

## Disease Mongering

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**Disease-mongering** is a term to describe the process of widening the boundaries that define medical illness in order to expand markets for those who deliver and sell treatments. It can take many forms, including framing risk factors as diseases, portraying mild problems as severe pathology, widening existing definitions and constructing whole new categories of medical illness. While the analysis of disease-mongering has to date focussed largely on pharmaceutical marketing, and unhealthy industry-professional entanglement, the phenomenon is broader and deeper than a critique of drug company promotions. The concern is that by transforming more and more of the ups and downs of ordinary life into the signs and symptoms of treatable conditions, we may be producing much iatrogenic illness, wasting many resources and fundamentally shifting what it means to be human. After a brief history of the concept, some examples will be provided, before concluding with some challenges facing those interested in the problem.

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An important context for the current debate about disease-mongering is the work of Ivan Illich (1976), the maverick thinker who expressed concerns in the 1970s that an expanding medical establishment was 'medicalising' life itself. He argued in his landmark book *Limits to Medicine, Medical Nemesis: The Expropriation of Health*, that the

medical establishment was undermining the human capacity to cope with the reality of suffering and death and making too many people into patients. He criticised a medical system “that claims authority over people who are not yet ill, people who cannot reasonably expect to get well, and those for whom doctors have no more effective treatments than that which could be offered by their uncles or aunts.”

In 1992, American health writer Lynn Payer published *Disease-Mongers: How doctors, drug companies and insurers are making you feel sick* (Payer, 1992), a lay book which generated interest in the problem. The book outlined numerous examples where doctors and drug companies were involved in strategies to widen the actual and perceived boundaries of illnesses, in order in part to see more patients and sell more drugs. The roots of this disease-mongering critique of course go back beyond Illich and Payer, featuring in popular literature of the early 20<sup>th</sup> century via characters such as Jules Romain’s Dr. Knock, who famously builds a healthy medical business by transforming the *people* of his village into *patients*. More broadly the work of many social scientists has contributed to current understandings of the related phenomena of medicalization and disease-mongering.

Inspired in particular by Payer’s book, a decade later in 2002, I co-authored a feature in the *British Medical Journal* or *BMJ*, which introduced the concept of disease-mongering to wider academic audiences. (Moynihan, et al., 2002) That article used a number of examples where the boundaries of illness were being widened in order to expand markets for drugs. It also documented how informal alliances of pharmaceutical manufacturers, doctors and patient advocacy groups often used the media to frame health conditions as being widespread, severe and treatable. As that paper demonstrated, questions, uncertainties and controversies surrounding the nature and prevalence of these conditions and the costs and harms of the promoted solutions are

often not present in the corporate sponsored “awareness-raising” campaigns that inform media coverage and public debate.

As outlined in that *BMJ* article:

- \* baldness was at the time being positioned in direct-to-consumer advertising as a medical problem for which you should “see your doctor”, in order to help sell a drug called finasteride

- \* a medical communications firm working for a major drug company was developing plans to re-shape medical and public perceptions of “irritable bowel syndrome” to make it a “credible, common and concrete disease” in order to help sell a potentially highly dangerous drug called alosetron

- \* the risk of future fracture was being promoted as a silent disease called osteoporosis to build markets for the bisphosphonates class of medicines and other drugs

- \* the prevalence of erectile dysfunction was being exaggerated in order to maximize sales of sildenafil (Viagra).

Following on from the *BMJ* article in 2002, a book called *Selling Sickness: how the world's biggest pharmaceutical companies are turning us all into patients* (Moynihan & Cassels, 2005) was published internationally, and translated into a dozen languages. A work of rigorous investigative journalism, the book examined ten common medical conditions, and explored how the definitions of those conditions had been broadened in recent times, in order to widen markets for therapies. In some cases the expansions had occurred with changing condition definitions, in others with shifting treatment

thresholds. Commonly the definitions, the consensus statements or the treatment guidelines which were expanding the patient pool were being written by “key opinion leaders” within the medical profession who had multiple financial ties to drug companies hoping to sell products for the target conditions.

In other cases, drug-company funded disease-awareness campaigns were helping shift public perceptions of behaviours previously considered normal, so that they would now be considered abnormal or pathological. Examples here included the rebranding of severe pre-menstrual problems as “pre-menstrual dysphoric disorder”, or reframing common sexual difficulties as the symptoms of a supposedly highly prevalent condition called “female sexual dysfunction”. To help illustrate the problem of disease-mongering, three detailed examples may be helpful.

