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Yes, we fuck! Challenging the misfit sexual body through disabled women's narratives

Ana Cristina Santos and Ana Lúcia Santos

Centre for Social Studies, University of Coimbra, Portugal

Abstract

Southern European society has been described in sociological literature as ableist, patriarchal and male-oriented. Under such conditions, many disabled women face multiple oppressions on grounds of gender, disability, class, age, sexual orientation, 'race' and ethnicity. The social construction of the impaired body as passive and dependent is conducive to a process of desexualization, presenting disabled people as inadequate for a full intimate life. The dominant biomedical model reinforces this process. This article draws on selected works in feminist disability studies to argue that rather than a body which is unfit, or does not fit, the 'misfit' is instead a cultural failure in accommodating and cherishing diversity. The authors also suggest that the desexualization of disabled women is replicating, as well as resulting from, historical tendencies to dehumanize and infantilize women. The empirical data is drawn from a larger project 'Disabled Intimacies? Sexual and Reproductive Citizenship of Disabled Women in Portugal'. Biographical narrative interviews with disabled women are analyzed to explore the notion of 'misfit' sexual bodies. Theirs are stories of counter-norms and the struggle for sexual fulfilment and recognition. The women's discussions of sexuality point to a need to change the ways that disability and intimacy are addressed in mainstream scholarly literature, institutions and the state. Narrow, heteronormative and ableist understandings of sexual intercourse and the linear character of mainstream stories of intimacy are shown as hindering the prospect of the recognition of disabled women as sexual citizens.

Keywords

disability, feminist disability studies, Portugal, sexual citizenship

Corresponding author:

Ana Cristina Santos, Centro de Estudos Sociais, Colégio de S Jerónimo, Largo D Dinis, Portugal.
Email: cristina@ces.uc.pt

Introduction

Following the overturn of the longest dictatorship in Western Europe in 1974, Portugal underwent an extensive process of legal and cultural change. Transformations were influenced by wider processes of modernization after EU accession in 1986, as well as the growing public intervention of women's organizations and other movements for sexual equality (Amâncio et al., 2007; Roseneil et al., 2012; Santos, 2013a; Tavares, 2011). However, many conservative features remain ingrained in the dominant culture. Considering the prevalent cultural features related to patriarchy and ableism in Portugal (Fontes, 2014; Martins, 2006; Tavares, 2011), many disabled women are in a particularly vulnerable position, accumulating inequalities based on ableism and sexism [1].

This article illustrates how intimacy remains domesticized within the constraining grid of expectations, roles and norms that outlaws (at least culturally) non-normative sexual practices and subjects. These include groups as different (and similar) as intergenerational (Burdick, 2014) or childless couples (Dhar, 2013), transgender (Davy and Steinbock, 2012; Morgan et al., 2010) or intersex people (Foucault, 1980; Santos, 2014), polyamorous families (Klesse, 2006), asexual (Houdenove et al., 2014) or single people (Sharp and Ganong, 2011) and disabled women (Rainey, 2011).

Within the specific themes of intimacy and disability, our study involved the gathering of life stories of disabled women living in Portugal. Their accounts are crucial for understanding the emotional management of identities which are situated at – and in many regards constitutive of – the complex intersection of sexism and disablism. The participants in the study spoke about obstacles and constraints they have encountered whilst striving to be recognized as fully intimate citizens (Roseneil, 2010) [2]. But the narratives also demonstrate resistance and an opportunity for agency that acts to subvert, reject or confront ableist discourses and the dominant (hetero)sexual citizenship regime in Portugal.

