

# Sexuality: Experience of Women with Physical Disabilities

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## Abstract

It was aimed to describe the experiences at the practice of sexuality of women with physical disabilities. This study is part of a doctoral thesis entitled sexuality in women with acquired deficiency: nursing in health promotion and empowerment. It was conducted an exploratory descriptive study with qualitative approach, which was carried out from June to October, in the year of 2010. The survey participants were six women members of an association of people with physical disabilities. Data collection was based on focal group. Analysis and discussion by means of the classification of the speeches were performed according to the analysis of content and pertinent literature. In the results, the following categories and sub-categories were identified: concepts, covering self-image and sexuality; social actors, responsible for the promotion of sexuality, with highlight for men, family and health professionals; challenges experienced in the practice of sexuality, with highlight on prejudice and fear of sexual abuse due to the disability. We could state that the focus groups favored the discussion and the self-knowledge of the women with respect to sexuality.

## Keywords

Nursing, Sexuality, Health Promotion, People with Disabilities, Woman

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## 1. Introduction

The human sexuality is a multidisciplinary and holistic phenomenon. The experience of sexuality in its fullness

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is everyone's right [1]. Nevertheless, in the everyday life, we notice distinctions imposed by the society against people with limitations, especially women with disabilities, who carry the disadvantage of gender discrimination, social exclusion, besides the disability itself.

The prevailing idea is that women with disabilities do not need intimacy or sexual expression and are incapable of having a sexual partner. In a society which prizes beauty, perfectness and youth, women with any disability are not appreciated by their potential, but are seen as a fragile person, with no attractiveness. This can trigger frustration, depression and low self-esteem. Strategies for recognizing the value of these women are important to the fullness of their lives, including the practice of sexuality [2].

So, this population faces numerous challenges. The discriminatory posture of the society causes people with disabilities to suppress and underestimate their potential with respect to their sexuality, since they are not allowed to have the opportunity to know themselves as sexual beings [3].

One of the gaps referred by researchers on this area is the lack of training by health professionals in a general form, especially with respect to treatment of people with disabilities [4] [5]. So, it is important to develop personal abilities not just of women with disabilities, but also for health professionals as to minimize the weaknesses that permeate the human sexuality. In this aspect, the nurse as a health promoter and an articulator is an important element in the process of recognition and coping the possible difficulties that affect women with disabilities. Additionally, the inclusion of the theme sexuality to disabled people alerts to the need for expanding the discussion on future research not only in the health sphere, but also within the schools to sensitize people to respect those who have any limitations.

The sexuality theme is important and necessary, since it keeps being a matter dominated by dualities on which we must meditate. So, giving women with disabilities the opportunity to express their concerns and frustrations configures a unique moment, since these people receive no attention and are not normally heard. Hence, this study contributes to a reflection on the role of health professionals about the guidelines and supports provided to this population. In addition it rescues the specific needs of this segment, thus contributing to the third millennium goal that highlights the importance of valuing women. For such, this article intended to describe the experiences of women with physical disabilities at their practice of sexuality.

## 2. Method

Exploratory descriptive study with qualitative approach, conducted in an association of people with disabilities. In the qualitative research, it was used focal groups, in the form of workshops, with the implementation of team techniques of collage, modeling, group dynamics, among others. Focal groups represent a recurrent method for evaluation of messages of health education, and to analyze the public understanding about diseases and health-related behaviors [6].

Data collection was carried out by one of the researchers and by a facilitator with the six women who were members of the association in the year of 2010. We scheduled five meetings to cover the theme under study, allowing one or more matters to be addressed in each meeting, respecting the rhythm of the participants. The themes used during the focus group meetings have emerged from the initial inquiries in the introduction, with the primary research question: How do women with disabilities acquired considered themselves and experience their sexuality in contemporary times? The material collected was treated through the analysis of contents [7]. First of all it was carried out a cursory reading, and then a thorough one, identifying the thematic categories. After that, the data were standardized and grouped. In doing so, it was organized the categories and sub-categories.