*Osteoporosis- risk factors as diseases:* Technically a risk factor for future fracture, the condition called osteoporosis has been heavily promoted for many years as a silent “disease”. The modern definition dates back to 1994, when a study panel of the World Health Organization arbitrarily decided to classify the diagnosis of osteoporosis as a certain number of standard deviations from the “norm” for a measure called bone mineral density. The “norm” was decided to be that of a young woman, automatically classifying a large proportion of older women as diseased. The study group’s deliberations were funded by a number of pharmaceutical companies, and the decision coincided with the emergence of a new class of osteoporosis drugs, which were subsequently heavily promoted globally, and which carry significant side effects. Given the large number of relatively healthy women classified as suffering with this “disease”, some observers have described its promotion as the “marketing of fear.” More recently there have been attempts to portray “pre-osteoporosis” or osteopenia as a treatable condition. (Alonso-Coello, 2008)

*Adult ADD- mild problems portrayed as medical conditions:* Adults who “drum their fingers” exhibit one of the signs of this purported condition. As one example of the promotion of this condition, an advertisement by a drug company marketing a product for “Adult ADD” appeared in a national current affairs magazine in the United States in 2004:

“Distracted? Disorganized? Frustrated? Modern life or Adult ADD?

Many adults have been living with Adult attention deficit disorder (Adult ADD) and don’t recognize it. Why? Because its symptoms are often mistaken for stressful life.” (Lilly, 2004)

Around the same time as this advertisement appeared another company with a drug for Adult ADD was delivering a presentation to merchant bankers in New York, arguing that a whole new “adult market” was about to open up for its drugs. Concurrently, an influential patient advocacy group who relied in part on funding from pharmaceutical companies was raising awareness about the problem of adults suffering the “lifespan” problem of ADHD. An advertising expert who has worked on what is called “condition branding” for drug companies has spoken publicly about how the new condition of “Adult ADD” was an example of the company-sponsored “branding” of a medical condition. (Moynihan & Cassels, 2005)

*Female Sexual Dysfunction- new conditions:* A third form of disease-mongering occurs when a new category of human illness is constructed, as is currently occurring with “female sexual dysfunction”, a condition claimed to affect up to 43 percent of all women. As with many conditions, the scientific meetings where this condition is debated and discussed, and its definitions revised, have been heavily sponsored by the same

companies working to develop drug treatments. And drug companies have not only sponsored aspects of the science of this new disorder, but in some cases drug company employees have directly helped construct it. (Moynihan & Mintzes, 2010) Key prevalence surveys, measurement instruments and diagnostic tools have been designed with direct input from company staff, and funding from company budgets. Moreover, key medical educational programs have also been sponsored. Since 2000 a small global network of academics practitioners and activists - called the New View - have campaigned to expose and challenge the corporate-sponsored medicalisation of female sexual difficulties, and what they see as the disease-mongering associated with the development of this new medical condition. ([www.fsd-alert.org](http://www.fsd-alert.org))



Credit: Giovanni Maki, PLoS Medicine Illustration

With growing interest in the topic, by 2006 the inaugural international conference on disease-mongering was held at the University of Newcastle in Australia, corresponding with a special theme issue of *PLoS Medicine*, (*PLoS Medicine*, 2006) a recently launched journal with a policy explicitly rejecting pharmaceutical advertising. The conference and the theme issue featured case studies including bipolar disorder, restless legs syndrome, attention-deficit hyperactivity disorder and female sexual dysfunction.

