

GENDER, SEXUALITY, AND EXPERIENCE OF DISABILITY IN WOMEN IN SOUTHERN BRAZIL

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Abstract

This study aimed to characterize the experience of sexuality in women with physical disability in Southern Brazil, emphasizing the intersection of gender and disability as limiting sexual and reproductive rights. The study included eight women with physical disability, aged 24 to 68 years, members of an association of people with physical disability. The information was obtained through in-depth interviews and later analyzed based on the method of discourse analysis. The theoretical framework was established by studies on disability based on the social model of disability and gender theories. The information gathered showed that women with disability face a process of oppression in the exercise of their sexuality. Such process is intrinsically related to the intersection of gender and disability, gives rise to vulnerability, and limits the guarantee of sexual and reproductive rights.

Keywords: Gender, Sexuality, Disability.

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Introduction

The intersection of issues of gender and of disability is an important aspect to be considered in the study of the experience of disability. Recent studies built upon the second generation of the social model of disability showed that the intersection of these elements gives rise to oppression and vulnerability (Dhungana, 2006; Petersen, 2006; Lang, 2009).

With that in consideration, this study aimed to characterize the experience of sexuality in women with physical disability in Southern Brazil, emphasizing the intersection of gender and disability as limiting sexual and reproductive rights. Consequently, we sought to give women with disability a voice so that they could narrate their life experiences, as proposed by authors such as McDonald, Keys and Balcazar (2007).

The violation of sexual and reproductive rights of people with disabilities is a recurring phenomenon in different countries around the world. There is evidence that the architectural barriers and mainly attitudinal barriers (myths, taboos, and prejudices) are elements that support the establishment of this phenomenon (McDonald et al., 2007; Maia & Ribeiro, 2010; Gesser, 2010; World Health Organization, 2011).

Aiming to promote sexual and reproductive rights of this social group, the Convention on the Rights of Persons with Disabilities (CRPD) was created. The Convention was developed from a long and extensive dialogue between the UN – United Nations – and civil society organizations, especially those of people with disabilities. The final document, approved in Brazil as a Legislative Decree in March 2008 (Legislative Decree No. 186/2008), recommends that States must take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood, and relationships, on equality of conditions with other persons. Such considerations indicate the need to break with the process of infantilization and asexualization to which many women with disabilities are subject on a daily basis. This process was identified in studies by Shakespeare (1998), Silva and Albertini (2007), França and Chaves (2005), Nosek and Simmons (2007), Soares, Monteiro and Costa (2008), and Maia and Ribeiro (2010).

Moreover, the Convention recognizes the intersection of gender and disability as potentiating discrimination and vulnerability. Thus, in Article 6, which refers to women with disabilities, the document also deliberates on the need for the States, by recognizing women and girls with disabilities as subject to multiple forms of discrimination, to adopt measures to ensure full and equal exercise of all human rights and fundamental freedoms, ensuring their development and empowerment.

Although the Convention on the Rights of Persons with Disabilities brings important contributions to the guarantee of sexual and reproductive rights, there is a need to review to what extent it has contributed to change oppressive processes experienced by people with disabilities (Gesser, Nuernberg & Toneli, 2012). Therefore, in this paper it has been chosen the presentation of studies that show the relationship of gender and disability as limiting sexual and reproductive rights, especially for women with disabilities.

Research by authors such as Joseph (2005-2006) in India and Dhungana (2006) in Nepal indicate, in contrast to women without disabilities, that the expectations of society toward women with disabilities often exclude them from the right to exercise sexuality, from work of any nature, and from motherhood. It is maintained in these contexts the belief that women with disabilities are unable to fulfill the traditional roles of a wife, a housewife, a worker, and a mother (Dhungana, 2006; Joseph, 2005-2006; McDonald et al., 2007).

Maia and Ribeiro (2010) show that there is an understanding that people with disabilities are asexual (that is, they do not have sexual needs and feelings). This issue is corroborated by Brodwin and Frederick (2010). These authors emphasize that the sexuality of people with disabilities is a subject rarely discussed in society. In addition, the stereotypes associated with people with disabilities assume that they are not attractive, are unable to manifest sexual desire, and that any kind of sexual expression is inadequate. Joseph (2005-2006) points out that this idea affects personal experiences and life projects of both sexes, although women are more vulnerable by the intersection of disability and gender inequality.

The idea that people with disabilities opting into motherhood will give birth to children bearing the same disease (Dhungana, 2006) is also present in everyday life. Therefore, women with disabilities are exposed to social stigma and stereotypes within their communities, which lead them to feel devalued, isolated, and ashamed in these spaces (Joseph, 2005-2006).

