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Abstract

The aim of this article is to bring together the notions of sexuality, disability and care of the self. This is done by illustrating the importance of care of the self and technologies of the self in the context of sexuality and disability. This paper is partly based on empirical data from a phenomenological study on perspectives of sexuality of Greek men with spinal cord injury. In this article we shift the focus from care offered from one person to another, to self care. Foucault's work on the care of the self is used as an analytical lens to consider care as a discourse, with associated ideas and practices.

In the care of the self what is important is the degree to which chosen practices help people live life as they choose and construct the self they desire. Like everybody, disabled people need to experiment, trying out different technologies of the self and different sexual possibilities. Care of the self is about enactment of identities and choice of how to live one's life. In other words, it is about control of one's body, power to guide representations of oneself and access to choices.

Key words: spinal cord injury; Foucault; men; sexuality; caring; United Kingdom; Greek men

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Introduction

Sexuality is increasingly becoming an accepted issue in daily and academic discourses. Or rather, normative sexuality is becoming increasingly accepted; sexuality that conforms to the whats, hows and whom with, that are perceived to be normal or desirable within a culture (1). Our daily lives are regulated by practices that control whom we can get married to, whether we have the right to bear or adopt children, and how we are recognized both as sexual but at the same time as more than sexual (2).

Sexuality is a part of life, a part of *a* life (3). What happens when we put together sexuality and disability? Putting together two constructs so pregnant with meanings and cultural scripts, two constructs that are social in their essence but so very related to physicality, makes evident the need for a multiple focus, from the physical body to the lived body; from the social to the physical. Sexuality is an important issue that people want to address in therapeutic encounters after the onset of a disability or disease (4-6), and the role of disabled people[1] themselves in dealing with their sexuality needs to be examined. In a way, what needs to be examined is how people take care of themselves in order to produce a self they are satisfied with.

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[1] The choice of the term 'disabled people' over 'people with disabilities' is a critical one, informed by social and activist perspectives on disability. The use of this term in this article points attention to an experience lived and expressed by some disabled people themselves. This is that, rather than 'having' a disability, people are actively being disabled through social and political attitudes, behaviors and practices. Furthermore, rather than being an individual characteristic, external to the one's self, disability can be part of one's identity. See also Marks (43) and Shakespeare and Watson (45) for a critical use of the term 'disabled people' and a discussion of its use in relation to issues of power and oppression.

Care however is still a contested term, and many conceptualizations of it co-exist (7, 8). It has been argued that care is not always prepared to meet persons where they are and support them in a way that makes sense to them (9, 10). The role of disabled people in handling their own self is often missed out in discussions of care, or else they are constructed as passive recipients of care (11, 12). The emergence of more nuanced appreciations of care that move beyond a rigid understanding of independence could highlight the role of the people in taking care of themselves.

In the context of caring for themselves, people can choose how to conduct themselves to the extent they can choose one idea or practice over the other, based on what is available and what is best for them, according to prevailing criteria. Thus, people choose to get married or not, have children, exercise, or lose weight. Depending on the historical period that acts as a framework and the group of people involved (men or women, disabled or non disabled, homosexuals or heterosexuals etc.), these practices can be seen to feed into a normalizing discourse that produces conforming, docile sexual bodies, or they can be subversive by way of appropriating, transforming or resisting the dominant practices. Resistance can, for example, be directed against a notion of independence, which is considered as the norm in much of the Western world.

Foucault's (13, 14) work on the care of the self offers us an analytical lens to consider care as a specific discourse (with associated ideas and practices/ technologies) people adopt in their effort to produce a certain kind of self and a certain kind of body that *does* sexuality. In this sense, the discourse of care deals with ideas and practices disabled people engage in, in order to produce a self that they are satisfied with. They subject themselves to certain technologies in order to produce a desired version of themselves (15). This can mean a self that conforms to certain social, ethical or political standards, a body that carries out desired or expected activities or a series of other practices, or technologies, pertaining to the care of the self. Technologies of the self 'permit individuals to effect...a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being. So as to transform themselves in order to attain a certain state of happiness, purity,...perfection...' (16, p. 225).

