Sexual rights, public policy and sex education on the discourse of blind people

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Abstract

This study seeks to analyze how people with congenital blindness realize their right to sexuality. Eleven blind people participated, of both genders, aged between 22 and 54 years, enrolled in two institutions to support the visually impaired in the city of Feira de Santana/Bahia. There were interviews and focus group sessions, analyzed qualitatively, articulating empirical data and assumptions of bioethics. Three categories emerged: 1. The right to sexual expression, little respected; 2. Assessment of blind people regarding public policies focused on sexuality; 3. Reflections on sex education. The results revealed: feeling of dissatisfaction, disrespect from society to sexual rights; awareness and need to seek their rights; scarce public policies or not accessible to the blind people; need for appropriate sex education to their needs. We conclude that blind people are still invisible and vulnerable. We advocate sex education as a path to social inclusion.

Key words: Sexuality. Blindness. Public policies. Bioethics.

Resumo

Direitos sexuais, políticas públicas e educação sexual no discurso de pessoas com cegueira

Este estudo objetiva analisar como pessoas com cegueira congênita percebem seu direito à sexualidade. Dele participaram onze pessoas com cegueira, de ambos os gêneros, com idades entre 22 e 54 anos, de duas instituições de apoio ao deficiente visual em Feira de Santana/Bahia. Realizaram-se entrevistas e sessões de grupo focal, analisadas qualitativamente, articulando dados empíricos e pressupostos das bioéticas. Emergiram três categorias: 1. O direito à expressão da sexualidade, pouco respeitado; 2. Avaliação das pessoas com cegueira, no tocante às políticas públicas voltadas para a sexualidade; 3. Reflexões sobre educação sexual. Os resultados revelaram: sentimento de insatisfação, desrespeito da sociedade ao direito à sexualidade; consciência e necessidade de buscar seus direitos; políticas públicas escassas ou não acessíveis às pessoas com cegueira; necessidade de educação sexual adequada às suas condições. Concluímos que as pessoas cegas ainda se encontram invisíveis e vulneráveis. Defendemos a educação sexual como caminho para a inclusão social.

Palavras-chave: Sexualidade. Cegueira. Políticas públicas. Bioética.

Resumen

Los derechos sexuales, la política pública y el discurso sobre la educación sexual de las personas ciegas

Este estudio tiene por objeto examinar y analizar cómo las personas con ceguera congénita ejercen su derecho a la sexualidad. Once personas ciegas participaron, de ambos sexos, con edades comprendidas entre los 22 y los 54 años, inscritos en dos instituciones para apoyar a los discapacitados visuales en la ciudad de Feira de Santana/ Bahía. Fueron realizadas entrevistas y sesiones de grupo focales, analizadas cualitativamente, con la articulación de los datos empíricos y las hipótesis de la bioética. Surgieron tres categorías: 1. El derecho a la expresión sexual, poco respetada, 2. Evaluación de los ciegos en cuanto a las políticas públicas dirigidas a la sexualidad, 3. Reflexiones sobre la educación sexual. Los resultados revelaron: sensación de insatisfacción, con poco respeto a su derecho de la sociedad al derecho a la sexualidad, la conciencia y la necesidad de buscar sus derechos, las políticas públicas escasas o no accesibles a la sexualidad del ciego; necesidad de una educación sexual adecuada a sus necesidades. Llegamos a la conclusión de que las personas ciegas siguen siendo invisibles a los ojos del Estado y de la sociedad, en una situación vulnerable. Seguimos en favor de la educación sexual como un camino hacia la inclusión social.

Palabras-clave: Sexualidad. Ceguera. Políticas públicas. Bioética.

Aprovação CEP UEFS nº 119/2011

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She declares no conflict of interest.

World Health Organization (WHO) classifies visual impairment in categories ranging from mild vision loss to total lack of vision. The International Statistical Classification of Diseases and Related Health Problems (ICD-10) defines blindness as a function of visual acuity in the better eye [1]. The International Classification of Functioning, Disability and Health (ICF) describes functioning and disability related health conditions, identifying what a person *can or cannot do in their daily life* [2], considering the functions of the organs or systems and structures of the body as well as the limitations of social activities and participation in the environment where they live.

In 2002, the International Council of Ophthalmology associated criteria of ICD-10 and ICF and proposed a categorization of visual impairment, revised in 2003 in conjunction with the WHO. It suggests that the term *blindness* should be used only for total loss of vision in both eyes and when the individual needs special aid to replace his visual skills [3]. In this study we use the terms *blindness* and/or *blind person* when we are referring to congenital blindness with total loss of vision in both eyes.

