

APO^RRIA

LA REVUE EN SCIENCES INFIRMIÈRES • THE NURSING JOURNAL

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2013: Vol.5, Numéro 3/Vol.5, Issue 3

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Commentaire / Commentary

La semaine de l’infirmière, qui fut instituée il y a 20 ans par l’Ordre des infirmières et infirmiers du Québec, se déroula cette année du 12 au 18 mai. Celle-ci visait précisément à valoriser et à promouvoir la profession d’infirmière, mais aussi, à reconnaître la contribution des infirmières au sein de notre système de santé. Pendant cette semaine, les infirmières recevaient des fleurs, des fines herbes en pots, des massages sur chaises, des crayons et des tasses à café, de la part des établissements au sein desquels elles exercent, le tout accompagné de bons mots. Nous ne voulons en aucun cas nous opposer à ces initiatives. Pourtant, nous croyons qu’il est impératif de porter une attention particulière à la reconnaissance quotidienne accordée aux infirmières.

La source primaire de reconnaissance

Les données que nous avons recueillies dans le cadre de nos recherches indiquent que les infirmières soignantes, celles qui sont en contact direct avec les patients et qui représentent la plus grande partie de l’effectif infirmier au Québec, n’obtiennent généralement de la reconnaissance que des patients qu’elles soignent. Cette reconnaissance, qui leur est vitale et qui est aussi la source de leur identité, se manifeste le plus souvent à travers diverses formes d’appréciation de leur travail.

La feinte de la reconnaissance

Les infirmières n’obtiennent que très peu de reconnaissance de la part des institutions pour lesquelles elles travaillent chaque jour. Lorsque cette reconnaissance est présente, elle n’est généralement pas associée au travail qu’elles effectuent à titre d’infirmières, mais plutôt à des initiatives prises par celles-ci qui se situent à l’extérieur du registre de leurs tâches. Les infirmières obtiennent ainsi de la reconnaissance lorsqu’elles acceptent de faire des heures supplémentaires, lorsqu’elles consentent à transformer leur horaire ou qu’elles endossent de nouvelles tâches — notamment des tâches administratives. Les infirmières ont donc l’impression que cette reconnaissance ne se déploie que lorsque leurs agissements correspondent à ce qui accommode les gestionnaires. Elles se doivent donc d’être extrêmement critiques d’une reconnaissance qui, lorsqu’elle est présente, est souvent déployée à des fins stratégiques pour le bon fonctionnement de l’organisation – une reconnaissance purement idéologique.

Des effets pervers

Plus grave encore, c'est l'effet pervers de cette reconnaissance selon lequel les infirmières en viennent à orienter leur pratique dans une direction qu'elles n'auraient jamais envisagé. Par exemple, une infirmière qui porte une attention particulière aux besoins des familles endeuillées obtient rarement la reconnaissance de son institution, même si ce type d'intervention se révèle extrêmement salutaire pour ces familles. À l'inverse, une infirmière qui s'abstiendrait de répondre aux besoins de ces familles et qui serait ainsi plus susceptible de terminer son quart de travail à temps verrait sa grande capacité d'organisation reconnue par le discours managérial. Cela ne constitue pas une véritable forme de reconnaissance qui valoriserait plutôt les aptitudes, les savoirs et la capacité des infirmières à organiser leur pratique en accord avec les besoins des patients, mais plutôt un mécanisme permettant la modification des comportements des infirmières.

Cette feinte de la reconnaissance, ou reconnaissance « idéologique », entraîne l'évacuation continue de préoccupations et de valeurs comme l'humanisme et l'altruisme qui sont propres aux infirmières – l'effacement progressif de l'idéal professionnel de celles-ci au sein des différentes institutions. Ces pratiques de reconnaissance « stratégiques » contribuent même à inverser les idéaux des infirmières vers de nouvelles exigences qui elles s'appuient sur une logique de rationalisation où le soin perd graduellement ses lettres de noblesse au profit d'une pratique infirmière superficielle et moins coûteuse. Les infirmières qui s'entêtent à donner des soins intégraux et personnalisés doivent maintenant déployer des efforts titanesques afin de répondre, tant aux besoins réels des patients, qu'aux attentes institutionnelles avec lesquelles ses besoins entrent en conflit. Administrateurs, gestionnaires, comptables et spécialistes en ressources humaines semblent en effet oublier que donner des soins éthiques et de qualité prend du temps. Pour prodiguer des soins, les infirmières doivent effectivement entrer en relation avec leurs patients, les accompagner, être sensibles à leur souffrance sans quoi, tôt ou tard, ceux-ci se représenteront aux portes des institutions de santé anéantissant du même coup les économies promises par le discours dominant de la rationalisation.

Remise en question des rapports de reconnaissance

Nous appelons les infirmières à remettre en question les rapports de reconnaissance trompeurs qui mènent à la dévalorisation de la profession d'infirmière. Les infirmières dispensent des soins qui sont essentiels à la vie et il est plus que temps que leur travail ne soit plus tenu pour acquis. Nous croyons qu'elles ont droit à une reconnaissance qui ne serait plus déployée suivant des finalités instrumentales, mais témoignerait de l'appréciation de leur travail au quotidien. Nous ne nous élevons aucunement contre la « semaine de l'infirmière », d'ailleurs nous utilisons cet

espace éditorial de manière à sensibiliser la population et les infirmières elles-mêmes quant à la reconnaissance qui leur est réellement dévolue au quotidien. Nous avons consulté les infirmières dans le cadre de nos travaux de recherche et nous nous appuyons sur des données empiriques pour affirmer que ce ne sont pas des fleurs, des fines herbes en pots, des tasses et des crayons dont les infirmières ont le plus besoin.

Reconnaître les besoins des infirmières

Au quotidien, les infirmières ont besoin que les institutions pour lesquelles elles travaillent soient à l'écoute de leurs besoins. Elles veulent que l'on tienne compte de leur réalité, elles veulent être respectées et demandent à être incluses dans les processus décisionnels. Elles ont besoin que l'on reconnaisse leur droit à l'autodétermination en tant qu'être humain, que les institutions mettent fin une fois pour toutes aux heures supplémentaires obligatoires et aux menaces qui sont associées à ces pratiques coercitives. Elles ont besoin que leur autonomie professionnelle soit reconnue et qu'elles puissent agir à la hauteur des connaissances qu'elles ont acquises, et ce, sans devoir se soumettre continuellement à l'autorité des médecins. Elles ont besoin que l'on reconnaisse le soin comme une activité essentielle à la vie, dans laquelle elles se doivent d'investir un certain temps, un temps qui ne peut être calculé quantitativement — parce que chaque être humain est différent. Enfin, les infirmières ont besoin que l'on reconnaisse leur valeur sociale réelle, que l'on reconnaisse ce qu'elles font, ce qu'elles sont, et que l'on réalise tout leur potentiel — parce qu'elles ont la capacité de transformer notre système de santé.

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Abstract

The sociology of diagnosis takes a new look at diagnostic categories, the means by which they are delivered, and the social consequences of diagnosis for patient and professional alike. Considering the social elements which contribute to the recognition of disease categories and their consequences highlights important phenomena which can enrich the thinking of nurses regardless of whether or not they diagnose as part of their practice. However, the principles of the sociology of diagnosis, while widely debated in academe, have yet to penetrate nursing literature. In this discussion article, we use obstructive sleep apnoea in women as an exemplar to illustrate how a clearly material, pathophysiological disorder has, nonetheless, significant social “content.” We demonstrate the social structures and interests which shape obstructive sleep apnoea as a male disease, and the risks, paradoxically, of both under- and over-diagnosis that arise from this social construction. We use this example to exhort nurses to consider how the social and the biological intermesh and shape how we perceive disease and its impact. This should open the door for more responsive and responsible health care.

Key words diagnosis, obstructive sleep apnoea, sociology of diagnosis

Pink Masks: Obstructive Sleep Apnoea and the Sociology of Diagnosis

SHARON HANCOCK & ANNEMARIE JUTEL

Introduction

The sociology of diagnosis is an emerging branch of sociology which focusses on how social forces help to frame biophysical conditions. First promoted by Phil Brown in the early 1990s in reference to psychiatric illness,[1] his call was echoed by Annemarie Jutel (a co-author of this paper) more recently, when she challenged sociologists and related scholars to consider how the social framing of disorders, as well as their social consequences could bring much to our understanding of health and illness.[2-4] “The classifications into which doctors and lay people slot their explanations of illness determine much about disease.” writes Jutel.

“Yet little is revealed about how these classifications are produced, the principles involved, the voices present and interests satisfied, or those silenced and disappointed.”[3 p15]

A ground swell of interest in the sociology of diagnosis has resulted in numerous critical reflections about taken-for-granted illnesses, contested diagnoses, and consequences of disease. Breast cancer, osteoporosis, female hypoactive sexual desire disorder, nuclear test exposure, medically unexplained symptoms, pharmaceutical industry disease promotion, Lyme disease, and many others are amongst the conditions and processes critically examined for their social framing and impact.[5-9]

While numerous other clinical and academic disciplines have acknowledged what the sociology of diagnosis can bring to their respective practices,[10-13] nursing is yet to reflect upon the sociology of diagnosis and the critical light it can bring to taken-for-granted information about common (and not so common!) diseases. Glaser and Strauss[14] whose methods have been widely used in nursing--were

sociologists, and described the sociologist's contribution to practice: The sociologist "reports what he[sic] observes in a way which rings true to an insider...but in a fashion they [the insider] would not have written it".[14 p9] The sociological perspective provides an informative, detailed, and different perspective on diagnosis which can enrich the thinking of nurses, some of whom may diagnose, and others of whom must respond to diagnoses as part of their practice.

In this paper, we will use the example of obstructive sleep apnoea as an exemplar to illustrate how social, political and commercial forces can frame who is likely to be diagnosed, why particular groups may be over-looked, or alternatively, targeted as candidates for treatment.

Obstructive sleep apnoea syndrome is a relatively new disease category. First described in the 1970s, it was initially recognised in the severely overweight (Pickwickian Syndrome) and subsequently differentiated from presumed insomnia.[15,16] It was recognised by the World Health Organization in the tenth revision of the International Classification of Diseases (ICD) in 1992. The advent of sleep laboratories, with the ability to monitor respiratory patterns, enabled the characterisation of this disorder, and the invention of Continuous Positive Airway Pressure (CPAP) provided an effective non-invasive treatment.

OSAS is characterised by recurrent collapse of the upper airways during sleep which results in frequent waking to restore airway patency.[17] It may have negative effects on both cardiovascular and neurological health as well as on social functioning, because of the persistent fatigue and sleepiness which it can induce.[18] Obstructive sleep apnoea syndrome has predominantly been considered a male disorder. The stereotypical sufferer is a plump, middle-aged man. Maleness and overweight are cited as important risk factors for the disorder;[19-22] however, these assertions may need adjustment. While men have as much as three times the overall prevalence of OSAS as women, in post-menopausal women, the numbers are much closer.[23] Despite the increasing identification of women with OSAS, they are still under-represented in studies,[24] underdiagnosed and possibly undertreated.[25]

Further, the impact of CPAP for OSAS is similarly understudied in women. CPAP is a treatment to which adherence is poor for many reasons, not the least of which is the fact that it requires nightly use of bulky and possibly socially embarrassing equipment.[26] Here too, as a result of the presumed gendered nature of this disorder, the experience of women on CPAP therapy has not been well researched.[27]

This article will consider the current literature regarding obstructive sleep apnoea, CPAP and women using a sociology of diagnosis framework. The sociology of diagnosis considers a priori the social nature of classification, its implementation and impact. Diagnosis may take its roots in pathophysiology, but will also have a social overlay. To be accepted as an official diagnosis, a disease must be technologically visible;[3,28] agreed-upon, usually by consensus;[5,29] and promoted by those who seek to affirm or promote recognition of the particular disease.[1]

A sociology of diagnosis framework considers the social frame of diagnosis from two interrelated perspectives. The first is based in social constructionism, or the way in which conditions, both physical and psychiatric may be reified as natural entities, separated from the social forces which recognise them. Aronowitz has modified the social constructionist debate to make it more palatable to empirical researchers, referring to "social framing" as a way of acknowledging that even in the presence of the material reality of diseases, the activities and values of many players and institutions nonetheless prod particular conditions into the shape which medicine is able to consider, and subsequently label, as disease.[5] The social model of disease presents a non-exclusive representation of social actions and structures which come in to play in the construction of diagnostic categories.[3]

The second perspective embedded in the sociology of diagnosis framework assesses the varying social impacts of particular diagnoses.[3] With a diagnosis comes a transformative explanation for the source of dysfunction. Diagnosis enables both treatment and prognosis, but is also gives access to social goods. Resources, legitimisation, and alternatively, stigmatisation are all contingent upon being diagnosed. Importantly, the degree of impact of a diagnostic label will feed back in to the category itself. The unpalatable, or stigmatising diagnosis may raise lay discontent, which in turn may result in the demedicalisation of certain conditions, as for example in the case of homosexuality[30] and late luteal phase dysphoric disorder.[31] In other cases, the desire for resources, treatment and recognition may push other contested conditions towards diagnostic recognition.[32]

With the diagnosis of obstructive sleep apnoea, social impacts can be significant. Driving licences can be revoked if a person is undergoing diagnosis related to excessive sleepiness, or either refuses or cannot use a CPAP machine. This is despite there being no universally accepted agreement as to what constitutes CPAP compliance.[33] The loss of a driving licence can have on-going serious social and

financial effects.

In the pages which follow, we propose a discussion of the social as well as the pathophysiological forces underpinning the diagnosis and treatment of women's OSAS. We have used the social model of diagnosis as an organising framework. The social model of diagnosis considers that physical diagnoses are shaped by a range of social factors and as such we have explored research focussing on pathophysiology and on social, cultural and gendered elements. Importantly, the social model does not refute the presence of the physiological condition, rather explores definitional and contextual factors which are social in origin

The aim of this discussion paper is to identify the factors which influence diagnosis and treatment of OSAS in women, to suggest research and nursing directions which may ensue from these findings. This paper is not an evidence appraisal. Our goal is not to make practice recommendations on the basis of a hierarchy of evidence. Rather, we seek to trawl through the information available to clinicians to adumbrate their social content. We look at the social and cultural elements that may variably highlight, and obscure women as potentially suffering from OSAS.

Data sources

We undertook an electronic search using the key words obstructive sleep apnoea, OSA and sleep disordered breathing along with a selection of key words focussing on gender, women and female in the Pubmed, CINAHL, EBSCO and COCHRANE databases without date or language restriction. Where there were differences, both North American and British spellings were used. We trawled the reference lists from relevant articles and journals, our own research archives, and sought input from colleagues. In each article, we looked at the assembly of biological and social factors which could contribute to understanding the diagnosis as a social frame. Twenty-six articles were selected. We describe our findings below in terms of firstly the biological, and secondly the social factors influencing the diagnosis of OSAS.

Discussion

Biological factors

Biological factors in the diagnosis of OSAS in women can be grouped in five different sub-themes. These include gender-related differences in testing, clinical presentation, causal hypothesis, distribution and treatment. We present these areas below.