This implies that the self must conform to certain socio-cultural standards, whether these refer to cleanliness of the body, conjugal relations, or sexual behaviors. People are free to choose from an array of technologies of the self, which are possible within a certain system of discourses (e.g. of sexuality or disability). In that context, where people choose technologies from what is available, the notions of resistance or normalization lose their meaning and their boundaries blur. Through engaging in certain technologies, people can actively work towards the construction of a desired version of themselves and in the process think of themselves as active agents (15).

The aim of this article is to illustrate the role of care of the self and technologies of the self in the context of sexuality and disability. This paper is partly based on empirical data from a phenomenological study on perspectives of sexuality of Greek men with spinal cord injury. Discourse in this paper is used to refer to 'practices that systematically form the objects [and subjects] of which they speak' (17, p. 54), rather than to a mere collection of symbols and signs. Discourse refers to actions, modes of behavior, attitudes, as well as ideas and their expression through language. The article will begin with a brief presentation of the research that forms the basis for the discussion. This will be followed by a discussion of sexuality and how it is regulated. The notion of care and also the concept of the body will then be discussed vis-à-vis disability and sexuality focusing on the role of disabled people in experimenting and choosing those practices that are most appropriate for them.

Methods

The discussion presented in this article is supported by empirical data from a phenomenological study on perspectives of sexuality of Greek men with spinal cord injury that draw attention to the active role of disabled people in care practices and also to the importance of the body in these practices (18). Ethical approval was granted by the Ethics Committee of Sapporo Medical University. Sampling was purposeful and six adult men were chosen to participate. As a result, the discussion in this article is focused on male sexuality vis-à-vis care practices, since the researcher is reluctant to draw inferences for female sexuality. All informants lived in an urban area and met the following criteria: males with spinal cord injury in their 20’s- 50’s, living in Greece and being fluent in the Greek language. Data were collected through in depth unstructured interviews that lasted between 1 and 1,5 hours and also through observation notes. Data were transcribed verbatim and analysed thematically using Moustakas’ (19) framework of analysis. Rigour was ensured through peer review (by a researcher fluent in both Greek and English); recording and verbatim transcription of the interviews; maintaining a detailed audit trail; asking probing questions and confirming the researcher's interpretation with informants. Detailed description of research procedures has been presented in previous publications (18, 20).

The regulation of sexuality

Sexuality refers to sexual desires, choices and behaviors (1). Historically it has been largely constructed and is still commonly perceived as a personal issue, connected with individual choices and desires. It was assumed that 'sexual desire is natural and automatic and heterosexual and universal' (3, p. 12). Sex has commonly been perceived as "a privilege of the white, heterosexual, young, single, non-disabled" (21) and physically attractive people (22). The gay liberation movement of the 1970s, informed by feminism and left-wing movements of the time, put the issue in the political agenda; the personal was reintroduced as political, asking for a deconstruction of the canonistic dichotomies of sexualities and gender.

Debates about sexuality and disability are essentially debates about choice, freedom and ability to choose and live one's life according to one's wishes. What is permissible? Or, as Weeks (1) asked, 'what can be said or performed by whom and in what settings?' Sexuality is regulated through the axes of gender and class and operates in the social organization of society, as evidenced for example through ablism and heteronormativity (i.e. reinforcing the absence of impairment or the presence of heterosexuality as a social norm respectively) of institutions like marriage, church, work and even the health professions, as several studies illustrate (1, 23, 24).

Whom we have sex with, what we do with our bodies and how we get erotic pleasure are all socially and politically regulated issues (1). Conceptions of what is permissible change over time and influence the technologies that people have access to.

