#### 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

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#### 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-forgranted 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 wakening 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 possible 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 article 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 genderrelated 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 sleepdisordered 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 then 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 pschyosomatising 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] Industrybased 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 underrepresented 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 behaves 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.

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