The gender dimension has rarely been considered in health care for women with disabilities. Studies conducted by Nosek and Hungnes (2003) show that the services provided to women are based on male standards and address the needs of women according to traditional social gender assignments. Joseph (2005-2006) pointed out that there is a hegemonic assumption that disability is the opposite of health, which indicates an understanding of this condition that is strongly rooted in the medical model of disability.

With further regard to the intersection of gender and disability, authors as Dhungana (2006) and Marques and Madeira (2007) observed that the process of infantilization experienced by women with disabilities gives rise to vulnerabilities. These vulnerabilities are due, among other factors, to the lack of information on health and sexual and reproductive rights guaranteed by the Convention on the Rights of Persons with Disabilities of the United Nations (Brasil, 2008).

Sánchez (2008) identified through literature review the existence of myths about the sexuality of people with disabilities that contribute to the rejection of sexual and reproductive rights. Furthermore, several studies show that these myths, by being appropriated

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by professionals in the field of sexual and reproductive health, end up limiting access to information about sexuality (Dhungana, 2006; Nosek & Simmons, 2007; Sánchez, 2008; Brasil, 2009; World Health Organization, 2011). This process comprises what Paiva, Pupo and Barboza (2006) call 'programmatic vulnerability' – barriers that further increase the forms of exclusion of an individual.

Despite the complexity of elements in the process of constitution of people with disabilities and of all studies on the relationship between physical disability, gender, social class, and other social determinants, feminist social movements have little studied issues related to disability (Thorne, McCormick & Carty, 1997). To this effect, Ferri and Gregg (1998) criticize such omission by emphasizing that disability is an issue of feminism and that gender is an issue of disability. Mirroring the thought of bell hooks, the authors emphasize that simply talking about diversity is not enough. There is a need for feminist movements to be collectively linked with women with disabilities, seeking to establish a policy of partnership. To that effect, Petersen (2006) emphasizes that through this dialogue it will be possible to consider the multiple determinants of oppression and their articulation in the process of constitution of the individual.

In Brazil, according to information obtained from the 2010 census conducted by the Brazilian Institute of Geography and Statistics (IBGE), at least 45.6 million Brazilians were experiencing disability, a figure representing 23.9% of the total population. According to these data, 26.5% of the female population (25.8 million) in 2010 had at least one disability, whereas in men this contingent was 21.2% (19.8 million). An analysis conducted by the study "Diversidade: Retratos da Deficiência no Brasil" (Diversity - Portraits of Disability in Brazil) (Neri, 2003) revealed that the increased tendency to disability in women is related to the fact that women present a longer life expectancy, thus being more prone to injuries and impairments that are characteristic to old age.

Disability has been considered in this work based on the social model of disability. The first-generation authors of this model have focused their studies on the criticism of the medical model of disability, by which disability is reduced to body injuries and impairments and rehabilitation practices. They have also put forward the sociological understanding of disability, by which disability is characterized as an experience of oppression resulting from the social barriers experienced by persons with disabilities. Furthermore, they have emphasized the need to develop public policies to ensure the participation of persons with disabilities in society (Diniz, 2007).

According to Diniz (2007), the first generation of disability studies had the important role of expanding the concept of disability, placing the issue beyond the biomedical discourse. The second generation of disability studies consisted of a dialogue with feminist studies, distancing from Marxist premises in order to reassess the assumption of achieving equality through independence. Researchers of humanities with disabilities or providing care for people with disabilities have drawn attention to the issues of body, pain, and subjectivity, and have introduced the issue of caregiving and interdependence as a human condition that is not limited to people with injuries (Kittay, 1999). The result was a big step forward suggesting the transversality of disability in relation to gender, generation, and ethnicity (Garland-Thompson, 2002).

These same feminist authors of studies on disability have improved the debate on the meaning of the experience of disability by addressing the issue in the context of the private sphere, since the public sphere was already well outlined by the first generation, which has explored issues such as labor. At the same historical moment of feminism, they promoted the focus on an experience of historically hidden cultural oppression (Garland-Thompson, 2002).

The gender dimension was understood as “a historical and cultural production, based on perceived differences between the sexes, that organizes social life through asymmetrical relations” (Toneli, 2006). Such dimension potentializes processes of social exclusion, as showed in this work and in studies on disability building upon the second generation of the social model. It also highlights the intersection of gender determinations with other identity markers, as proposed by Nogueira (2013), since they interrelate creating a system of oppression that mirrors the intersection of multiple forms of discrimination.