The depiction of disability as a relatively exclusive identity supports a mono dimensional depiction of disabled people as asexual service users without autonomy (20). Disabled people are often regarded as asexual, denied the right to express themselves sexually or to have a sexual identity (20, 25). In a way their active role in producing a sexual self they are satisfied with is either not acknowledged or else restrained by social attitudes. In societies where social behaviors and manifestations of sexuality in particular are well defined and regulated by a complicated nexus of beliefs, expectations and regulations, sexuality is viewed as a state rather than a possibility. Dominant discourse is that of *the* sexuality. Beneath the dominant discourse and between its cracks we can sometimes sense the refracted language of people who do not belong to the normative ideal of society and whose needs often remain unmet. Given the nature of sexuality, can we ever talk of *the* sexuality? Or perhaps we need to refer to sexualities instead?

On care

Care can be viewed as a process and a practice, and has been discussed in terms of a logic (7) or in terms of an ethic (26) or multiple ethics (27). As an analytical category it was developed by feminist scholars and first examined within the family, focussing on issues of care vis-à-vis unpaid labour distribution and responsibility (28). The initial focus of discussions of care was on the carer within the context of the family, but this was later expanded to include both formal and informal care, paid and unpaid labour in various domains beyond the private/family sphere, most predominantly in healthcare and in particular in the practice of nursing (28).

Several authors (e.g. 9, 27) argue that care refers to two interconnected yet distinct domains. In the first domain, care is used to indicate a mental disposition or an emotional attachment, which leads to a process of concern, worry and attentiveness. In the second domain, care refers to actual practices that are carried out, either as a response to a process of concern or as a response to an identified need. These attitudes and practices require the presence of a caregiver (i.e. a person who offers care) and a care recipient (a person who receives care) (8). Care is viewed as an interaction between these two parties, although the relative roles of these are not always clear (e.g. is the recipient a passive actor, or can he play an active role in the interaction?).

In disability studies informed by a notion of a social model, care has been associated with a role of people as passive recipients of care, which can perpetuate dependency and detract attention from the political dimension of disability (29). It has been argued that it can signify oppression or patronizing attitudes and has been associated with dependency as Hughes, McKie, Hopkins and Watson (11) discussed in an overview of conceptualizations of care in the disability movement and in feminist literature. Indeed, care practices have often been disempowering and controlling, constructing disabled people as *objects of care* (30, 31) and locating them in the place of a passive receiver and as a burden, as is evident from literature on care (see for example 32). In disability studies care is thus often seen as a practice of normalization that contributes to the construction of a disabled self.

Recent conceptualizations of care place more emphasis to the notion of interdependence over independence (33). By challenging the notion of passivity and dependency, the emergence of interdependence has reconstituted disabled people as active participants in the process of care, leading to a critical examination of the concept of care in relation to disability beyond the binary of dependency/ independence (29, 34). Although the instrumental role of disabled people in the process of care is becoming increasingly visible in the literature, this is usually done under two main suppositions; firstly, that care refers to an interaction between at least two parties, and secondly that when it forms part of practices of normalization, care is doing a disservice to the cared for or to the carer, depending on the perspective taken.

However, people, whether disabled or not, often need to care for themselves, for their own body, or manage their care, as is the case with the system of direct payments in the United Kingdom (35). People are free to choose those practices of care that are suitable for them; those practices of care that will lead to the construction of a self they envisage for themselves. In this process they need to take decisions about what is best for them, but also for people around them. Letiche (36) referred to care as being *in-between* or *being-two* since it cannot be defined by a single process but it is always situation-bound. Although Letiche was referring to care as a dyadic interaction, its in-betweeness can also refer to the space between practices of normalization and practices of resistance; care of the self does not have to be one or the other but sometimes occupies the space between the two.

Handling of the body, handling of the self

The body has a central role in the context of sexuality and disability. As an analytical category the body has for a long time been conceptualized in two distinct ways; as lived and as physical. This bifurcation can be problematic. Impairment or illness might in part be located within the physical body of a person, but for it to manifest as a problem it often needs to affect a *lived* body, a body-in-the-world. The body has a central role in Merleau-Ponty's (37) phenomenology of perception, where he perceives the body as the main means we have to make sense of the world; through our body we are constantly engaged in a dynamic dialogue with our surroundings. Several researchers have followed on from his ideas and explored the centrality of the body in the experience of disability (see for example 6, 38, 39), and also the process of re-embodiment after disability (40).