Project approved by the Committee for Ethics in Research of the State University of Paraíba under protocol number 0010.0.133.000-10, the women signed the Informed Consent Statement. In order to preserve their identities, we will refer to these women by the names of Greek goddesses: Artemis, Athena, Hestia, Hera, Demeter and Aphrodite.

## 3. Results

The women who participated in the research were between 32 and 45 years old, and had physical disabilities resulting from sequels of infectious diseases, such as meningitis and poliomyelitis, and due to deformities and traumas of the skeletal system (scoliosis). They moved by means of wheelchairs or prostheses. Two of them stated to have no active sexual life, and another one declared to be a mother.

The analysis of the speeches resulted in three categories: concepts; social actors co-responsible for the promo-

tion of sexuality; and challenges experienced in the practice of sexuality. From these categories emerged the sub-categories. The category was subdivided into concepts about the self-image and concepts about sexuality. The social actors category dismembered into the sub-categories male figure; family; and health professionals. The challenges category split into prejudice and fear of sexual abuse due to the disability. **Table 1** presents the guiding questions categories and sub-categories.

**Table 1.** Description of the speeches concerning categories and sub-categories.

Categories	Sub-categories
Concepts	<b>Self image concepts</b> Guiding question: When looking in the mirror what do you envision? <i>Well, I wish I were A (referring to a famous actress), but it is a shame I'm not, she is very beautiful and sexy, and I'm not.</i> (Hera) <i>I feel somewhat embarrassed because I would like to have a perfect body, since I admire the other able-bodied woman who attracts everyone else's attention, specially men's.</i> (Artemis) <i>When I look at this (referring to the self-image in a mirror) I see my qualities, my flaws, what I really am.</i> (Aphrodite) <i>Sometimes we who have disabilities attract much more attention than the able-bodied ones.</i> (Athena)
	<b>Concepts about sexuality</b> Guiding question: In your opinion what do you mean by sexuality. <i>For me, sexuality has to do with a sensual gaze, indeed, all men fall for a sensual gaze.</i> (Artemis) <i>Sexuality comprises cleanness. Men like when they find cleanness in the woman.</i> (Athena) <i>My husband likes finding me all dressed up when he comes home, especially when I'm wearing a short skirt, he loves it. This is sexuality, for me.</i> (Hera)
Social actors co-responsible for the promotion of sexuality	<b>Male figure</b> Guiding question: How do you feel about your partner in the exercise of sexuality. <i>I must be dressed up and use makeup all the time for my husband, otherwise he goes out and looks for another woman.</i> (Hera) <i>Nowadays, though it's a long time I'm with my husband, I often feel embarrassed, sometimes I want to have sex, but have no courage to approach him.</i> (Artemis)
	<b>Family</b> Guiding question: How is/was your relationship with your parents? <i>I was raised in a different manner. When I was younger, nobody approached me. Well, I was a little fool, did not get dressed up, my mom did not guide me.</i> (Hera) <i>I wanted to have a child, but I can't because my mom won't let me, She said: if one day I had a child, she would leave. She warned me: the child comes and I (the mother) go.</i> (Demeter) <i>My relationship with my mother has always been very open. Nowadays, the few things I know, since I have not much study, I learned from my mother.</i> (Aphrodite) <i>I always talk to my mom, and she says: my daughter, you are already of age. Until you were 20, I was all very careful with you, but now you more mature, and if you find someone who fits, stay with him and just let it happen.</i> (Hestia)
	<b>Health professionals</b> Guiding question: Have you had any positive or negative experience to be attended by health professionals? <i>I went for an ultrasound exam with Dr. Z, and he looked at me and asked: Are you married? Do you have kids?</i> <i>Have you ever felt the weight of a man on you? Then I said: No, doctor. Why do you ask? I felt like saying something... but I calmed down, and he gave an ironic smile.</i> (Hestia) <i>The doctor asked me how long since I had my last sex relation. I said it was about eleven years, and she said: No way, I can't believe this. And I said: If you don't believe, there's nothing I can do about it.</i> (Athena)
Challenges experienced in the practice of sexuality	<b>Prejudice</b> Guiding question: What are the most important needs for you in the exercise of sexuality? <i>I think the biggest problem with people with disabilities, which we must face, is prejudice. Only doing so, we can think about sexuality.</i> (Hestia) <i>Sometimes, inside the buses, people do not sit close to us, as if they were afraid of contracting a disease, I can't believe such a thing!</i> (Hera) <i>Some people look at us as if we were some kind of E.T.</i> (Demeter)
	<b>Fear of sexual abuse due to the disability</b> Guiding question: Are there any obstacles for you to experience sexuality? <i>I'm afraid of everything. If someone is looking at me, an instantly think: Gosh! He's making fun of me. When they touch my shoulder, I always think they want to take advantage of me, I won't let them. The word disability is stuck in my head.</i> (Demeter) <i>In my previous relationships, one of my ex-boyfriends just wanted to take advantage of me. He just wanted to take me to motels.</i> (Hestia) <i>This boy was in a hurry for sex with me, I got lost very soon, but it's not because I'm a woman (in this case, being a woman means not being a virgin anymore) that I will meet a guy today and get laid with him tomorrow.</i> (Athena) <i>I've never seen a gynecologist, this think of opening my legs to someone, God save me; when I had the surgery in my legs, it was like this: the doctor working and I covering with a cloth not to show my intimate parts.</i> (Demeter)