As for the understanding of sexuality, it is assumed that it is a discursive production. The religious discourse is one still very present in the production of sexuality in contemporary society. In this discourse, sexuality is reduced to vaginal intercourse and understood as something in which only adults in reproductive age who wish to have children should engage (Gesser, Oltramari, Cord & Nuernberg, 2012). Lastly, the prevailing suspicion is that disabled people would not be able to reproduce the species, and that sexuality would be eminently associated with this capability (and not to desire and pleasure). This discourse presents itself as a limiting factor to the development of individuals with disabilities (Dall’Alba, 2004; Costa, 2000).

The medical discourse also traverses sexuality in the contemporary world. In this discourse, the predominant understanding takes heterosexuality as the norm and other expressions of sexuality as pathological. (Foucault, 1988.) From the early twentieth century, pleasure has been established after the work of Kinsey and Masters and Johnson as an expression of “healthy” sexuality. Since then, there emerged a growing attention on sexual pleasure as an emphasis on sexual performance and on orgasm. A normal sexual response should culminate in orgasm not to be characterized as sexual deviance (Tepper, 2000). Shakespeare (1998) points out that, from this moment, the sexuality of people with disabilities came to be seen as a medical tragedy arising from their disability and, in some cases, imbued with a concern that faulty genes would come to be replicated.

The next section will present the methodological approach of this study. Next, the main results obtained will be presented with an emphasis on the intersection of gender and disability and its implications for the sexuality dimension. Lastly, it will be given some considerations related to the intersection of gender and disability and its effects on the lives of the women interviewed.

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Method

This paper was prepared by the authors from an excerpt of the information obtained in the doctoral research “Gênero, corpo e sexualidade: processos de significação e suas implicações na constituição de mulheres com deficiência física” (Gender, Body and Sexuality: Processes of meaning and their implications to the constitution of women with physical disabilities) (Gesser, 2010). The research aimed to study the process of constitution of women with disabilities according to the dimensions of gender, body and sexuality, seeking to identify the mediations that were important in this process as well as the changes occurred since the participation of women in a group for discussion and reflection about the dimensions presented above.

The subjects were eight women with physical disabilities affiliated to an association of people with disabilities focused on human rights and participants of a group, coordinated by one of the authors, of women from the organization. This group aimed to: a) discuss the implication of the existence of a dominant body pattern in the constitution of women with physical disabilities; b) provide discussions on topics such as dating, sexuality, family, and work, and c) provide a space for the participating women for exchanging experiences regarding different spheres of life. The study was conducted based on the needs identified among women and is one of the actions undertaken by the association of people with disabilities that aims at the social inclusion of its members.

After approval of the research by the Ethics Committee on Human Research of the Federal University of Santa Catarina, the participants were invited to participate in the study. At that time, the participants were presented the Statement of Informed Consent with its goals, rationale, and the technical procedures of the research. The participants were also informed that the interviews would be recorded on an audio device and that their identity would be preserved in the dissemination of results.

All interviews were conducted in the homes of the participants in dates and times scheduled in advance according to their convenience. This was important in order to make it possible to learn about the social context in which they lived. However, due to the presence of family members during the interviews and the inability to maintain privacy, one interview had to be rescheduled and another finalized in a soundproof room available in the association of people with disabilities, of which the participants were members.

The subjects were mostly Catholic, aged 24 to 68 years. Five subjects were white and three were pardas (brown). There were three single subjects, one widow, and one divorcee, while the other subjects were married or in stable relationships. With regard to injury, one subject had congenital dislocation, two had infantile paralysis, one had paraplegia, one had amputation of the left lower limb, one had Crohn's disease, one had a herniated disc, osteophytosis, and osteoporosis, and lastly one had physical limitations on the right side of the body due to a cerebral aneurysm, osteoarthritis, and degenerative changes of the spine. Seven of them were from lower classes and had a *per capita* income equal to or less than the legal minimum wage.

Information was obtained through in-depth interviews and participant observation, and analyzed using the technique of discourse analysis based on Vygotsky (Rossetti-Ferreira, Carvalho, Amorim & Silva, 2004). On the basis of the author's work, it is highlighted the importance of investigating the phenomena present in the daily life from the process that formed them and their relationships with the multiple historical and cultural determinants. It also seeks to emphasize the processes of appropriation of these determinants and their mediation in the way the subject thinks, feels, and acts.

Regarding the procedures used in discourse analysis, the first step consisted of a detailed transcript of the speech, in which the authors sought to identify both text and subtext. Next the authors proceeded to perform an initial reading of the material, searching for the meanings that the respondents attached to issues related to gender, body, and sexuality and their intersections or other elements present in their historical and cultural context. Lastly, these elements were grouped into categories of analysis.