According to the 2010 Census, in Brazil there are 45.6 million people with a disability, representing 23.9% of the population. Visual impairment affects 35.8 million, of which 506,300 are blind – namely 0.3% [4].This significant number of people that deserves attention in order to know the reality lived by them in relation to their citizenship rights.

The Brazilian Constitution of 1988, Article 10, section III, elected the principle of human dignity as one of the foundations of the Federative Republic of Brazil [5]. *The Universal Declaration on Bioethics and Human Rights* establishes as principle (Article 3) *that human dignity, human rights and fundamental freedoms must be respected in their entirety* [6]. Convention on the Rights of Persons with Disabilities has the purpose to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all people with disabilities and to promote respect for their inherent dignity [7], legally defending those rights conquered. Despite the assurances defined in these instruments, in our society, the sexuality of people with blindness, as well as other people, is loaded with prejudices, stigma and inequalities that can worsen their situation of vulnerability.

According to Garrafa and Porto [8], only through the recognition of differences and diverse needs of individuals we can achieve social equality. In this perspective of recognizing the society in its diversity and plurality is that we can, in fact, socially include all human differences. Thus, we understand how important it is to insert this topic – sexuality of people with blindness – in bioethical discussions.

In this sense, this paper aims to reflect on rights, public policy and sex education for the blind people, supported the assumptions advocated by bioethics as dignity, citizenship, autonomy, care, tolerance, otherness and others – especially on a bioethics committed to social issues of neglected minorities. To do so, it was aimed to identify and analyze the perception of people with blindness regarding their sexual rights, from the experience of two institutions goers to support people with visual disabilities.

Method

This is an exploratory-descriptive study of a qualitative nature. The project was approved by the Ethics Committee on Human Research of the State University of Feira de Santana, Bahia. The study was conducted with the voluntary participation of people with congenital blindness attending the Pedagogical Support Center for the Visually Impaired of Jonathan Telles de Carvalho Foundation and Feirense Association of Visually Impaired in the city of Feira de Santana. These institutions were selected because we could only find in them people that met the inclusion criteria of search.

Inclusion criteria were: being blind diagnosed with total blindness to two years of age; not showing another loss associated with blindness; being older than 18 years old and younger than 65 years old. Six men and five women participated in the survey, all with congenital blindness, aged between 22 and 54 years old and with education level of the complete primary education to incomplete higher education.

Data were collected through individual semi-structured interview based on the following guiding questions: *How do you notice your right to expression of sexuality? Do you think this right is respected?* After the individual interviews three focus group sessions were conducted as complementation strategy and perception of group behavior.

Data collection began in April and ended in July 2012. Interviews and focus group sessions were conducted at the premises of the two institutions mentioned, after the participants agreed to participate in the research by presenting and signing the informed consent (in Braille). With the consent of the participants, the two procedures for data collection were recorded.

For the identification of the participants, we used words referring to sexuality, which were chosen by them, such as: Elegante, Amorosa, Sensual, Carinhoso, Coração, Afetuosa, Apaixonada, Sedutor, Belo, Delicado e Comunicativo.

After transcribing the interviews and focus group session the data were subjected to content analysis, which, according to Bardin [9], consists of a systematization of objective procedures to describe the content of messages, and the indicators (quantitative or otherwise) that may lead to the inference of the conditions of production and reception of these messages. The analysis took place in three stages : 1) comprehensive analysis seeking a shared vision and understanding of the particularities of the interviews and the material generated in the focus group, identifying the themes expressed in the statements; 2) conducting clippings excerpts of testimonies from horizontal reading aimed at identifying the similarities and different ideas of the participants; 3) vertical reading to analyze how each participant was manifested before themes that emerged, showing what else was repeated (expressions , words and phrases) and indicating concepts and theoretical expressions for the rights to the sexuality of the blind person, seconded by the clash between the individual statements with the statements of the group. Finally, there was a link between the empirical material (interviews and focus group) and the theoretical frameworks of research, trying to answer the guiding questions, based on the proposed objective, through three categories: 1- *The right to expression of sexuality, which is little respected*; 2- *Evaluation of the people with blindness, regarding public policies on sexuality*; 3- *Reflections on sexual education*.

Results and discussion

Perception of little respect for their rights

The rights of free exercise of sexuality, parenthood and family planning are covered in various international documents, such as Article 16 of the Universal Declaration of Human Rights: *From the marriageable age, men and women have the right to marry and found a family, without due to race, nationality or religion constraint* [10]. Similarly, the Convention on the Rights of Persons with Disabilities also provides, in Article 23, the right to a family, fatherhood, to the appropriate information to family planning: *the United Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others* [7].