Disabled women and the missing discourse of sex

There are two trajectories of theoretical and analytic attention to the body that are relevant to this research – gender studies and disability studies. The field of gender studies has explored how corporeality and embodied performances mediate self and/or socially perceived identity and praxis. The female body has been historically regarded as unstable, uncontrollable and permeable (Evans and Lee, 2002), a 'leaky body' (Shildrick, 1997) and a transgressive signifier (Shildrick, 2002) that defies sociocultural notions of normalcy and containment. The regulation and surveillance of female bodies throughout history has been of great scholarly interest to feminist researchers. Concomitantly, issues of sexuality and intimacy are increasingly relevant topics for social scientists (Richardson, 2000, 2004; Richardson and Turner, 2001; Roseneil, 2010; Roseneil et al., 2012; Santos, 2013a, 2013b). Particularly important is the work of Ken Plummer, who understands intimate

citizenship as building upon the feminist citizenship project that is focused on the ways that the process of citizenship is gendered. Intimate citizenship also draws on analyses of sexual citizenship that demonstrate the heterosexual, patriarchal principles that inform citizenship within societies and the construction of subjects to which sexual rights are ascribed (and denied). In these ways, the 'intimate citizenship project' looks at

the decisions people have to make over the control (or not) over one's body, feelings, relationships; access (or not) to representations, relationships, public spaces, etc.; and socially grounded choices (or not) about identities, gender experience; erotic experiences. (Plummer, 2003: 14)

Intimate citizenship can be used as a wider signifier that encompasses the gendered, sexual and reproductive aspects of citizenship. For this project, it was useful in drawing attention to the ways in which disabled women have had histories of medical, legal and cultural (often religious) intervention regarding their experiences of sexuality.

A second important body of literature relevant to this research is in the field of Disability Studies, with its historical emphasis on the Social Model of Disability (SMD) theorized by Michael Oliver in *The Politics of Disablement* (1990). In 1976, the Union of the Physically Impaired Against Segregation (UPIAS) published a document that soon became the basis for the SMD. This document was called *The Fundamental Principles of Disability*. This was the first time that disability was defined in sociological terms in opposition to a strictly medical approach. A major premise of SMD is the split between impairment – i.e. biological and physical individual features – and disability, understood as a socially produced phenomenon of exclusion of disabled people, regardless of the specific type of impairment (Barnes, 2000). Instead of being a direct result of impairment, disability is understood as the consequence of a society that disables people by regulating, constraining and occluding people with different impairments. In so doing, SMD transformed disability from a medical and individual problem into a social and political issue. In relation to issues of the forced sterilization of disabled people, for example, the social model recognized this as a result of eugenics and ableist discourses in which the bodies of disabled people were considered asexual, hypersexual or unable to give consent. This resulted in the limitation of many disabled people's experiences of sexual intimacy and desiring practice.

Criticism of this model has included its alleged disregard towards simultaneous intersectional oppressions and its occlusion of the corporeal, lived elements of disability (Rembis, 2010). Oliver (1990) admitted that disabled movements focused on men's interests, and particularly on sexuality and employment, because disability had been structured through a masculine ideology. Similarly, and despite the importance of feminism in promoting cultural, political and epistemological changes in patriarchal and heteronormative societies, mainstream gender studies overlooked the impact of ableism on women.

Partially as a response to such criticisms of mainstream gender studies and disability studies for these omissions, a third body of literature emerged: feminist disability studies (FDS). In 1989, Susan Wendell argued that 'we need a feminist theory of disability ... because the oppression of disabled people is closely linked to the cultural oppression of the body. Disability is not a biological given; like gender, it is socially constructed from biological reality' (1989: 104).

FDS is concerned with intersectionality and the ways that disability is inextricably linked to other categories of identity such as gender, sexual orientation, ethnicity, age and class (Garland-Thomson, 2001; Ghai, 2003; Shildrick, 2002; Valentine and Skelton, 2007). Garland-Thomson (2005: 1580) explains that FDS

aspires to retrieve dismissed voices and misrepresented experiences. It helps us understand the intricate relation between bodies and selves. It illuminates the social processes of identity formation. It aims to denaturalize disability. In short, feminist disability studies re-imagines disability. In other words, it finds disability's significance in interactions between bodies and their social and material environments.

Importantly, FDS calls for the public validation of a variety of sexual relationships and practices for disabled women. Among its many interests is a concern with rights pertaining to self-identity and self-definition as a sexual person, and rights to sexual education and pleasure.