Leder (41) remarked that in disability the body *dys*-appears; it makes its presence felt when the way we engage with the world changes. From the background where it was located, the body emerges into the foreground of consciousness and the way it is experienced is changed. However, in disability studies informed by a social model of disability, the body instead of dys-appearing, it just disappears.

The focus of disability studies based on social models of disability has been with the social and political environment, and more specifically with the construction of disability as oppression by a disabling society. Social models of disability have thus been constructed as discourses of resistance to what has been perceived to be a normalizing biomedical discourse that supports rather than resists the social construction of disability. But what began as a discourse of resistance has now produced its own normalizing discourse that decrees what is right and what is wrong (42). Marks (43), discussed some of the problems of the ‘either/or models of disability’ (pg. 611) demonstrating that they are inadequate as their focus is too narrow, while more recently Siebers (44) discussed the re-evaluation of the importance of corporeality within disability studies. As Shakespeare and Watson (45) asked, where does impairment end and where does disability begin? The boundaries are fluid and permeable. Sexuality and disability are concerned with daily practices, and in these the role of the body is often prominent; it is problematic to separate bodily from social experiences, as this might lead to needs being overlooked.

Several authors are moving beyond the lived body/physical body divide and acknowledge the body in all its complexity. Work by Longhurst (46), Papadimitriou (40) and Shildrick (2), for example, take into account multiple dimensions of the body, illustrating the fluidity of boundaries. Negotiating sexuality and disability depends exactly on an ability to move between the different dimensions of a disease, a disability or a body (7, 47).

Disability: social construct, something missing or something in excess in a body, barriers and facilitators in the environment (33). Disability can be all these but much more as well; it refers to an individual’s life, not just a body and not just an abstract society, but a specific life that one person leads (44). Annemarie Mol (47) referred to a specific disease, atherosclerosis, as being more than one but less than many. Disability is more than one but less than many; it is enacted through many practices, in many different settings, by different people. It involves a body, and a society in dialogue between them (33). But at the same time it all comes together in a specific person's life and all the seemingly heterogeneous practices become part of this life, in all their inconsistencies.

Manos is a smartly dressed, educated young man in his early thirties, financially independent and with a sense of humor. He only had a girlfriend once, when he was in his middle twenties. One night when he was 18 years old he and his friends decided to go for a car ride; Manos was to drive. Wanting to show off to his friends he sped up, but the friend sitting by him thought he had lost control of the car and grabbed the steering wheel. Then Manos really did lose control of the car. The next thing he remembers is being in the hospital, not knowing what was happening. The accident resulted in paraplegia. After the accident, he moved back with his parents, in a small semi urban town, with limited opportunities for socialization. Frustrated by his extended sexual abstinence he turned to pornography only to realise that it is not, for him, a viable alternative to sex:

"I did a lot, a lot of it, a lot of pornography, but it can't replace the real stuff. At the end of the day you feel a total jerk"

He even tried paid sex once, without much success. He got cheated out of 60 euros without even getting to meet the sex worker.

Living in a small community where he was identified (or misrecognized, according to Fraser, 48) as 'disabled', it was hard for him to meet potential sexual partners, mainly because he was not recognized as a potential sexual partner himself. He started using pornography and prostitution as a way to care for a self that wanted to have sex. He cared for his self using technologies that were at the same time empowering and disempowering (for others, but for him too). His experience of his body, both lived and physical at the same time, was central in the technologies he engaged in. Was his practice to buy sex services representative of his power as a man reflecting a normalizing discourse of manhood, or did he express resistance to a society that views disabled people as asexual, or unworthy of sexuality? There might not be a single answer to these questions. Manos chose to engage in certain technologies that were available to him, in order to care for his self and thus achieve a certain level of happiness and conformity to social norms (and bodily needs).

