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SEXUALITY EXPERIENCE AS FROM REPORT OF PEOPLE WITH INTELLECTUAL DISABILITY [1]

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ABSTRACT. This qualitative descriptive study investigated the experience of sexuality and sexual health from reports of 12 people, men and women, with intellectual disabilities who participated in an interview. The participants showed difficulties in verbalizing concepts about sexuality, but were capable of expressing it without any aloofness or weirdness. They report the occurrence of dating, usually without sex and guarded by adults; when reported, the intercourse occurs in places of little privacy and often without condoms. There are those who covet marriage and reproduction, but also those who postpone or avoid maternity / paternity, revealing choices about their reproductive lives. Due to superficial information provided by an ineffective sex education and taking on affective and sexual lives, they are found in vulnerable conditions. We conclude that the sexuality of people with intellectual disabilities is quite similar to that of other people when referring to the expression of erotic desire and exposure to social standards; this population should receive sex education that contributes to the full exercise of their sexuality and to the respect of their sexual rights.

Keywords: Intellectual disability; sexuality; sex education.

VIVÊNCIA DA SEXUALIDADE A PARTIR DO RELATO DE PESSOAS COM DEFICIÊNCIA INTELECTUAL

RESUMO. Esta pesquisa qualitativa-descritiva investigou a vivência da sexualidade e saúde sexual a partir de relatos de 12 pessoas, homens e mulheres com deficiência intelectual que participaram de uma entrevista. Os participantes demonstraram dificuldades em verbalizar conceitos sobre sexualidade, mas a expressaram sem ser ela ausente ou atípica. Relataram a ocorrência de namoros, geralmente sem sexo e vigiada por adultos; as relações sexuais relatadas ocorreram em lugares de pouca privacidade e quase sempre sem preservativo. Há aqueles que desejam o casamento e a reprodução, mas também os que adiam ou não querem a maternidade/paternidade, revelando escolhas sobre sua vida reprodutiva. Por demonstrarem informações superficiais de uma educação sexual ineficaz e assumirem uma vida ativa afetiva e sexual, encontram-se em condições de vulnerabilidade. Conclui-se que a sexualidade das pessoas com deficiência intelectual é bastante semelhante a das demais quanto à expressão do desejo erótico e a exposição aos padrões sociais e que essa população deve receber uma educação sexual que contribua para o exercício pleno da sua sexualidade e o respeito aos seus direitos sexuais.

Palavras-chave: Deficiência intelectual; sexualidade; educação sexual.

LA EXPERIENCIA DE LA SEXUALIDAD BASADO EN RELATOS DE PERSONAS CON DISCAPACIDAD INTELECTUAL

RESUMEN. Este estudio descriptivo y cualitativo investigó la vivencia de la sexualidad y la salud sexual de los informes de 12 personas, hombres y mujeres, con discapacidades intelectuales que participaron en una entrevista. Los participantes mostraron dificultades para verbalizar conceptos de la sexualidad, pero se expresaron sin estar ella ausente o atípica. Reporte la ocurrencia de las citas, por lo general sin sexo y custodiado por los adultos; sus relaciones

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sexuales ocurren en lugares de poca intimidad ya menudo sin condones. Hay aquellos que quieren el matrimonio y la reproducción, sino también a aquellos que no quieren posponer o maternidad/paternidad, revelando decisiones sobre su vida reproductiva. La información superficial de una educación sexual efectiva hace que se encuentran en condiciones de vulnerabilidad. Llegamos a la conclusión de que la sexualidad de las personas con discapacidad intelectual es bastante similar a la otra como la expresión del deseo erótico y la exposición a las normas sociales y que esta población deben recibir educación sexual que contribuya al pleno ejercicio de su sexualidad y respeto sus derechos sexuales.

Palabras-clave: Discapacidad Intelectual; sexualidad; educación sexual.

Introduction

The scenario of an inclusive society has allowed the struggle for equity of conditions to all people, also considering those with different disabilities who should be included in a social, economic, educational and political context (Priestley, 2001). Disability is understood as a socially constructed phenomenon (Omote, 2004); it is a condition that configures the social identity of a person (added to identities of gender, ethnicity, sexual orientation, nationality, class, etc.). That is, although disability is revealed in an organic body, the social model of disability moves the individual issue to the representations and social conditions that determine it (Mitchell & Synder, 1997; Siebers, 2008).