## 4. Discussion

We live in a society full of conducts, concepts and models which have a remarkable influence in the construction of personality and, consequently, in the elaboration of sexuality. Women with disabilities avoid discussing their sexual attitudes and experiences around sexuality, faced with a prejudiced and excluding society. Giving these women the opportunity to express their conceptions can create a positive aspect in the practice of sexuality. Like the able-bodied, women with disabilities are influenced by the beauty stereotype sold by the media: thin women, beautiful and with no disabilities.

Sexuality is fundamental for health, life quality and general well-being. It affects our relationships with our own self-images, with sexual partners and with everyone else [8]. In this context, the attitude of the society may favor or hinder the practice of sexuality and the personal fulfillment. The way a woman faces her limitations depends, partially, on the acceptance or rejection that she receives. Feeling deficient depends on the social context and on the individual trajectory in the construction of the experience with the deficiency, in which the identity is formed, rejecting or accepting some attributes [9]. The denial of the condition of being a woman with disabilities is sometimes the outcome of a prejudiced society, which excludes people with have some difference. This assertion can be verified in the speeches: “*Sometimes, inside the buses, people do not sit close to us, as if they were afraid of contracting a disease, I can’t believe such a thing! (Hera). Some people look at us as if we were some kind of E. T. (Demeter).*” This kind of circumstance may compromise the self-image, leading to the development of self-destructive behaviors such as anorexia, lack of care with the own body and self-aggression [10]. Paradoxically, being a person with disabilities does not imply in low self-esteem. Some of the women in this study demonstrated high self-love and self-esteem; they had accepted their disabilities and adapted themselves to the imposed limitations; disability cannot be labeled as a synonym for impotence and displeasure. This fact is inferred from Athena’s speech, when she said: “*Sometimes we who have disabilities attract much more attention than the able-bodied ones*”. Furthermore, disliking some part of the body is not an exclusive condition of women with disabilities; the most important thing is to have the sexuality settled, regardless of the physical conditions, since sexuality is a dynamical process and is part of everyone’s life, inherent to the human being. However, sexuality must not be taken as a synonym for sex.

Sex, or gender, refers to biological characteristics that define the human being as either male or female, while sexuality is a subjective and wider concept. The ambiguity of the concept concerning sexuality is not a result of chance, especially when we talk about female sexuality. In history, for a long time and up to the beginning of the last century, even in occidental cultures, women did not have the opportunity and were not allowed to express their sexuality. They were in charge of household work and taking care of children, as well as promptly satisfying their husbands’ demands and needs. Though some advances in terms of women’s freedom of expression regarding sexuality occurred, the traces of that repressing times keep impregnated in the minds of some women; women have emancipated politically, however they are not free from the social command of beauty [11].