Results and discussion

The stories of the women interviewed showed that the experience of disability was marked by processes of prejudice, oppression, and social exclusion, corroborating authors such as Higgins (2010), Esmail, Darry, Walter and Knupp (2010), Soares et al. (2008), Sánchez (2008), McDonald et al. (2007), and Nosek and Hungles (2003). These processes were very much in interpersonal relations and mediated the process configuration of the constitution of the subject.

Specifically with regard to the intersection of gender and disability and its implications to the experience of sexuality, four elements stood out. They are: a) the process of infantilization and asexualization of the disabled person; b) the failure to recognize the *status* of wife and mother; c) the refusal to erotize the disabled body, and d) the resistance of women with disabilities to oppressive discourses. These elements are presented below.

The Process of Infantilization and Asexualization of a Person With Disability

The information obtained in this study showed that the respondents were infantilized and characterized as asexual over the course of their lives. This process hindered the guarantee of sexual and reproductive rights advocated by the UN Convention, as stated above in the introduction to this article.

Regarding infantilization, this was evidenced mainly through overprotection and by removing the ability of the participants to decide on their own lives. The most representative testimony of this process was Monica's, a woman aged 68 who has limited mobility due to polio acquired at the age of two and who currently uses a wheelchair. She reported that since adolescence she had her sexuality curtailed by relatives. They maintained that, as a

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result of impairments, she was not attractive and therefore men would only approach her with financial interests. In addition, her relatives believed that she was not able to discriminate the intentions of the people who were to approach her and would end up giving away the property left to her by her father to a person who was not family. When she found a boyfriend, her relatives came to the point of making her sign a document renouncing her house for the benefit of her sister. The following is a report on a situation that occurred when a boyfriend called her and her mother answered:

(...) it just happened that he called me at home, right? When I was not home, then my mother would give him a piece of her mind, called him a shameless bum and all, and that the only thing he wanted to grab was what I had inherited. [She asked him] if he was not ashamed of dating a disabled woman.

There are several factors that can contribute to the process configuration of infantilization of people with disabilities. Among these factors, a phenomenon that stands out is the association made between physical disability and cognitive problems (Costa, 2000; Mogollón, 2008). According to Mogollón (2008), another myth that can contribute to the configuration of this process is that sex is a source of danger, therefore it is thought that people with disabilities, particularly women, should be protected. In relation to this myth, these people are not considered qualified to reproduce, let alone to be able to experience sex for pleasure (Tepper, 2000; Mogollón, 2008). Specifically in the case of Monica, from the information obtained in her testimony, the notion maintained by her relatives that men who wished to date her could unduly take advantage of her inheritance, since she had no cognitive ability to identify their intentions, seemed to be more present than the signification of sex as a source of danger.

The understanding on the part of some people within the context in which the respondents lived that people with disabilities are asexual was an aspect experienced by some respondents. Simone, a 41-year old lady who became paraplegic at 18, reported to have been through situations in which comments were made stating that she was beautiful and regretting that she had a disability. It was questioned whether she could have sex, according to the statement below:

I get dressed and all, and there's always someone who goes, like, 'Oh, you're so pretty! But you're on a wheelchair, right?' I get a lot of these. I've been asked, 'Oh, can you have sex?' They came to the point of asking me that. So they think that because we are in this situation [pause] we can't.

The experience lived by Simone shows a significance attributed to people with disabilities already widely pointed out in the scientific literature on the idea that they are asexual (Esmail, Darry, Walter & Knupp, 2010; Brodwin & Frederick, 2010; Sánchez, 2008; Soares et al., 2008; Mogollón, 2008; Silva & Albertini, 2007; França & Chaves, 2005; Shakespeare, 1998; Thorne et al., 1997). According to Thorne et al. (1997), the understanding that women with disabilities are asexual was present even among some feminist theorists. The authors also point out that this idea is related to the fact that the bodies of women with disabilities diverge from the normative standard of the contemporary world.

Tepper (2000) draws attention to the fact that there is a preconceived notion that the physically limited body would also be a sexually limited body, that is, there is a common sense meaning that the expression of sexuality and obtaining of pleasure do not exist for people with disabilities. Shakespeare (1998) pointed out that the idea that people with disabilities are neutral in respect to sexuality is also related to the fact that sexuality is hege- monically understood as the ability to complete the sexual response cycle, something not always possible for people with disabilities.

Intrinsically related to the process of infantilization and asexualization of disabled wom- en there was a question referring to the failure to recognize them as possible wives and mothers. This question will be presented in the next section.

Failing to Recognize the Status of Wife and Mother

The intersection of gender and disability also contributed to the failure to recognize the *status* of wife and mother. Considering that the UN Convention emphasizes the right of the person with disability to willingly marry and found a family, it is important to give visibility to this issue.