Sexuality of persons with intellectual disability (ID) still is a controversial subject, even in an inclusive society. This is about a double taboo; on the one hand sexuality, represented by values and various social concepts and, on the other hand, the ID that implies cognitive limitations and carries the stigma of "difference" and "social disadvantage". When these two conditions are associated the question sounds "problematic". However, a greater coexistence of persons with disability and their families with the entire community linked to the clarification derived from researches, have allowed to these persons better conditions to express themselves and to be sexually recognized.

Possible difficulties on the experience of sexuality of persons with ID are more due to social issues, such as attitudinal barriers, than inherent to the organic aspects and thus it is necessary to consider the discussion on sexuality and disability in the social and human rights fields (França-Ribeiro, 2012; Gesser & Nuernberg, 2014). The Universal Declaration of Human Rights, including sexual rights, recognizes that the rights must be equal to all persons, without distinction, including persons with disabilities. However, in the face of the exclusion and invisibility conditions that, even today, these people are living, conventions and legislations are necessary to reaffirm and defend these rights. Documents resulting from the "Convention on the Rights of Persons with Disabilities" of the "World Program of Actions Concerning Disabled Persons", or from the "Charter of Sexual and Reproductive Rights", for instance, highlight the rights of persons with disabilities to constitution and family planning, as well as sexual health, emphasizing the need of attention to ensure these sexual and reproductive rights (Ministério da Saúde, 2009).

Sexuality represents the individual expression of desire that is manifested in different social contexts; involves the forms of feeling affection and emotions and experiencing sexual practices and the expression of socially constructed values (Anderson, 2000; Couwenhoven, 2007; Schwier & Hingsburger, 2007). The intellectual, sensory, physical disability that the person possesses does not imply definitive constraints that exclude the dimension of sexuality, inherent to the human being. However, the social imposition of difficulties to affective and sexual life of these people can limit the exercise of sexuality in an upright manner (França-Ribeiro, 2012; Gesser & Nuernberg, 2014; Maia, 2006).

Erroneous beliefs about the sexuality of the person with ID were propagated from the common sense and from studies that focused on the inappropriate behaviors related to the disability understanding the issue from a medical model and not from a social model and these beliefs helped to reproduce and maintain prejudices (Amor Pan, 2003; Anderson, 2000; Kaufman, Silverberg, & Odette, 2003; Maia & Ribeiro, 2010).

Representations about the sexuality of persons with ID are, in general, different to parents and educators, being among the parents a prevailing idea of an absent and ingenuous sexuality and,

among educators, an exaggerated and aberrant sexuality (Giami, 2004). These beliefs are derived from the observation of behaviors of persons with ID as being "exacerbated" for being public and, perhaps, frequent and "ingenuous" for being of persons considered and treated as "eternal children", whose immaturity and dependency feed a general childishness, also in the field of sexuality (Anderson, 2000; Giami, 2004; Heighway & Webster, 2008; Kaufman, Silverberg, & Odette, 2003).

It can be affirmed that, even today, is common the erroneous notion that people with ID are "oversexed" or "asexual", unable to express their sexuality adequately, healthy and pleasantly. Couwenhoven (2007), Glat (2004), Maia and Ribeiro (2010), stress that the behaviors regarded as inappropriate exist by reasons of a precarious sexual education and not by a question inherent to disability.

Many difficulties in the sexuality of persons with ID occur more for psychological and social reasons (self-steam, shyness, social inability, prejudice and restrictive socialization) than for those organic related to disability or syndromes. An intellectual disability must not be precondition of constraint or prohibition of manifestation of sexuality, including the possibility of exchanging affection, communication, loving, sexual intercourse and also the procreation, social and affective activities that are part of the human relationships (Denari, 2012).

In the period of puberty, the maturation of the biological body and the development of the secondary sexual characteristics of young people with ID occur in the same way as in the persons who do not have the disability, especially in non-syndromic cases (Anderson, 2000; Amor Pan, 2003; Gherpelli, 1995). The body develops with chronological age, but the expression of sexuality will be related to the cognitive and emotional capacity (Schorn, 2005).

Some features are observed in the case of persons with Down syndrome: women are fertile, although they present an increase in the probability of abortion. Men are almost always infertile, because there is a small or absent amount of spermatozoids in the testicles; there is a reduction of facial and axillary hairs and, in some cases, less developed genitals and dysfunctional hormonal fluctuations (Amor Pan, 2003; Moreira & Gusmão, 2002). Despite this, these alterations do not reduce the feelings of affective and sexual desire and the possibility of enjoying love, sexual and reproductive life. Schaefer et al. (2011) describe a study case of a 31-year-old man with Down syndrome who describes behaviors of kissing, hugging and dating that are not different from other youths. He bothers with the short stature, but this is not an obstacle for his affective relationships; he wants to get married, have children, attend college and work, that is, he has aspirations of independence for the adult life.