Whatever works; trying out possibilities

As a topos of care, sexuality brings together multiple dimensions of the human experience, social and political environments and cultural ideas about sexuality and its role in the society (1). The location of sexuality both in the physical and the lived body and its association with notions of shame, guilt, but also pleasure and joy, demands careful negotiations between all these different elements.

In his exploration of technologies pertaining to care of the self, Foucault (13) showed the complexity of the associated decision making process. To care for one self requires close attention to the kind of self one needs to care for, within a certain social and historical context. In other words, it requires an acknowledgment of the discourses that construct the self that one needs to strive towards.

Pavlos, a 52 year old heterosexual man, brought up sexuality as an issue to his medical team soon after his accident and he was happy to find that there were still ways to get an erection. Consequently he decided to use pharmaceutical products. As he says: 'this means that I can have sex three times a week, maybe four, but I cannot go beyond that'. Nick made other choices: 'I used a pharmaceutical product for some time, in an injectable form, but in the end I decided it was too time-consuming and also a bit off-putting, foreign to the eroticism of the moment. Somewhat painful too, mentally, as it's not great to inject yourself with all these substances. Best solution I found was the pump…There are many, many ways…'. Many ways to choose from, many issues to consider. Is it better to get a vacuum pump that you can you use for as often as you want and achieve erections that will last for half an hour each time or to use medication? But if you choose the latter you have to observe rules as to how often and at what intervals medication can be injected. There are many ways one can care for a body that needs help to achieve an erection, and these men had to decide which way was best for their own life. Alexandros on the other hand chose to approach the issue of erection from a different viewpoint "I could even dare to say that through and because of my current situation I get to spend more time on my partner in bed. You know, we, guys, are a bit selfish. Our first worry is to get satisfaction ourselves. I don't care about that anymore, especially since I know there's not going to be any ejaculation…"

Choosing to use a vacuum pump, or pharmaceutical products is perpetuating normalizing attitudes about the penetrative nature of male sexuality and the role of men as active partners in the sexual transaction. Equally though, choosing to use these technologies is a technology of freedom, exactly because it is the choice of the men which of these technologies to use and which not. Similarly, shifting focus from erection to other elements of sexual practices is another choice men might make; in fact these two sets of choices are not antithetical and should not be viewed as such. They represent just a few of the many technologies of self men might make use in caring for their self. These choices are essentially experiments with games of truth (49), in the sense that they reflect perceptions on what is considered as a valid (desired) or invalid (not desired) outcome. These men had to decide what was a desired outcome, and then they followed certain procedures in order to attain that outcome. The choice is not always easy. These decisions involve constant negotiations between what they need and what they want and these men were engaged in 'tinkering' practices (50) in order to produce their desired self.

Alexandros is a 33 years old, bisexual man and lives with his parents while trying to establish himself professionally. Three years have passed since the accident that caused an injury at the level of the 6th thoracic vertebra and subsequent paraplegia. For Alexandros flirting is an important part of his identity and he enjoys engaging in it, using the element of surprise and curiosity that he elicits in other people to his advantage, often using his body as a Trojan horse, gaining access to potential lovers as they perceive him as being out of the sexual game, safe. He confides that he does not miss erection as it happened before the accident, since he is exploring several ways of engaging in the sexual act. In fact he considers his sexual life to be considerably enriched as a result of the changes in his body. But he is not happy with having to empty his bowel before intercourse. The function of excretion requires his active participation in several activities and some of them need to be performed before engaging in sexual activity. And he does not like this blending of pleasure with excretion (see 51 for a more extensive discussion on this); it draws him back to a body that needs his attention in order to operate. Anthony, one of Seymour's informants (6, pg. 166) expressed similar concerns: "one of the things that really affected my sexuality was that for about the first seven years I wore a condom and an external drainage bag".

Excretion and flirting: is one more important than the other? In Alexandros' life both have their place, and he feels they are important enough to mention when talking about sexuality. A body that gets tired with the management of excretion is no less important than the ways that the image of that body is negotiated in social interaction. Caring about sexuality means caring for a body that needs to perform excretion; one is tied with the other. The technologies that Alexandros chooses to use facilitate his engagement in sexual activities, despite signifying a shame for one's body (see 52 for a discussion of the 'disabled body'). The important point is that he is enabled to choose from those technologies that will enable him to engage in sexual activities in a way that makes him feel comfortable with himself.