The diagnosis of OSAS is made on the basis of a history of snoring, excessive daytime sleepiness, witnessed apnoeas and diagnostic tests of oximetry and/or polysomnography. [34-36] NICE guidelines, for example, stipulate that an AHI of 5-14 constitutes mild OSAS, 15-30 is moderate, and over 30 is severe. However, there is some evidence that in women, a lower ratio is associated with more severe symptoms than in men.[27] Apnoeas and hypopnoeas tend to occur in rapid eye movement (REM) sleep in women whereas they occur in both REM and non-rapid eye movement (NREM) in men.[25]

Clinical presentation may also differ in men and women. In 130 matched pairs of women and men with OSAS, women with OSAS were more likely to present with insomnia rather than snoring. They were less likely to have had a witnessed apnoea and complained more of palpitations and ankle oedema than men. They were also more likely to have a diagnosis of depression, to be taking psychiatric medications, to have had a previous diagnosis of hypothyroidism or asthma or were taking hormone medications.[37] Confirming this, a prospective study by questionnaire of patients referred for sleep studies found that women were more likely to complain of insomnia, restless legs and depression than men.[38]

Several studies attempt to explain gender related differences in presentation and in distribution of OSAS on the basis of anatomical differences between men and women. Women with OSAS more often have a reduction in the posterior airway space and a lengthening of the soft palate and long mandibular plane-hyoid bone distance which predisposes to collapsibility of the airway.[39] Although women have a smaller pharynx than men, men have a greater collapsibility of their airway when asleep and have different mechanisms of ventilation, making men more likely to develop apnoea or hypopnoea in response to hypercapnoea during sleep.[40]

The incidence of OSAS in women is not constant. In a random population sample premenopausal women were found to have a lower incidence of OSAS than post-menopausal women.[23] Progesterone has a respiratory stimulant affect and is thought to explain this; lower levels of testosterone may also be beneficial.[41] Women appear to have less severe OSAS symptoms until they are menopausal and they are also generally ten years older when diagnosed.[23] A retrospective cohort study found that two thirds of premenopausal women with chronic sleep disorder had sleep-disordered breathing, as confirmed by polysomnography.[42] Interestingly, pre-menopausal women in this study had different symptoms to both menopausal women and men.

A number of other conditions in women correlate with

OSAS, including polycystic ovary syndrome (PCOS),[43] hypertension in pregnancy,[44] and obesity.[45] Women with OSAS tended to be more obese than men with similar severity of symptoms.[25,46]

There was little research discussing women's response to treatment for OSAS. A retrospective chart review study with a small group of women (n=47), found that women diagnosed with OSAS and treated with CPAP had a 3.44 times greater mortality risk than men and also had more co-morbidities.[47] There have been no significant studies or conclusive findings considering gender differences with respect to CPAP adherence.[24] As a result of this limited evidence, gender is largely ignored when deciding on treatment.[41]

Social factors

A number of social factors can affect the diagnosis of OSAS in women, not the least of which is what Kroll-Smith refers to as a change in the approach of the popular media to sleep, sleepiness and sleep disorders.[48] Sleeping disorders which were previously barely noted, are currently described as dangerous conditions in need of scientific attention, affecting great swags of the population.

Overlaying this assignment of sleep disorders to medical attention, a social partitioning in itself, there are a range of other non-biological factors which affect incidence, recognition, and treatment of OSAS in women. Paradoxically, there are factors which both exclude women from diagnostic recognition, potentially limiting access to treatment; and simultaneously promote the disease in women in a potentially exploitative manner. We juxtapose these factors below.

Limiting social factors

The low prevalence of OSAS in women may come from gender bias in medicine and research. As we have discussed previously, there are differences in the ways in which men and women physically experience apnoea and hypopnoea. This means that women may have a lower AHI than men if scored on the same criteria, and so the polysomnography results on which a diagnosis of OSAS is often based may under-identify women. Additionally, several clinical screening tools available to health professionals score male symptoms of OSAS and do not include female symptom lists, leading to missed diagnosis in women.[49] Similarly, the Epworth Score, which subjectively measures sleepiness, has also been found to be a less robust measure in women.[50] This may be partly explained by the results of a cohort study by Ye, Pien, Ratcliff and Weaver who discussed that although

women report more sleepiness than men, they also tend to describe it differently.[24]

Gender bias is also present in research in general, where numbers of female participants is low, and questions concerning women are not being posed. CPAP compliance studies have predominantly reported findings on male subjects.[24,33,51] As Kapsimalis points out, this also may be due to study locations (ie: in veterans hospitals) which makes recruiting female participants difficult.[27]

The consequence of this male orientation towards the diagnosis is unequal distribution of resources, and subsequently, unequal care. CPAP funding by Medicare (in the US) and some insurers, is contingent upon obtaining a particular cut-off apnoea index. Because female presentation of the disease is typified by lower scores on the apnoea index, women have less ease of access to care. This may further result in women having more severe co-morbidities before being diagnosed.

The frequency of co-morbidities may be influenced by more than just disease-specific factors. As Tarasiuk et al posit, being female is an independent risk factor for low socioeconomic status (SES), which, in turn is a risk factor for cerebrovascular disease (CVD) amongst OSAS patients and for comorbidities associated with OSAS.[52] Similarly, low employment grade was associated with increased mortality from OSAS. Miller and colleagues hypothesized that because women tend to be in lower paid occupations they may be exposed to additional stressors which are associated with increased levels of inflammatory markers. Inflammatory mechanisms have been linked to the development of cardiovascular disease and some short term studies have shown that sleep deprived people have raised inflammatory markers.[53]

Women with OSAS use health care more than men with similar severity of symptoms.[54] This should perhaps not be surprising. Women are far greater consumers of these services than men, as a result of historical medicalization of women's health.[55-59] However that depression is also more commonly seen in women with OSAS may be because of the often long diagnostic trajectory in their gender-determined atypical presentation.[54] The woman's complaints may end up classified as medically unexplained symptoms, a catch-all diagnosis by exclusion which is frequently used interchangeably with a range of psychosomatising disorders.[60] Health care utilisation decreased after assessment in a sleep clinic, suggesting that accurate diagnosis results in effective treatment and in a decrease in symptoms.[61]

The gender bias in research extends to exploration of treatment options, compliance and outcomes. CPAP has a clear social impact beyond symptom management which can interfere with its effectiveness. Poor CPAP adherence in men is associated with marital conflict.[51] Women are yet to be studied and the potential for variation in modes of use and impact is certainly present. For example, Body Mass Index (BMI) has been shown to increase significantly in non-obese CPAP users.[62] Concern about body image is unequally gendered, with female angst over body fat far exceeding that of men[63] leading to potential differential in treatment compliance and outcome.

Adding to the gender differential, Brostrom and colleagues argued that women were likely to be under-diagnosed because of embarrassment or humiliation for having what is essentially being treated as a 'male' problem.[64] Furthermore patients reported being ridiculed and humiliated by family and friends regarding their symptoms and were thus reluctant to seek help. Wearing a CPAP mask and using a machine at night could add to an already-damaged self-image.

Promotional social factors

One setting in which awareness of the gender bias in the diagnosis of OSAS is high and in which people are actively seeking to reverse the trend of under-diagnosis is the commercial industry which seeks to increase its market share of OSAS treatment devices. Manufacturers of CPAP masks have seen an opportunity to promote a particular a feminised product range which allays women's anxieties about having a "men's" disease, and which highlights the diagnosis in women. CPAP masks called "Swift™ FX for Her," "406 Petite" are designed with "women in mind" and with female-friendly names. They are promoted as lighter, smaller and sleek, and stylish and are made in gender-coded pink.[65] Industry-based web sites acknowledge the commercial potential for promoting OSAS as a condition. The website for the Resmed manufacturer of CPAP machines promotes the idea that 80% of estimated 43 million Americans with sleep disordered breathing are undiagnosed. They are ideally situated to "develop this underpenetrated market." [66] Resmed also host a web -based "support community" which highlights the risks of untreated sleep apnoea (www.wakeuptosleep.com).

Moreira has described sleep apnoea as emerging from a process of medicalisation.[67] He argues that sleep apnoea was differentiated from snoring and sloth in the early 1970s, and represents an opportunity for increased specialisation. The increasing recognition of OSA has been constructed by these specialists as an important public health concern, but

also by the sleep laboratories they control and the treatments they prescribe. As we mentioned in the introduction, OSA became diagnosable when technology enabled it to be observed. Access to diagnosis and to CPAP is enabled by a "sleep industry" which has focussed on medicalising, argue some, normal variations in sleep.[68] Williams refers to this as both a commercialization and a colonization of sleep by medical expertise with interests which may far exceed the actual therapeutic requirements of the truly ill.

Social consequences

In line with a sociology of diagnosis framework, it is important to reflect upon the potential impact of an OSAS diagnosis in women. While on the one hand, recognition of the disorder in those who suffer its physiological consequences may offer an important succour, it may also impose a stigmatising burden. Because the disease has been identified as a putative male condition, more common in the overweight male, considering and accepting the definition in women may potentially raises gender-based resistance to treatment and to the label itself.[69]

Implications for Nursing

What this review shows is that women do exhibit significant differences in how they experience OSAS. There are differences in presentation, in upper airway morphology and function, in amount and distribution of body fat, and inflammatory response, in socioeconomic status, and in attitude towards and reaction to the disease. Further, they are often under-diagnosed by physicians who have a gender-bias towards the diagnosis, and tools ill-suited for diagnosing the disease in women.[41]

Importantly however, the Wisconsin Sleep Cohort study identified a high mortality risk with untreated OSAS. For those with severe OSAS the increase in all cause and cardiovascular mortality was 4 to 5 fold.[70] However, 93% of women with moderate to severe OSAS were not clinically diagnosed. This should give us pause, and has implications for further education of health professionals in recognising OSAS in women. As Brostrom et al. recommend, nurses should make questions about sleep a part of regular health assessments.[64]

However, as our sociological model prompts us to consider, we must also critically evaluate calls for expansions of diagnostic categories. Whilst there may be a strong pathophysiological rationale for increased awareness of particular forms of disease, "disease branding" or the promotion of disease awareness by industries who stand to benefit from diagnostic

expansion[71] may underpin what seems like a long-awaited shift in the awareness of women's OSAS. The commercial promotion of diagnoses by the pharmaceutical and the medical equipment industry has been well-documented, and cannot be dismissed acritically.[72-75] Notably, of the empirical articles reviewed in this study, five authors disclosed a relationship with the industry. However, many of the authors failed to make disclosures, neither denying conflict of interest nor declaring it.

Despite recognition that women do have OSAS in greater numbers than previously thought, they are still under-represented in research studies in comparison to population studies. Unless women exhibit the stereotypical male symptoms of OSAS, the symptoms they complain of are not recognised as OSAS and so a selection bias leads to inequitable care. Simultaneously, though, women are a potential target for commercial exploitation, and commercial funding research may result in over-promotion of a disease whose impact in women has not been adequately established. However, nurses are in a unique position, as they are often the first health professional seen by patients, and keeping the social and biophysical context of sleep disorders to the fore in the nursing contact may help women to achieve optimal health outcomes.

Conclusion

The sociology of diagnosis assists us to assess OSAS, its foundation, the other forces which shape its presentation and distribution, and further consider the other ways that the social may influence what we (and the wider public) see as ontological disease. It behoves nurses to tread carefully in the area of OSAS, whether they are diagnosing, providing care for women already diagnosed with OSAS, or simply answering questions about the condition. One the one hand, there is evidence that a wide group of individuals are not receiving care that would improve their health and sense of well-being. On the other, we must ensure that we have robust research and diagnostic tools, independent of the industry, which can give us a clear picture of the risks, scope and treatment of what may be a much bigger problem than assessed by current research findings. Considering how the social and the biological intermesh and shape how we perceive disease can open the door for more responsive and responsible health care.

Very importantly, this sociological view should provide a kind of critical distance for health care providers (nurses and others). What it is very difficult to do is to stand back and see the value content in the practice activities in which we

routinely engage. This is the point to which the Glaser and Strauss comment in the introduction refers. Mary Douglas makes the point even more clearly: "How can an individual [in the grip of iron hard categories] turn round his [sic] own thought-process and contemplate its limitations?"[76 p16] We suggest that the answer is in multi-disciplinarity. Nursing can't step out of its own episteme to critique it, but a social perspective can bring in a much needed external view. By welcoming social perspectives on diagnostic categories and processes, nursing can make important strides in improving health outcomes.

References

1. Brown P. Naming and framing: the social construction of diagnosis and illness. *J Health Soc Behav.* 1995;Health Module:34-52.
2. Jutel A. Sociology of diagnosis: a preliminary review. *Sociol Health Illn.* 2009;31(2):278-99.
3. Jutel A. Putting a Name to It: Diagnosis in Contemporary Society. Baltimore: Johns Hopkins University Press; 2011.
4. Jutel A, Nettleton S. Towards a sociology of diagnosis: Reflections and opportunities. *Social Science & Medicine.* 2011(Special Issue):793-800.
5. Aronowitz R. Framing disease: An underappreciated mechanism for the social patterning of health. *Social Science & Medicine.* 2008 29;67(1):1-9.
6. Barker KK. Electronic Support Groups, Patient-Consumers, and Medicalization: The Case of Contested Illness. *J Health Soc Behav.* 2008;49(1):20-36.
7. Ebeling M. 'Get with the Program!': Pharmaceutical marketing, symptom checklists and self-diagnosis. *Social Science & Medicine.* 2011;73(6):825-32.
8. Jutel A. Framing disease: The example of female hypoactive sexual desire disorder. *Social science & medicine* (1982). 2010 27;70:1084-90.
9. Trundle C. Commonwealth nuclear test veterans and the quest for recognition Graduate School of Nursing, Midwifery and Health Research Seminar Series; 5 May 2010; Victoria University of Wellington. 2010.
10. Wykes T, Callard F. Diagnosis, diagnosis, diagnosis: towards DSM-5. *Journal of Mental Health.* 2010;19(4):301-4.
11. Prior JA, Kadam UT. Cardiovascular disease and musculoskeletal disorder labels in family practice acted as markers of physical health severity. *J Clin Epidemiol.*

2011;64(5):547-55.

12.Cramer H, Evans M, Featherstone K, Johnson R, Zaman MJ, Timmis AD, et al. Treading carefully: a qualitative ethnographic study of the clinical, social and educational uses of exercise ECG in evaluating stable chest pain. *BMJ Open*. 2012;2:e000508.

13.Daker-White G, Sanders C, Greenfield J, Ealing J, Payne K. Getting a diagnosis v. learning to live with it? The case of the progressive ataxias. *Chronic Illn*. 2011;7(2):120-33.

14.Glaser BG, Strauss AL. *Awareness of Dying*: Aldine Publishing Company; 1968.

15.Carroll D. Pickwickian syndrome, 20 years later. *Trans Am Clin Climatol Assoc*. 1975;86:112-27.

16.Guillemainault C, Eldridge FL, Dement WC. Insomnia with Sleep Apnea: A New Syndrome. *Science*. 1973;181(4102):856-8.

17.Giles TL, Lasserson TJ, Smith BJ, White J, Wright J, Cates CJ. Continuous positive airways pressure for obstructive sleep apnoea in adults. *Cochrane database of systematic reviews*. 2006(1):CD001106.

18.Smith CE, Daus E, Clements F, Werkowitch M, Whitman R. Patient education combined in a music and habit-forming intervention for adherence to continuous positive airway (CPAP) prescribed for sleep apnea. *Patient Educ Couns*. 2009;74(2):184-90.

19.Young T, Palta M, Dempsey J, Skatrud J, Weber S, Badr S. The occurrence of sleep-disordered breathing among middle-aged adults. *The New England journal of medicine*. 1993;328(17):1230-5.

20.Guillemainault C, Bassiri A. Clinical features and evaluation of obstructive sleep apnea-hypopnea syndrome In: Kryger M, Roth T, Dement W, editors. *Principles and practices of sleep medicine*. Philadelphia: Elsevier; 2003. p. 869-78.

21.American Sleep Apnea Association. *Sleep Apnea*. 2013 [cited 2013 13 June]; Available from: <http://www.sleepapnea.org/learn/sleep-apnea.html>.

22.Mayo Clinic Staff. *Sleep apnea: Risk factors 2013* [cited 2013 13 June]; Available from: <http://www.mayoclinic.com/health/sleep-apnea/DS00148/DSECTION=risk-factors>.

23.Bixler EO, Vgontzas AN, Lin HM, Ten Have T, Rein J, Vela-Bueno A, et al. Prevalence of sleep-disordered breathing in women: effects of gender. *Am J Respir Crit Care Med*. 2001;163(3 Pt 1):608-13.

24.Ye L, Pien GW, Ratcliffe SJ, Weaver TE. Gender differences in obstructive sleep apnea and treatment response to continuous positive airway pressure. *Journal of clinical sleep medicine*. 2009;5(6):512-8.

25.Young T, Hutton R, Finn L, Badr S, Palta M. The gender bias in sleep apnea diagnosis. Are women missed because they have different symptoms? *Arch Intern Med*. 1996;156(21):2445-51.