The influences of the SMD are evident in the shift from identifying disability as an individual problem to one that accounts for the impact of ideology, public policy, cultural institutions and the physical environment on the creation and experience of disability: 'Within the critical framework of FDS, disability becomes a representational system rather than a medical problem, a social construction instead of a personal misfortune or bodily flaw' (Garland-Thomson, 2001: 5). Garland-Thomson recognizes that our lived space is designed in such a way that only certain types of body shape can inhabit it, and this tendentious environment creates 'misfits': 'Fitting occurs when a generic body enters a generic world, a world conceptualized, designed, and built in anticipation of bodies considered in the dominant perspective as uniform, standard, majority bodies' (Garland-Thomson, 2011: 495).

The problem of misfitting does not stem from the body, but from the encounter of that body with the environment. Within FDS this relation between body and world is fluid and never fixed, and the access and inclusivity in the structured environment can only be achieved through changing the environment itself, not through modifying or occluding certain bodies.

The salience of understanding the sexual and erotic experiences of disabled women through an approach that draws on FDS is its concern with cultural representations of the body and sexuality. Also, FDS considers subjectivities, different embodiments, invisible injuries, temporarily non-disabled bodies, the role of caregivers, aging, and chronic diseases, amongst other aspects of the lived experiential body in the intersubjective realm, which have historically been largely disregarded by mainstream disability studies and feminist studies.

Informed by feminist disability studies, the stories of disabled women collected in our research are crucial for understanding the broader social and cultural contours in which these women enact their sexual desires and lived sexual experience. Empirical research was carried out using the biographical narrative interpretive method (BNIM) (Wengraf, 2001, 2007). We interviewed 30 disabled women between 29 and 49 years old, with and without children. The sample was selected using a snowball method as well as a call for interviewees on websites of partner institutions and social networks. Most of the participants in the study were white, Portuguese, self-identified as heterosexual and non-practising Catholic. It is important to note that the Catholic doctrine considers sexual activity between husband and wife as moral and ethical whilst practices outside this relationship are presented as an issue of moral concern. In our research only one of the women spoke (and very briefly) about the impact of her Catholic faith on her sex life. The vast majority only mentioned religion when the researcher asked for specific biographical data. Participants' marital status, educational background and job status varied greatly, as well as the range of impairments included in the sample. The next two sections offer our analytical account of the women's stories as they discuss their experiences of disability, sex and sexuality. For ethical reasons, personal details have been fully anonymized.

De-sexualization and infantilization: Recognizing normative conceptions of sex

Difficulties in recognizing the right to, and practice of, erotic desire are particularly striking when it comes to non-normative bodies, especially those that resist 'normative recuperation' (Shildrick, 2004, 2009). Both in cases of congenital deficiency or acquired disability, desexualization is simply naturalized (Shakespeare et al., 1996). There are many factors that explain the desexualization of disabled people, especially of women. In challenging the ableist, western capitalist discourse of autonomous individuality (Shildrick, 2009: 127) and in revealing the unstable character of all corporealities (2009: 128), disability can be seen as a threat to the normative constraints of sexuality. The idea of the erotic, eroticized and desiring disabled body defies the laws of heteronormative, able-bodied desire. Manuela, 45–49 years old, spinal cord injured, explains:

It has happened to me, people asking out of nowhere, strangers or friends, if I have sex and how is it possible to have sex. I answer with humour trying not to be rude, 'I have sex like everyone else who enjoys having sex'.

The very idea of sexual life is ableist (Rainey, 2011; Siebers, 2012) to the extent that its heterosexist assumptions and underlying practices are supposedly only achievable by certain bodies. In this framework, sexual engagement is inaccessible to those bodies that do not fit a particular aesthetic or functional ideal. Therefore, norms for sexual activity are imposed by external mechanisms in a regulated form,

replicating the hetero-reproductive and patriarchal sexual regime. Siebers (2012) explains that normative sexual practices imply a set of sequential steps and are primarily concerned with the role of genitals. Sexual practice is compulsorily regulated and genitalized by focusing on penis–vagina intercourse, assuming penetration as a legitimating factor in sexual conduct and leading to the idea that there is no sex if there is no genital penetration [3]. This focus on genitalia is projected onto some of the women in this project like Maria and Joana, inducing a situation of temporal and permanent sexual abstinence:

When my mother heard I had a boyfriend she asked me what was the point of having a man if I didn't feel, for example, when putting in a catheter, to which I replied ... if she was with my father just because of that, because there are so many other things other than sex, a caress, a hug ... Because it was like, 'you are in a wheelchair, you cannot have sex anymore.' (Maria, 35–39 years old, spinal cord injury)

As I have difficulties in spreading my legs I thought I would have difficulties in sexual intercourse, in such a way that all suitors who showed up I'd send them away. (Joana, 40–44 years old, cerebral palsy)

The lack of specialized information about sexuality in disability leads to ignorance and fear. For instance, Magda, who is 30–34 years old and is visually impaired, told us that she preferred to go to a private gynaecologist because National Health Service staff were not well prepared:

When I go to the appointment [at public service], sometimes I feel like a freak. They look at me, assessing if I can get dressed or undress myself ... when I ask questions about pills etc., they are very brief and seem to get nervous about my presence.

Manuela also had bad experiences at gynaecology clinics:

I found an absolute ignorance amongst gynaecologists about sexuality of disabled women, particularly spinal cord injuries acquired. In their minds we have no pleasure, nor should we have children, because it only gets complicated, due to their misinformation. For example, I had to educate my gynaecologist about this matter. And concerning psychologists and psychiatrists it is the same. It remains a taboo subject. (Manuela, 45–49 years old, spinal cord injury)

The lack of professional training about the diversity of sexual desires and practices of disabled people was one of the most common complaints we gathered. Marisa, 35–39 years old, talked about her experiences after having an accident that injured her from the waist down. Marisa tried to speak to her mother about her sexuality but her mother did not know how to answer her questions and suggested a medical appointment. Once there, Marisa did not get any answers because the doctor would not give her advice about sex and sexuality, and advised Marisa to clarify her

doubts with another woman who was paraplegic as well. Marisa never approached this woman because she was a stranger and much older, which made her feel uncomfortable. Faced with a wall of silence, Marisa felt the need to discover her sexuality on her own. Her interview demonstrates that medical professionals should have the necessary training to discuss issues around sex and sexuality with disabled patients, particularly because different injuries can impact on different bodies in different ways, and despite changes in bodily functions, opportunities for sexual pleasure can continue to be embraced.

For Rita, the idea that disabled people do not have sexual desires can lead to a lack of privacy, particularly for those who have reduced mobility and are dependent on others for care:

I am still a virgin and my experience at the level of affective relationships has not been satisfactory in that there is a great lack of privacy. This prevents me from being with whom I want, where I want, and having my intimacy fulfilled. (Rita, 45–49 years old, cerebral palsy)

If the hospital is not, in principle, a place considered conducive to (i.e. desirable and 'proper' to) sexual engagement, this can affect the sexual and intimate lives of people like Rita who spend much of their time hospitalized. The lack of privacy in these institutions – for example, shared rooms, health professionals with regular access to rooms – prevents the exercise of sexuality for those who live in that space, even if temporarily. Tinashe Dune, who worked as a personal assistant to students from the University of Ottawa, also reports cases in which patients were not allowed to lock the doors of their room. This, amongst other examples, hinders sexual expression, reinforcing the infantilization that affects many people and leading, in turn, to the idea that disabled people – particularly those who are hospitalized long-term – do not need privacy or sexual engagement (Dune, 2011: 83). Albertina was hospitalized for several months and experienced these constraints:

I was three months in the hospital ... there were times when I felt a sex drive, when I missed my boyfriend, and we were there together at visiting hours and we exchanged a caress or a kiss and I felt like 'I miss you, my body misses you', and he felt the same. (Albertina, 25–29 years old, amputee)

The disability movement has been involved in criticizing institutions as places of segregation. Yet Shakespeare et al. (1996) remind us that these sites may also offer opportunities for sexual encounters, despite the lack of privacy. Maria, for example, referred to the rehabilitation centre as the place where, after the accident, she started to think about the possibility of having a sex life again.