We also understand as a right to sexuality *the right to live and express themselves freely without violence, discrimination and charges and with full respect for the body of partner; right to safe sex to prevent unwanted pregnancy and STD/HIV/AIDS; right to health service that ensures privacy, confidentiality and quality care and without discrimination; and right to information and sexual and reproductive education* [11].

Although the right to exercise the sexuality of people with disabilities is included in general or specifically in these official documents, some study participants converge on the perception that their right to sexuality is little respected: "*The right to sexuality blind person is barely respected, there is not all this respect in fact... I'd say that there are those who joke about this, the sexuality*" (Sedutor). Prejudice was also mentioned by respondents as a way of not respecting their rights, as revealed in the following quote: "*Sometimes yes sometimes not, when a person is prejudiced with the blind person they do not respect their right, they try to get away from them*" (Amorosa).

According to Anache [12], the difficulty in accepting blindness by society can bring problems for the social inclusion of people with this disability, since inclusion is a complex process that involves both mutually blind person and the context that they are inserted. Some participants referred to this difficulty alluding to the lack of understanding of the family as well as society. They state, however, that the right to exercise their sexuality and other human rights must be sought by each individual, as shown by the following statements:

"There is a lack of understanding of families, people in general to accept the blind person and respect their sexuality... I think our right is not respected, now we have to search each day to show that we have the same rights than other people" (Elegante);

"We, people with disabilities, we have to appreciate ourselves, it is about being better than the others, it about being as important as the others, I think it has to be this way to overcome prejudices" (Coração).

Once again the feeling of these people is strengthened in relation to the lack of understanding and respect for their sexuality, evidencing their rights in seeking the role of family and the need of citizenship. The awareness of the need to seek their rights may reflect the inclusion policy instituted in the country, which drives these people to be aware of their rights and seek to live their sexuality freely, despite the discrimination and social prejudice still existing. It can be seen that, even if they do not fully meet its objective or that in some respects cease to focus on specific groups of people with disabilities, as will be seen below, the public policy area can be connoted as mechanisms of social awareness of the matters relating to the rights of disabled people.

In this sense, for Rios [13] the democratic right to sexuality, rooted in the principles of human rights and fundamental constitutional rights must act simultaneously towards the recognition of equal respect to the various manifestations of sexuality and equal access *for all, without distinction*, to necessary goods for life in society. In the comparison of individual and group speech is evident the feeling of dissatisfaction with the behavior of blind people with society regarding their sexuality. They seek to justify this behavior referring to the lack of knowledge about the blind person and their ability, not only in the field of sexuality, but in all fields of life.

It is clear, therefore, that awareness of participants' rights and the need to search them in order to minimize prejudice; we understand as a citizen attitude. We believe that this manifesto showed by interviewees may be the mechanism to encourage the construction of morals able to respect differences and to alienate the injustices, promoting thereby the child care for the other [14], in an attempt to minimize bias in regarding the sexuality of people with blindness. Such attitude can extend care to others with a view to balancing society that shows unilateral, with lack of care and services that create loveliness.

Assessment of blind people regarding public policies on sexuality

All participants were unanimous in stating that there are no public policies – related to sexuality – facing blind people, as evidenced by these statements below:

"The lack of policies for blind people is normal, so we try to make everything about politics in general" (Comunicativa).

"There is none... It's a little discussed topic, people do not approach that subject, it is difficult" (Sensual).

"I think information materials are not easy, you know, those ones about sexuality available to people with disabilities are few, the person has to want it, because if you depend on information materials you can't learn anything about it" (Apaixonada).

Supported in intervention bioethics area [15], which proposes bioethics politically committed to the needy and also the recognition of the social responsibility of the State in order to promote and foster the release, emancipation and empowerment of individuals, groups and vulnerable populations [14], it is inferred that it is the duty of the State to provide blind people an effective participation in policies for the sexuality of the disabled. While there are initiatives in this sense, such as disabled public policy of health of the disabled person, which contains specific guidelines relevant to sexual and reproductive health of people with disabilities, for example, the exhortation to recognize the *right to expression and experience of sexuality, addressing the theme always in a judicious and ethical way, as part of the attention to sexual and reproductive health* [16], this strategy does not seem to respond to the needs and desires of people with visual impairments.

Therefore, it is urgent to direct specific actions for this audience, considering their inability to achieve informational materials such as brochures, films and others which are not translated into Braille – language accessible to blind people literate in the method. It is also necessary to consider that there may be blind people not yet fully literate in Braille, for which it is appropriate that there were also other types of information material in the audio format, for example, aimed to facilitate their seizure of information. Thus, as the intervention bioethics presupposes, the public policy implemented by these guidelines could encourage an attitude of liberation, which is one that promotes favorable policies for vulnerable (in this case, blind people), in order to offer them conditions for the expression of sexuality in a safe and healthy way.

