

Inaugural Conference on Disease Mongering

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I attended the Inaugural Conference on Disease Mongering (ICDM) in Newcastle from 11-13th April 2006 with support from the Health Consumers Council (Inc) of Western Australia. I have been an active member since 1994 and I was grateful for the opportunity to participate, reflect and listen to the presentations at this conference. There were both national and international contributors and the number of attendees (approximately 80 people) gave it “a workshop feel” rather than that of a large conference.

Writing this report has been a challenging and intense process. The issues around disease mongering require careful thought and enquiry. As the author of this report my role is to present some of the conference proceedings from a consumer perspective. At the time of writing the conference report was not available so I have attempted to describe the highlights as best I can.

Disease Mongering can be described as trading in disease “the seeking of sickness that widens the boundaries of illness and grows the market for those who sell and deliver treatments”. During the two and half days in Newcastle diseases paradigms were challenged, scientific and research processes dissected and a great deal of cultural reflection occurred. The usual post presentation discussions took place during the breaks. This conference had a different purpose. Relationships were examined, challenges thrown up, directions and what’s next for disease mongering discussed. My thinking cap was working overtime, as I grappled with the enormous tasks of being part of group that was questioning the dynamics of our health systems. The warm autumn weather in Newcastle invited participants outside, but the conference program kept us focused on the enormous task of beginning as a group, to unravel disease mongering.

As a health consumer, my relationship with health care providers is essentially one of receiving rather than taking services. The concept of disease mongering untangles all the influences that bring together the knowledge and exchange that takes place within the provider health consumer context. In this report, I will both report on the conference and give the reader the opportunity to further research the area.

The conference program is available from the ICDM website at <http://www.diseasemongering.org/content/program.jsp>

The first plenary began with the chair and one of the co organizers of the conference, Professor David Henry, a Clinical Pharmacologist at the University of Newcastle, telling us that the idea for the conference started as a bit of a joke and got out of hand. The messages were “stop some of the selling of disease,

disease awareness is appropriate but there is a line that is crossed to disease mongering". The conference aims to define "where that line is".

Professor Leth Argos, a respected neuroscientist at University of Newcastle, presented a brand new fictitious disease called Motivational Deficiency Disorder or MODeD. Expanding on MODeD Professor Argos discussed trials of a new drug called *Indolebant* used to treat the disorder and early results are highly promising. The structure to Professor Argos's presentation paralleled how diseases and new drugs to treat them are promoted in the marketplace. This insightful presentation set the scene for the conference.

Martin Palin a communications consultant then challenged us with debate on the role that public relations plays in disease mongering. Public relations amplifies, elevates and directs health care messages. In the media, the news decision makers and news editors also play a role. Is there evidence of partnerships? Yes, but not necessarily sinister, stated Palin. Companies are given information. They can not just issue media releases. He said many partnerships lead to positive outcomes and cited the examples of quit campaigns and the work done by surgeons with gastric banding for the obese. There are so many players in the messages that get delivered, commencing with the researcher, committees, scientists, big business development and big pharmaceutical companies.

Consumer groups are keen for awareness. Debate continued on whether the commercial test determines disease mongering. Palin closed his presentation by questioning whether disease mongering was a PR creation. There are no PR creations. They are clearly created by someone not by a PR consultant or agency. It is not appropriate to assume guilt by association because there is a third party.

A collection of articles on Disease Mongering is available in the April 2006 edition of Public Library of Science PLOS medicine at <http://collections.plos.org/diseasemongering-2006.php> . Articles by major speakers at the conference are easily downloaded from this site.

Ray Moynihan, conjoint lecturer at Newcastle University, a co organzier of the conference and co author of the 2005 book "Selling Sickness: How drug companies are turning us all into patient's, expanded on the invented disorder MODeD. It had attracted worldwide attention when written about in the April Fools Day edition of the British Medical Journal. He also introduced the 1992 book by the now deceased Lynn Payer 'Disease-Mongers: How Doctors, Drug Companies, and Insurers are Making You Feel Sick'.

