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Sleep, health and the dynamics of biomedicine

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Abstract

This paper examines the relationship between sleep and health from a sociological perspective. Two interrelated case studies are explored: the emergence of the category of obstructive sleep apnoea syndrome, nowadays the most commonly diagnosed sleep disorder, and the shaping of continuous positive airway pressure, the therapy of choice for sleep apnoea in contemporary clinical practice. Data were gathered through a historical review of relevant literature and observation of online patient discussion groups. The examples analysed show that although the social organisation of the relationship between sleep and health can be understood as a process of medicalisation, this framework is insufficient for understanding how researchers, clinicians and patients interactively deploy the knowledge, techniques and technologies through which different 'sleep problems' are understood and managed. By exploring the generative aspects of those processes of contestation and divergence within biomedicine it is possible to initiate a re-evaluation of the role of patients' identity in the transformation of sleep medicine and associated health technologies.

Keywords: Sleep medicine; Obstructive sleep apnoea; Continuous positive airways pressure; Medicalisation; Biomedical knowledge

Main text

While the association between sleep (or the lack of) and health has been common knowledge for centuries, in the past two to three decades this relationship has been detailed by biomedical research and has become the basis of growing public health concerns. The US National Centre on Sleep Disorders Research (NCSDR) estimates that at least 70 million Americans suffer from some kind of sleep problem, either chronic or intermittent.[1] In the United Kingdom, a 1999 Gallup survey found that 29% of respondents have said that their work is affected by sleepiness, and 16% that their driving is disturbed by sleepiness.[2] Sleep disruption has furthermore been associated with other major public health problems such as obesity, diabetes, and cardiovascular disease. This has led Dr. Carl Hunt, director of the NCSDR to recently declare that:

> We are all affected by sleep problems. Even if you personally get sufficient sleep to feel refreshed each day, chances are you interact with someone who has a sleep problem. It could be your mother, whose sleep apnea increases her chances of developing heart disease; your carpool driver, who might be at increased risk for a car crash because of poor sleep; or your child, who

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[1] http://www.nhlbi.nih.gov/about/ncsdr.

[2] Data supplied by Prof. Neil Douglas, Royal Infirmary, Edinburgh.

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has trouble in school because she doesn't get enough sleep at night.'' [3]

How are we to understand the process by which 'we all' became affected by sleep problems? This paper addresses this question from a sociological point of view. It focuses on the role of medical knowledge and expertise in mediating the relationship between sleep and health. The character of this expert mediation has been researched and debated by sociologists mainly through the concept of medicalisation (e.g. Williams, 2002). From this perspective, the changes in the understanding of the relationship between sleep and health are the outcome of a negotiated expansion of the *medical boundaries of knowledge and treatment*. The medicalisation perspective emphasises the control and constraints on action derived from medical knowledge (Conrad, 1992). I suggest in this paper that research drawing on the theory of medicalisation should be complemented by studies that focus on the dynamics of the creation, evaluation and use of biomedical knowledge. This would help us understand not only how the experience of 'sleep problems' is socially *framed* but also how, in practice, researchers, clinicians and patients interactively deploy the knowledge, techniques and technologies through which different 'sleep problems' are understood and managed. By describing these processes, it is possible to emphasise their *generative*, *creative* aspects and to show how they underpin the *invention* of new arrangements between research and clinical practice, new professional and patients' identities, and novel spaces of action and intervention for these actors. For this purpose, it is advisable to attend empirically to the controversies, uncertainties and heterogeneities that permeate medical knowledge not only across the expert/lay divide but also across changing demarcations within biomedicine itself (Berg & Mol, 1998) and through emerging collaborations between researchers, clinicians and patients (Rabeharisoa & Callon, 2002; Rabeharisoa, 2006).

This paper examines two case studies: the emergence of the medical diagnosis of obstructive sleep apnoea syndrome (OSAS) and the development of one of the treatments for this condition—continuous positive airway pressure (CPAP). Obstructive sleep apnoea—the periodic reduction or cessation of breathing due to narrowing or occlusion of the upper airway during sleep—was the first condition to be developed under the jurisdiction of sleep medicine and is nowadays the most commonly diagnosed 'sleep disorder'. The paper describes the process through which two specialities—respiratory and sleep medicine—argued about and negotiated the patho-physiological and clinical character of sleep apnoea over a period of 20 years. Through this process a set of new biomedical objects, professional identities and practices emerged that neither of the constituencies could have anticipated.

These novel biomedical configurations of research and practice were the context in which the chronic character and high prevalence of OSAS was brought to public attention. This was based on the view that sleep apnoea constitutes an important public health problem with considerable social and economic implications, related not only to increased morbidity but also to do with an increased risk of road traffic accidents. The shape, effectiveness and diversity of uses of CPAP have thus become important matters of negotiation. In this process, patients played various pivotal roles, not only contributing to the outline of the original device in its experimental phase, but later shaping and transforming the device in the contexts of their lives and, furthermore, by refusing to engage with the therapeutic routines that CPAP entails. This non-engagement has been a powerful driving force in shaping a new knowledge domain and space of intervention where biomedical perspectives are collaborating with behavioural and social scientists.

Finally, drawing a picture of biomedicine as a multifarious set of practices might have consequences for the way we understand the processes of medicalisation because the shift in life-world of the patient that follows from this view of biomedicine cannot be said to be coherent and unambiguous. In the last section of the paper, I outline how this represents a challenge for research on how patients' experience of and identities within biomedicine might mediate their involvement in research and technological development.

Methodological note

The paper explores two paradigmatic cases in the history of sleep medicine. The case studies were constructed by drawing on an historical literature review of the emergence and development of research on OSAS and CPAP. Conventional

[3] http://www.medicalnewstoday.com/medicalnews.php?newsid=6805.