26.Bollig SM. Encouraging CPAP adherence: it is everyone's job. *Respir Care*. 2010;55(9):1230-9.

27.Kapsimalis F, Kryger MH. Gender and obstructive sleep apnea syndrome, part 1: Clinical features. *Sleep*. 2002 15;25(4):412-9.

28.Wailoo K. *Drawing Blood: Technology and Disease Identity in Twentieth-Century America*. Baltimore: Johns Hopkins University Press; 1997.

29.Aronowitz R. When do symptoms become a disease? *Ann Intern Med*. 2001;134(9 part 2):803-8.

30.Mendelson G. Homosexuality and psychiatric nosology. *Aust N Z J Psychiatry*. 2003 Dec;37(6):678-83.

31.Rodin M. The social construction of premenstrual syndrome. *Social science & medicine* (1982). 1992 Jul;35(1):49-56.

32.Aronowitz R. Lyme Disease: The Social Construction of a New Disease and Its Social Consequences. *Millbank Q*. 1991;69(1):79-112.

33.Sin DD, Mayers I, Man GC, Pawluk L. Long-term compliance rates to continuous positive airway pressure in obstructive sleep apnea: a population-based study. *Chest*. 2002;121(2):430-5.

34.Fietze I, Penzel T, Alonderis A, Barbe F, Bonsignore MR, Calverly P, et al. Management of obstructive sleep apnea in Europe. *Sleep Med*. 2011;12(2):190-7.

35.National Institute for Health and Clinical Excellence. *Continuous positive airway pressure for the treatment of obstructive sleep apnoea/hypopnoea disorder*. London: National Institute for Health and Clinical Excellence. 2008.

36.Ruehland WR, Rochford PD, O'Donoghue FJ, Pierce RJ, Singh P, Thornton AT. The new AASM criteria for scoring hypopneas: impact on the apnea hypopnea index. *Sleep*. 2009;32(2):150-7.

37.Shepertycky MR, Banno K, Kryger MH. Differences between men and women in the clinical presentation of

- patients diagnosed with obstructive sleep apnea syndrome. *Sleep*. 2005;28(3):309-14.
- 38.Valipour A, Lothaller H, Rauscher H, Zwick H, Burghuber OC, Lavie P. Gender-related differences in symptoms of patients with suspected breathing disorders in sleep: a clinical population study using the sleep disorders questionnaire. *Sleep*. 2007;30(3):312-9.
- 39.Verdaguer M, Levrat V, Lamour C, Paquereau J, Neau JP, Meurice JC. [Obstructive sleep apnoea syndrome (OSAS) in women: a specific entity?]. *Rev Mal Respir*. 2008;25(10):1279-88.
- 40.Zhou XS, Shahabuddin S, Zahn BR, Babcock MA, Badr MS. Effect of gender on the development of hypocapnic apnea/hypopnea during NREM sleep. *J Appl Physiol*. 2000;89(1):192-9.
- 41.Lin CM, Davidson TM, Ancoli-Israel S. Gender differences in obstructive sleep apnea and treatment implications. *Sleep Med Rev*. 2008;12(6):481-96.
- 42.Tantrakul V, Guilleminault C. Chronic sleep complaints in premenopausal women and their association with sleep-disordered breathing. *Lung*. 2009;187(2):82-92.
- 43.Lee KA, Baker FC, Newton KM, Ancoli-Israel S. The Influence of reproductive status and age on women's sleep. *J Womens Health (Larchmt)*. 2008;17(7):1209-14.
- 44.Champagne KA, Kimoff RJ, Barriga PC, Schwartzman K. Sleep disordered breathing in women of childbearing age & during pregnancy. *The Indian journal of medical research*. 2010;131:285-301.
- 45.Laaban JP, Mounier L, Roque d'Orbcastel O, Veale D, Blacher J, Melloni B, et al. Cardiovascular risk factors in men and women with obstructive sleep apnoea syndrome. *Respir Med*. 2010;104(7):1063-8.
- 46.Quintana-Gallego E, Carmona-Bernal C, Capote F, Sanchez-Armengol A, Botebol-Benhamou G, Polo-Padillo J, et al. Gender differences in obstructive sleep apnea syndrome: a clinical study of 1166 patients. *Respir Med*. 2004;98(10):984-9.
- 47.Morrish E, Shneerson JM, Smith IE. Why does gender influence survival in obstructive sleep apnoea? *Respir Med*. 2008;102(9):1231-6.
- 48.Kroll-Smith S. Popular media and 'excessive daytime sleepiness': a study of rhetorical authority in medical sociology. *Sociol Health Illn*. 2003 Sep;25(6):625-43.
- 49.Flemons WW. Clinical practice. Obstructive sleep apnea. *The New England journal of medicine*. 2002;347(7):498-504.
- 50.Baldwin CM, Kapur VK, Holberg CJ, Rosen C, Nieto FJ. Associations between gender and measures of daytime somnolence in the Sleep Heart Health Study. *Sleep*. 2004;27(2):305-11.
- 51.Baron KG, Smith TW, Czajkowski LA, Gunn HE, Jones CR. Relationship quality and CPAP adherence in patients with obstructive sleep apnea. *Behav Sleep Med*. 2009;7(1):22-36.
- 52.Tarasiuk A, Greenberg-Dotan S, Simon T, Tal A, Oksenberg A, Reuveni H. Low socioeconomic status is a risk factor for cardiovascular disease among adult obstructive sleep apnea syndrome patients requiring treatment. *Chest*. 2006;130(3):766-73.
- 53.Miller MA, Kandala NB, Kivimaki M, Kumari M, Brunner EJ, Lowe GD, et al. Gender differences in the cross-sectional relationships between sleep duration and markers of inflammation: Whitehall II study. *Sleep*. 2009;32(7):857-64.
- 54.Greenberg-Dotan S, Reuveni H, Simon-Tuval T, Oksenberg A, Tarasiuk A. Gender differences in morbidity and health care utilization among adult obstructive sleep apnea patients. *Sleep*. 2007;30(9):1173-80.
- 55.Barker KK. A ship upon a stormy sea: the medicalization of pregnancy. *Soc Sci Med*. 1998;47(8):1067-76.
- 56.Bell SE. Changing ideas: the medicalization of menopause. *Soc Sci & Med* 1987;24(6):535-42.
- 57.Hartley H. The 'Pinking' of Viagra Culture: Drug Industry Efforts to Create and Repackage Sex Drugs for Women. *Sexualities*. 2006;9(3):363-78.
- 58.Tiefer L. The medicalization of sexuality: Conceptual, normative, and professional issues. *Annual Review of Sex Research*. 1996;7:252-82.
- 59.Vertinsky PA. *The Eternally Wounded Woman: Women, Doctors, and Exercise in the Late Nineteenth Century*: University of Illinois Press; 1994.
- 60.Jutel A. Medically Unexplained Symptoms and the Disease Label. *Social Theory and Health*. 2010;8:229-45.
- 61.Banno K, Manfreda J, Walld R, Delaive K, Kryger MH. Healthcare utilization in women with obstructive sleep apnea syndrome 2 years after diagnosis and treatment. *Sleep*. 2006;29(10):1307-11.
- 62.Redenius R, Murphy C, O'Neill E, Al-Hamwi M, Zallek SN. Does CPAP lead to change in BMI? *J Clin Sleep Med*.

2008;4(3):205-9.

63. Bordo S. Unbearable weight : feminism, Western culture, and the body. Berkeley: University of California Press; 1993.

64. Brostrom A, Johansson P, Stromberg A, Albers J, Martensson J, Svanborg E. Obstructive sleep apnoea syndrome--patients' perceptions of their sleep and its effects on their life situation. *Journal of Advanced Nursing*. 2007;57(3):318-27.

65. The CPAP People: Sleep Therapy Solutions. New CPAP Masks Target Sleep Apnea Therapy Options for Women. Richmond, VA: CPAP Connections, Inc; 2010 [cited 2011 21 December]; Available from: <http://blog.thecpapppeople.com/blog/2010/11/8/new-cpap-masks-target-sleep-apnea-therapy-options-for-women.html>.

66. ResMed. Respiratory Care Solutions. 2012 [cited 2012 28 May]; Available from: <http://www.resmed.com/au/index.html>.

67. Moreira T. Sleep, health and the dynamics of biomedicine. *Social Science & Medicine*. 2006;63(1):54-63.

68. Williams S, J. Sleep and Health: Sociological reflections on the dormant society. *Health (London)*. 2002;6:173-200.

69. Sparks B. Sleep Well Clinic - personal communication. Wellington, NZ2012.

70. Young T, Finn L, Peppard PE, Szklo-Coxe M, Austin D, Nieto FJ, et al. Sleep disordered breathing and mortality: eighteen-year follow-up of the Wisconsin sleep cohort. *Sleep*. 2008;31(8):1071-8.

71. Parry V. Disease Branding: What is it, why it works and how to do it. *Pharmaceutical Executive*. 2007;Oct:22-4.

72. Dear JW, Webb DJ. Disease mongering: A challenge for everyone involved in healthcare. *Br J Clin Pharmacol*. 2007;64(2):122-4.

73. Menkes DB, Jutel A. From Snake Oil to Statins: Defining the Scope of Disease Mongering. in press. 2007.

74. Moynihan R, Doran E, Henry D. Disease Mongering Is Now Part of the Global Health Debate. *PLoS Medicine*. 2008;5(5):e106.

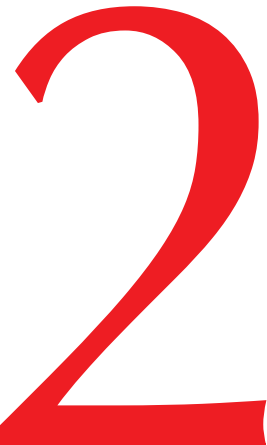
75. Wolinsky H. Disease mongering and drug marketing. *EMBO*. 2005;6(7):612-4.

76. Douglas M. Purity and Danger. London: Routledge and Kegan Paul; 1966.

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Abstract

This essay is at once a critical analysis, an experiment in form, and – with some irony – a cautionary tale. Triggered by the inclusion of prodromal diagnoses in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders, and the recent call by the United States' (U.S.) Obama administration for increased mental health screening, I argue that shifts toward identifying and intervening on one's potential madness, or risk, circulate with/in the contemporary U.S. climate of intensified discipline and terror, and use Bipolar Disorder as a site to critically explore how and with what implications this circulation occurs. Specifically, I weave Massumi's 'political ontology of threat' with the narrative of a woman diagnosed with Bipolar Disorder in order to trace the pre-emptive politics and affective logic of a risk-based approach to madness. I contend that the diagnosing and drugging of potential is a self-perpetuating loop that is personally and politically harmful, and consider alternatives to this burgeoning practice.

Key words affect, Bipolar Disorder, embodiment, risk, security

Loopy: The Political Ontology of Bipolar Disorder

RACHEL JANE LIEBERT

Introduction

The question becomes, what are the experiential political implications of the a priori rightness of smokes to future fires? What are the existential effects of the body having to assume, at the level of its activated flesh, one with its becoming, the rightness of alert never having to be in error? Of the body in a perpetual innervated reawakening to a world where signs of danger forever loom? Of a world where once a threat, always was a threat? A world of infinitely seriating menace-potential made actual experience, with a surplus of becoming, all in the instant?[1 p66]

I used the example like a zit being popped. Like there was just so much pressure and pressure and pressure and it just had to come out and that's just how it came out. And ... in retrospect I'm glad for the epiphany ... and all of that stuff 'cos it definitely was like an earthquake you know that opened something out. ... The typing, the writing, just the actual break – I mean it needed to happen otherwise it just would've been pushed down pushed down pushed down. (Lauren)

Here, affect theorist Massumi[1] asks about the experiential consequences of living in a world of intensified securitisation – one that is predicated on, and consistently alerted to, an ever-present threat of terror. In this paper, I explore how this world enters the bodies and lives of people – like 'Lauren' speaking above – labeled with Bipolar Disorder. In doing so I question more broadly our risk-based approach to madness; a critique that seems all the more immanent given the recent inclusion of prodromal diagnoses in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM) and the current call by the Obama administration for

heightened mental health screening following several school shootings in the United States (U.S).

Bipolar Disorder, as a diagnostic label, entered the DSM in its third edition.[2] At this time, the disorder was considered to exist within 0.1 percent of the U.S. population.[3] Come the turn of the century however, and – while some put prevalence estimates as high as 24 percent[4] – the ‘lifetime risk’ most commonly cited in scientific articles was (and continues to be) five percent;[5] a number twice as high as worldwide averages⁶. It follows that, since 1980, one could conservatively claim a fifty-fold increase in Bipolar Disorder, while a 240-fold increase can also be substantiated. These rises can in part be attributed to the expansion of the DSM’s diagnostic criteria in 1994 to include the Bipolar Spectrum Disorders (BSDs); diagnoses that have come to land disproportionately in the bodies of women.[7]

The analysis put forth in this paper comes out of a qualitative research project in which I sought to critically examine this recent, dramatic increase in Bipolar Disorder diagnoses. I collected a range of archival and interview material to map the discursive landscape of Bipolar Disorder over the past three decades, scope out how this landscape is enacted with/in drug company and clinical practice, and contemplate its embodiment and/or disruption by women who have received the diagnosis.[8-10] In turn I argued that the high and growing numbers signify and reproduce a *circulation of risk*; it is by-and-large one’s potential madness that has become aggressively marketed, intimately surveilled, clinically classified and perpetually drugged.

This circulation of risk is enacted through a number of discursive and extra-discursive technologies that are contingent upon the notion of ‘recurrence’. That is, a presumption that people’s experiences stem from a mental disorder – an underlying, pathological entity – that will build in intensity and frequency unless chronically medicated. Despite the questionable nature of its foundations[8,10] recurrence remains a powerful psy technology in the contemporary milieu; one that constructs people with Bipolar Disorder as dangerously at risk for future escalating episodes of mania and depression, and thus used to justify early intervention.

And these moves to intervene ‘early’ on madness resonate with/in the current U.S. climate of intensified discipline and terror. Contemporary approaches to Bipolar Disorder combine neoliberal emphases on personal responsibility, self-regulation and individual freedom with efforts to predict, prevent and/or contain the threatening and the unexpected.

This means that discourses and practices with/in mainstream mental healthcare promote both the disciplinary self-surveillance and self-formation of the ‘good mad citizen’ and the nullifying, limiting and checking of psyches that may terrorize this ‘freedom’ – of one’s self and of others. In this sense, rather than fabricating them into being (as is the work of the former disciplinary mechanisms), these latter security mechanisms aim to ‘treat uncertainty’ or ‘manage contingency’; effectively, to patrol our psychic borders for risk.

These biopolitical apparatuses – documented by Foucault[11,12]– mimic the increasing move toward security, or ‘regulating disorder’, alongside and beyond discipline, or ‘producing order’, that has come to characterize the U.S. political context following the events of 9/11.[13] In this essay, then, I use Bipolar Disorder as a site to explore how and with what implications such mimicry occurs.

Process

The analysis I present here draws on a narrative constructed by Lauren during a three-hour interview I conducted with her in 2011. Lauren was a 36-year-old European American woman living in New York City and working in education after being raised in New York suburbia with her upper middle class family. She received a Bipolar Disorder diagnosis in 1995, experienced both public and private mental health systems and, at the time of the interview, was taking Seroquel, Zoloft and Lamictal. While Lauren’s was one of three interviews I conducted (with approval from the CUNY Institutional Review Board), I chose to explore only her account here as she had been living with this diagnosis for a significant amount of time and was able to provide substantial detail and reflection on her experiences of both madness and a range of interventions.