The incorporation of negative social feelings related to disability can interfere in the expression of sexuality of persons with ID, especially in the adolescence, such as low self-steam and an undervalued image of themselves and this harms the possibility of themselves to feel erotically desirable persons (Amor Pan, 2003).

Besides, generally, the fact of existing, among people with ID, higher difficulty in understanding social rules, need for sexual education and clarifications, the incorporation of a disadvantageous social image, less opportunities to engage and live love relationships, higher control from adults and little incentive to sexual autonomy makes these people vulnerable, physically and emotionally, to situations of violence and/or abuse and sexual exploitation (Glat, 2004; Vieira & Coelho, 2014).

According to Dantas, Silva and Carvalho (2014, p. 566), the gender questions are also important, because they place "the woman with disability in situation of double disadvantage and vulnerability". Paula et al. (2010) also stress that this population is more vulnerable in relation to sexually transmitted diseases (STD)/aids and although the contamination rate has been improved between people with ID, there are few preventive concerns in this respect, perhaps by the belief of their asexuality. Youths with ID, as all human beings, have desires and live their sexuality, however, they tend to act in a less safe manner for physical and emotional health because, according to Vieira and Coelho (2014, p. 210), by reason of the "little or nonexistent sexual education and support, resulting from several taboos and denial of their sexuality on the part of the family and educators, they expose themselves to several risks".

Littig, Cardia, Reis and Ferrão (2012) investigated the conception of mothers of young people with ID about their sexuality and observed that they have an idea of asexuality, dealing with the children in an infantilized and overprotective manner. Believing that their children would not understand a dialogue

about sexuality, many mothers do not provide sexual education and reproduce the erroneous concepts denying their sexuality.

Bastos and Deslandes (2012) studied the narrative of parents of teenagers with ID who observed in their children the self-eroticism behavior that, in the case of parents of boys, this was considered something that occurred due to puberty, whereas for parents of girls, this was something instinctive, without "malice". In all cases, as for the masturbation behavior, this occurred publically and was regarded inappropriate. It was prioritized the reprehension and judgement of an "abnormal" sexuality related to the disability. To reduce the sexual desire of male children, parents cited the use of medications and prostitution; in the case of girls, the concern was pregnancy and it was used sterilization, although this did not prevent HIV/aids infection, or the risks of sexual violence. Attention is given in the discourse of parents to the questions of gender and to the evidence of difficulties for educative and less repressive actions.

Glat and Freitas (1996) consider that people with ID have conditions to express their emotions, desires and feelings. The authors heard 25 men and 26 women with ID who reported about relationships of affection between colleagues of the same institution and dating experiences limited to physical contacts, without intercourse. Most women affirmed that were dating and, sometimes, in a fanciful way: few assumed kissing on the mouth or have had an intercourse. In contrast, among men, kissing on the mouth occurred more times and eight of them reported sex for at least once.

Vieira and Coelho (2014) analyzed the reports of youths with ID about sexuality and sexual education who indicated to receive little information on the part of the family and school. When there was dialogue about this, the main emphasis was the prohibition of sex and the recrimination. Many youths reported dating with family supervision, involving the act of hanging out and kissing, exchange of affections, without sexual intercourse. Three cases reported histories of sexual abuse describing feelings of "suffering, shame, guilt and hard overcoming" (p.207).

Dantas, Silva and Carvalho (2014) analyzed the life history of a woman with ID, revealing in her the overcoming of the stereotype of incapability and the recognition of a sexual condition, with desires and loving and sexual expectations. It is more common for women with ID to get married and have children than for men (Amor Pan, 2003) and the choice of a loving partner will depend on the degree of impairment of the disability and the social support, but in all cases, it is common the expression of affection and the search for love relationships (Gherpelli, 1995).

Some studies have stressed that people with ID have access to information about sexuality; however, they show little understanding about body functioning, sexual relation, pregnancy and birth and some topics are more complex than other topics for understanding (Glat & Freitas, 1996).