The duality between understanding sexuality as either an individual or collective characteristic is not contradictory. Women victim of cancer, when asked about their concept of sexuality, state that having a good appearance and being attractive to their partners were a high priority in their definition of sexuality [12]. Confirming these findings, we observed a similar statement in the present study by the following speeches: *For me, sexuality has to do with a sensual gaze, indeed, every men fall for a sensual gaze (Artemis). Sexuality comprises cleanness. Men like when they find cleanness in the woman (Athena).* These statements suggest that sexuality is something collective, since another person is needed so that it can be put into practice. However, sexuality is actually individual.

Dealing with the female sexuality requires investments in education and the vanish of the power dichotomy in the male/female gender relation. In fact, this has been changing over the years, and these changes are the results of the advances in the women’s achievements with respect to their insertion in spaces considered as masculine [13].

Over history, the symbolic systems were designed by and for men; today, the young people realize sexuality as something inherent to their nature and that they have the right to enjoy it [14]. However, many women are seen and treated simply as guardians of the family’s well-being, either acting as mothers/wives or acting as autonomous individuals with their specific needs. The servility, culturally made up and socially accepted, can be, among other damages to women, a source of violence, since men keep considering themselves as the dominant subjects.

Furthermore, this violence is not just sexual, but also psychological, since women feel coerced to vanish before their partners. Such coercion can be represented by Hera's speech when she emphasizes that regardless of her will to get dressed up, use make-up or even having a sexual relation, she must do it to meet her husband's desires. This condescension rooted in the women's speeches is often the result of the education received in family

The construction of people's sexuality, both with and without disabilities, starts in family. In anthropology and sociology, family is not constrained to people living in the same house, since the connections extrapolate home. In this research, the term family covered those people who were responsible for the raising and development of the women under observation. In this environment, the person receives sexual education, and therefore the sexual constraints are built, or are affected by the sexual orientation received in the family environment. As pointed out, some teenager who develop delinquent behavior are normally the product of a negative environment, characterized by communication issues with the parents [15]. This way, we observe the importance of the dialogue in the construction of the sexuality of a person.

Regarding sexuality, families present various attitudes towards their members who have disabilities, from omission to over-protection. In this aspect, as we observed in this study, the relationship between father/mother and daughters was characterized by the absence of sexual education, lack of complicity and orientations from the parents, as well as the daughters' dissatisfaction, who made clear that they were not supported when they had some issue related with sexuality, as in the speech: *I was raised in a different manner. When I was younger, nobody approached me. Well, I was a little fool, did not get dressed up, my mom did not guide me* (Hera). However, the values passed vary according to the culture and to the personal experiences.

The interference of family in the sexuality of people with disabilities is something decisive about the success or failure in the practice of this sexuality. Regardless of being a person with disabilities, a woman has dreams, objectives, as any other human being. In this study, we observed that one of the great dreams of one of the participants was being a mother, described in the speech: *I wanted to have a child, but I can't because my mom won't let me, She said: if one day I have a child, she would leave home. She warned me: the child comes and I (the mother) go* (Demeter).

The open dialogue in family, the exchange of viewpoints between parents and children in an empathetic manner, with respect and love, has positive effects over the behavior and construction of the children's personalities and, as a consequence, in the formation of sexuality [16]. In this study, certain stories reveal harmonic relationships between mothers and daughters, where the participants show high self-esteem and dealt with the obstacles imposed by their limitations in a clear and conscious manner, which can be inferred from the speeches: *My relationship with my mother has always been very open. Nowadays, the few things I know, since I have not much study, I learned from my mother* (Aphrodite). *I always talk to my mom, and she says: my daughter, you are already of age. Until you were 20, I was all very careful with you, but now you more mature, and if you find someone who fits, stay with him and just let it happen* (Hestia). However, a study highlights the fact that families rarely manage to deal with the sexuality theme in a direct manner with their children, directed towards their lives, transferring to the media or to health professionals a task which should be in charge of the family [17].

