Tidsskriftet Tidsskrift for Den norske legeforening

Power shift

STINE BJERKESTRAND

Stine Bjerkestrand (born 1972) is development editor of *Tidsskriftet*. She has a *Cand. mag*. degree with the subjects journalism, media studies and political science.
Email: stine.bjerkestrand@legeforeningen.no

Why is it that some studies attract extensive media attention, shape opinion and lead to political action, while others are passed over in silence?

Subjects that satisfy the traditional criteria for news in the media – current interest, materiality, immediacy, possibility of personification/identification – or are controversial, have good chances of reaching the newspaper columns (1). Organised pressure groups also have the power to influence whether a study becomes news or not. Since the advent of the social media, this power has expanded. Two studies of chronic fatigue syndrome, or myalgic encephalomyelitis (ME) published in 2011 may serve to illustrate this. Many people with chronic fatigue syndrome are active in social media. Through this activity, they have established themselves as a pressure group. They take part in net debates and posts relating to health and comment regularly on links to material on this condition (2) – (4).

In January 2011, Lillebeth Larun and Kirsti Malterud published an article in *Tidsskriftet* on a meta-analysis of randomised, controlled trials of treating chronic fatigue syndrome with exercise (5). The article concludes that individually adapted exercise treatment can lessen the fatigue of these patients, and the authors find no evidence that it is harmful. We produced a clip for *Tidsskriftet's* YouTube channel (6), distributed the article in social media and published a press release about it. It was met with silence.

On 19 October 2011, Fluge et al. published in PloS One the results of a limited clinical trial that involved treating patients with chronic fatigue syndrome with rituximab (7). The trial indicates that the illness is an autoimmune disease. It appears on the internet, is the top feature on Norwegian TV2 news at the same time (8) and is hailed as a breakthrough. The facts that it is in an early phase, includes only 30 patients, and that we know little about the long-term effects and side effects, are toned down. All those interviewed have positive things to say. Few or no critical questions are put to the interviewees.

The following day, 20 October, saw the release of Jørgen Jelstad´s book *De bortgjemte – om hvordan ME ble vår tids mest omstridte sykdom* [The hidden ones – how ME became one of the most controversial illnesses of our time] (9). Jelstad has followed Fluge et al. closely while they conducted the trial. Over the next few days, TV2 has a number of human interest reports where patents weep tears of joy at the startling result and recount what it has been like not to be taken seriously by the healthcare system. On 21 October, Professor Ola Didrik Saugstad demands an investigation into the treatments Norwegian patients with chronic fatigue syndrome have received. He believes that the healthcare system has incorrectly relegated the illness to the category of psychological disorder (8). Several bloggers, including Maria Gjerpe with Marias Metode, publish blog posts about the study. At the same time, a review (10) of the book is launched on the day of its release (11). There are expressions of gladness and enthusiasm on Twitter, with frequent references to the trial, TV2, the coming book and blog posts that describe the study as sensational. Words like «sensation» and «medical breakthrough» occur repeatedly.

In the weeks that follow, articles, blog postings and tweets keep our attention focused on the healthcare system's treatment of these patients. The theory that chronic fatigue syndrome is an autoimmune disease that can be treated with rituximab is a recurring theme. There is a book launch at which the same players take the floor. The publishers get far more publicity about the book than they could have dreamed of achieving with huge promotion budgets.

The media pressure is strong. On 20 October the Minister of Health promises to follow up the study. On 21 October opposition politician Erna Solberg delivers an interpellation to the Storting in which she urges the minister to invest more in research on treatment of chronic fatigue syndrome. On 28 November TV2 brings good news: «ME researchers get two million kroner for further research» (8). The granting of funding, for example via the Research Council, is normally a long, drawn out process. Both the studies satisfy a number of the criteria for newsworthiness and have been published in peer-reviewed journals. Normally, sensational new results are more interesting for the media than meta-analyses, but nevertheless not so much more interesting that it can explain the great difference in media focus received by these two studies.

All those involved in the autumn campaign about chronic fatigue syndrome are on *one* side of a polarised debate on understanding of the illness. This was not clearly projected in the media. The cover given to the rituximab trial in October and November is an excellent, but far from unique example of campaign journalism, where information is systematically over-interpreted in one direction, and objections are ignored with the justification that it is for a good cause. What is sensational about the findings would have been counterbalanced by statements from persons with a different understanding of the disease and knowledge of clinical trials and the potential for financial gain inherent in these trials.

The bloggers have ensured the dissemination of Fluge et al.'s article like a virus, just as they do with other information that supports their viewpoints. Unlike the participants in established media, they have no tradition of promoting a nuanced debate, and are not obliged by professional ethics to do so. Whereas there are methods for ensuring quality and for identifying conflicts of interest in scientific publication and investigative journalism, bloggers are free to promote one point of view. The combination of campaign journalism and bloggers' power has contributed to broad-based support for *one* view of a complex illness of which nobody knows the cause, and has given one research community a tail wind. The strategists behind the autumn campaign have demonstrated that the general public has the power to set the political agenda, define how an illness is to be understood, and influence the allocation of research funding.

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Publisert: 24 January 2012. Tidsskr Nor Legeforen. DOI: 10.4045/tidsskr.12.02E1