In the study of Maia and Camossa (2002) the reports of youths with ID were obtained with the presentation of drawing of human figure, sexed dolls and illustrations with scenes about dating, marriage, self-eroticism, sexual games, menstruation, sexual relation, pregnancy, childbirth, breastfeeding and sexual abuse. From these strategies, the authors concluded that they had notion of a gender identity and diffuse and incomplete knowledge about sexuality, reinforcing the need of implementing programs of sexual education.

Likewise, the authors Morales and Batista (2010) studied the understanding of sexuality concepts of youths with ID finding that they showed doubts, difficulties and values equal to youths without disability. The authors highlight the importance to offer them clarifications recognizing them as subjects of rights and comment that the access to sexual education decreases their inappropriate behaviors.

Sánchez (2011) defends that the persons with ID have affective and sexual rights related to the integrity and possession of their bodies and right to exercise a desirable sexual and affective life and that is possible to have, depending on the personal characteristics and level of support of families/guardians and professionals. Besides, they have the right to receive sexual education in the family and educational centers. To Gesser and Nuernberg (2014) the attitudinal barriers, such as the prejudicial actions, violate these rights.

In this sense, many authors have defended that for the persons with ID to develop socially sexuality, enjoying the right to sexual expression, the right to rewarding affective and sexual relationship and the right to sexual and reproductive health, it must be ensured a complete process of

sexual education (Anderson, 2000; Couwenhoven, 2007; Heighway & Webster, 2008; Sánchez, 2011; Schiwer & Hingsburger, 2007; Walker-Hirsch, 2007; Wilson & Burns, 2011).

In accordance with the literature, this qualitative-descriptive research (Freixo, 2010) had as objective to investigate the experience of sexuality and sexual health from the point of view of persons with ID and, more specifically, the understanding that they have about sexuality and the expectations of affective and sexual relationships, and prevention behaviors and sexual education received.

Method

Twelve persons (four women and eight men) participated. They were diagnosed with intellectual disability with need of broad, extensive and/or limited support, with chronological ages varying between 18 and 39 years old, students of Elementary Education I, coming from an underprivileged social and economic class, who attended a special institution that assists a public of students with Autistic Spectrum Disorder (ASD), multiple physical and intellectual disabilities. The participants were selected through a convenience sample from the indication of the psychologist of this institution and were named herein with the capital letter P, followed by the letter M (woman) or H (man) and by a sequential ordinal number. All ethical procedures were respected, including the request of the signature of parents/guardians and participants in the Informed Consent Form. The project was submitted and approved by the Committee on Ethics of a public university (Case Number 5193/46/01/11). After its approval, it was initiated the data collection. Besides, the rehabilitation institution for people with disability where the participants were recruited also requested the project for evaluation in Committee on Ethics, and the project was approved in the Letter No. 06/2011-CEP.

Data were collected through an interview that was tested in its functionality together with two participants who were equivalent to those of the sample. There was a program of questions about concept of sexuality, sexuality and sexual education received, experiences and expectations about dating, marriage and reproduction and affective and sexual behaviors. Each participant was interviewed individually in a private room in the special institution and all interviews were recorded as audio and transcribed in full for the content analysis, such as proposes Bardin (2011), and proceeding as follows: fluctuating and exhaustive reading of the report and identification of the units of record (a word, a theme) and context (here the stigmatizing condition of disability), defining and naming the theme categories that are characterized as mutually exclusive: (a) Knowledge about sex/sexuality and Sexual Education received; (b) Affective, sexual and reproductive life (Dating/sexual relationships, Expectations of marriage/reproduction; Social patterns of aesthetics/beauty).

Results

Knowledge about sex/sexuality and the sexual Education received

The participants did not know to define and conceptualize “sexuality”; some persons do not do them, others relate to marital and erotic situations such as kissing, sex, marriage and, probably, sexual abuse (“doing evil things”):

> [Sexuality] It is commenting on people. Sex is making love, kissing, getting married (P3H, 18 a)
>
> [Sexuality] I do not know”. [Sex?] I have heard of it before, but I have never seen anyone making it [But what is it?] I do not know how to explain … it is marriage (P4M, 18 a)
>
> *I do not know … it is when the person do evil to others [What would evil be?] I do not know, I forgot … but it is wrong! (P11M, 18 a)*

The participants show a relative understanding about prevention, especially, infection by STD and the use of condom, but not everyone is able to describe appropriately, what would be HIV/aids or other themes of sexuality showing a precarious understanding about the information received and/or an ineffective sexual education:

> *... it is through the uterus that the woman becomes pregnant, the woman has the uterus and the ovary that are transformed into a child when she makes love (P4M, 18 a).*
>
> [Pregnancy] I do not remember; [Birth] The doctor goes in there and cuts the belly and takes the baby out (P7H, 16 a)
>
> *[Aids] Ah, I forgot … [Condom] It is that thing that is placed on the penis … to have sex (P8H, 19 a).*
>
> [Aids] No, I never heard of it. [Birth] I do not know, I never saw this (P9H, 39 a).
>
> *Aids is a disease that kills [Masturbation] It is a liquid [Menstruation?] It is the liquid that leaves the woman. [Pregnancy] Dating, getting married and making love. One person approaches other person, and then this turns into a baby. The belly goes on expanding. The child is born through the umbilical cord (P10 H, 33 a)*
>
> [Menstruation] It is when the blood flows from the woman. You have taking care of yourself, cleaning yourself [Pregnancy] It is when the woman does not use condom, so she becomes pregnant (P11M, 18 a)
>
> [Birth] I do not know how they takes out, but it is in the hospital (P12M, 24 a)

In some cases, the participants with ID related sexuality to television models involving expressions of affection and romance and the internet was also mentioned as source of learning:

> *I watch many soap operas … seeing the man kissing the …the girl in the magazine, the man kissing the girl in this way [Aids] I do not know, I only saw on television … No way! It must be used condom, you must not have sex without using condom (P1M, 31 a).*
>
> *… in soap opera has… I always do internet researches (P4M, 18 a).*
>
> *... I like to see the girl naked… I have already seen sex, I saw on a website (P8H, 19 a).*
>
> *… I watch (laughs) woman having sex with man, naked woman… touching her tits, vagina; in my house, I have a lot of DVD that my brother bought me. I also watch the movies from Bandeirantes Channel, but just on Saturdays. I have a lot of funk DVD….of watermelon woman, melon woman (P10H, 33 a).*

It was also noticed the reproduction of defining standards of normality from a sexual education with a heteronormative view of sexuality:

> *… man dating another man, I have already seen; a man kissing another man. No, it is not right, because man cannot kiss another man, this has to be with woman (P6H,16 a).*
>
> *… gay is woman who likes woman. It is wrong, because man must like woman. Also, there is man who likes man … but it is wrong. [Who said that for you?] My teacher said that (P11M, 18 a).*

The participants with ID showed a sexual education that has not yet reached the goal of clarifying, informing and preparing them for the autonomy of their sexuality. The little information that they received was provided from physicians, psychologists and some relatives. They talk about the issue with difficulty, showing that they have already received guidance on sexuality, or have already heard of many things, but they have a precarious knowledge. According to some reports, the clarifications occurred on the part of some professionals, such as physicians and psychologists from other institutions, who focused specifically on the use of condom as prevention, even though this may sound a limited and senseless information for them. Only a young girl seemed to be informed receiving

explanations from several sources, showing the importance of repeated and systematic sexual education:

> [Do you talk about this?] No. [Your father?] No. [With friends?] No. [Aids] No way! It must be used condom (P1M, 31 a).
>
> *… But … ah … condom, you have to use condom, to avoid contracting disease [Aids] So you cannot get Aids [Where did you hear of this?] "at the doctor" (P2H, 37 a).*
>
> *T. (friend) explained me: be careful and use condom not to get Aids. [Aids] it is a worm that enters the body. Then you have to use condom. (P3H, 18 a).*
>
> *... she speaks (mother) that if I am having sex with my boyfriend one day, to get pregnant … she says to take care of myself… with my friend … [Aids] It has to be used condom to avoid contracting… teacher explained to us, the psychologist, my mother my grandmother explained (P4M, 18 a).*
>
> *… "Aids kills" [Where did you learn this?] At the … (mentioning the institution and the psychologist who was assisting him) (P5H, 18 a).*

Here, it is observed the gender differences with the concern of educators about the use of condom for prevention, being used to avoid STD, when dealing with boys, and to prevent pregnancy, when dealing with girls.