I read and re-read Lauren’s transcript with a gaze toward how her experiences might enact contemporary politics of surveillance and security. Initially, this meant looking for evidence of the discursive and extra-discursive mechanisms that I had mapped out in an earlier analysis as pushing the circulation of risk.[8] However, in the Introduction to her work on ‘ordinary affects’, Stewart argues that social structures (in this case, those of surveillance and security) need to be approached as “a scene of immanent force” rather than as “dead effects imposed on an innocent world”. [14 p1] She thus advocates for attending to those modes of power that shape matter through the affective realms. That is, those “public feelings that begin and end in broad circulation” and are “the stuff that seemingly intimate lives are made

of".[14 p2] I therefore subsequently overlaid Massumi's exploration of 'semiosis' with/in a securitised context (namely, that of post-9/11 U.S.). According to Massumi, semiosis is the process by which a sign (in this case, a Bipolar Disorder diagnosis) "*dynamically* determines a body to become, in actual experience"[1 p65] – resulting in what he calls the 'political ontology' of threat, and driven by both the 'productive power' of pre-emption and the 'affective fact' of fear. Massumi further argues that any analysis of this process must be grounded in a 'metaphysics of feeling' (attending both to the epistemology and ontology of people's experiences) and situated in interaction with regimes of power.

In what follows, then, I explore the pre-emptive politics and affective logic of our current and pending approach to Bipolar Disorder by weaving together Massumi's theory and Lauren's story. Specifically, I use his concepts of 'alert', 'threat-potential', 'contagion', 'unconsummated surplus', 'affective fact' and 'political ontology' to trace how and with what implications fear attaches to Lauren's becoming through the pre-emptive treatment of 'her' Bipolar Disorder, and in doing so contemplate how our risk-based approach to madness moves with/in the current U.S. climate of intensified discipline and terror. In doing so, however, I by no means wish to imply that experiences of madness are not real, that suffering is not significant, or that some sort of support is not sometimes needed. More, I use this analysis to argue that the ways in which mainstream psy is doing these three things is deeply problematic – indeed, risky.

Analysis

"Eyes shut, eyes open": Alert

The immediate shock gave way to lingering fear, relaying the danger into a remainder of surplus threat. September 11 was an excess-threat-generating actual event that has perhaps done more than any other threat-o-genic source to legitimate pre-emptive politics.[1 p60]

So I'm alone in this freezing cold room and I'm just staring like, "What the hell is happening?" It's like a holding pen. Then they get me out of there and they put me in four-point restraints ... By that point they had injected me with Haldol and I was twitching like crazy because you know that's what that does to you, and ... the restraints were loose, and I pulled out of them. And then they tightened them and I had a guard next to me. And ... that's kind of like eyes shut, eyes open you know. Then everything else happened after that. (Lauren)

Here, Lauren narrates the end to a 36-hour psychotic break that began with her accidentally taking a narcotic and led to her being diagnosed with Bipolar I Disorder when she was 19 years old. A diagnosis that invited high doses of psychiatric drugs including Prozac, which landed her back in hospital:

When they gave me Prozac I just lost it. I mean I was violent ... I was like destroying my room. ... I slammed the door off its hinges ... [I was] throwing shit and making holes in the walls, and just [being] like a caged animal. ... My hands were shaking from it [the Prozac] and it just it set me off. ... I think that bought it to a head enough that I went back in to the hospital this time for the depression ... on the outside.

Lauren's diagnosis then, involved two episodes of drug-induced hospitalization – one for 'mania', and one for 'depression'.

These experiences were not completely out of the blue, however. Lauren spoke of an upbringing that was oppressed by familial expectations. She constantly received "crazy-making", "Catch-22" and "contradictory" messages about what she was/not allowed to speak about, or do with, her life. Moreover, by the time she was 16 years old Lauren "clearly knew, and was pretty much shouting to anyone who would listen, that stuff isn't quite right in this family where everything on the outside looks perfect – pretty house, you know, upper middle class suburb". Indeed overall Lauren constructs herself as consistently resisting silence or invisibility, "I was just really angry ... combat boots, shaved head, green hair ... I was just messing up this scene". When finally able to leave the suburbs and move to New York City then, Lauren experienced a sense of "complete liberation". This intensified when she started at an exciting and "crazy" workplace. Here, Lauren "felt a sense of connectedness to everyone", was "starting to like speed up", and "would just like work work work, and then pass out, and then like work work work" – culminating, she believes, in her psychotic break (as 'triggered' by the narcotic).

It follows that Lauren embeds her madness with/in a moment of dramatic transition in her life. Yet post-hospitalisation these linkages were effectively ignored. Lauren felt like she "came home from 10 days in [the hospital] to nothing" – there was no move to even "just talk about what the fuck just happened" with "everybody involved". Instead drugs – Haldol, Congentin, Lithium, Prozac – were used to "crush her", while her family insisted that she, "Like, 'just keep moving'. Like, 'just keep doing stuff'". Lauren's experiences were shouted over with pharmaceutical and behavioral pushes toward normality, productivity and forgetting. Pushes that Lauren depicts as moving her from having "fight in me

that this [Bipolar Disorder] wasn't me" and "was caused by all these crazy circumstances", through being "beaten down emotionally" and a "zombie" from taking drugs, to feeling simply "under submission" and accepting that "this is my life".

This shift from fight to submission echoes through the aftermath of Lauren's hospitalisation-cum-diagnosis. Entering her into an assemblage of concepts, practices and systems commanded by risk, Lauren's psychotic break became what Massumi¹ calls an 'alert'. That is, a "performatively signed" threat event, which "extrudes a surplus remainder of threat-potential that can contaminate new objects, persons and contexts"¹(p60). Like the signification of 9/11 as a symptom of an underlying, orientalist regime of anti-U.S. terror, Lauren's initial madness came to be diagnosed as an underlying, recurring mental disorder dripping with excess threat-potential. For the rest of this analysis, I continue with Massumi to consider how this "threat-o-genic source" came to "contaminate" Lauren's life.

"Squashing possible future mania": Threat-potential

Question: How could the nonexistence of what has not happened be more real than what is now observably over and done with?[1 p52]

You know I don't remember as much about them telling me what it was, as much as them telling me what I needed to do. Like, "You need to take medicine. You need to go to therapy". ... Because it came off of a manic episode it was like, "We have to prevent that from happening again" and it felt like at whatever cost – even if that meant completely numbing me. ... So I just remember as far as the diagnosis it being like, "This is how you have to manage it" more than an understanding of really what it is or what caused it. ... It was almost like, "The psychosis is looming at all times". ... Like it was less dealing with depression that was really underlying like the whole time than it was like squashing possible future mania. (Lauren)

Here, Lauren locates and problematizes the response to her madness within a policy of prevention or "squashing possible future mania" through drugs. She argues that this approach demanded a (re)construction of her psychosis as a perpetual, looming threat and enacted a refusal to explore the past or present meaningfulness of her madness. In other words, as Massumi writes, what was yet to occur took "blaring precedence over what has actually happened".[1 p52]

In the following account, Lauren portrays how this precedence of her potential over her actual experiences continued during her second hospital stay and affected her subjectivity:

There was no sense of ..., "This is how this fits in to

the rest of your life". Like ... orientation as far as ..., "What's now? ... I'm 19 does this mean that I'm set up for a life of this? Is this what I am now?" ... I feel like if it had been contextualized-. ... [But] the message I felt that I got was you know, "You're exhibiting symptoms. We need to squash the symptoms". ... And, "You're going to need this medicine probably for the rest of your life". That, "With this medicine you can't have children". You know, "That you can't".

Lauren thus felt that her experiences were insufficiently contextualized such that she lacked an orientation about what her madness meant for future or self, beyond that she would likely be under life-long medication and therefore what she could not do. This approach worked to not only ignore Lauren's crazy-making contexts but also contain her in a narrow trajectory of 'chronic illness' that seeded a questioning of her subjectivity.

Overall then, Lauren constructs the diagnostic process as classifying her experiences, indeed her self, in terms of a threat-potential to be managed with drugs. As mentioned above, this risk-based approach is contingent upon her experiences being performatively signed as Bipolar Disorder. That is, diagnosed as symptoms of a speculative, underlying mental disorder – one that will recur unless perpetually regulated. In effect then, what Massumi calls a "non-existent entity" has "come from the future to fill [her] present with menace".[1 p5] This haunting is depicted in the following extract where Lauren talks about how her doctors justified their approach:

Lauren: I would write about this feeling of just being like connected. Just connected. And I think what's bad about that is that the medicine stops that, or ... it can numb it sometimes to the point where you feel like you'll never get that feeling again. ... You know they [doctors] were like, "Previously you'd gone up to a 10 and down to a one, well where we're trying to get to with the medicine is bring down the lows and bring up the highs" [sic]. And I'm like, "I don't want to be a five, like I don't wanna be a seven, I want the ability to be a 10 when I want to be a 10". And they were kinda saying like, "This is a dangerous place. You can't. Other people can go there but you can't", almost.

Rachel: What was dangerous about it?

Lauren: Well psychosis. I mean they're saying, "There's a point where you can't bring it back" ..., "Your ability to control bringing it back is diminished". And you know to a certain extent that's my experience you know, that it's true.

Here, Lauren constructs with a sense of sadness and injustice what it means to be told that she is not allowed to "be a 10" and consequently "numbed" with drugs. This prophylactic protocol is because of concerns that her feelings may

escalate to an uncontrollable “dangerous place” that could continue into psychosis. In turn, her feeling of “just being like connected” operates as what Massumi¹ calls an ‘alarm’ – a warning sign that threat is near – thus becoming the mechanism by which her Bipolar Disorder comes to haunt her present. In the following section I further explore how Lauren’s diagnosis affects how she experiences her feelings and body.

“I called them artgasms”: Contagion

Two weeks later, the powder is identified. It is flour. News articles following up on the story ... continue to refer to the incident as a “toxic substance alert”. No one refers to the incidence as a “flour alert”. The incident is left carrying an affective dusting of white-powdered terror. Flour has been implicated. It is tainted with the fear of anthrax, guilty by association for displaying the threatening qualities of whiteness and powderiness. In preemptively logical terms, the incident was a toxic substance alert – not because the substance was toxic, but because the alert was for a potential toxic substance.[1 p57-58]

[I] constantly had like really paranoid thoughts in my head. Um like, “People are talking about me”, “People are looking at me”, “People are saying things about me”, “They are like judging me”. ... It got to the point where it was so bad that I literally believed that I smelled and that people were like avoiding me because I did, and that like created a force-field around me. Like I wouldn’t go close to anybody. It was really, really bad. (Lauren)

Situated within a context in which she was overwhelmed and isolated by ongoing issues with her family and friends, Lauren speaks here about her feelings in high school. That is, pre-diagnosis. While presented in this extract as paranoia, later in the interview Lauren relates her sense that she smelled to her having “artgasms” when in creative spaces:

When I was at high school ... I was definitely hypomanic. I even had ... a discharge. Like I was kind of wet ... I felt like it was out of my control, it wasn’t just normal, it was like I was getting turned on. ... That’s also why I thought I smelt. I was like, “This stuff is coming out of me!” And I made my Mom take me to the gynecologist ... but there was nothing happening and ... anything that would be there would be normal ‘cos you’re a girl you know this stuff will be there, but not in copious amounts that are making your underwear uncomfortable. ... It’s like a feeling of ... your whole body just being on. ... I even can get it now. ... I can sweat because of like a feeling of just being really excited about what’s going on, and I feel like ... my threshold for being excited is very low. ... Imagine what that does if you already have self-image or self-esteem issues, and now you’re sweating and you’re coming in your own pants [laughs]. ... I called them “artgasms”.

Lauren, then, retrospectively reconstructs her artgasms and sweating as hypomania. Of note is that her sense of abnormality was in part because of what she portrays as the “copious” nature of her discharge combined with her “very low” excitement threshold. Lauren draws on discourses of excess to construct her body and pleasure as pathological and therefore signify that she was (is) hypomanic and at risk for future mania.

According to Massumi, alarms render “innocent objects” (or persons, or behaviors, or feelings) “officially threatening for the duration of the alert” and afterward “remain tainted by their affective involvement in the incident”.[1 p58] Lauren’s diagnosis has put her on alert such that she has come to interpret – indeed, experience – her body as an alarm, and therefore as signifying potential threat. Thus, while at the time the artgasms activated Lauren to seek gynecological intervention, post-diagnosis they came to be felt as symptoms of an underlying mental disorder requiring psychiatric intervention.

This dynamic embodiment of her diagnosis is also enacted through Lauren’s account below when I asked directly about her experiences of mania in the present:

It’s funny when I’m in environments ... where I feel very connected ... I can get myself very excited and that’s not necessarily a bad thing ... I definitely feel like my antennae are more sensitive and that I pick up stuff other people don’t pick up. And so like ... the first [activist group] meeting when we were all there – like this feeling of, “Wow I’m energized by this” – but then that can’t just be a period at the end of that like, “Wow I’m energized by this, now I’m gonna go to sleep ‘cos its bedtime”. No now I’m up and I’m thinking, “What can I do with this group?” and, “This group is going to be daaaaadadadadada” and it’s like my brain just takes off with possibilities. And I think that’s what is so frustrating ... – I don’t want to say it’s out of my control – but the ... rate of acceleration is like so fast. ... It’s like this feeling of connection with ideas ... or being in a group where you feel really at home or being in an environment that’s super creative. ... I get like tingly.

Thus, retrospectively affiliated with her then-pending psychosis and therefore classified with threat-potential, Lauren’s thoughts, artgasms, sweating, excitement, connection, energy, possibilities and tingles – past and present – have become her mania. Woven with risk, Lauren’s excessive, embodied feelings are experienced through and as the looming menace of her future: Bipolar Disorder. A menace that has come to legitimate a self-renewing loop of pre-emptive action, as discussed below.

“Living to avoid”: Unconsummated surplus

Threat is from the future. It is what might come next. Its eventual location and ultimate extent are undefined. Its nature is open-ended. It is not just that it is not: it is not in a way that is never over. We can never be done with it. Even if a clear and present danger materializes in the present, it is still not over. There is always the nagging potential of the next after being even worse, and of a still worse next again after that. The uncertainty of the potential next is never consumed in any given event. There is always a remainder of uncertainty, an unconsummated surplus of danger.[1 p53]

Rachel: So wait, 19 [years old at the time of diagnosis], 36 [years old at the time of the interview], so 17 years [after first being diagnosed] – so have you found that it comes back? Like the mania? Like are they right?
Lauren: Ummmmm. [Long pause].

Here, Lauren’s long pause conveys a hesitation as to whether or not her mania recurs. Her uncertainty offers an illustration of Massumi’s[1] above depiction of threat as an “unconsummated surplus of danger”. Constructed through risk and affected by fear, there is always the “nagging potential” that her mania might recur even if there has been no clear and present evidence of such.

It is this nagging potential that gives threat its capacity for self-renewal. As conveyed by Lauren in the following account, this capacity is generated through pre-emptive actions that are intended to prevent any future madness from occurring:

You’re living to avoid rather than living to move toward things. You’re living to prevent. ... And there’s a lot of decisions that I have either made or stopped myself from making because ... I’m afraid of feeling good. ... Its like, “Well I know this thing is really what I want and that will make me happy, but that might be too unstructured and creative and high energy and then that will be my undoing”. And boom boom boom I unravel.

Lauren constructs herself as “living to avoid” because she is “afraid of feeling good” and this could be her “undoing”. Yet as Massumi[1] notes, via such preemption her future of threat cannot be falsified; it can only be deferred. As such Lauren has been entered into an “open-ended” threat: her riskiness “will have been real for all eternity”. [1 p53] Through pre-emption, Lauren’s future menace – her Bipolar Disorder – is “once and for all in the non-linear time of its own causing”. [1 p53]

Threat’s capacity for self-renewal is also depicted in Lauren’s account of her pharmaceutical use:

Lauren: I’ve been on Zoloft for years, and I’m kind of okay with it. ... It doesn’t bother me that I take it at this point ..., I don’t really notice it ... and ... why

mess with it right now if it’s okay? And it doesn’t have terrible effects Zoloft. But like Seroquel ... has been really great just because it helps me sleep. So I don’t know ... do I need something? And then I take Lamictal which I’m weaning myself off of because I do not like it.

Rachel: Because of the side effects?

Lauren: Yeah ... dry mouth is I think the worst one.