As the concept of disease-mongering has attracted wider attention an increasing number of individuals and organizations have joined the debate about how to understand the phenomenon and confront the problem, with creative artists, writers and comedians constructing their own fictional conditions, including AMDD - Adolescent Motivational Deficiency Disorder – and others, created by Alan Cassels. (Cassels, 2007) By 2010, more conferences have featured debates, some health consumer groups have taken up the issue and the pharmaceutical industry has publicly rejected criticisms relating to disease-mongering. A number of academic institutions and professional associations have begun offering courses on the topic, and within the media, some high-level reporting on health is incorporating concerns about the problem into its coverage. Interestingly in a number of countries, medical media-watch groups ([www.mediadoctor.org.au](http://www.mediadoctor.org.au); [www.mediadoctor.ca](http://www.mediadoctor.ca); [www.healthnewsreview.org](http://www.healthnewsreview.org)) routinely include an assessment of whether a medical news story has contributed to the process of disease-mongering. (Moynihan, et al., 2008)

A significant caveat, often attached to any discussion of disease-mongering, is that the critique of the definition of a particular condition, or its promotion by way of corporate – sponsored “awareness” campaigns, in no way implies that the target condition does not exist. As an example, the authors examining how disease-mongering is occurring in relation to restless legs syndrome acknowledge that “for some people symptoms are severe enough to be disabling.” (Woloshin & Schwartz, 2006) The focus of their critique was on how media reporting tended to exaggerate the numbers affected by the condition, with the risk the media was helping to literally “make people sick.” Similarly, in relation to osteoporosis, treating and preventing the genuine problem of hip fractures is an extremely legitimate public health concern.

It is important to note here that, notwithstanding this caveat, disease-mongering is a controversial concept. Where some people observe a crude *selling of sickness* to grow drug sales or widen professional territory, others see the legitimate expansion of the patient pool, in order to improve human health. The increasing popularity of early diagnosis and preventive medicines, designed to treat even those at low risk of future illness – as occurs with the conditions of high cholesterol or low bone mineral density – are seen by many as the elements of sound public health policy. Similarly, the metamorphosis of mild ailments into medical illness – as with hyperactivity or sexual dysfunction – is widely regarded as a response to a growing public demand for “lifestyle” products to enhance quality-of-life.

Turning to scientific evidence to try and judge the merits of the competing claims of disease-mongering versus legitimate disease-awareness raising holds its own challenges. In the context of a medical establishment heavily entangled with the pharmaceutical industry, finding independent assessments of the validity of disease-definitions is an extremely difficult task, perhaps even harder than searching for unbiased evidence about the risks and benefits of treatments. (Lexchin, et al., 2003) Certain examples of disease promotion- as with corporate-sponsored efforts to raise awareness about HIV-AIDS for instance- may well be largely uncontroversial. However with many other conditions, the line between legitimate awareness-raising to improve public health, and crude disease-mongering to enhance private wealth, may be a lot more difficult to locate, and often deliberately blurred.

Finally, it is worth noting that there are some key challenges in both understanding and addressing this relatively new and controversial phenomenon described as disease-mongering. Firstly, some thinkers have wanted to locate this concern within a wider social and historical context. Nikolas Rose for instance has observed that it is “too simple



to see actual or potential patients as passive beings acted upon by the marketing devices of Big Pharma who invent medical conditions and manipulate individuals into identifying with them.” (Rose, 2006) Using a number of psychiatric disorders as examples, Rose has argued there are many processes that “lower the threshold at which individuals are defined, and define themselves, as suitable cases for treatment” which are turning non-patients into actual patients. Secondly, notwithstanding its growing acceptance as a problem of concern, operationalising the concept and its various components for the purposes of research is proving challenging, though academic study of the problem is underway. Third, there has as yet been little explicit interest from policy-makers, though that situation may change as health technology assessment bodies globally become more aware of the controversial nature of disease-definitions, and the ability to disaggregate the financial and other costs of over-medicalization becomes more possible. (Conrad. et. al., 2010)

***...a systematic attempt to redefine common categories of human illness, with fresh new groups of professionals and public representatives, may be required.***

To close: some simple, tentative suggestions. In line with broader recommendations to disentangle medical professionals and healthcare industries in order to achieve more independence in medical decision-making, (IOM, 2009) I suggest that the panels which define and refine diseases and conditions, write consensus documents and develop clinical guidelines should be as free as possible of professionals with relevant financial conflicts of interest. Given the heavily conflicted nature of these processes to date and the concern that the over-pathologising of normal life may have occurred across many conditions, a systematic attempt to redefine common categories of human illness, with fresh new groups of professionals and public representatives, may be required. Similarly a fresh approach to the provision of information, and a move away from

reliance on corporate-funded material about health and disease may be indicated. More valid and useful information about health and disease for professionals, patients and the public might well be better generated by public or not-for-profit sources, rather than those with a vested interest in maximising the markets of the sick.

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