After the familiar orientation, the health professionals stand out as important actors in the construction of sexuality. The perceptions of people about health professionals were included in this study because they are part of the life experiences, as well as important actors in the experience regarding the sexuality of these people.

Despite sexuality is something inherent to every person, sexual problems receive little attention from health professionals in various clinical situations [18]. Nevertheless, these professionals are important pieces in issues related to sexuality, since they are the connection between the society and people with disabilities. Furthermore, they are the ones who people with disabilities put their trust on and who they look for when they need help. Also, many health professionals are educators, and their attitudes can influence future assistants.

In general, people with disabilities interact with many types of health professionals, from those involved in direct care to those who develop educational tasks. The quality of these relationships may contribute or not to the recovery and well-being of these people. Parents of children with disabilities have reported adverse experiences and unsatisfactory relationships with health professionals [19]. As for other professionals, those in the health field, especially, must have, among other attributes, ethics, respect for differences and wisdom in the situations which may lead to an embarrassment in the professional-patient relationship.

Regarding sexuality, the abilities of these professionals must even be higher since this is a very sensitive area, which must be addressed with privacy, in a confidential and impartial manner. The health professional must



promote a reliable and respectful environment so that the woman who is being assisted can feel comfortable to express her difficulties or doubts in the practice of sexuality. This recommendation, however, is often neglected. Some professional do not care about being ethical and do not respect the individuality of their clients.

Analyzing Hestia's speech, reporting the physician's question: *Have you ever felt the weight of a man on you?* The dissatisfaction is evident due to the disrespectful, unethical and inhuman question made by the professional. From her speech, we realize how embarrassed she felt in that situation, as well as her sensation of helplessness with respect to the professional. It is as if, besides being disrespected and morally offended, she had to remain silent before someone who, in her understanding, was hierarchically superior. We must recall that respect and promotion of autonomy are ethical principles which should guide the practices of health professionals [18]. Ethics in health is the crucial point in the professional-patient relationship, and must be faced as a mandatory praxis in the routine of those who claim to be health promoters. Faced with these reports, we ask how actually happens the interaction between some health professionals and people with disabilities.

Another report of power abuse by the professional can be seen in Athena's speech, when she stresses that the physician called her a liar. Such a posture reveals the lack of training and knowledge about the integrality of assistance and the complete absence of respect for the patient. Attitudes like this cannot be part of a relationship in which the listening and the respect to privacy should be a constant. Furthermore, it constituted a moral and ethical coping to the woman. Training on ethics is, therefore, of paramount importance. In addition, this knowledge acquisition must leave the speeches and be put into practice by the health professionals, minimizing, so, the challenges experienced by the people with disabilities at the practice of their sexuality.

Health professionals must develop abilities capable of promoting a relationship based on empathy and trust, thus improving the quality of the services provided. In this scenario, we highlight the figure of the nurse. Due to their narrow relationship with patients, nurses are in a favorable position to promote the sexual health of the individuals who they take care of. Besides, they help the health system managers and demand intervention actions that prioritize the promotion of the sexual health of the people, preventing abuses and assist the community in order to enforce their rights, assured in the Brazilian law, and so minimizing the main challenges experienced by these people, such as prejudice.

Though the various forms of prejudice-ethnic, religious, social-being considered illegal and socially unacceptable, subtle behaviors like getting away from stigmatized targets, such as people with disabilities, are practices commonly seen in the everyday life [19]. Besides the distancing from able-bodied people, people with disabilities still face prejudices which hinder their integration in the work environment, at schools and in other public environments [20]. For this reason, the posture of the society towards people with disabilities is of great importance. Disability has always been a phenomenon seen with prejudice, sometimes not openly expressed. And concerned with women with disabilities, they are even more discriminated than men [21]. Such a difficulty for the society to accept people with disabilities is a result of the lack of investments in an education, which could encourage people, accept the different. This is actually a big challenge, dismissing the pre-formulated concept of the helplessness of people with disabilities.