(See book review <http://bmj.bmjournals.com/cgi/content/full/324/7342/923/a>)

Professor David Healy, University of Cardiff United Kingdom, gave a presentation entitled "The Latest Mania Selling of Bipolar Disorder". It touched on many

important issues, including the labeling of children, the marketing of drugs and their possible serious long term side effects. Worryingly, were the use of mood diaries provided for young children to fill-in and the use of story books that feature a bear character. Professor Healy challenged the prevalence of these conditions and the extrapolation of trial figures to the wider population and the growth in the use of the word “mood stabilizer” in scientific articles. The rationale for prescribing to treat mood disorders needs examining. The increasing use of such language in written and visual information normalises acceptance of these conditions. To further understand the issues addressed by this academic psychiatrist and a world leader in his field consumers could read the April edition of PLOS medicine (see web address listed earlier).

Professor Leonore Tiefer of New York University School of Medicine presented “Female Sexual Dysfunction A continued Case Study of Mongering and Activist Resistance”. She stepped us through the history of Viagra and again the subtle use of its marketing to the public. One promotional advertisement used the line “A lot of guys have occasional erectile problems. I chose not to accept mine”. The drug companies subtly shifted their advertising to a younger and younger profile. Tiefer touched on many different issues around female sexuality such as sexual motivation, importance of sexuality, and methods used by companies to prepare the drug market during the clinical trials period. . Sex disease mongering capitalizes on the psychological appeal of biology and recruits key opinion leaders

Tiefer has a web site called New View Campaign an Educational Campaign to Alert Women to the Dangers Of Medicalising Sex at www.fsd-alert.org

Joel Lexchin from York University and University of Toronto Canada also gave a talk on “Bigger and Better: How Pfizer Redefined Erectile Dysfunction”. I was unable to attend this parallel session as I went to another concurrent session. However in the introduction of his article in the April edition 2006 PLOS he states. “In the pursuit of profits, pharmaceutical companies are continuously looking to expand the market for their products. This article examines how Pfizer transformed Viagra from an effective product for erectile dysfunction due to medical problems, such as diabetes and spinal cord damage, into a drug that “normal” men can use to enhance their ability to achieve an erection and to maintain it (in a “harder” state) for a longer period of time.

The rise of lifestyle drugs is an important emerging issue in health care because availability of medications to treat what until recently have been regarded as the natural results of aging or as part of the normal range of human emotions.

Steven Woloshin and Lisa Schwartz Dartmouth Medical School Hanover USA gave a presentation called “Giving Legs To Restless Legs - A Case Study of how the Media Help Make People Sick”. They demonstrated the ways companies

work with the media to exaggerate the numbers suffering from particular conditions in order to build markets for soon-to-be-released drugs. To get a sense of how the media worked, they examined news coverage of “restless legs” syndrome. In 2004 there was a rev up in the restless legs campaign. In 2005 the US Food and Drugs Administration (FDA) approved the first drug (previously used to treat Parkinson’s disease) specifically for this indication. The figures banded around were that it affected 12 million people, or one in ten Americans

Highlighting the disorder to health care professionals and consumers and constantly talking about it created an increased awareness. Balanced media articles (including both the benefits and harms) are vital. Steve and Lisa’s critically analyzed the news coverage and the potential to over diagnosis this disorder. They called for balanced reporting and reminded us that the medical news reporting is to inform readers not just make them sick.

Bob Burton, a freelance journalist from Canberra, gave a presentation called “Reclaiming health from the spin drs” He talked about the notions of convincing healthy people that they are sick. Again the facilitator role of the media was discussed, including the constant challenge of deciding where the dividing line is. What about when the treatment side effects are worse than the disease?