Coupled with the denial of sexuality is the infantilization regarding disabled people (Guzman and Platero, 2012; O'Toole, 2002; Rainey, 2011), as well as the restriction to the domestic sphere, particularly for women. Maria experienced

familial surveillance and regulation based on her perceived disability and her gendered identity and the moral/functional expectations affiliated with these identities. This continual surveillance prevented her from having leisure time and access to sexual engagement, as her mother did not understand the 'need' for a boyfriend:

[While still living at my parents' house] I had lunch and went to the cafe. If I'd stayed there for 5 additional minutes, they would call me, what was I doing because for a wheelchair person it was already too long for being outdoors. And then I felt trapped, and not trapped to a wheelchair. I did not even remember my chair. Because the prison was so much inside of me that to be or not to be sitting no longer made much difference ... If I went out I should be careful since I was a woman who already had two children and who was in a wheelchair. That was always thrown in my face. If I was at the cafe for five minutes more they would come looking for me ... and humiliated me: 'It is better for you to come home, what are you doing there?' There were many situations. Going out by car to meet my boyfriend and my parents closing the front door at 9.30 pm, midsummer, because I was not home at 9 pm ... And I could only go out on Sundays. (Maria, 35–39 years old, spinal cord injury)

To reiterate, the social construction of the disabled body as passive, vulnerable and dependent is conducive to a process of desexualization (Rembis, 2010), restricting experiences of intimacy and sexuality. Faced with such stigma and prejudice, opportunities for a subversive reclaiming of the right to sexual pleasure demand our analytical attention, as well as political awareness.

Re-sexualization: Defying normative conceptions of sex

In ableist, patriarchal contexts where disabled women's sexuality and desires remain largely unacknowledged, the struggle for agency regarding one's own body and sexual rights, challenging excessive medical power, becomes crucial [4]. There is a political imperative to fight for access to public spaces and the political agency of sexual minorities and disabled activists (Siebers, 2012: 38), to reformulate the socio-cultural imagery of disability and to rethink normative ideals about bodily representation and sexual performance. All 30 interviewees reported situations of precarious access to sexual citizenship, but all of them found different ways to overcome these limitations and to create their own sexual regimes. Re-sexualization presupposes a creative process of undoing normative sexuality by, for example, removing the focus on genitals during sex and eroticizing other body parts, by adapting practices to the body, or by remapping places to have sex. As Marisa (35–39 years old) explained, 'pleasure is not in the sexual act exclusively, pleasure is where we want it to be.'

If sexuality covers a spectrum of possibilities, as feminist disability studies and queer theory suggest, then functional diversity, a term increasingly used as an alternative to disability, will further contribute to the enrichment of sexual

practices. As Shakespeare et al. (1996: 106) note, 'because disabled people were not able to make love in a straightforward manner, or in the conventional position, they were impelled to experiment and enjoyed a more interesting sex life as a result.' This finding also emerged from the testimonies we gathered:

I began to have sensitivity in other body parts such as breasts, whereas before I did not feel anything, even with my ex-husband, I felt uncomfortable. Today it is where I get most of the pleasure I can get. I started to get pleasure from touching the scar, to enjoy it. Because of the surgery, touching the scar stimulates me, as well as the breasts ... Right now I can say that even without feeling, I feel more than I've ever felt when I did feel. (Maria, 35–39 years old, spinal cord injury)

I often speak to my husband, especially on how we can have more pleasure and shifting erogenous zones. We had to adjust. Our sex is experienced with humour. (Manuela, 45–49 years old, spinal injury)

Maria highlights that sexuality and sexual pleasure do not follow the normative standards attributed to penis–vaginal penetration. Similarly, Manuela refers to the search for new erogenous zones. As Siebers (2012: 47) states, desire and erotic sensations are flexible and people who have lost sensations in traditional erogenous zones eroticize other body parts. Concerning Maria's experience, the scar and breasts are erogenous zones par excellence; nevertheless she practises vaginal penetration with her partner. Rainey (2011) also finds that people with acquired paralysis, even without having sensitivity in some body parts, have bodily memory, and so they can still feel touch. As Maria contends, the rest of the body becomes more sensitive. 'Some people with disabilities report being able to remap their bodies so that they are able to orgasm from stroking on the head, nape of the neck, or nipples, or even just thinking about it' (2011: 151).