Hestia, in her speech, harnesses the right to practice the sexuality to the society's acceptance, like something of ultimate importance for her personal satisfaction. Prejudice not only excludes people, but causes feelings of anger and inferiority in its victims. Statements like *people look at us as if we were some kind of ET* give a precise idea about the indignation with the behavior of able-bodied people at the interaction with those who have some disability.

This uncomfortable situation reported by these women is the result of an excluding society which always talks about equality, but is not aware that equality does not mean treating everyone in the same manner, because people with disabilities frequently have special needs. Equality is treating the different people with all their peculiarities and rights that must assured. When these differences have, in fact, the society's respect, then maybe people with disabilities will have more freedom to fully practice their sexuality.

Another challenge cited by the participants related to the practice of their sexuality regards the fear of being sexually abused. Violence against people can be classified under different aspects. The most evident type is physical violence; sexual abuse covers from the sexual act to insinuations, it can be implicit for the obtainment of personal or economic advantages; it also covers bullying, creating stereotypes and creating a situation of social and psychological discomfort. Sexual abuse can involve different forms of aggression—verbal, visual or any other behavior that coerces a person to have undesired sexual contact. Scales can measure the type of violence, indicating intervention actions according to the diagnosis made [22].

With respect to women with disabilities, they are more vulnerable to sexual abuses. Several hypotheses have been formulated in the attempt to explain why women with disabilities are more likely to suffer sexual violence. One of these hypothesis claims that these people are seen as helpless, and so less likely to resist or report the sexual violence [23]. This silent behavior is one of the factors that contribute with impunity and violation of human rights. Moreover, sexual violence frequently occurs inside the family environment and, in most cases, is silenced not only by the victim, but also by the relatives, in the attempt to avoid the dissolution of the family because of the sexual crime [24].

Hestia demonstrated that, despite having a romantic relationship, she felt threatened because she noticed that her partner wanted to have a more intimate contact, which, in her viewpoint, meant that the man wanted to take advantage of her. The fear of being victim of sexual abuses, often experienced by women with disabilities, is not limited to partners. In some cases, even the professionals who take care of these women may be involved. This situation is inferred from the speech: *I've never seen a gynecologist, this think of opening my legs to someone, God save me; when I had the surgery in my legs, it was like this: the doctor working and I covering with a cloth not to show my intimate parts* (Demeter). Attitudes like this lead us to think over the importance of the health professionals in the promotion of a peaceful, and more than everything else, welcoming and including environment for all those who look for health services, with or without disabilities.

## 5. Conclusions

The speeches women, recorded throughout the work with the focus groups, allowed the elaboration of concepts to be one of the categories in the study, specifically the concepts of self-image and sexuality. The fragments of the composition of the self-image refer to the imperfect body, which is permeated by the will for overcoming. This way, the look tunes to the inner person, overcoming the disability. The starting concept of sexuality is attached to the sexual act, but throughout the work with the groups, this concept gets wider, covering the romantic relationship.

The social actors co-responsible for sexuality come out as a second category in the study. The social actors co-responsible for sexuality come out as a second category in the study. Currently, the stronger is the male figure. As a consequence, women must please the partner, be attractive, and attend male expectations. The past recalls family with two sides: the moral or repressive development of sexuality and the absence of dialog about sexuality and sexual activity.

Experiencing sexuality for these women includes facing prejudice and fear of being sexually abused. The prejudice results from collectivity's idea that, in order to be sensual, the woman must be perfect; since they are considered as disabled and see themselves as such they are denied the right to sexuality. When a potential partner approaches, he can be thought of as, and even actually be, a predator, and this is the source of the fear of sexual abuse: the disbelief in their own capability to seduce, and the physical limitation for escaping or self-defending.

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