There is a need for open transparency about funding of campaigns and this could be achieved with electronic communication and political will. Furthermore, the profit incentive does not explain all the behaviours in the market place. There are also strong cultural influences. Interestingly, the trend towards ghost medical writers preparing journal articles for signature of key opinion leaders was brought up.

During the conference there was ample time to reflect on the relationships between health care practitioners and the drug companies. Consumer groups can also have relationships with drug companies.

There was also much discussion of mental health care. Some of the issues raised were:

- o Reading the methods, results and discussions, sections of scientific papers rather than just the introduction and conclusion gives readers a full understanding of the research presented. This principle applies to all medicine but was raised during discussions of medications to treat those with mental illness.
- o Ethical implications in the doctor patient relationship are fundamental to successful outcomes. Ethical issues of information provision to consumers was discussed.
- o Vulnerability of consumers
- o Reciprocity and input from the public sector
- o The ethics of mental health care and the importance of empathy.

- o The lack of sufficient time in the primary health care setting to always provide good quality mental health care.

Direct to Consumer Advertising (DTCA) and the part it plays in disease mongering was well covered. We saw many powerful advertisements each illustrating the three types of DTCA.

- o full product ad, brand name and health claims risk info required.
- o reminder ad brand name only
- o help seeking ad health condition only no brand name , but suggests you ask your dr about a treatment

Two countries have DTCA United States and New Zealand. Barbara Mintzes from the University of British Columbia said DTCA is illegal in the European Union. There has been an exponential growth in DTCA. The regulation of drug promotion remains a grey area and it is one of political will. Some of the questions raised are

- o milder symptoms and disease promoting
- o are misrepresentations of disease risk covered under existing regulation
- o disease mongering broadening the definition of off-label prescribing (ie prescribing medications for illnesses other than those that it was listed for)

Jo Fitzpatrick of the Women's Health Action Trust NZ discussed the example of the

DCTA weight loss advertisements aimed at the vulnerable. There theme is "lose weight gain a life". She also discussed the acne drug (which is an oral contraceptive) and the insufficient information that women receive. She had many more examples of DTCA, particularly the normalising of a "pill for every ill" (even when the side effects are not pleasant). She touched on prescription pharmaceuticals as a commodity in the market place. Also the industry code of conduct has consumer representatives, but it is an industry controlled and dominated ethics process. She also discussed industry self regulation and how it does not work

Dr Ian Kerridge from the University of Sydney who is an ethicists and a haematologist talked about "DTCA beyond legislation".

The advantages of DTCA:

- o Moral claims rather than evidence based claims
- o Increased health
- o Increase in appropriate prescribing

The adverse impacts:

- o Promotes premature uptake
- o Increase costs adds little of value
- o Diverts spending and clinical attention
- o Drowns out other messages

- o Delivers flawed information
- o Increase difficulty of finding information
- o Creates unrealistic information
- o Drives inappropriate prescribing
- o Increase unhappiness and anxiety
- o Medicalises normal human experiences
- o Leads consumers down a path to receiving prescribed medicine

He talked about possible limitations on DTCA but why it cannot be stopped. There is a direct relationship between DTCA and consumer demands on health care professionals. Also, advertising to professionals increases their awareness. An example was given of conferences for school nurses being sponsored by the makers of ADHD medications.

Some of the contributing factors to continuation of DTCA are:

- o Information revolution
- o Rise of global markets
- o Advocacy and patient rights
- o The affect of the Internet on the volume , flow and control of information
- o Patient preferences and shared decision making
- o Drs only one area of health information
- o All informers may claim that they are promoting autonomy
 - o No information value neutral
 - o Quality of information and manner of its presentation
 - o Vary according to available resources
 - o Self regulation treats drugs like other commodities.