For the women in this research who had different body modifications following injury or disability, there was a progressive corporeal and functional re-adaptation through which they experimented with different methods of sex and sexual engagement. This demonstrates the creative work involved in the development of sexual identity and practice which are not taught in ableist society:

There was this phase of a new exploration of sexuality with a new body or with a body that had differences, and I remember there were some positions that I couldn't take ... And yet, today I can say that I don't feel limited because we always find alternatives [laughs] and because everything is done, even if it's done differently from what we're used to ... I like the position in which the man is behind ... and it was not possible, because as I'm amputated above the knee there aren't two knees ... And yet I found it was as simple as putting two or three pillows underneath [laughter]! But it wasn't as immediate as that. There was some frustration and sadness. (Albertina, 25–29 years old, amputee)

I found out that it is not that difficult to have sexual intercourse because despite the difficulty in spreading my legs there are several positions and, therefore, it was a ghost I had in my head. (Alexandra, 40–44 years old, cerebral palsy)

I have sex just like everyone else, we have to adjust to situations, of course. It's not easy because every time I have sex, as I am catheterized, I have to put in a bag because there may be leaks. There may be loss of faeces ... At first we thought it was over, but then time after time, and if we find the right person, it will all be as it was before, or even better. (Maria, 35–39 years old, spinal cord injury)

Albertina discusses how she developed new sexual techniques and practices through creative experimentation with her new body. As a general rule, people adjust their bodies during sex; they have the ability to create or reconfigure their bodily sexual geography. In the above excerpts, Albertina discovered the usefulness of the pillows, Maria overcame the prejudice of having sex with a draining bag and now enjoys sex through the discovery of new erogenous zones. Alexandra learned that there are several sex positions that enable sex regardless of leg spreading. There are positions not tolerated by some due to pain; the person may have to change position, take a painkiller, or just stop during the activity. In relation to people with sensory disabilities, deaf people may choose to have sex with the lights on; blind people may prefer sexual acts that value verbal communication instead. Disability may well contribute to the reconfiguration of sexual pleasure and, more specifically, to practices that lead to the optimization of pleasure [5].

The geographic reconfiguration of spaces for sex is also part of the re-sexualization process disabled people face due to the lack of physically accessible public places or places designed especially for disabled people. Thus technology assumes a significant role by providing accessible places for exchanging contacts and developing relationships. One interviewee reported using Facebook and dating websites as an excellent mechanism for networking and dating:

I have been in touch with several men but mostly by internet, where I have been exposing myself, but nothing ventured nothing gained. I've kissed more men than what I was hoping for, thanks to the internet ... Around 13 men have come to my house. (Joana, 40–44 years old, cerebral palsy)

Because of Joana's reduced mobility, and as a way to circumvent physical barriers and the lack of suitable cruising places, Joana found an alternative in virtual spaces. The emphasis of Joana's narrative was on the positive outcomes stemming from her proactive approach to sexual citizenship, through which she established herself as a subject of erotic desire [6].

Most of the narratives evidenced agency and self-determination, contrary to the cultural assumptions attached to women in general, and disabled women in particular. During not only sexual intercourse, but also the seduction process and flirtation, agency and creativity are key resources for all people, especially for

those who lack role models or access to an inclusive sex education. Magda shared with us several events of her life in which she made use of her disability as a resource for seduction:

I used my strategy of asking him to explain to me how the car transmission worked. It's funny. It's a way of trying to show something. I think people who see will also use signals [to show their interest or desire]. As I don't know the signals of someone who is not blind, I invented my own ... Of course, I misbehaved a little and took advantage of the lack of vision ... I also used the technique of teaching him braille. Braille gives birth to relationships, seriously! (Magda, 30–34 years old, visual impairment)

For Magda, her lack of vision was never an obstacle to flirting. On the contrary, her story shows that what is culturally perceived as disability or impairment does not necessarily lead to a limitation on interaction. This case illustrates that, despite the dominant heterosexist contexts that assign women as passive recipients of seduction, Magda actively subverts this paradigm by taking the lead and uses her own strategies for intimate engagement.