Affective, sexual and reproductive life

Dating and sexual relationships

Some participants do not date and never dated; others become involved in relationships with or without the occurrence of sexual intercourses. In general, they describe dating with well-infantilized attitudes of fellowship and friendship, reporting walks and exchange of kisses, always under supervision of an adult that, generally, is the mother:

> *Walks, dating … I go to his house, then he comes to mine, and my mother helps (P1 M, 31 a).*
>
> *I date R., I am his boyfriend … it is been a while... it is certainly good [How do you date a girl?] well, kissing, hanging out, going to the mall, giving caress …sex, being naked, out of the question … R.'s mother takes her to the meetings. She likes me (P2 H, 37 a).*
>
> [Sex] I have never had sex; I wish I could have. I have already dated, but I broke up … she replaced me with another. [If did I kiss on her mouth?] No. It was only friendship [Sex?] At the right time. I do not know when my time will come. I am single. I had never kissed a girl on the mouth (P3H, 18 a).
>
> [Have you ever dated a boy?] Twice … we talk, date a while, go out to date… we walk. [Does your mother know about him?] She does, she likes him very much … yes, we kiss each other on the mouth, but not touching with the hands, he respects me about this … I have never had sex in my life; I want to have sex after I am married (P4M, 18 a).
>
> *… I have never dated … I want it, because it is good [How do you know that it is good?] I imagine that it is good (P5H, 18 a).*
>
> *[What is dating?] I do not know, but I know people who date. I am not going to date…not yet! (P11M, 18 a).*
>
> *I have already dated S., but now I am no longer dating. Once I dated C., but I am also no longer dating her. Did you know what she did once? She rubbed her legs against my penis. Then her friend saw and she stopped (P10H, 33 a).*
>
> *I almost have not seen E, only on weekends. He goes to my house and then we stay in the living room. [How do you date?] kisses and hugs [do you have sex?] No! Really? Not Yet! (P12 M, 24 a).*

In some cases there are reports of sexual intercourses and in these situations, it is unveiled the vulnerability in the fact that they occur in places with poor privacy and without preventive behavior against the infection by STD or pregnancy:

> *I had this there at my mother's house. I had sex. Then she broke up and left me [Did you use condom?] No, I do not remember, I do not know (P7H, 19 a).*
>
> *I had sex with a girls at the school … she was my girlfriend… it was good… in the toilet, hidden, I had sex with her and nobody saw, only with her (P8H, 24 a)*
>
> *Yes, I had (sex). Yes, it was (good), it was in the street, nobody saw us (P9H, 39 a)*

However, we also found the report of a man who said to use condom during the sexual intercourses that he had with the girlfriend, hidden from his mother. The brother is the social support for clarifications, in the case, for payment of costs or providence of condoms:

> [Sex] I have already had (laughs) with a woman who my brother paid for me to go to the motel, but this was a long time ago. (with the current girlfriend). At her house… she sits beside me in the sofa. This makes me horny!! (laughs). You have no idea … my dick gets hard. Then we kiss each other. We grasp each other… then we go to the bedroom, but just when it is dark, otherwise her mother gets mad … we have to use condom, haven´t we? Did you know that one day she even placed the condom on my penis? … my brother gives me condoms (P10H, 33 a).

The love and sexual relationship or the desire of these occurrences appear in the discourse of these youths, as well as we observe in youths who do not have disability. In this group, girls did not report experiences of sexual intercourses.

Expectations of marriage and reproduction

The interviewees see possibility of a married and family life, with marriage and affiliation, but they would not assume this experience at the current moment, whether because they do not consider themselves able to this or because they incorporated the idea that this would be difficult or, even, because they occasionally express a planning to the reproductive life. It emerges the argument that to have and raise children is hard work and a man participant, with Down syndrome, is concerned with the possibility of also having a child with this same syndrome. In the general, this group of people with ID does not show themselves as irresponsible or incapable of autonomous choices.

> [Child] Only one, a girl (P1, M, 31 a).
>
> [be married, have children] R. wants [Do you?] I do also [be married] I think, but … later, in the future (P2H, 37 a)..
>
> *I want to get married one day. However … I have to complete 18 years old first … Oh! No girls appear to date me [Children?] I never had [Do you want?] No, only woman has children. [Would you be a father?] Yes, I would (P3H, 18 a)*
>
> *… oh, I think that it is important, when I get married … then I would be happy, wouldn´t I? [Children?] I want to have only one, they require a lot of work … I do not want to have children yet, but when I get married I will quite enjoy the marriage, and only later I will think about to have children (P4M, 18 a).*
>
> [Marriage?] I want, [Children?] Oh, they require work, wake up early, such as my tiny nephew (P5H, 18 a).
>
> [Marriage?] It will take long. [Children?] They take a lot of work … no, I do not want (P11M, 18 a)
>
> [Marriage?] Yes, but I want to be very rich (laughs) [Children?] No, Down like me … oh! perhaps … imagine how cute they would be … This is prejudice, you know, for me to say that I do not want Down, just like me. Disabled or not I will love my baby (P10H, 33 a)

> [Marriage?] No, never [Children] Wow, worse, I do not want. I like kids, but I do not want. It is better not to have (P12M, 24 a).