Here, Lauren portrays the presence or absence of adverse effects – as opposed to the presence or absence of positive effects – as contributing to her decision-making about drugs. A decision-making that is based on her not knowing what would happen if she came off the drugs. As she depicts elsewhere, “You know like people take an allergy pill ... whether or not it works or you need it that day, you kind of just take it as a precaution”. The felt reality of threat then, legitimates ongoing preemptive pharmaceutical action on Lauren’s potential madness – despite what her present feelings of madness or drug benefit actually are.

Massumi[1] argues that such pre-emptive logic is based on a double conditional – the ‘would-have/could-have’. Present threat, he explains, is a “step by step regress from the certainty of actual fact”. [1 p55] The ‘actual fact’ would be that Lauren is psychotic; one step back is that Lauren has the capacity for psychosis; another step back is that Lauren does not have the capacity but she would have if she could have. This ‘would have’ is grounded in the ever-present assumption that a Bipolar Disorder diagnosis signifies the existence of a recurring, pathological entity; the ‘could have’ is grounded in the assumption that prophylactic drug treatment is actually blocking one’s future madness. However, not only does threat (re)activate pre-emptive action and become eternalized by it, threat is also materialized by preemption. I explore this productive power in the next section.

“Bing!”: Affective fact

Proposition: the security that preemption is explicitly meant to produce is predicated on it tacitly producing what is meant to avoid: preemptive security is predicated on a production of insecurity to which itself contributes. Preemption thus positively contributes to producing the conditions for its own exercise. [1 p58]

From having a diagnosis I feel like my sense of who I am ... has been very elusive for me. ... I moved apartments, I moved jobs, I ... started and ended relationships. ... There’s a lot of ... peeling of identity and just like running, ... moving because I didn’t want people to get to know me well enough to see that there’s something going on. I felt like there were people who had ... happy normal lives and got married and had lots of friends, and I just felt like that life wasn’t gonna be mine. ... I never did want kids.

... And I feel like there's ... what's for everybody else, and then there's like what I'll get. ... It's a feeling of ..., "I'm not gonna be able to have the same kind of life that other people get to have". And there's the feeling of like, "Well I don't know if I want it anyway". (Lauren)

Here, Lauren depicts her diagnosis as making her run from potential communities and relationships because she is afraid that people would find out that she was "not gonna be able to have the same kind of life that other people get to have". This fear is embedded in assumptions about what is a normal life juxtaposed against Lauren's own supposed abnormality. Her account thus portrays running as a reaction to the diagnosis-induced threat-potential that she will not be able to live her life in line with social ideals. In turn, this pre-emptive action (running) has given her a shaky "sense of who I am".

In addition Lauren argues elsewhere that a Bipolar Disorder diagnosis "definitely makes a person second-guess you know responses or even impulses". It follows that she feels as though "you can't trust what you experience" and that, "The way you ... perceive things – that your way of interacting with the world – is just bad. And that you know you're gonna have to do these things in order to fit in". Notably, these things are once again pre-emptive actions; as Lauren continues, "doing the more traditional route" was "the safe way to avoid" her potential "undoing". Yet, this living "in-authentically but safely" was also considered to "cause so much of a disconnect between who you are and what you're doing that that creates its own like set of problems".

It is this problem-making ability of pre-emption that moves threat from future potential to present fact. This is illustrated in the following extract – notably constructed directly in response to my question earlier about whether or not her mania recurs – where Lauren expands on the "set of problems" caused by her living "safely":

What's been cyclical ... is my attempts to achieve, and then me giving so much of myself to keep up a façade, and like get a certain job and certain status and certain ... goal that ... isn't what I really want, but what I think I should have ... for some external reasons that have nothing to do with me, taking on too much, realizing that's not authentic, and then just crashing. And then trying to build myself up again. ... The latest thing I've been saying to my doctor is that a lot of this stuff is not bipolar – it has nothing to do with any illness. It's just ... patterns that I've used to navigate ... the circumstances of my life. ... And my doctor I believe is very much of that same mind you know. She's telling me that, "You know you can control a lot of this". ... Things like her saying, "Why did you live in 20 places over the last 20 years?" ...

– no one ever asked me that before. I feel like a lot of the decisions I've made have been ... like the protozoa – getting to a point where things are untenable and then just, bing!, going the other way.

Thus when asked about her mania, Lauren offers an account of her recurring "attempts to achieve" certain unwanted goals, trying to keep up a "façade", having an "existential crisis" and then "crashing". Moreover, as shown by Lauren constructing her account around the assumption that she has mental illness and despite being triggered by her diagnosis-induced insecurities about her ability to make the 'right choices' in life, these patterns are pathologised. As Lauren depicts, "They would never talk about like, ""Why?"". Her diagnosis is the lens through which her behaviors are interpreted and experienced.

It follows that Lauren's behavioral patterns both become 'her disorder' and immerse her even more deeply in the diagnosis that activated them in the first place. A similar, looping dynamic is conveyed in the following extract about Lauren's work as a teacher, when I had once again asked her about the recurrence of her mania:

This has been like a pattern. Things get stressful, I start to react to the stress and ... the fear too it's like I feel like its escalating. I need to take a day off. ... One day becomes two, two becomes three, then I don't wanna go back because now I've been gone too long and, "What'd I do with the kids?" and, "I didn't grade the papers". And it just like snowballs until I take a week. ... So then I talk to my principal or my boss and I say, "Listen I have this illness".

Lauren portrays her fear as leading to an escalating sense of insecurity and absences from her work that she then justifies with the notion that she has "this illness", thus further entrenching her in an endless loop of pre-emptive politics. Lauren's future menace – Bipolar Disorder – creates an insecurity in the present that feeds its own renewal.

This productive power of pre-emption also occurs with regard to prophylactic drug treatment. As mentioned earlier and shown above in Lauren's experiences with Prozac, a Bipolar Disorder diagnosis means that people are preemptively drugged and any adverse drug effects – including from withdrawal – are interpreted as 'their disorder' coming through: the threat materializing. This interpretation affirms and perpetually re-instates the justification for the treatment in the first place, thus enacting some sort of drug-induced diagnostic looping.

According to Massumi pre-emption captures "for its own operation the self-causative power native to the threat-potential that it takes as its object".[1 p58] The never-ending,

nagging potential of Lauren's future madness is rendered immortal by pre-emptive actions (avoidance, running, attempts to achieve, days off, prophylactic drug treatment), which themselves lead to insecurities (self-doubt, crises, crashing, self-diagnosing, adverse drug effects) that lead to further pre-emptive action. Via pre-emption, threat is both deferred into eternity and realised in the present. Thus, as Massumi argues, pre-emptive action becomes "retroactively legitimated by future actual facts".[1 p56]

Importantly, this looping is triggered by Lauren's diagnosis signifying an internal, recurring disorder: her riskiness is *inside of her*. Lauren depicts this as leading to a dependence on others and drugs that she finds "scary", a sense of being "in danger" when she does not have access to mental healthcare and portrays herself as "afraid" when she starts feeling good or in "fear" when she feels herself getting stressed. Massumi argues that it is this circulation of fear that maintains the self-renewing properties of threat, "Whether the danger was existent or not, the menace was felt in the form of fear. What is not actually real can be felt into being".[1 p54] Through a risk-based approach to madness then, Lauren's potential Bipolar Disorder has become what Massumi calls an 'affective fact' in the present.

Her diagnosis – her threat-potential – is crazy-making. And it is this materialization of risk – realised via pre-emption and driven by fear – that lubricates the 'political ontology' of Bipolar Disorder.

"You're off your meds": Political ontology

Problem: how can preemptive politics maintain its political legitimacy given that it grounds itself in the actual ungroundedness of affective fact? Would not pointing out the actual facts be enough to make it crumble?

Observation: Bush won his reelection.[1 p55]

Inflated self-esteem or grandiosity; decreased need for sleep (e.g. feels rested after only 3 hours of sleep); more talkative than usual or pressure to keep talking; flight of ideas or subjective experience that thoughts are racing; distractibility (i.e., attention is too easily drawn to unimportant or irrelevant external stimuli); increase in goal-directed activity (either socially, at work or school, or sexually) or psychomotor agitation; excessive involvement in pleasurable activities that have a high potential for painful consequences (e.g., the person engages in unrestrained buying sprees, sexual indiscretions, or foolish business investments). [15 p332,336]

As shown in Lauren's story above, affect-driven logic "saves threat from having to materialize as a clear and present danger – or even an emergent danger – in order to command

action".[1 p55] Indeed it is its operation on this affective register that, at least in part, explains the dramatic rise and staying power of Bipolar Disorder diagnoses despite the lack of evidence for their validity and the surplus of evidence for their political and economic construction.[5,8,9,16-18] The subjectivities, bodies, lives and numbers of Bipolar Disorder enact the "future birth of the affective fact".[1 p52]

Massumi argues that understanding and/or interrupting this sticky spiral requires an 'ecological approach' that situates preemptive power in a 'field of interaction' with other regimes of power. The circulation of risk needs to be interrogated in and through epistemology, ontology *and politics*. And so, aside from resonating with/in post-9/11 U.S. politics, what relations of power does Bipolar Disorder threaten; what does its surveillance and securitisation serve?

First, whether refusal, anger, green hair, sweat, artgasms, excitement, dreams or homes, Lauren's accounts are woven with discourses of excess. Within medical, psychological and cultural spheres, female excess has long been linked with pathologising categories.[19] This is depicted in the DSM-IV criteria for a Hypomanic and Manic Episode above; these symptoms embrace a range of "excessive" behaviors that 'nice girls' should not do – being proud, loud, ambitious, sexual, seeking pleasure, taking risks. McClelland and Fine argue that female excess swirls with/in the "French twist" of desire and risk: desire materializes into risk the moment it is enacted.[19 p92] Such twisting is suggested in Lauren's account of her first hospitalisation whereby, "Before I was able to be released they gave me like a full gynecological exam and they gave me like pamphlets on safe sex and all this stuff". Moreover, she commented in passing that if a Bipolar Disorder woman is sexual the first assumption and concern is, "You're off your meds". Narrating an assumption that Bipolar Disorder is associated with an excessive, risky sexuality that is usually contained by drugs.

As also portrayed here, Bipolar Disorder threatens contemporary ideals around control. Martens[16] argues that extreme fluctuations in mood and behavior are pathologised as Bipolar Disorder because they challenge neoliberal expectations of internalized, self-regulated and moderated emotions. In the above accounts Lauren consistently depicted self-control when normalizing her experiences and an inability to control her own feelings and behaviors when pathologising them, "And they were saying like, 'You're ability to control bringing it back is diminished'"; "I felt like it was out of my control, it wasn't just normal"; "I don't want to say it's out of my control"; "It has nothing to do with any illness ... She's telling me that, 'You know you can control a

lot of this”.

In turn these arguments are bound with notions of citizenship. Elsewhere I have argued that excessive and unstable white, middle class, female bodies (such as Lauren’s) are constructed as a risk to themselves, their families, and the nation; their route to becoming the bipolar subject par excellence – a ‘good mad citizen’ – is through treatment compliance and self-management, both of which require an ‘acceptance’ that one has a chronic, risky mental disorder and the ‘choice’ to consume pharmaceuticals. However not all have access to these forms of self-governance. As a biopolitical project, Bipolar Disorder also works to exile – coercively treat and/or institutionalize (in hospitals, or in prisons) – incorrigibly threatening psyches; a designation that falls disproportionately on people who are brown, black, poor and/or alien.[9]

Such ‘population racism’ [20] is once again contingent on the circulation of fear, which, according to Clough and Willse [21] provides neoliberalism with a ‘rhetoric of motive’. This twinning is enacted in Bipolar Disorder: people diagnosed come dripping with historical assumptions, and affective arousals, of inter/national threat. Not the least of which is how madness confronts the ‘obligations of freedom’ on which contemporary governance depends.[22] It delineates those who do/can/will, or not, fulfill the duties of neoliberal citizenship; illuminating that the ‘freedom’ of some is dependent on the ‘unfreedom’ of Others.[23] Including the potential mad Other in all of us. These raced and gendered currents swirl with/in an ‘enlightened’ history of denigrating feelings and flesh as uncivilized and irrational; [24-27] feeding an ‘ontological obliteration’ central to the colonial project.[28] To refuse madness any witness beyond the borders of psy assemblages that manage it as a threat, thus allows us to evade, domesticate and/or banish feelings that might otherwise contaminate the imperialist project.

And feelings that, in addition, threaten to expose the crazy-making contexts with/in which they speak. As depicted in the opening quote to this paper, while Lauren felt that her initial, drug-induced hospitalisation “opened something out” – creating a space for dialogue, meaning making, and possibility – her experiences were by-and-large ignored by the affective, discursive and material enactments of risk management that came to dominate her treatment. A disturbing twist given that it is the chronic denial of her feelings – “pushed down pushed down pushed down” – that built the pressure under her psychic plates in the first place.

Discussion

The terrorist series includes torpedoing buildings with airplanes, air missile attacks, subway bombs, suicide car attacks, roadside bombings, liquid explosives disguised as toiletries, tennis-shoe bombs, “dirty” bombs (never actually observed), anthrax in the mail, other unnamed bioterrorist weapons, booby-trapped mailboxes, Coke cans rigged to explode, bottles in public spaces... The list is long and ever-extending. The mass affective production of felt threat-potential engulfs the (f)actuality of the comparatively small number of incidents where danger materialized. They blend together in a shared atmosphere of fear.[1 p61]

If I had ... someone to give you the perspective that, “You’re not this.” ... That, “There’s like a spectrum of beliefs and of ... stress ... that for whatever reason right now they’re affecting you more than everybody else.” And not, “They’re always going to affect you more than everybody else.” But, “Right now, at this point in your life, with whatever bought you to this point, you’re there. But like you’re not always going to be there, and you’re not like damaged because you’re there now. Like anyone would feel this way in your situation.” But I didn’t get that. I didn’t hear that. (Lauren)

Enacted with/in a context of intensified psychic securitisation, Lauren’s initial excess-threat-generating event signified a looming threat-potential that triggered alarms and preemptive actions, which in turn materialized insecurities that also fed further actions. All driven by neoliberal, imperial fears around excess, citizenship and freedom, Lauren has been entered into an endless loop of pathologisation and prevention.

Thus while Massumi argues that, preemptive power is washing “back from the battlefield onto the domestic front”, [1 p57] it seems things are getting even more intimate. Emerging from socio-political conditions of discipline and terror, preemptive power is now entering our feelings. Effectively, we are witnessing the deployment of security measures on the psychic front. Further, given that these measures produce the very experiences they claim to thwart, the boundary between defensive and offensive action is blurred.[1] The circulation of risk in the bipolar milieu enacts both the securitisation and the militarisation of the psyche. That is, we are not just preventing madness, but creating it.

And with its pending institutionalisation of prodromal syndromes and their associated prophylactic treatment, the DSM-5 threatens to only further intensify this process; Section III contains ‘Attenuated Psychosis Syndrome’ – a cluster of ‘symptoms’ to identify and intervene on people at *risk* of becoming psychotic.[29] In turn these ‘symptoms’ will themselves become alerts that will be quick to form their own iterative series, “thanks to the suppleness and compellingness

of the affective logic generating them".[1 p61] As shown above and noted by Massumi, this 'long and ever-extending' list, "combines an ontology with an epistemology in such a way as to endow itself with powers of self-causation".[1 p62]

This potential proliferation of threatening 'prodromal' experiences will be joined by a heightened surveillance of self and others; one that is propelled through not only the Whitehouse, but also the circuits of the pharmaceutical industry. The long-standing lead U.S. lobbyist[30] and third most profitable industry worldwide,[31] the pharmaceutical industry has benefited greatly from Bipolar Disorder. In 2009 the industry was worth \$837.3 billion worldwide, with three Bipolar Disorder pharmaceuticals making the top 15 individual global products in terms of U.S. sales.[32] Critics have already documented the 'disease-mongering' techniques deployed by drug companies to encourage people to interpret their own, their loved ones' and/or their patients' fluctuations in mood as a biochemical imbalance – Bipolar Disorder – in need of pharmaceutical intervention.[5] And, like the threat-potential underlying it, the market for – and therefore profitability of – a risk-based approach is endless.