Some participants reported to the lack of inclusion of the blind in public policies focused on the prevention of sexually transmitted diseases STD/HIV/AIDS: "*Such policy doesn't exist, the policy available there is the STD/AIDS, that is for everyone, they do not bother to explain to the visually impaired. Public health agencies should invest in this area, but the thing is looked upon with much disdain and disregard, I think they think that blind does not have sex*" (Sedutor).

The vulnerability of these people is evident in this speech, which indicates that the state ignores that this group of the population, that is sexually active and does not receive due attention, is vulnerable to contamination and transmission of STD/AIDS.

Studies conducted by organizations Aids-Free World [17] showed that people with visual impairments are at risk of becoming infected with HIV at over twice proportion that of the general population. Therefore, the absence of proper public policies to the needs of the disabled, presented this speech, appears as problematic as it is considered that the number of blind people in Brazil is not small. Thus, the lack of information available to the visually impaired through public policies adapted to their needs, denotes little respect for ethical and epidemiological principles of public health.

According to Cordeiro and Pinto [18], the disabled person must be regarded by the health system as an autonomous and law subject, including sexual and reproductive rights. Regarding the visually impaired, so that these rights are preserved and respected, the production of materials and the development of methods of transmitting knowledge able to report effectively become urgent, without creating or increasing the embarrassment that sometimes surrounds the discussion of theme. Furthermore, it is essential to build a network of reference and counter-reference among health care services of the person with disabilities and specialized in STD/AIDS, which will ensure comprehensive and fair care.

It is important to note, however, that since 2006 the National STD and AIDS has been developing discussions with the goal of elaborating strategies for integrating theme disabilities to public policy actions in the area of promotion of sexual and reproductive health and the prevention and care for STD and HIV within the country. From these discussions there have taken advice on cross-cutting issues in the area of prevention and care of HIV/AIDS on four pillars: alliances; public education and communication; participation and empowerment of people with disabilities; and monitoring, evaluation and research [19]. As seen, public policies exist but they have not been effective to the point of reaching all disabled people, as reported by the participant.

In the confrontation between the individual lines and the focus group, it was also possible to see that the issue of accessibility to the programs is striking. Respondents consider that the policies exist but they are not accessible. They reported a great difficulty to get up in the daily life other rights to health, such as queries and gynecological exams. Therefore, it is evident the dissatisfaction of those people with the health system, which they consider disrespectful to their citizenship rights.

Gil and Meresman [20] agree with the perception of respondents, arguing that initiatives aimed at raising awareness and prevention of STDs and HIV/AIDS for people with disabilities are isolated (i.e., restricted range), sporadic (they do not have continuity), they rarely preserve accessibility (use language and inadequate media to the target audience), they do not document the process nor the results and do not promote the exchange of information between those responsible for them. Then, in the perception of respondents and expert analysis, one can only argue it is essential that State action is effective, both in order to consolidate access to services as promotion of existing programs to provide assistance to people with disabilities. Moreover, it can be inferred in their speech the importance of improving those programs, taking into account the peculiarities of the various types of disabilities and systematization of sex education aimed at this population.

Reflections on sexual education

In recent years, some researchers have devoted themselves to the study of sexual education and disabilities, bringing important contributions to society to clarify that these people have the same needs and rights of expression of sexuality as the other citizens [21-23]. The participants of this study show converging ideas, considering the importance of sexual education to their lives: "*I think sexual education important because so we'll understand more things and treat it as a normal thing. We wouldn't be so shy if we had to deal with things related to sexuality, so I think that's pretty good*" (Belo).

This statement reveals the need that these people must be recognized as social beings in their fullness. Like any individual, they need to find space to hold the desire to love and be loved, demonstrating ability to express their sexuality in the social environment and achieve their reproductive and marriage aspirations, which are something important for social integration. The affirmation of sexual life is crucial for the development of personality, especially during adolescence and youth, when everyone tries to demonstrate to themselves and those around them, that they are desirous of human emotional and sexual life, as everyone else [24].

Another aspect discussed was the need for sex education for the blind person to start from childhood, as reports this participant: "*Sexual education* *is very important, since childhood; when I was a kid I was analyzing how the sexual organ of women would be, the one who are able to see it looks a child and he knows how, and he knows the difference of the male body and the female body and the blind child doesn't have the opportunity to see it, it is important that they know the difference of male and female sexual organ*" (Elegante).