As regards the maternity dimension, four of the eight respondents had had children. Three out of the four were already mothers by the time they suffered brain injury and/or body impairments, while one opted for motherhood after the injury.

Architectural barriers (lack of accessibility) and attitudinal barriers (myths, prejudices, and stigma) operated as limiting the exercise of motherhood to all respondents who had children. They reported as a major architectural barrier the lack of transport for taking their children to see a doctor and to leisure activities, as well as for participating in other activities they associate with motherhood, such as attending school meetings. In this sense, there are gender norms, which according to Guimarães (2010) naturalize the assignment of care for women and also operate as limiting the motherhood dimension.

As regards the attitudinal barrier, some respondents were questioned both about the possibility of exercising sexuality and about their ability to generate healthy children and care for them. However, as already shown in the previous section, there had been a curtail- ing of romantic and/or sexual contact and the asexualization of their bodies.

One of the most representative testimonials in this category was Serena's, a 41-year old woman who suffered a motorcycle accident at the age of 18, resulting in the amputation of the lower left limb. She had been dating her current husband for three months by the time of the accident. In his family's judgment, it was not right that he stayed with her since they had been dating for a short time and she "would ruin his life." "(...) There was a whole future ahead, one that (...) I was going to ruin, because **he'd have to be taking care of me all the time**. So that was a pretty tricky situation, right?" (Serena).

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The perception of Serena's husband's family was very close to the meaning, significantly present in the social context, associating disability to general inability and identifying the person as a burden in the life of a person without disabilities.

Serena and her husband had twins. When they were born, there was a concern that Serena, being a person with disability, would raise two children. For that reason, it was suggested that they give their children up for adoption by her husband's siblings. This event is also revealing of discrimination – especially gender discrimination – since it is an evidence of the existence of the belief that it is up for the woman to care for the children and that a person with disability, by not being able to take care of her- or himself, similarly could not take care of other beings. In short, it is evident that gender and disability are categories that intersect and therefore cannot be analyzed separately in the process of constitution of the subject.

The views on behalf of Serena's husband's family regarding the possibility for her to exercise the duties culturally characterized as female have also been identified in other studies relating gender and disability. These studies, as already emphasized in the introduction to this study, showed that there is a cultural meaning that women with disabilities are unable to fulfill the traditional roles of homemaker, wife, worker, and mother (McDonald et al., 2007; Dhungana, 2006; Joseph, 2005-2006; Ferri & Gregg, 1998).

Therefore, it was observed that the intersection of gender and disability can limit the rights recommended in the UN Convention, namely the rights to marry and found a family. The following section shows how this intersection produces a body whose eroticization had been removed.

The Removal of the Eroticization of the Disabled Body

This section shows the relationship of the respondents with a body comprised by the stigma of disability. Although six out of the eight respondents are also obese and have reported to feel more judged by their obesity than by their injuries and impairments, the stigma of disability was also present and mediated their relationship with sexuality.

The most representative testimony of such relationship was Simone's. It shows the process of appropriation of the idea that a body should be a sexually attractive body without disabilities, and that when the body is "defective" there may be rejection by another body, especially when this presents no disability. These elements contributed for Serena to conclude, from conversations with other women with disabilities, that she would only date someone who also had a physical disability, since she would be ashamed to show her "defects" to someone without disabilities. Let us consider her testimony below:

Yeah (...) our own body is a bit like this, it is defective, it has scars. If we meet a person, there's going to be pressure. There's also the shame and awkwardness. Because I think like this – but it is really because of the deformity we have, the problems we had with scars, having [dark] wounds and deep scars, right? So I think, like, all of these count.

The meanings attributed by Simone to her defective body, outside the normative standards and undesirable – along with the belief that it could be rejected in the interaction with non-disabled bodies – helped preventing her from seeking that kind of relationship. França and Chaves (2005), based on a survey of paraplegic women, explained that the behavior of people with disabilities of being prone to maintain relationships with each other follows the common sense idea that the more beautiful and attractive the sexual partners are, the more intense and satisfying would be the feeling of orgasm. Furthermore, according to the authors, the process of sexual socialization, learned and stimulated daily, increasingly tends to establish for the subjects what are the desires, feelings, roles, and sexual practices typical of each social group, and what are the sexual alternatives allowed by their cultures. Thus, “the way people react to others and are perceived by them encourages the assumption of sexual conduct between equals, because it is assumed an understanding of the difficulties in the sexual performance of the other” (França & Chaves, 2005, p. 18).

Fontes (2007) points out that the idea that a body with injuries and impairments is less desirable is replicated mainly by medical and media discourses through the establishment of a certain body standard and the definition of this body as erotic (Fontes, 2007). According to the author, this idea helps configuring the meaning that people who do not match that body standard have less value in the affective and marriage “market”.