To consider these potentials is to critically question the ways in which we do madness and to take seriously the possibility that these themselves might be risky. This questioning is *itself* dependent on not seeing people's experiences in terms of an internal, recurring entity and thus a perpetual, looming threat. As Lauren argues above, it requires a refusal to place people in life-long, self-perpetuating categories of damage. Instead, we might nourish and respect the subjective, embodied and collective expertise of people diagnosed; the meaningfulness of feelings and the 'irrational'; diverse approaches that move beyond illness models for engaging with madness; and constructions of madness as a capacity and as contingent and transitional.[10] While how these ideas look in practice will differ depending on the context, all demand intervention into the circulation, indeed the post-9/11 political economy, of fear – only then might we be able to open a space for imagining how we could do madness differently.

References

1. Massumi B. The future birth of the affective fact: The political ontology of threat. In: Gregg M, Seigworth G (eds) *The Affect Theory Reader*. Durham & London: Duke University Press, 2010. 52-70.
2. APA. *Diagnostic and Statistical Manual of Mental Disorders: Volume III*. Arlington, VA: American Psychiatric Association. 1980.
3. Healy D. *Mania: A Short History of Bipolar Disorder*. Baltimore, MD: The John Hopkins University Press, 2008.
4. Angst J. et al. Toward a redefinition of subthreshold bipolarity: Epidemiology and proposed criteria for bipolar II, minor bipolar disorders and hypomania. *Journal of Affective Disorders* 2003; 73: 133-146.
5. Akiskal H. et al. Re-evaluating the prevalence of and diagnostic composition within the broad clinical spectrum of bipolar disorders. *Journal of Affective Disorders* 2000; 59: 5-30.
6. Merikangas K. et al. Prevalence and Correlates of Bipolar Spectrum Disorder in the World Mental Health Survey Initiative. *Archives of General Psychiatry* 2003; 68: 241-251.
7. Curtis V. Women are not the same as men: Specific clinical issues for female patients with bipolar disorder. *Bipolar Disorder* 2005; 7: 16-24.
8. Liebert RJ. 'A progressive downward spiral': The circulation of risk in 'bipolar disorder.' *Journal of Theoretical and Philosophical Psychology* 2012; Advance online publication. doi: 10.1037/a0030456
9. Liebert RJ. Synaptic peace-keeping: Of bipolar and securitization. *Women's Studies Quarterly* 2010; 38: 325-342.
10. Liebert RJ. A (re)view of ambivalence in Bipolar Disorder research. In review.
11. Foucault M. *The History of Sexuality, Vol. 1: An Introduction*. New York: Random House, 1978.
12. Foucault M. *Security, Territory, Population: Lectures at the College de France, 1977 – 1978*. New York: Picador, 2009.
13. Agamben G. *On Security and Terror*. *Frankfurter Allgemeine Zeitung* 2001; 219: 45. Translated by Soenke Zehle.
14. Stewart K. *Ordinary Affect*. Durham and London: Duke University Press, 2007.
15. APA. *Diagnostic and Statistical Manual of Mental Disorders: Volume IV*. Arlington, VA: American Psychiatric Association, 1994.
16. Martens C. Theorizing distress: Critical reflections on bipolar and borderline. *Radical Psychology* 2008; 7. <http://radicalpsychology.org/vol7-2/Martens.html>.
17. Martin E. *Bipolar Expeditions: Mania and Depression in American Culture*. Princeton, NJ: Princeton University Press, 2007.

18. Ng E. Heartache of the state, enemy of the self: Bipolar disorder and cultural change in urban China. *Cultural Medical Psychiatry* 2009; 33: 421-450.
19. McClelland S, Fine M. Rescuing a theory of adolescent sexual excess: Young women and wanting. In: A. Harris (ed). *Next Wave Cultures: Feminism, Subcultures, Activism*. London: Routledge, 2008. 83-102.
20. Clough P. The affective turn: Political economy, biomedicine, and bodies. *Theory, Culture and Society* 2008; 25: 1-22.
21. Clough P, Willse C. Gendered security/national security: Political branding and population racism. *Social Text* 2010; 28: 45-63.
22. Rose N. *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century*. New Jersey: Princeton University Press, 2007.
23. Grewal I. Transnational America: Race, gender, and citizenship after 9/11. *Social Identities* 2003; 9: 535-561.
24. Fanon F. *Black Skin, White Masks*. Editions du Seuil, 1951.
25. Foucault M. *Madness and Civilization: A History of Insanity in the Age of Reason*. New York: Random House, 1965.
26. Oliver K. *The Colonization of Psychic Space: A Psychoanalytic Social Theory of Oppression*. Minneapolis, London: The University of Minnesota Press, 2004.
27. Spivak G. *A Critique of Postcolonial Reason*. Cambridge, MA: Harvard University Press, 1999.
28. Bhaba H. Framing Fanon. In: Fanon F. *The Wretched of the Earth*. Presence Africaine, 2004.
29. Psychotic Disorders Work Group. Rationale: Attenuated psychosis syndrome (proposed for section III of the DSM-5). American Psychiatric Association DSM-5 Development 2012; dsm5.org/proposedRevisions/Pages/proposedrevision.aspx?rid=412#.
30. Angell M. *The Truth About the Drug Companies: How They Deceive Us and What To Do About It*. New York: Random House, 2004.
31. Fortune 500. Top Industries 2009: Most Profitable." *CNNMoney.com* 2010; money.cnn.com/magazines/fortune/fortune500/2009/performers/industries/profits/
32. IMS Health. Top-Line Industry Data." IMS Health Incorporated 2010; imshealth.com/deployedfiles/imshealth/Global/Content/StaticFile/Top_Line_Data/Top%2015%20

Global%20Products_2009.pdf

Acknowledgements

Special thanks to Lauren, and to Chloe and Willow, whose stories and expertise all inspired this analysis, and to the Private and College Psychiatrist who I also interviewed as part of this research project. Also to Michelle Fine for her continued mentorship, and Michelle Billies for her ongoing support and advice. And to the feedback and support of two anonymous reviewers.

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3

Abstract

The article undertakes a theoretical discussion of the online sociability of men who have sex with men. The main objectives of this theoretical exploration are to investigate the links between the ways that bodies are publicized/advertised on online profiles and the concept of sex as a regulatory category; the connections we can make between images/descriptions of certain parts of bodies shown online and the concept of face as an assemblage; and finally, the possibility of resistance against the regulation of the “heterosexual matrix” within so-called same sex desire. Drawing on a set of empirical data gathered through online participant observation on a cruising-for-sex website for men, this analysis hopes to foster our theoretical and political understandings of the ways Internet users are experiencing their bodies in relation to technology, providing new conceptual approaches regarding sexuality on the online cruising for sexual partners.

Key words body, Internet, post-structuralism, sexuality

Face Assemblages & Sex Machines: A Theoretical Exploration of Online Sociability of Men who Have Sex with Men

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The spectres of discontinuity and incoherence, themselves thinkable only in relation to existing norms of continuity and coherence, are constantly prohibited and produced by the very laws that seek to establish casual or expressive lines of connection among biological sex, culturally constructed genders, and the “expression” of “effect” of both in the manifestation of sexual desire through sexual practice.[15 p23]

It is not the subject who chooses faces (...), the faces choose their subjects. (...) Face is politics.[11 p208]

Introduction

This article seeks to engage readers in a post-structuralist understanding of a new body politics emerging out of social interactions of men who have sex with men who use the Internet as a space to (re)produce and experiment with sexualities. Based on participant observation of social interactions on a (cyber) network for sex and on encounters among men who have sex with men, it raises important issues related to how users experience their own bodies and how bodies play a crucial role in the ways that the Internet is currently used as a social network. The following theoretical discussion regarding this emerging body politics attempts to establish links between Deleuzo-Guattarian conceptualizations of face, assemblage, and machines, and Butler’s insights on sex as a regulatory category.

This paper is divided into five distinct but interrelated sections in which we provide an explanation of online social interactions and a brief description of the website settings. We also situate the Internet as a space of social interaction in

the broader context of other meeting spaces that are used by men in order to arrange sexual encounters with other men, arguing that the Internet should be analyzed as a space that provides a particular spatial politics. Moreover, we introduce the concepts of face, assemblages, sex, and machines, in order to underline the importance of the body within these specific (cyber) settings. We also explore both the theoretical and political implications of the emerging body politics we observed through these online interactions, especially regarding the ways that users are presently embodying technology and sexuality. Finally we propose a conceptual perspective that may enable a critical understanding of the emerging body politics found in this social network.

Log on and get off: online social interactions and website architecture

At present, one can find several websites that have been developed specifically to function as spaces for cruising and for erotic/sexual encounters. They offer a variety of tools and services that enable Internet users to meet online and are geared toward promoting online interactions between men who have sex with men. The number of websites available demonstrates the relevance of these spaces—at least three of them are internationally known and one of them announces that it has more than 6 million users from 140 countries around the world (Data available on www.gaydar.co.uk, accessed on March 15th, 2012). The specific gay social-networking site on which this participant observation study took place posts on its homepage that in a regular day it can have more than 57,000 members online throughout the world (Data available on www.manhunt.net, accessed on March 15th, 2012).

Whether these social networks are free or charge for their services, they offer a mix of possibilities for online text descriptions and images through which users can create their profiles and advertise themselves. This “public dimension” of a profile is important to online connections since “public texts” and “public photos” increase the chances of being seen by others. Once a profile is created, it appears on an online directory that displays profiles of all users available to chat, and users can engage in an online conversation or arrange offline encounters.

Using nicknames for their online presence, users fill in the required information on body characteristics like height, weight, eye/hair color, ethnicity, as well as age, city, and neighborhood where the users live. Usually provided as well are descriptions of their personalities, nationalities/ethnicities, families, friends, jobs, etc. A few (rarely) may substitute

images of landscapes, for example, for photos of their bodies and some profiles have neither written text nor pictures. Most of these gay “cruising” networks make it possible to describe what the users are looking for (relationship, sex, friendship, networking, etc.), and they allow men to reveal both their relationship status (single, married, open relationship, etc.) and HIV status (negative, positive, unknown).

It is important to underline that both the written texts and the images are chosen by the participants themselves. Despite the purported autonomy to choose the images through which users want to be seen, these images are regulated and their use depends on consenting to guidelines launched by the website administration. Images uploaded by users are related to their identity within this space and become the very presence of their bodies online, but they are actually constrained by the conditions mentioned above. The guidelines establish the rules, rights, and obligations both for the website and for the users in order to publicize their images. The same administration also imposes a waiting period and requires that all images uploaded by users be approved. Therefore, in order to take part in online interactions, users must agree with external and anonymous control over the information they advertise on their profiles, control that filters the uploaded images and allows (or not) their online publication.

Spatial politics and bodies in the Internet-as-a-space

Understanding the emerging body politics from the interactions of men who have sex with men on online social networks demands the examination of ‘the social and historical processes through which certain locations come to be favored as sites for sexual encounters, as well as the social and historical consequences of certain sites being designated as sexualized locations,’ [1 p3]. The Internet should be understood as a space, rather than a place: ‘Space emerges when practices are imposed on a place, when forms of human activity impose meanings on a given certain location,’ considering that both space and place ‘are not static arrangements, but topics continually being constructed, negotiated and contested’.[1 p7] In this sense, we say that the Internet is a space exactly because its different and heterogeneous forms of inhabitation are an unstoppable flux that somehow leads subjects to use those websites in the ways we currently find them using them.

For this reason, part of the emerging body politics of online interactions of men who have sex with men is directly related to a correspondent ‘spatial politics’.[2 p4] In other words, the different ways that subjects use the Internet as a space

where they can experience their own bodies and sexualities raise 'complex intersections of these themes as they unfold in the lives of men-who-have-sex-with-men and as they shape the participants' claims to sexual experience and gendered identities'. [1 p4] This is the main reason we use the expression "men who have sex with men" throughout the text, since the characterization of these online interactions as "gay" would probably lead to a misunderstanding about the relations that the users themselves sustain between their sex (male), gender (masculinity), and their sexuality. As we shall argue in what follows, it is the exact relationship among these three terms that this article seeks to analyze from a critical perspective. However, we preserve the identification of the websites under study here as "gay social networks" because they advertise online as being "gay."

In the last decades, several authors have explored relations between place-space and the experience of sexuality. Especially significant are the works of Bell and Valentine [3] and Ingram, Bouthillette and Retter [2]. Both of these books have enabled us 'to think about the ways in which the spatial and the sexual constitute one another'. [3 p2] The central argument in Ingram, Bouthillette and Retter's [2] edited collection, *Queers in Space*,

maintains that studying and understanding the perceptions, ideas and priorities that characterize each community and its relationship to its environment are necessary prerequisites to building "effective affinities" which in turn can lead to new alliances between lesbians, gay men, bisexual, transsexuals, and other groups of "sexual minorities" perceived by some to threaten the heteronormative status quo. [2 p4]

At that time that they were writing, none of the foregoing authors knew the enormous impact the Internet on the lives of many men in subsequent years. Jean-Urlick Désert [4] mentioned in his article *Queer Space* that *Cybermind* was an electronic forum for discussion of the philosophical and psychological implications of subjectivity in cyberspace. In its increasingly queer spaces, many new framings of issues have emerged, including the psychology of intimacy, the role of gender in the experience of electronic space, the phenomenology of the terminal screen, neurosis and paranoia on the Internet, the relationship of lag to community and communication, sex/gender/sexual orientation theory and electronic subjectivity, the role of the symbolic or the imaginary in computer communication, the implications of symbolic extensions of the human external memory and the 'psychoanalysis of lurking', all of which attest to the interest in reflecting on the relations between the experience of sexuality and so-called cyberspace since the inception of

that space.

Nonetheless, this argument remains useful as a means to analyze the perceptions, ideas, and priorities of men who use the *Internet-as-a-space* for social interactions and to examine what "affinities" are enabled or not among them. At a political level, it can also be used to examine the ways that the heteronormative status quo can be threatened or empowered by the specific uses that subjects make of the possibilities afforded by the Internet. In this sense, it is important to comprehend that the politics of the body that has arisen within these interactions is inseparable from a spatial politics that organizes and constrains certain practices in this very same space.

Therefore, when analyzing the texts and the images shown on online profiles, we need to understand that those very ways of self-description are somehow produced by specific architectures of the Internet and of the website, that they are more than just the result of users' free will. We should also keep in mind that the *Internet-as-a-space* is itself an assemblage, as we are going to argue in the following pages: *Internet-as-a-space* assembles bodies with computers, smartphones, webcams, digital cameras, cables, and keyboards, creating a whole new space—that is, the dimension of the spatial politics we emphasize here.

It is no coincidence that Sherry Turkle [5] chose to entitle her famous book *Life on the Screen*, for it highlights the important dimension of her argument that makes visible the underlying connections Internet users make between their bodies and the technological devices necessary to inhabit and continuously create that space. In other words, in our approach to the *Internet-as-a-space*, the connections and links that users make that enable them to be part of online interactions are crucial to 'the relationship between spatial processes and social process'. [6 p2] We are thus led to 're-conceptualize the spatial realm in ecological and relational terms'. [6 p2] We will explore the forms of these 'relational terms' and how Internet users live their 'life on the screen,' producing this space as a location for experiencing their sexuality. We will then examine the body politics emerging within this context for its aspects of 'effective affinities,' as Ingram, Bouthillette, and Retter suggest. [2] What types of body assemblages do we find on the online gay cruising sex website? What role do they play within the body politics that we seek to comprehend? What are the implications of the 'effective affinities' that this space can produce among its users?