Another woman, Joana, virtually and physically made contact with several men, deciding the terms on which the development of these initial contacts would proceed. She acknowledges:

I am always sincere, I always say I make contact with several men and I'm doing my screening. So either they accept me as I am, with my disability and the characteristics I have and the fact that I have already made contact with various men, or not. I don't know if they also make contact with several women, so I don't feel bad. (Joana, 40–44 years old, cerebral palsy)

This excerpt shows Joana's agentic power as she is aware of the right to engage in a sexual life under equitable conditions with her male partners.

Carolina's over-protective upbringing caused growing suspicion against men, further contributing to a general feeling of loneliness in her childhood and teenage years. But as she grew up, she stopped being afraid of men. She says:

I knew it would be me who decided about my own body, not boys. And the argument 'If you'd love me, you'd sleep with me' was never an issue because it did not strike me as a condition for love. When I want may be different from when the boy wants. (Carolina, 35–39 years old, physically impaired)

Instead of abiding by the boundaries of intimacy established by others – the family, health professionals, etc. – Carolina decided to reset those boundaries according to her own terms. The practice of self-determination and the critical rejection of other people's norms and standards allowed Carolina to escape a strictly heteronormative sexual biography. She said: 'And actually my first erotic encounters were with women, with girls, not boys. Not sure why, really. Not sure whether this is because

I am a little bit bisexual.' Carolina feels comfortable engaging sexually with women, and the issue of disability was not raised at all during her discussion about these encounters.

Arguably, Carolina's protective upbringing may in fact have offered safe grounds for her to experiment and connect to other girls and women, instead of being forced into the dominant heteronormative plot from an early age, as would most probably have happened had her circumstances been different. In the absence of pressure or expectations to become a full intimate (heterosexual) citizen, the instruments of heteronormativity were less fierce and her unvalued sexuality remained relatively free from constant supervision. Ironically, Carolina's story highlights how discourses of compulsory heteronormativity can work instead to facilitate opportunities for non-heterosexual engagement.

Concluding notes

Undoing sexism and ableism through the stories of intimacy, sexuality and sexual engagement of disabled women in Portugal was a central aim of our research. Several of the narratives demonstrated evidence of stigmatization, desexualization and infantilization. Yet the women we interviewed did not portray or consider themselves passive victims when they discussed their sexual lives and the potentials of realizing sexual and intimate citizenship. Experiences of stigmatization often emerged when recounting episodes throughout childhood and youth in the statements and/or attitudes of family members, friends and health professionals. Stigmatization therefore was external in origin, but it was also sometimes internalized, through shame, the fear of abuse, the postponement of sexual life (and the related issue of late emancipation), and the tendency to be portrayed as a child (hopeless, vulnerable, naïve).

In some cases, sexuality was invisible, a non-issue, something which was dismissed as unimportant. There was also a great deal of resentment about the cultural expectations and ableist representations of disabled women's bodies and sexualities that stand in sharp contrast with what the women in this research aspire to and demand.

Although scholars of sexuality predominantly suggest that human beings are sexed – a contention that has been rightly disputed by activists and researchers in the field of asexuality – disabled people have been considered asexual in ableist discourse (Kim, 2011). According to Siebers (2012) and Rainey (2011), the very idea of a sex life is ableist because the ideology of ability values certain practices and devalues others, influencing stereotypical understandings of sex practices. Along the same line of thought, Guzman and Platero (2012) argue that dominant heterosexist assumptions involve certain practices that are only possible in relation to certain body patterns. Therefore, functionally diverse bodies do not fit this model and are thought to lack a full sexual life. Following from this, despite the increasing sexualization of society and the growing consumption of pornography – which makes up for almost 40 percent of the internet usage (Lyell, 2014) – disabled

bodies remain largely deprived of the right to sexuality. Even pornography continues to obscure disabled sexuality, as the lack of a disability-related category in the Adult Video News Awards illustrates (Rainey, 2011) [7].