Therefore, the normative discourses of gender and body operate violently in the constitution of the body with disabilities. These are appropriated by women and constitute the way they experience sexuality.

The Resistance of Women with Disabilities to Oppressive Discourses

As already highlighted above, women with disabilities interviewed for this study were oppressed over the course of their lives by social barriers imposed in the intersection of gender and disability. However, by participating in a group of women with disabilities, they managed to build a space of resistance to the discourses that tagged them asexual, infantile, non-erotic, and unable to reproduce the duties of a wife and mother. Therefore, this section will aim to give visibility to the detachment that emerged from the discourses that divest women with disabilities of the dimension of sexuality.

The respondent Mônica expressed an act of resistance identified in this research. As previously mentioned, her family sought to curtail romantic and sexual contacts over the course of her life. However, following her inclusion in the group of women with disabilities, she began to question the social position assigned to her according to the following testimony: “Because [her mother and sister think that] the disabled person should not date, should not marry, should not do anything. **If you have a bed and food, that’s enough! Nothing else is needed.** It’s no use. The disabled person doesn’t need anything else.”

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The participation of Mônica in the group of women and her wishing for different experiences related to the experience of sexuality made her find her way to a job in a public environment and in some leisure spaces where, without her family knowing, she had the chance to flirt and thereby feel feminine.

Another issue raised by a participant with acquired paraplegia concerned a piece of information that was obtained from a medical professional. After Luana asked how would the dimension of sexuality be dealt with after spinal cord injury, the physician told her that this issue was not important and that she should focus on recovery, showing a professional attitude attached to the biomedical model of disability. Luana has brought the issue up to the group of women, and together with the other participants, managed to reinvent the way of experiencing sexuality.

Thus, some participants were able to identify experiences oppressive for sexuality and to deconstruct the moral and religious precept divesting them of female pleasure. Let us consider the testimony of Magali on the issue:

It's because he [the ex-husband] did, I'm going to put it like that, OK? He did, but did not (...) did not get where I wanted, got it? (...) So it was just like that, and it was, like, over, right? It only served him, but for me nothing, right? Yeah right. So I felt like (...) Oh my God! It's as if I were just a piece of cloth to be used, flipped over and that's it, you know? Yeah right. Then, after I found this boyfriend (...) it was very good, you know? (...). Then I saw that I had desires. (...) I took pleasure in that, you know? (...) I thought I didn't! (...) So I thought (...) no, now we're talking – I realized that I ... that I feel pleasure, I have something inside me, like, a fire, right? (Magali, our emphasis)

Testimonies like that corroborate the fact identified by Shakespeare (1998, 2007), Tepper (2000) and Sakellariou (2011) that people with disabilities, both within and outside of a stable relationship, can feel pleasure through sex. Sharing those experiences with the group of women has promoted a space for reconstruction of sexuality for other participants as well, who reported on the role of the group in helping them to be able to know their bodies and feel pleasure through them.

It is believed that giving visibility to the eroticization and sexual needs of the body with disabilities is a political act. Putting forward the issue of sexual and reproductive rights of people with disabilities, as guaranteed by the Convention on the Rights of Persons with Disabilities, can contribute to the deconstruction of the 'sexless' social place assigned to persons with disabilities.

Final considerations

The information obtained in this study showed that the process of constitution of women is related to a multitude of social determinants. Among them, the following stand out:

issues of gender, assigning to women a place of fragility and defenselessness; the hegemonic body standard, which excludes and marginalizes the elderly, obese, and disabled; and the myth that a person with disability does not have the same needs as those without disability (especially those related to the dimension of sexuality). Other constituents of these women refer to the idea that people with disabilities are summed up by their injury, that they lack attractiveness, and that a non-disabled person will only approach them if it is to get some advantages. Lack of accessibility also hampered the social inclusion of the respondents. These elements mediated the relationship of the respondents with their families and the community.

This study showed that the intersection of disability with gender issues gave rise to several vulnerabilities in these women's lives and limited the assurance of sexual and reproductive rights. However, collective spaces such as the group of women to which the respondents were affiliated can contribute to the detachment of oppressive discourses about disability and the reinvention of some aspects of the experience of sexuality.

While the importance of the guidelines recommended by the Convention on the Rights of Persons with Disabilities for the guarantee of sexual and reproductive rights is unquestionable, this study showed that it has little echo in the experience of the women interviewed. Therefore, there is a need to create mechanisms enforcing the Convention in order to ensure the dignity of persons with disabilities. More than a legal device, the Convention is an ethical treatise, that is, a reference to the social change in relation to the human rights of people with disabilities.