It is interesting to notice in the report of some participants, the realistic perception that caring for a child requires work and dedication and that they would not be prepared or willing to this; and the report of the boy P10 who assumes the fear by the birth of a child equally stigmatized by the disability.

Social standards of aesthetic and beauty

In the reports, some participants are satisfied with their bodies; others reported a wish to improve their appearance, especially given the current aesthetic standards, such as the slim body. The "beautiful" body means either the expression of self-esteem, as well as the possibility or guarantee of loving bonds. More than this, one girl attribute the unhappiness with a loving partner (get a girlfriend or get a marriage) to the body that can be modified with cosmetic surgery, for instance.

> [What part of your body do you like the most?] arm … forearm … and legs. Also feet (P1M, 31 a).
>
> … Yes, it is beautiful (the body); [Does your girlfriend like?] Yes. [Is she beautiful?] "Yup". [What do you like most about her?] Her …her face. (P2H, 37 a).
>
> [Body] Beautiful [Do you want to change something in it? No (P5H, 18 a).
>
> … May a woman like me chubby? … My body is a little … chubby. Belly, I cannot stand it anymore. [What part of your body do you like the most?] "From here to here" (he showed the legs). [Do people think you are beautiful?] They do not get too close (P3H, 18 a).
>
> *I think my body a bit ugly … [What would you change in it?] I would make plastic in my nose, mouth, belly; I would make a stomach reduction, my dream is to make a reduction, but we have no money... I am too fat… and I cannot lose weight … I want to have sex after I get married … I want, and I want to be skinny with stomach reduction to marry him (P4M, 18 a).*
>
> *Am I good looking, don´t you think? But I wanted to change the belly. Belly is ugly. It is too fat. I have to take more swimming (P10H, 33 a).*

It is emphasized here, the expression of existing sexual repression imposing defining standards of normality regarding an aesthetic model, and in addition, not being "beautiful" for this group of persons with ID does not appear related to the stigma of disability, which would be possible somehow to occur.

Discussion

The participants have a restrictive view of sexuality related to the sexual body and sexual practices and they do not conceive the phenomenon of sexuality as being social and historical, as Anderson (2000), Couwenhoven (2007) and Schwier and Hingsburger (2007) argue.

Besides, Vieira and Coelho (2014) also found these data in the understanding about sexuality of youths with ID as something biological restricted to prevention and hygiene.

Sexuality is a fundamental aspect in the lives of all people (Heighway & Webster, 2008). Although people with ID can demonstrate difficulties to express or talk and verbalize concepts of sexuality, they are sexual beings and in much of their experiences, express similarities with people without disabilities, meeting the claims of Anderson (2000), France- Ribeiro (2012), Glat, (2004), Gherpelli (1995), Maia (2006) and Schorn (2005).

The participants express sexuality through affective and love relationships, but they are still treated in a childish way, without privacy and with parental overprotection (Anderson, 2000; Dantas, Silva & Carvalho, 2014; Giami, 2004; Walker-Hirsch, 2007).

They engage in romantic relationships, often without sex, reaffirming the claims of Amor Pan (2003), Vieira and Coelho (2014), Gherpelli, (1995) and Glat and Freitas (1996).

The fact that they are treated as "eternal children" can direct the behavior of adults to allow the "dating" under supervision, because this relationship is seen as "childish" or because they fear a sexual relationship that necessarily will raise risks and problems. This, however, does not prepare the young people for the responsible exercise of their sexuality, because this feeds dependency and immaturity.

In the study of Dantas Silva and Carvalho (2014), there were also attitudinal and social barriers, once behind the discourse of freedom and encouragement of affective relationships of parents, there were restrictions and control over the sexual life of their daughter with DI and her boyfriend, being justified by the argument of "protection." Similarly, Vieira and Coelho (2014) emphasize the attitude of parents who, trying to protect their children, "seek strategies to avoid them from having more intimate relationships" (p.209). Alternatively, they hire a prostitute to satisfy the sexual urges of the male child, as also is observed in the study of Bastos and Deslandes (2012).

