent of the mother, but hidden from the father:

I've dated. Was good. We did a lot of things. He's from my aunt's church, but the church forbides it. We kissed only on the cheek, didn't hold hands or hug. [Does your family know?] Only my mother, she thought it was good, we are friends. My dad can't know because he would beat me (Minnie, our translation).

There is the authoritarianism and the taboo that permeates this subject. Parents and educators often deny the existence of sexuality and prefer to view their disabled child and student as asexual. People with disabilities do not need pity, but understanding about their condition and, above all, convincing clarification to adapt their behavior, making it less exclusive. One of the main sources of prejudice is the lack of information about the potential, desires and difficulties of this population group (LITTIG *et al.*, 2012). When the topic becomes sexuality of people with disabilities, prejudice and discrimination are intensified and cause controversy as to the different ways to approach it, both with the adolescents themselves, with their families and at school. However, parents and educators must educate them frankly in the aspect of sexuality so that they realize that they have a defined sexual role and with needs equal to those of any human being (MAIA *et al.*, 2015).

When asked, for participants who have never had a relationship, if the family talks about dating, relationship and sex, most reported that they do not talk and also do not let them date, for various reasons such as those mentioned: that it is ugly, that they are not yet of age, or simply because they can't. The only one who said that the family talks was Batman, but that the mother only says that it is ugly and that he cannot, there is no explanation about these issues.

Every family needs time and space to explore their fears and anxiety related to the sexuality of their teenagers and they need specific guidance to educate them for each stage of life. Sexuality is part of the human being's life and development and education process and, as such, must also be addressed with people with disabilities, in a gradual construction of the human being, favoring a psychologically healthy and socially adequate personality (CABRAL; MOURA; MOURA, 2016).

The relationship between parents and children with intellectual disabilities shows an infantile characterization in this contact. Parents educate their children thinking about their difficulties and not about the skills that can be developed and/or improved during their development. Thus, children have difficulties in enhancing their own opinion about sexuality, which is sometimes neglected by the family (LITTIG *et al.*, 2012).

Sex education has the knowledge and information that parents, caregivers and other professionals make available and share about the sexuality of these individuals, this allows them to behave appropriately in terms of their experiences and behavioral changes in the face of their sexual maturation. In other words, it is a task that belongs to the family, the school or the professionals involved in the care of children and adolescents. It must start in the family context and expand throughout the life of each human being. In a more systematic way, it should take place through qualified advisors, aiming at: making the person with intellectual disability understand what is happening to their own body; prevent sexual abuse, disclose the main codes that govern sexual behavior, offer subsidies to the family and the institution to address the relationship between them and the person with a mental disability, regarding social behavior (CABRAL; MOURA; MOURA, 2016).

Final considerations

The study points out that the participants in this research, people with intellectual disabilities, know little about sexuality and affective relationships. Still, that their perceptions are formed from daily observations or television and social network programs through which they learn what they believe to be the exercise of sexuality, without having sex education by family members, nor systematized by the institutions in their lives.

There is concern about the scarcity of publications on this topic, considering that research such as these should be published, since sexual activity is considered an activity of daily living and an occupation that occupational therapy is engaged in.

In general, families and educators need a space that provides a moment to provide guidance on sexuality, but they also need support and reference on how to do it. In view of these notes, it is considered that occupational therapy can implement actions to contribute not only to people with intellectual disabilities, but also to their parents and educators, in order to promote guidance for these people, in addition to enabling changes in social representations about the sexuality of people with intellectual disabilities, thus contributing to a greater understanding of the affective relationship of this group and the right to practice and healthy expression of sexuality.

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