Lastly, another point worth mentioning is the fact that the experience of disability is marked by processes of gender, leading to the mutual constitution of these two dimensions in the subject. This highlights the importance of broadening the discussion on this issue in the context of human sciences and gender studies. It is believed that further studies in the area of sexuality and disability from a critical conception of gender is needed to promote the development of practices more engaged at the breaking of myths, taboos, and prejudices related to the sexuality of people with disabilities.

References

- Brasil (2008) *Decreto Legislativo n. 186*. (de 09 de julho de 2008). Aprova o texto da Convenção sobre os Direitos das Pessoas com Deficiência e de seu Protocolo Facultativo, assinados em Nova Iorque, em 30 de março de 2007. Brasília, DF: Presidência da República. Recuperado em 7 de maio, 2012, de <http://www2.senado.gov.br/bdsf/item/id/99423>.
- Brasil (2009) Reproductive and sexual rights of care for Peoples with disability. Secretaria de Atenção à Saúde, Departamento de Ações Programáticas, e Ministério da Saúde. Brasília.
- Brodwin, M. G. & Frederick, P. C. (2010) Sexuality and societal beliefs regarding persons living with disabilities. *Journal of Rehabilitation*, 76(4), 37-41.
- Costa, J. R. da. (2000) "Educação inclusiva e orientação sexual: dá para combinar?" *Psicolo-*

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- gia Ciência e Profissão*, 20(1), 50-57.
- Dall'Alba, L. (2004) Educação sexual da pessoa caracterizada como deficiente mental: construção da autonomia. In: L. Bianchetti & I. M. Freire (Orgs.). *Um olhar sobre a diferença: interação, trabalho e cidadania*. (pp. 21-51). 6. ed. Campinas: Papirus.
- Dhungana, B. M. (2006) The lives of disabled women in Nepal: vulnerability without support. *Disability & Society*, 21(2), 133-146.
- Diniz, D. (2007) *O que é deficiência*. (Coleção Primeiros Passos). São Paulo: Brasiliense.
- Esmail, S.; Darry, K.; Walter, A. & Knupp, H. (2010) Attitudes and perceptions towards disability and sexuality. *Disability & Rehabilitation*, 32(14), 1148-1155.
- Ferri, B. A. & Gregg, N. (1998) Women with disabilities: missing voices. *Women's Studies International Forum*, 21(4), 429-439.
- Fontes, M. (2007) Uma leitura do culto contemporâneo ao corpo. *Revista do Centro de Artes, Humanidades e Letras*, Recôncavo, 1(1), 37-46.
- Foucault, M. (1988) *História da sexualidade: Vontade de saber*. V. 1. Rio de Janeiro: Edições Graal.
- França, I. S. X. de & Chaves, A. de F. (2005) Sexualidade e paraplegia: o dito, o explícito e o oculto. *Acta Paul. Enferm.*, São Paulo, v. 18, n. 3, 253-259.
- Garland-Thomson, R. (2002) Integrating Disability, Transforming Feminist Theory. *NWSA Journal* 14(3). 1-32.
- Gesser, M. (2010) *Gênero, corpo e sexualidade: processos de significação e suas implicações na constituição de mulheres com deficiência física*. Tese (Doutorado em Psicologia). Florianópolis: UFSC.
- Gesser, M., Nuernberg, A. H., & Toneli, M. J. F. (2012) A contribuição do modelo social da deficiência à psicologia social. *Psicol. Soc.*, 24(3), 557-566. doi: <http://dx.doi.org/10.1590/S0102-71822012000300009>.
- Gesser, M., Oltramari, L. C., Cord, D., & Nuernberg, A. H. (2012) Psicologia escolar e formação continuada de professores em gênero e sexualidade. *Psicol. Esc. Educ.*, 16(2), 229-236. doi: <http://dx.doi.org/10.1590/S1413-85572012000200005>.
- Guimarães, R. (2010) *Gênero e deficiência: um estudo sobre as relações de cuidado*. In: D. Diniz (Org.), *Deficiência e discriminação*. (pp. 197-228). Brasília: Letras Livres: EdUnB.
- Higgins, D. (2010) Sexuality, human rights and safety for people with disabilities: the challenge of intersecting identities. *Sexual and Relationship Therapy*, 25(3), 245-257.
- IBGE (2010) *Censo Demográfico*. Recuperado em 15 de junho, 2012, de http://www.ibge.gov.br/home/estatistica/populacao/censo2010/resultados_preliminares_amostra/default_resultados_preliminares_amostra.shtm.
- Joseph, M. V. (2005-2006) Diversity in Women with Disabilities. *International Journal Of The Diversity*, Champaign, USA, 5(6), 213-220.
- Kittay, E. F. (1999) *Love's Labor: Essays on Women, Equality and Dependency*. New York: Routledge.
- Lang, R. (2009). The United Nation Convention on the right and dignities for persons with disability: a panacea for ending disability discrimination? *European Journal of Disability*, 3, 266-285.
- Maia, A. C. & Ribeiro, P. R. M. (2010) Desfazendo mitos para minimizar o preconceito sobre a sexualidade de pessoas com deficiências. *Rev. bras. educ. espec.*, 16(2), 159-176.
- Marques, A. & Madeira, R. (2007) Deficiências: Direitos humanos e saúde sexual e reprodutiva. APF. Em *internet*: agasim-m.ccems.pt/file.php/373/Fichas_APF/deficiencias_e_ssr.pdf. Acesso em 15.09.2009.