Kerridge finished his talk with these points re the evidence of not having DTCA:

- o Community values goals of the health system
- o Increase public transparency and support of government
- o Skill based training of health professionals
- o Moratorium of DTCA of new drugs
- o Incentives for public private consortium
- o Public health of the community

Professor Lloyd Sansom of the University of South Australia gave a presentation on “Counteracting Disease Policies through Reimbursement Policies”. He is the chair of the Pharmaceutical Benefits Advisory Committee (PBAC). He started with a background of the PBAC. The PBAC looks at submissions on a cost utility analysis. The Pharmaceutical Benefits Scheme is the best subsidy system in the world. The transparency of decision making is very important and “the record of reasons for listing”, (the decisions made by the PBAC) are publicly available documents.

The timely and universal access to healthcare under Medicare is valued by Australians. The PBS is an important component of Medicare. Professor

Sansom reminded the audience that what is presently missing from the scheme of things, is the link to health outcomes, after decisions made by the PBAC. The linkage of Medicare and PBS data would be helpful. There is some work being done in this area. (after careful consultation with many national agencies). Sansom encouraged the group to “have a broad debate on medicine use but not to marginalize particular groups”. Finally, he reminded us that the Australian government is supportive of quality use of medicines and it is towards this direction that the disease mongering debate could go.

The PBAC Web site is

<http://www.health.gov.au/internet/wcms/publishing.nsf/Content/Pharmaceutical+Benefits+Advisory+Committee-1>

Professor Julie Byles Director of the Centre for Research and Education in Ageing at the University of Newcastle talk was called “Old Age is Fatal”. Ageing is the ultimate in disease mongering. Freud theorized that youth is curable but old age is fatal. He had many neuroses himself and had 30 operations. We now have preventable death at younger ages so people can survive to get old. Some of the weapons in the battle against old age include eg molecular and genetic approaches, nutrient and hormonal therapies. Consumers demand anti- ageing products. Many older people have poor diets. Many of the problems of old age are social not biological. Physical conditioning in old age is good and there are some things that are unavoidable and others that are avoidable. Decent health care and pain relief is important. This was just a small part of her excellent presentation which she concluded by saying “I am not against aging I am all for it”.

Website The Womens Health Australia project

<http://www.newcastle.edu.au/centre/wha/Staff/julie.html>

Dr Iona Heath GP practicing in London UK gave a presentation called “Combating Disease Mongering What is the way Forward?”

The integrity of science is called into question in disease mongering. The confusion of a risk factor and a disease. The following are extracts from her article in PLOS.

The medical profession needs to do much more to define sensible limits to medical intervention. There is a clear and urgent need for more research into the psychological impact and the wider health consequences of being labelled “at risk” Doctors, and society as a whole, need to stop confusing health with happiness. This confusion is at the root of much of the medicalisation of normal human variation that we are witnessing. Male pattern baldness and shyness, to take just two examples, are not diseases but normal parts of the range of human experience.

She makes the great point that as thresholds are lowered for treating various risk factors, the benefit/risk ratio changes markedly. "We are witnessing diagnostic drift in a whole range of conditions, from depression to hypertension, with pressure for more and more people to be included within the range of abnormal and offered treatment. The justification for these treatments is often based on short-term studies, which are then extrapolated over much longer time periods. There is insufficient recognition of the fact that the less the need for treatment, the higher the number needed to treat for given outcomes and the higher the risk to patients, since the rate of adverse effects remains constant."

Other notes from her talk include

- o Diseases and risk factors are little more than socio economic deprivation
- o Poor more at risk
- o Greed and fear
- o Fear of dying
- o Ultimately the only way to combat disease mongering is to value the manner of our living above the timing of our dying

The pharmaceutical industry spends millions of dollars supporting the education of doctors because it is in its economic interest to do so. There is no such thing as a free lunch www.nofreelunch.org

When pharmaceuticals are used to treat risk factors, the vicious circle is completed because anyone who takes medicines is by definition a patient.

I am aware that I have internet based resources in this article. I urge consumers who do not have internet access at home to visit their local public library where this facility is usually available.