There is no doubt that the first guidelines for sexuality must occur in the home environment, and the notions that were cited, should be incorporated in a natural way. However, when it comes to sexuality the family does not always cooperate, because it involves taboo issues, shame and lack of knowledge on the part of family.

According to Alzugaray and Alzugaray [25], it is easy to hide the reality of the blind child; for example, some people hesitate to give names to the genital areas and do not allow the children to know certain body parts of other people. Thus, it can be mistaken as to the size, shape or location of the genitals. Therefore, it is necessary to familiarize them since childhood with their shape and function, both their own sex and the opposite sex. This procedure may contribute to their protection against abuses, minimizing their vulnerabilities.

It is important that young people and adults with any kind of disability learn to know the functioning of their bodies and receive adequate information in order to protect themselves from abuse, prevent sexually transmitted diseases and live in the fullness affective and sexual desires in a socially accepted form. In addition to information, it is desirable that blind people experience sexuality as social behavior expressing affection, libido and pleasure [26].

Sexual education was also identified as a means of acquiring specific knowledge, thus enabling the breaking of prejudices towards sexuality of these people, as revealed by the following statement: "*It would be interesting if I had had sexual education to teach more, encourage and break more prejudice*" (Amorosa). If prejudice is a positive or negative attitude, prior to any knowledge, and stereotyping is the achieving of a qualitative judgment based on prejudice [27], then sexual education for everyone, including disabled people, can contribute to social inclusion, softening prejudice.

The teaching resources which are facilitators of the teaching-learning process were also claimed by the research participants, as revealed by the following statement: "*It's interesting that blind people have sexual education, it doesn't need to be a special method for the blind, they can usually participate as any other person, what is needed is a proper and ready stuff... and then we can go far...*" [laughs] (Comunicativa).

In fact, blind people are fully able to understand the contents discussed in the proposed sexual education directed to non-blind people; what is lacking is a proper material to meet their needs. Some authors suggest that for the visually impaired is ideal using concrete objects to be touched, with specific textures, shapes and forms that facilitate the understanding of what is intended to explain [28,29]. Thus, people with visual disabilities can acquire knowledge about sexuality, enabling their manifestation safely and pleasurably.

In the comparison of individual lines and the focus group, it was confirmed the perception, by respondents, of the need for sex education that takes into account the limitations of blind person, in order to facilitate to them acquisition of knowledge, thus contributing to the personal and sexual development.

Final considerations

Despite the existence of official documents that ensure sexual and reproductive rights of people with disabilities, respondents considered that these rights are poorly respected by society, but they showed to be aware of them and the need to get them. We discussed the need for society to aggregate the value of otherness proposed by intervention bioethics, which states that it is only be possible to work with the differences if there is recognition of the other in all their diversity [14]. Thereby only the rights of these people may be respected in their fullness.

Although there are public policies focused on sexual and reproductive rights, to people with disabilities, blind people are not covered by them, nor included in many programs, such as prevention of STD/HIV/AIDS. We understand that is the State's duty to direct actions to promote public policies that protect people in vulnerable condition, besides allowing them access to available services. Only through a health policy for everyone is that we can actually build an inclusive society.

People with disabilities should not be deprived of the opportunity to experience their sexuality, have sexual relationships or have children. Member states should promote the adoption of measures to change the negative attitudes towards marriage, sexuality and parenthood of persons with disabilities, especially of girls and women with disabilities [30].

We believe that the most promising way for this change of attitude is through sexual education, pointed out by the participants as something important and with perspectives of not only acquiring knowledge but, above all, to reduce prejudice, since there is no need for special classes for a blind person, one only needs educational resources adapted to their actual needs. In so doing we will be taking measures to protect and at the same time, promoting autonomy, hence including blind people. In the words of Maya [31], inclusive society should be a place where diversity is recognized in all its social dimensions, including in relation to sexuality and sexual education, because it is a right of everyone, including people with disabilities.

It is under this perspective that bioethics seeks to provide reflections in order to redeem the dignity and citizenship of these people, supported the assumptions of autonomy, care, tolerance, otherness, among others, which permeate the bioethics discussion and are closely related to questions involving social inclusion, in order to ensure protection to people with disabilities who are in a situation of vulnerability, without denying their importance as a subject of law. According to Zoboli [32], this protection must be liberating to cause the passage of moral heteronomy to autonomy, which is a unique and compatible condition with the dignity and human freedom. Thus we can find ways to really become an inclusive society in which the dignity and differences can be respected.

Special thanks
To my advisor Dr. Eliane S. Azevêdo, for reading and commenting to this work.

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Received: 26. 6.2013

Revised: 16.10.2013

Approved: 2.12.2013