In general, participants wish dating, marriage and reproduction but demonstrate ability to think about this, even in the case of reproduction, thinking about this in a future life, and in some cases, they choose not choosing neither marital nor maternity / paternity. It is important to highlight that, despite the limitations on the understanding of sexuality, there were those who considered marriage and reproduction as something to be decided by themselves, appearing as a deferred or unwanted plan, showing a condition of maturity and autonomy, contrary to the notion that people with ID are always uncontrollable and inconsequential with their sexuality.

Another point to highlight is that people with ID are also affected by rules and repressive social models and they value the ideal body related to thinness and also follow a heteronormative view. The model of social beauty influences the construction of the human eroticism and this is intensified when the body has a disability that is out of the standard imposed (Anderson, 2000; Couwenhoven, 2007; Kaufman, Silverberg & Odette, 2003).

The reports clarify the myths and prejudices about the sexuality of people with disabilities, as described in the literature (Anderson, 2000; Giami, 2004; Heighway & Webster, 2008; Kaufman, Silverberg & Odette, 2003), mainly, explaining that they are people who feel sexual desire as others, without this being uncontrollable or atypical. They also aim dating or already have a relationship; and they have sexual life or not depending on opportunities and not on intellectual limitation; that is, they live a sex life that, according to Gesser and Nuernberg (2014), should be supported by the sexual and reproductive rights.

It is also evident that, although they have love and sex life, there is lack of information and the knowledge about sexuality is superficial, as Couwenhoven (2007), Glat (2004), Glat and Freitas (1996) and Maia and Camossa (2003) commented to occur. Some cited the Internet and television as sources of information about sexuality, as it was observed in the study of Vieira and Coelho (2014).

Sex education coming from family, school and even professionals, when occurs, seems to be deficient and prioritizing preventive issues without the due explanation, as also recorded by Glat and Freitas (1996). Gender issues were also perceived in the preventive discourse of educators, by making differences when it comes to boys and girls, highlighting this important discussion that, in this case, has no relationship with disabilities, because this sexist education is generally present.

Several authors have shown the need and the importance of sex education and proposed educational actions for people with disabilities, whether to reduce the risk of violence, disease, lack of family planning, or to ensure them a full and satisfactory sex life (Couwenhoven, 2007 ; Heighway & Webster, 2008; Maia, 2006; Schwier & Hingsburger, 2007; Walker-Hirsch, 2007; Wilson & Burns, 2011).

It is important to notice that, the participants receive sex education that is informal and unsystematic, and this is insufficient. Thus, it is defended the need to provide formal and planned sex education to ensure the pleasant expression of sexuality as well as sexual and reproductive health to reduce the vulnerability in which they live, as alert Glat and Freitas (1996), Vieira and Coelho (2014) and Paula et al (2010). In this respect, France-Ribeiro (2012, p.43) points out that the development of the sexuality of people with DI should be part of an "inclusive sex education", and argues that sex

education programs aiming at these people should respect the differences and exist as a goal for the fulfillment of human rights, including the sexual rights.

Final considerations

The results corroborate previous studies whose protagonists were people with ID, mainly with respect to the genitalized understanding of sexuality, superficial sex education, expression of erotic desire, of dating generally devoid of sex and supervised by adults or of vulnerable sexual practices, in addition to marriage and reproduction expectations. What has drawn attention as a new element was the concern with aesthetics as a condition for loving happiness, a central element in the current studies on sexual repression and that demand further researches on the defining standards of normality in sexuality, also imbricated in gender issues, when associated with stigmatizing condition of disability.

The reports show that people with ID express their erotic desires as others, without being "absent" or "exaggerated", they live loving and sexual relationships, even though , in many ways, it is a "childish" dating and under supervision of adults. The relationship between sexuality and ID, observed in the analysis of the reports, corroborates with other national and international studies: the existence of social prejudice, unveiling of sexual myths, a precarious sexual education, the psychosocial and non-organic difficulties of the sexual experiences that place the person with ID in a condition of vulnerability.

As this is a qualitative research, there is no pretension to generalize the data, but the reports both show a convergence with the consulted literature and raise important discussions, such as gender issues and the influence of aesthetic standards and normative values that deserve deepening in new researches.

People with disabilities are sexual beings, have voice on their desires and report possibilities and difficulties of expression of their sexuality, arising mainly from educational and social processes, which may favor or not the autonomy that they need to fully experience sexuality in adulthood. The conclusion is, there is the need to invest in educational projects both for families, professionals and educators involved, and for people with ID, because everyone has the right to expression of sexuality and guarantee of conditions for sexual and reproductive health in an inclusive society .

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