Face trouble and possible assemblages

'Defined through the assemblages they make with others, bodies become subjects able to interact with the social world'.[7 p254] In this sense, we understand assemblages, in a Deleuzo-Guattarian perspective, as 'preliminary connections ... connections that can be multiple and intense ... [and] that lie at the core of desire ...[or] collections of desires'[7 p254] that actually lead objects, subjects, bodies, animated and inanimate things to get together, to link, to connect in order to produce a new unprecedented sort of existence. 'The bodies enjoy forming assemblages with others, whether persons or things, in order to allow desire to flow in different directions, producing new potentials (becomings) and therefore new subjectivities'.[7 p254]

All life is a process of connection and interaction. Any body or thing is the outcome of a process of connections. A human body is an assemblage of genetic material, ideas, powers of acting and a relation to other bodies. [...] There's no finality, end or order that would govern the assemblage as a whole; the law of any assemblage is created from its connections.[8 pxx]

The *Internet-as-a-space* is itself an assemblage that forges the Internet as a space of social interactions, an important assemblage found within the online community of men who have sex with men and one that is established between bodies and technology. When a user types a description of himself and uploads a picture of his body on his online profile, more and more assemblages are made. There are assemblages between the body and the digital camera he uses to take the picture; between the body and the keyboard he uses to type his description; between the body and the screen in which he sees images and reads texts; and between the body and the cables that connect him to the Internet: electronic devices such as computers, notebooks, netbooks, tablets, and mobile phones with Internet access, and the digital technology of the Internet are actually connected to users' bodies, thus creating a complex assemblage.

Therefore, an image of a user's body publicized on his online profile has been enabled and constrained by previous conditions: political, historical, cultural, spatial, technological, and financial. We thus can say that any and all images of bodies that users display on their profile can be understood as an 'outcome of a process of connections' and a 'political surface,' and as long as the bodies shown on these images are 'situated along a vector of meaning that is in flux,'[7 p253] these images fully express the vectors and meaning(s) that constitute these bodies. It is important to underline that the *Internet-as-a-space* and all technology that

makes it possible leads the subjects not only to an isolation or separation of the social and political world but it also actually creates a whole new politics within this space that should be analyzed without any fear or excitement related to the obsolescence of the material body[9] or to contemporaneous individualism[10].

Once the body is conceptualized in these terms, we can assert that 'face is politics'.[11 p209] The face is not simply 'the front part of the head,' but neither does it belong to the body. It actually is the very opposite: the body belongs to a face--or to multiple faces. As a politics and as a map, the face captures and moves throughout the body, signifying it along 'a vector of meaning that is in flux.' In other words, face is a 'black hole' where signification, meaning, [and] identity exist as static sediments.[11 p207] From this perspective, it is easy to understand the enormous moral and aesthetic evaluation that Western societies invest in the face or, more precisely, in 'the front part of the head.' Levinas[12] and Sontag[13], among others, have analyzed the important role that 'the front part of the head' plays in the construction of our identity and its implications for our social and political recognition. 'The front part of our heads' is directly connected to the conception of who we are; it is associated with the imagined 'inner self' that supposedly exists as an essence inside of us. This 'inner self' is apparently seen and expressed from the inside to the outside world through 'the front part of our heads. However,

the head belongs to the body, but not the face. Face is a surface: traces, lines, face wrinkles, long face, squared, triangular; face is a map. [...] Face does not function here as individual, it is the individuation that results from the necessity of an existing face.[11 p208]

Deleuze and Guattari draw on a new conception of face, where it is not 'the front part of the head,' but 'a map, a politics' that signifies the body. For this reason, they assert that it is not that subjects choose their faces, but that faces choose their subjects, and that individuation actually results from the necessity of an existing face. We only have a face after we are (maybe not comfortably) situated within a 'map' that signifies and produces the self. Articulated within a Foucauldian perspective, the 'politics' of the face functions through discourses and politics of truth that produce subjectivity.[14]

Therefore, face is itself an assemblage: face connects discourses to bodies and links bodies to identities, assemblage spaces, and technologies. Only after the foregoing conceptualization is understood are we capable of comprehending the ways gay cruising website users publicize their bodies through

images and describe themselves through texts on the Internet. Seldom is 'the front part of their head' shown: it is common, though, to see/read descriptions and images of chests, arms, thighs, legs, abdomens, and, less frequently, penises. Both in images and texts, users create new faces to signify themselves on the online site. As already mentioned, the face moves over the surface of the users' bodies: an abdomen can be a face, as well as a chest, a hand, or even particular parts of 'the front part of the head' such as eyes and mouths. All of these become the users' face, in the sense that the images become the users' identity, which means that a single body can have multiple faces.

Nonetheless, all bodies shown and described are still captured by a more powerful discursive apparatus that stratifies them. Even if it is true that all parts of the body can become faces, and even if it is possible that a single body has multiple faces, these multiple faces are still fixed in a more rooted 'black hole.'

Sex trouble and machines of capture

We can say that all bodies shown and described on online profiles have multiple faces, but to the extent that all of them are *male* bodies, and *want badly* to be recognized as male/masculine bodies--clearly separating them from all female/feminine characteristics--we can also say that each and every single face has a '*machine abstraite de visag  it  *,' a machine that operates in the process of producing a face or, in this case, a male face; it is the 'process of *visag  ification*' (capturing subjects) within what we call here a 'sex machine.' Each and every single face has its codification and recodification; 'the head and its elements are not going to become faces unless the whole body can also be, or is brought to be, in an inevitable process'.[11 p208-9]

It is precisely because the face depends on a machine *abstraite* that it will not be satisfied in recovering the head, but it will affect other parts of the body and also with objects without resemblance. The question from now on is to know in what circumstances this machine is launched, which produces the face and *visag  ification*. [11 p208]

As many faces as a body may have within this very specific cyber setting, there is still a unique "*machine abstraite de visag  it  *" operating on its surface: the machine is 'an assemblage that has been given the attribute of consistency or fixity--an assemblage that has been nailed down and forced to remain the same'. [11 p255] The sex machine is, then, an assemblage ossified by the definition of sex, reinforced by the inscription of sex on bodies.

Self-descriptions on users' profiles often underline their masculine characteristics, clearly mentioning that despite the fact that they are men who have sex with other men, they keep on being *male*. In a sense, users contend that their body sex (meaning, in this particular case, not physical intercourse but the definition of maleness inscribed on one's body) is not corrupted or diminished because they have sex (meaning physical intercourse) with other men.

This kind of statement leads us to examine the connections between sex-gender-sexuality that are involved in such affirmation: somehow, the feeling of betraying one's male sex by having sex with another same-sex person--the phantom of interrupting a crucial coherence in the sex-gender-sexuality--makes the subjects reaffirm their sex as if this was a way of reestablishing a continuity that was supposedly lost. However, this feeling of betrayal, this phantom of interruption, this coherence, and this continuity are directly connected to 'the idea that sexual practice has the power to destabilize gender', [15 pxi] which means, as quoted earlier, that incoherence and discontinuity are only thinkable in relation to corresponding norms that regulate and impose coherence and continuity to sex, gender, and sexuality. In Butler's words, we should try to 'understand some of the terror and anxiety that some people suffer in "becoming gay," the fear of losing one's place in gender or of not knowing who one will be if one sleeps with someone of the ostensibly "same" gender'. [15 pxi]

In Butler's argument, the coherence between sex-gender-sexuality is called 'the heterosexual matrix'. [15,16] By theorizing sex and gender as effects of institutions, discourses, power relations, and practices, Butler claims that one's gender is actually something that is performed. [15 p33] Being a man or being a woman is something that is enacted and re-enacted during life, and this enactment is highly constrained by regulatory practices within the heterosexual matrix that exhorts subjects to sustain the coherence and continuity of sex-gender-sexuality.

By criticizing the classification of "woman," widely used by feminism as the main object of political thought and action, Butler refuses the idea that 'woman' can be a common category or a universal identity. She argues that the split between sex and gender within the feminist framework, where gender is considered to be culturally constructed, suggests that sex is then still conceptualized as a biological pre-existent category that remains out of history, politics, or discourse¹⁵. Radically situating sex as part of the 'apparatus of gender construction', [15 p11] she states that,

... there will be no way to understand "gender" as a cultural construct which is imposed on the surface of matter, understood either as "the body" or its given sex. Rather, once "sex" itself is understood in its normativity, the materiality of the body will not be thinkable apart from the materialization of that regulatory norm. "Sex" is, thus, not simply what one has, or a static description of what one is; it will be one of the norms by which "one" becomes viable at all, that which qualifies a body for life within the domain of cultural intelligibility.[16 p2]

Therefore, sex is not apart from culture and political struggle: it is actually one product of the cultural construction of body, and we might even argue that sex is, if not the first, probably one of the strongest reiterated norms that materialize bodies as viable matters. The very same explanation should make it appropriate to think of 'man' as a culturally constructed gender. In a certain sense, a sexed body, a male body, would be the politically 'neutral' surface on which masculinity would be constructed. However, the exact assumption that describes the body as male is already marking it with its 'true sex,' supposedly defined by its biological characteristics. Thus, the 'male sex' is already a regulatory category produced by the heterosexual matrix in order to sustain coherence and continuity in that matter--that matter that matters--a convincingly sexed male body of man.

The image of an erect penis used by some users to identify themselves on their profiles may be one of the multiple faces they have on the online site, in the same way that images of chests, abdomen, arms, and legs can also become their faces. Nonetheless, by showing their penises, these users are actually displaying the 'hard core' of their sex--the very stratified and fixed part of their bodies that is captured by the 'sex machine.' When the penis becomes the face of one's body, we can say that the 'sex machine' is recovering all of the body, pulling it into the 'black hole' of the heterosexual matrix that produces the binary sexes, genders, and one single 'natural' sexuality.

As a regulatory system, sexuality primarily operates by investing bodies with the sex category, producing bodies as basis of an identity principle. Affirming that bodies have one or the other sex seems to be merely a descriptive affirmation. However, this statement is itself the legislation and the production of bodies, a discursive demand, as it were, that bodies become produced according to the principles of heterosexualizing coherence and integrity, unequivocally as male or female. Where sex is taken as a principle of identity, it is always positioned in a field of two mutually excluding and fully exhausting identities: one is male or female, never both at the same time and never none of them.[17 p99]

Therefore, claiming to be men in suitable male bodies,

the users of the online gay cruising sites--men who have sex with men--get stuck in the 'sex machine' that captures and signifies them. Self-descriptions written on profiles that underline their masculinity and that try to keep their distance from the 'effeminate men,' or images shown on profiles that display erect penises or other parts of so-called male bodies--all these are stratification lines of the 'sex machine.' Even naked, the bodies shown on online profiles are fully dressed with their sex. Moreover, these stratification lines of the 'sex machine,' thought of as part of the 'apparatus of gender construction' performed within the heterosexual matrix, also need to be understood as an important part of the body politics emerging within the online community of men who have sex with men.

Profiles that matter: On the limits of men who have sex with men's online interactions

All the spatial conditions of the *Internet-as-a-space* lead users to expose themselves and to connect with other users of social networks; this is a very important aspect of the spatial politics raised by the idea of social interactions on the Internet. The technological possibilities of the equipment (cameras, webcams, mobiles with cameras, high-speed data transmission devices, photographs, videos) used on the Internet can create a radical visibility and connectivity for those who share its premises. However, users are somewhat fearful of showing 'the front part of their heads,' because, as we have already argued, 'the front part of one's head' is not just one's face but is one part of the body that is directly related to one's identity. Users of the online site of men who have sex with men walk a thin line in showing themselves as they are through images, texts, cameras, videos and, at the same time, hiding themselves as men who feel desire for the 'same sex.'

That allows us to claim that the old metaphor of the closet remains a paradigm for the way gay men and men who have sex with men live their lives, as Sedgwick[18] has discussed, and it may still be an important component of the emerging body politics we find online. The *Internet-as-a-space* may be the new closet for these men, but it is made of glass; because bodies are exhibited in thousands of images and an overwhelming discursive production of bodily descriptions takes place in online profiles, exposure becomes an urgent demand. Yet, the experience of having sex with another 'same sex' person is still something that users of online social interactions want to hide or, at least, they feel that this experience must be discreet. Echoes of the 'deviant experience of sodomy' are still present, indicating

that the heterosexual matrix remains a hegemonic influence, even in a space that is supposedly free of constraints. Users claim to be male but at the same time they fear the 'spectres of gender incoherence' by being men who have sex with men. As Butler[15] suggests, sexual practices seem to have the power to destabilize coherence and truth of gender and sex. The new challenge for users of online cruising websites is to actually deal with this pressing demand for exposure. Although they are men who have sex with other men, they want to preserve their sex and gender as a coherent continuity. Even the most discreet gay man seems to have to balance the desire to demonstrate that he is gay to other users with the simultaneous need to prove that he remains a man. This task can be difficult, maybe even irreconcilable, since users' bodies, masculinity, and sexual desire are themselves being constructed within the heterosexual matrix--the very same matrix that produces 'same sex' desire as 'deviant.'

Most of the bodies shown on the online site are 'lean, young and muscular,' but even those with 'fat, old and flaccid' bodies claim to be male bodies. Beyond the 'body fascism of fitness'[19] remains the 'microfascism'[20] of the 'sex machine' that captures and covers all bodies with its 'true and single male sex.' This notion excludes any possibility of identification with its opposite and correspondent 'true and single female sex,' prohibiting any experimentation that is not somehow situated within this binary field of the sexed/gendered body intelligibility. The profiles that matter are those in which the users claim to be male and are able to display the 'hard core' of maleness to others.

While multiple faces may float on the surfaces of bodies, a very particular 'sex machine' interrupts any movement toward a new creativity: the body politics raised within the gay cruising websites does not defy the apparatus of the 'sex machine,' which captures bodies within its stratification lines and does not challenge the 'heterosexual matrix' that creates and governs it. Bodies always return to this 'black hole' that signifies them as male, since the 'fascism' of 'same sex' desire operates by supposing, if not implying and demanding, that sexed bodies be completely filled with the so-called truth of sex. In other words, 'same sex desire' only exists because the 'sex machine' apparatus stratifies bodies and divides them into male and female. The struggle thus lies in the potential for experimentation--to materialize bodies not only in opposition to this 'sex machine' (it is an ontological and political challenge to attempt to materialize a body that can escape from the 'heterosexual matrix'), but in ways in which its sex does not matter that much, as well as to create a thinkable 'desire' that can overcome and surpass

the category of 'sex' as its 'hard core.'

Final Remarks

To conclude, we believe that it is possible to think of a politics of friendship as an alternative escape from the "microfascism" of 'same sex' desire, critiquing the myth of men who have sex with men as hypersexualized subjects. This is not a moralistic statement, since casual sex practices and anonymous sexual encounters play an important role in experimenting with new forms of pleasure that do not borrow from the monogamous heteronormative experience of sexuality. However, these practices and encounters can lead its practitioners to some sort of friendship, without excluding the possibility that friends might have sex. We stress the importance of a friendship politics as an alternative to the 'microfascism' of same sex desire because we understand that men who have sex with men can actually be part of a cyber community not only (but also) to look for sexual partners. Some of them, or maybe most of them, can have online profiles that describe themselves through texts and images in order to connect with and to get to know other users whom they otherwise would never have met. It is not that sexual practices are not important, or that they should be bypassed in the name of a 'clean' friendship in which sexual desire has no place. It is actually the very opposite: we indicate that all the technological possibilities launched by the *Internet-as-a-space* enable a productive connectivity that can be used to increase relations among its users. One of the components of 'effective affinities' enabled by this kind of connectivity is sexual desire, but we also contend that sexual desire must be thought about in addition to other kinds of relations that may be possible online. Therefore, in stressing the importance of a friendship politics in this emerging body politics of online interactions of men who have sex with men, we call attention to the importance of living and experiencing sexuality in connection with other relationships that exceed same sex desire and that do not depend exclusively on it to exist.

References

1. Leap, W. *Public Sex, Gay Space*. New York: Columbia University Press, 1999.
2. Ingram, GB, Bouthillette, AM and Retter, Y. *Lost in Space*. In: *Queers in Space – Communities, Public Places, Sites of Resistance*. G Ingram, A Bouthillette and Y Retter (Eds). Seattle: Bay Press, 1997; 3-16.
3. Bell, D. and Valentine, G. *Mapping desire*. New York:

Routledge, 1995.

4. Désert, J. *Queer Space*. In: *Queers in Space – Communities, Public Places, Sites of Resistance*. GB Ingram, AM Bouthillette and Y Retter (eds). Seattle: Bay Press, 1997; 17-26.