- McDonald, K. E.; Keys, C. B. & Balcazar, F. E. (2007) Disability, race/ethnicity and gender: themes of cultural oppression, acts of individual resistance. *Am J Community Psychol*, Baltimore, 39, 145-161.
- Mogollón, M. E. (2008) *Cuerpos diferentes: sexualidad y reproducción em mujeres com discapacidad*. Em Internet: <<http://libertadeslaicas.org.mx/pdfs/sexualid/08010811.pdf>> Acesso em 04 de junho de 2008.
- Neri, M. (2003) *Diversidade: Retratos da Deficiência no Brasil*. Rio de Janeiro, FGV/IBRE, CPS.
- Nogueira, C. (2013) A teoria da interseccionalidade nos estudos de gênero e sexualidades: condições de produção de “novaspossibilidades” no projeto de uma psicologia feminista crítica. A. L. C. Brizola, A. V. Zanella e M. Gesser (Orgs.). *Práticas Sociais, Políticas Públicas e Direitos Humanos*. (pp. 227-248). Florianópolis: ABRAPSO.
- Nosek, M. A. & Hughes, R. B. (2003) Psychosocial Issues of Women with Physical Disabilities: The Continuing Gender Debate. *Rehabilitation Counseling Bulletin*, Stanford, 46(4), 224-233.
- Nosek, M. A., & Simmons, D. K. (2005) People with Disabilities as a Health Disparities Population: The Case of Sexual and Reproductive Health Disparities. *Health Disparities & Social Justice*, 5, 68-81.
- Paiva, V.; Pupo, L. R. & Barboza, R. (2006) O direito à prevenção e os desafios da redução da vulnerabilidade ao HIV no Brasil. *Rev. Saúde Pública*. 40(Supl), 109-119.
- Petersen, A. (2006) An African-American woman with disabilities: the intersection of gender, race and disability. *Disability & Society, Washington*, 21(7) 721-734.
- Rossetti-Ferreira, M. C., Carvalho, A. M., Amorim, K. S., & Silva, A. P. (2004) Rede de significações: uma nova perspectiva teórico-metodológica. Porto Alegre: Artes Médicas.
- Sakellariou, D. (2011) Sexuality and Disability: A Discussion on Care of the Self. *Sexuality and disability*, 30 (2), p. 187-97.
- Sánchez. P. R. (2008) Sexualidad de los niños, niñas y jóvenes con discapacidad. *Revista Educación*, 32(1), 157-170.
- Shakespeare, T. (1998) Poder y prejuicio: los temas de género, sexualidad y discapacidad. In: L. Barton (Ed.) *Discapacidad y sociedad*. (pp. 205-229) Madrid: Morata.
- Shakespeare, T. (2007) Disability, Normality, and Difference. In: *Psychological challenges in obstetrics and gynecology*. (pp. 51-59). London: Springer.
- Silva, L. C. A. da & Albertini, P. (2007) A reinvenção da sexualidade masculina na paraplegia adquirida. *Rev. Dep. Psicol., UFF*, 19(1), 37-48.
- Soares, A. H. R.; Moreira, M. C. N. & Monteiro, L. M. C. (2008) Jovens portadores de deficiência: sexualidade e estigma. *Ciência e Saúde Coletiva*, Rio de Janeiro, 13(1), 185-198.
- Tepper, M. S. (2000) Sexuality and Disability: The Missing Discourse of Pleasure. *Sexuality and Disability*, 18(4) 283-290.
- Thorne, S, McCormick, J. & Carty, E. (1997) Deconstructing the gender neutrality of chronic illness and disability. *Health Care for Women International*, 18(1), 1-16.
- Toneli, M. J. F. (2006) Homofobia em contextos jovens urbanos: contribuições dos estudos de gênero. *Psic*. 7(2), 31-38.
- World Health Organization (2011) *World report on disability*. Geneva: The World Bank.

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