There are other dimensions to be explored too, for example personal assistance. How is it negotiated and by whom? At the time of the study Yiannis was in the process of moving into a flat by himself after having lived for several years with his parents. Moving in to a place of his own, and hiring a personal assistant, are decisions he took in order to become more independent, something he feels he needs particularly since he entered into an intimate relationship. He still requires assistance for some of his daily activities, this is not changed by the house move or the transition from family to paid care, but he wants to receive this assistance in his own terms, and in a way appropriate for his life. He wants assistance for a *lived* body, not for a body-as-a-tool. In effect, he wants to be able to engage in a process of caring for himself, where he will be able to make the decisions that are right for him. In a way, he wants to be able to manage how his body will be cared for, assuming control of the process.

This is very close to the notion of assistance as advocated by disability discourses coming from social models of disability. In fact, the notion of assistance (in the sense of enabling independent living) has been proposed as an alternative to the concept of care, under the premise that in assistance disabled people are in total control of a situation, which can be perceived as a service transaction (53). The problems with this notion have been elaborated elsewhere (33). For the argument put forward in this paper, it is enough to point out that by constituting a human need solely into terms of a service transaction, the power differentials of the relationship might be overlooked. Care does not need to be disempowering and construct disabled people as objects; or put differently, dependency and independence, are parts of the same continuum and people move between the two extremes.

Other participants were concerned about other issues. Yiannis confided that he misses being able to masturbate. He misses touching himself in an erotic way, feeling his body with his hands. Pavlos misses making love in a standing position. And Nick, a 34 year old heterosexual man misses sensation in his penis. Where should the focus be then? For Pavlos "it's all one. Not being able to walk, get up a ladder, sexual issues…to not be able to do things that you used to do. You have to learn everything anew". Not just social or physical, sick body or lived body, dependency or independence but all of them together. A life is the composite of many parameters and care can be constructed only when all parameters are taken into account. However, all these parameters refer to one life, and this life is enacted through one body, however complex. Debates about sexuality and disability are essentially debates about practices of daily life and how these can be facilitated through a process of care of the self.

Concluding remarks

Sexuality, disability and care, encompass several dimensions. The informants of this study cared for their self in the sense that they sought to create a self they felt comfortable with. Care was illustrated as a discourse people adopt in their effort to produce a certain kind of self. This took many meanings, depending on what was most important to each person.

A Foucauldian analysis of as the choices made by the informants as care of the self highlights the central role of the individual in the process of negotiating their own sexuality. The men whose stories are presented in this article were at once care givers and care recipients, at least for some aspects of their daily life. They did not rise above disability, but lived *with* it, engaging in truth games, trying out and choosing those knowledges (rules, procedures, principles) that were valid in the context of their life. Rather that being subordinated to these knowledges, these men handled themselves in different ways in order to construct the care that would best meet their needs. They chose how to handle themselves to the extent that this was possible within the greater social and political discourses they operated in. According to

Wynance (50, pg. 111) ‘to care is to tinker (...) until a suitable arrangement (material, emotional, relational) has been reached’. This tinkering can be about choosing practices or knowledges, and about shaping them. In effect, these men subjected themselves to certain technologies in order to produce a desired self, according to their chosen knowledges. Through choosing which technologies of the self to be subjected to, they became active agents rather than passive recipients of care. While it is acknowledged that different conditions will require different arrangements, the data presented here show that in the care of the self the role of the individual is very important.

In the care of the self what is important is the degree to which these technologies help people live life as they choose and construct the self they desire. Like everybody, disabled people need to experiment, or as Rogers (54) puts it, engage in (s)experimentations, trying out technologies of the self. Care of the self is about enactment of identities and choice of how to live one’s life. It is about control of one’s body, power to guide representations of oneself and access to choices.

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