Narrow understandings of sexual intercourse as penis–vagina intercourse hinder the potential to more broadly recognize the diverse practices that constitute sex and sexuality for disabled women and the ways they experience intimacy and erotics.

The participants' narrative accounts speak directly to the concerns of feminist disability studies. This is because they shed light on bodily differences in such a way that challenges normative assumptions concerning the misfit sexual body and attend to the sexist and patriarchal conditions under which women become sexual and intimate citizens. Theirs are stories of counter-norm, counter-expectation and the struggle for sexual and reproductive fulfilment and recognition.

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Notes

[1] In this article we use 'disabled people' and 'disabled women' throughout. We are aware of the critique formulated for theoretical and political reasons to the use of these expressions, as well as to the expression 'people with disability'. In that lively debate, we tend to follow what social movements and activists in the geographical locations we spoke from agree to use. We also consulted the works of Margrit Shildrick and Rosemarie Garland-Thomson, both of whom are international experts in the field of feminist disability studies and were our consultants in the research project this article stems from. They both use the expressions disabled people and disabled women. In the case of Garland-Thomson, despite her use of both disabled people and people with disabilities, in her most recent work her preference for using disabled people instead of people with disabilities is clear.

[2] According to Roseneil (2010: 82), the demand for a full intimate citizenship aims for the freedom and ability to construct and live selfhood and a wide range of close relationships – sexual/love relationships, friendships, parental and kin relations – safely, securely and according to personal choice, in their dynamic, changing forms, with respect, recognition and support from state and civil society.

[3] For example, the famous incident between Bill Clinton and Monica Lewinsky in the 1990s. Another example that illustrates the impact of this imagery is the notion of rape throughout time, and the legal distinction between a 'sexual act of relief' and 'sexual act of relief consisting of copulation' (Articles 171 and 172 of the Portuguese Criminal Code).

[4] For a similar argument regarding trans* sexuality, see Davy and Steinbock (2012).

[5] For more readings on this, see Shakespeare et al. (1996).

[6] There are several contributions in the literature that establish a link between disability and kink groups through virtual media. Parallel to this, some authors have also written extensively on the ambiguous role of fetishizing and/or desiring disabled bodies as both a source of empowerment (re-sexualization) and disenfranchisement (objectification) (see Kafer, 2004, 2012, and Rainey, 2011).

[7] One place where disabled sex can be included is in post-pornography. The post-porn movement started in the 1990s with Annie Sprinkle (www.anniesprinkle.org) who produced a series of alternative porn movies raising political awareness. Post-porn movies emerged as a result of a disagreement with mainstream pornography. Based on these assumptions, the documentary Yes, We Fuck (www.yeswefuck.org) addresses the sexuality of disabled people and non-normative sexualities, defying mainstream patterns of sex, beauty and body, and involving disabled people and non-disabled people from post-porn collectives.

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Ana Cristina Santos is a sociologist and holds a PhD in gender studies from the University of Leeds, UK. She is currently a Senior Researcher at the Centre for Social Studies, University of Coimbra, Portugal, and coordinator of the International PhD Program Human Rights in Contemporary Societies. She has been involved in and/or coordinated a number of research projects exploring issues of gender, sexual and reproductive rights, citizenship and human rights and is the principal investigator (PI) of 'INTIMATE', a 5-year comparative project funded by the European Research Council (www.ces.uc.pt/intimate). Her most recent book is *Social Movements and Sexual Citizenship in Southern Europe* (Palgrave Macmillan, 2013).

Ana Lúcia Santos holds a degree in philosophy and a Master of Arts in feminist studies at the Faculty of Humanities of the University of Coimbra, Portugal. She is a doctoral student in feminist studies from the same university. She is a junior researcher at the Centre for Social Studies, University of Coimbra, working on the research project 'INTIMATE – Citizenship, Care and Choice: The Micropolitics of Intimacy in Southern Europe', funded by the European Research Council. Her research interests focus on feminist studies, intimate citizenship, crip theory and queer theory. She is also an activist in the LGBT/queer and feminist movements in Portugal. Address: Centro de Estudos Sociais, Colégio de S Jerónimo, Coimbra, Portugal.
Email: analucia@ces.uc.pt