5. Turkle, S. *Life on the Screen: Identity in the Age of the Internet*. New York: Simon & Schuster, 1995.

6. Murdoch, J. *Post-Structuralist Geography*. London: SAGE, 2006.

7. Holmes, D. O'Byrne, P. Murray, SJ. *Faceless sex: glory holes and sexual assemblages*. *Nursing Philosophy* 2010; 11: 250-259.

8. Colebrook, C. *Understanding Deleuze*. Crows West: Alain & Unwin, 2002.

9. Kurzweil, R. *The Age of Spiritual Machines : When Computers Exceed Human Intelligence*. Viking: Penguin Books, 1999.

10. Bauman, Z. *Liquid Love*. Malden: Polity Press, 2003.

11. Deleuze, G. and Guattari, F. *Mille Plateaux – Capitalisme et Schizophrénie 2*. Paris : Les Éditions de Minuit, 1980.

12. Levinas, E. *Totally and Infinity : An Essay on Exteriority*. Pittsburgh: Duquesne University Press, 1969.

13. Sontag, S. *Illness as metaphor, AIDS and its metaphors*. New York: Picador, 1990.

14. Foucault, M. *Politics of Truth*. Los Angeles: Semiotext(e). 2007.

15. Butler, J. *Gender Trouble*. New York: Routledge, 1999.

16. Butler, J. *Bodies that matter – on the discursive limits of sex*. New York: Routledge, 1993.

17. Butler, J. *Inversões sexuais [Sexual inversions]*. In: *Poder, normalização e violência – incursões foucaultianas na atualidade [Power, Normalization and violence – Foucauldian incursions in actuality]*, IF Passos (Ed). Belo Horizonte: Autêntica, 2008: 90-108.

18. Sedgwick, EK. *Epistemology of the closet*. Los Angeles: University of California Press, 1990.

19. Pronger, B. *Body fascism – Salvation in the Technology of Physical Fitness*. Toronto: University of Toronto, 2002.

20. Galli, T., Thomazoni, AR, Costa, LA, Souza, VL. Lockmann, VS. *Microfascismos em nós – práticas de exceção no contemporâneo [Microfascism in us – exception practices in contemporaneity]*. *Psicologia Clínica [Psychological Clinic]* 20, 2008: 31-45.

Acknowledgments:

This paper is one of the outcomes of an array of theoretical research activities fully funded by CAPES Foundation, Ministry of Education of Brazil, which granted Luiz Felipe Zago with an international PhD scholarship.

Financial Support:

This paper is one of the outcomes of a period of Doctoral studies funded by CAPES Foundation, Ministry of Education of Brazil, Brasília (DF –70-040-020), Brazil.

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Introduction

We are writing to express our solidarity with 20 members of the University of Ottawa's (henceforth uOttawa) research ethics board (REB) who openly challenged their institution's refusal to support two colleagues in a legal battle to protect the confidentiality of their data. In this commentary we briefly describe the case and reflect on the implications of this collective action for rethinking the role of REBs within the academy. In particular, we argue that REBs should be forums of critical interdisciplinary debate about the relationship between researchers, the academy, knowledge production,

and society. Before entering into the larger discussion, it is worth reminding readers of the much maligned status of REBs and ethics review. REBs are often characterized as being secretive bureaucracies overly focused on risk management.[1-3] Certain forms of research, especially qualitative and participatory, have been reportedly subjected to inappropriate standards better suited for biomedical research.[4] As well, the growing infrastructure and resources needed to support ethics review has been likened to a 'research ethics industry.'[3, 5] However, the most troubling critique charges ethics review with being a form of "imperialism"[6] and a threat to academic freedom.[7-9] Haggerty[8] introduced the term "ethics creep" to account for the process whereby ethics review is expanding to colonize aspects of the research process previously outside of its purview. While there are certainly many examples of REBs being paternalistic and risk averse, there are also less discussed examples of REBs that are methodologically savvy and supportive of emerging research approaches. [10-11] Wolf[12] has asked researchers to remember that

REBs “are not the enemy” but that they are constrained by various requirements that shape their reviews. Guta and colleagues[13] have argued that the so called “ethics creep” is symptomatic of the impact of neoliberal restructuring which has imbued universities with market logic and has turned knowledge into a commodity. Here, the virtues of competition, efficiency, and risk management have replaced other ethical considerations. Yet, ethics review is relatively new and there are still opportunities to improve the system. If researchers feel oppressed and unsupported by ethics review in its current state, they should organize to reclaim it. We now turn our attention to recent events at uOttawa to demonstrate that REBs have the potential to transcend their bureaucratic origins.

The case

The case in question involves two uOttawa criminology professors who are challenging an attempt by Montreal police to seize a confidential interview transcript believed to belong to a murder suspect. The interview was part of a study conducted by Professors Colette Parent and Chris Bruckert on the experiences of Montreal sex workers. The two researchers in question have filed motions with the Superior Court of Quebec to prevent the police from obtaining these data because of what they argue is “confidentiality privilege.”[14] Unfortunately, uOttawa is refusing to assist them in their legal battle, with President Allan Rock having stated that “The University of Ottawa recognizes its role...in safeguarding entrusted information. However, the University does not consider that its role extends to the payment of legal costs if researchers decide to challenge the seizure of research records in the context of criminal proceedings.”[15] This is reminiscent of an earlier high profile Canadian case at Simon Fraser University, involving graduate student Russell Ogden, who interviewed people with HIV/AIDS who were seeking assistance to end their lives. In the Ogden case the university refused to defend the researcher and uphold the confidentiality of the data. The REB subsequently imposed a condition of “limited confidentiality” requirements on future research.[16] In the uOttawa case, however, there has been a different response from the REB. Instead of closing ranks against the researchers, 20 members of the uOttawa REB have written to President Rock protesting the administration’s refusal to support their colleagues. The letter stated that “The inaction on the part of university officials entrusted with advancing intellectual inquiry is inexcusable” and warned of the “dangerous precedent” being set.[17] While the case will be reviewed in court later this year, and the argument for whether researchers have “confidentiality privilege” will

likely be challenged, this case has important implications for how we think about the role of REBs within academic institutions. Here, a group of interdisciplinary scholars representing the Social Sciences & Humanities Research Ethics Board and Health Sciences & Science Research Ethics Board have come together in solidarity with their colleagues to protect academic freedom and promote institutional accountability.

The REB as a critical space?

With the aim of theorizing the uOttawa REB action as a form of critical resistance and truth telling, we turn to Michel Foucault’s[18] writings about the relationship between forms of governance and questions of politics and ethics. Foucault’s[19,20] conception of ethics started with the relationship of self-to-self (or self-governance), and the process of stylizing oneself as an ethical subject. Foucault may seem an unusual figure to invoke in a discussion of ethics review, for he rejected normative ethics and was interested in larger questions about the relationship between truth, power, and subjectivity. However, recent scholarship in critical bioethics has considered the implications of Foucault’s work for resisting prescriptive forms of ethics found in medical relations of power.[21-23] The uOttawa REB members’ action has caused us to reflect on Foucault’s [24] definition of critique as “the art of voluntary insubordination, that of reflected intractability...[which] insures the desubjugation of the subject in the context of what we could call, in a word, the politics of truth.” The uOttawa action represents an important example of resisting the prescribed model of what an REB ought to do, as well as its ostensible role within the academy. This group of scholars have chosen, in their role as REB members, to call attention to the injustice of their institution colluding with law enforcement. This institution, like many universities today, profits from the research being conducted under its name but appears to shirk its responsibility to researchers, participants, and society as a whole. This action further reminds some of us, and may finally prove to others, that REBs are not faceless entities, but are comprised of our peers and colleagues. Many REB members are uncomfortable with aspects of research ethics review and their role as arbiters of what constitutes ethical/unethical research. Their insider perspectives are especially important for understanding the inner workings and logic of research governance. Yet, too often the collective response is to discredit those who volunteer their time and discount their scholarly expertise. Is it any wonder that REBs struggle to find committed members who are passionate about the role? If research governance has overtaken research ethics,[25]

then critique is the process of resisting such governance, or in Foucault's[24] terms "the art of not being governed quite so much."

While forms of governance within the academy are ubiquitous, these 20 members of the uOttawa REB are demonstrating a form of ethics that requires them to speak out and challenge what they perceive as injustice within their institution. The identification of injustice further gives us pause regarding Foucault's[18] concept of parrhesia from antiquity, which he described as "the act of telling all (frankness, open-heartedness, plain speaking, speaking openly, speaking freely)." Foucault[26] understood truth telling as an obligatory form of resistance to being governed, saying:

...we can demand of those who govern us a certain truth as to their ultimate aims, the general choices of their tactics, and a number of particular points in their programs: this is the parrhesia (free speech) of the governed, who can and must question those who govern them, in the name of the knowledge, the experience they have, by virtue of being citizens, of what those who govern do, of the meaning of their action, of the decisions they have taken.

Here the members of the uOttawa REB are openly questioning their administration from the position of their shared role on the REB, and demonstrating a commitment to the principles of ethical research set out in Canada's Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans, 2nd edition.[27] While not all REBs are comprised of such scholars, and not all will be willing or able to put themselves at risk within their institutions, we hope the action of the uOttawa REB invites others to consider their own voice in the ethics review process. We see the action of these REB members as the beginnings of rethinking REBs as critical spaces and reclaiming their bureaucratic functions to promote greater critical engagement with ethical questions. For instance, while in this case the action was directed outwards to call attention to uOttawa's refusal to protect confidentiality, such action could also be directed inward to challenge taken-for-granted practices within REBs. The review process represents a microcosm of issues affecting the academy and society. It can unintentionally reproduce forms of oppression and discrimination when certain groups are portrayed as 'at risk' and others not; as competent, or not. Those of us involved in the REB process, on either side of the review, must continue to work towards unpacking the claims made about these imagined others by interrogating our individual and collective values and assumptions. This requires the ability to reflect on one's own role within the system, through the application of what Murray and Holmes[28] have called

"critical ethical reflexivity." While their intention was to add a phenomenological understanding of language to bioethical inquiry, we see "critical ethical reflexivity" as relevant for ethics review. We encourage scholars with a range of perspectives to join their REB and to use it as a space to speak out and to challenge all forms of oppression, especially those that reach participants in the form of discriminatory research, but also those that circulate within their institutions to privilege some forms of scholarship over others.

Conclusion

Foucault[29] famously remarked, "Where there is power, there is resistance." This is evident in the example of 20 members of the uOttawa REB defending their colleagues and standing up against their institution's inaction. We hope this will represent an important first step towards improving relations between researchers and their REBs. Upshur [30] has called on researchers to "Ask not what your REB can do for you; ask what you can do for your REB." We would add that it is important to ask what we, collectively, can do for our REBs, and for our fellow researchers. Such an approach requires working within and across our respective roles as REB members and researchers who submit protocols and to recognize these are one and the same. By collectively resisting the pressure to produce certain kinds of research, and rejecting prescribed notions of objectivity when interacting with participants, we can promote a conception of research ethics within the academy that better reflects our scholarly interests and commitment to preventing research related harms. We believe this aspirational proposition will be achievable if we continuously practice critical ethical reflexivity and remain committed to promoting the virtue of parrhesia within the academy.

References

1. Ashcroft RE, Pfeffer N. Ethics behind closed doors: Do research ethics committees need secrecy? *British medical journal* 2001;322(7297):1294-6.
2. O'Reilly M, Dixon-Woods M, Angell E, Ashcroft RE, Bryman A. Doing accountability: a discourse analysis of research ethics committee letters. *Social Health Illness* 2009;31(2):246-61.
3. Allen G. Getting Beyond Form Filling: The Role of Institutional Governance in Human Research Ethics. *Journal of Academic Ethics* 2008;6(2):105-16.
4. Lincoln YS, Tierney WG. Qualitative Research and Institutional Review Boards. *Qualitative Inquiry*

- 2004;10(2):219-34.
5. Ashcroft RE. The new national statement on ethical conduct in research involving humans: A social theoretic perspective. *Monash Bioethics Review* 1999;18(4 (Ethics Committee Supplement)):14-7.
 6. Schrag ZM. *Ethical imperialism: institutional review boards and the social sciences, 1965–2009*: Johns Hopkins University Press; 2010.
 7. Dingwall R. The ethical case against ethical regulation in humanities and social science research. *Contemporary Social Science: Journal of the Academy of Social Sciences*. 2008;3(1):1-12.
 8. Haggerty KD. Ethics Creep: Governing Social Science Research in the Name of Ethics. *Qualitative Sociology*. 2004 winter;27(4):391-414.
 9. Lewis M. New Strategies of Control: Academic Freedom and Research Ethics Boards. *Qualitative Inquiry* 2008;14(5):684-99.
 10. Hedgecoe A. Research Ethics Review and the Sociological Research Relationship. *Sociology* 2008;42(5):873-86.
 11. Guta A, Nixon S, Gahagan J, Fielden S. "Walking Along Beside the Researcher": How Canadian REBs/IRBs are Responding to the Needs of Community-based Participatory Research. *Journal of Empirical Research on Human Research Ethics*. 2012;7(1):15-25.
 12. Wolf LE. The research ethics committee is not the enemy: oversight of community-based participatory research. *J Empir Res Hum Res Ethics*. [Research Support, Non-U.S. Gov't]. 2010;5(4):77-86.
 13. Guta A, Nixon S, Wilson MG. Resisting the seduction of "ethics creep": Using Foucault to surface complexity and contradiction in research ethics review. *Social Science & Medicine*. 2012.
 14. Fiebel A. Police investigators believe U of O professors interviewed accused killer for sex trade study. *Fulcrum: The University of Ottawa's independent English-language student newspaper*. 2013.
 15. uOttawa criminologists go to court to protect research confidentiality [database on the Internet]2013 [cited January]. Available from: http://www.cautbulletin.ca/en_article.asp?articleid=3574.
 16. The Research Confidentiality Controversy at Simon Fraser University [database on the Internet]2000. Available from: <http://www.sfu.ca/~palys/Controversy.htm>.
 17. REB members deplore uOttawa's refusal to defend confidentiality [database on the Internet]2013 [cited January]. Available from: http://www.cautbulletin.ca/en_article.asp?ArticleID=3623.
 18. Foucault M. *The Hermeneutics of the Subject: Lectures at the College de France 1981-1982* Davidson AI, editor. New York: Picador; 2005.
 19. Foucault M. *The Use of Pleasure: The History of Sexuality - Volume 2*. New York: Vintage Books; 1985.
 20. Foucault M. *The History of Sexuality, Vol. 3: The Care of the Self* Vintage books ed. New York: Vintage Books; 1990.
 21. Chambon AS, Irving A. "They Give Reason a Responsibility Which It Simply Can't Bear": Ethics, Care of the Self, and Caring Knowledge. *Journal of Medical Humanities*. 2003;24(3/4):265-78.
 22. Murray SJ. Care and the self: biotechnology, reproduction, and the good life. *Philosophy, Ethics, and Humanities in Medicine* 2007;2(6):1-15.
 23. Frank AW, Jones T. Bioethics and the Later Foucault. *Journal of Medical Humanities* 2003;24(3/4):179-86.
 24. Foucault M. What is critique? . In: Lotringer S, Rajchman J, editors. *The politics of truth*. Los Angeles, CA: Semiotext(e); 2007. p41-82.
 25. Sieber JE, Tolich M. Research ethics and research governance. *J Empir Res Hum Res Ethics* 2012;7(2):1-2.
 26. Foucault M. *An Aesthetics of Existence* In: Kritzman LD, editor. *Politics, philosophy, culture: interviews and other writings, 1977-1984* New York: Routledge; 1988. p47-54.
 27. Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada. *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, December 2010.
 28. Murray SJ, Holmes D. Toward a critical ethical reflexivity: phenomenology and language in maurice merleau-ponty. *Bioethics* 2013;27(6):341-7.
 29. Foucault M. *The History of Sexuality: An Introduction*. New York: Vintage Books; 1978.
 30. Upshur REG. Ask not what your REB can do for you; ask what you can do for your REB. *Canadian Family Physician* 2011;57(10):1113-4.

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