



Chronic fatigue syndrome in the media: a content analysis of newspaper articles

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DECLARATIONS

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None declared

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Ethical approval

The project protocol was presented for the Norwegian Regional Ethics Committee for Medical Research.

As the objects of the project were newspaper articles, this was not considered medical research and no objections to the project were raised

Guarantor

AM

Contributorship

AKK contributed to the design of the study, analysis and interpretation of the data, literature

Summary

Objectives Although cognitive behavioural therapy and graded exercise treatment are recognized evidence-based treatments for chronic fatigue syndrome/myalgic encephalomyelitis (ME), their use is still considered controversial by some patient groups. This debate has been reflected in the media, where many patients gather health information. The aim of this study was to examine how treatment for chronic fatigue syndrome/ME is described in the newspaper media.

Design Content analysis of newspaper articles.

Setting The digitalized media archive Atekst was used to identify Norwegian newspaper articles where chronic fatigue syndrome/ME was mentioned.

Participants Norwegian newspaper articles published over a 20-month period, from 1 January 2008 to 31 August 2009.

Main outcome measures Statements regarding efficiency of various types of treatment for chronic fatigue syndrome/ME and the related source of the treatment advice. Statements were categorized as being either positive or negative towards evidence-based or alternative treatment.

Results One hundred and twenty-two statements regarding treatment of chronic fatigue syndrome/ME were identified among 123 newspaper articles. The most frequent statements were positive statements towards alternative treatment Lightning Process (26.2%), negative statements towards evidence-based treatments (22.1%), and positive statements towards other alternative treatment interventions (22.1%). Only 14.8% of the statements were positive towards evidence-based treatment. Case-subjects were the most frequently cited sources, accounting for 35.2% of the statements, followed by physicians and the Norwegian ME association.

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Conclusions Statements regarding treatment for chronic fatigue syndrome/ME in newspapers are mainly pro-alternative treatment and against evidence-based treatment. The media has great potential to influence individual choices. The unbalanced reporting of treatment options for chronic fatigue syndrome/ME in the media is potentially harmful.

Introduction

Chronic fatigue syndrome, also known as myalgic encephalomyelitis (ME), is a disorder which has attracted considerable controversy, with debate continuing around its aetiology, diagnosis and the effectiveness of treatments being offered.^{1,2} Despite these ongoing debates, cognitive behavioral therapy and graded exercise treatment are now widely recognized as the most beneficial evidence-based interventions.³⁻⁵ Other potential interventions, like homeopathy, dietary supplements, pharmacological treatment or prolonged rest have been studied, but lack sufficient evidence to be rated as effective.^{3,6} Case-stories have reported the effectiveness of the training program Lightning Process,⁷ but randomized controlled trials of this intervention are lacking.

In spite of the existence of evidence-based treatment for chronic fatigue syndrome/ME, many general practitioners (GPs) feel dissatisfied with the level of care they are able to provide patients with symptoms of chronic fatigue syndrome/ME.⁸ Further, up to two-thirds of these patients report being dissatisfied with the quality of care they receive, and perceive their physicians as not having knowledge about chronic fatigue syndrome/ME.⁹ The dissatisfaction with information and care from their GPs may lead patients with chronic fatigue syndrome/ME symptoms to search for and trust information about their condition from other sources, like the media.

The media's potential to reach large audiences gives them an important role in providing health-related information, shaping public health-related beliefs and influencing health behaviour. Contentious disorders, such as chronic fatigue syndrome/ME, often attract considerable media attention, however, due to the different perspectives of researchers and journalists, there is not always agreement on how that information should be presented.¹⁰⁻¹² A number of recent high profile cases have raised particular concerns

about the way in which the media presents evidence surrounding treatment options for chronic fatigue syndrome/ME.¹³

The aim of this study was to examine how treatment of chronic fatigue syndrome/ME is presented in the newspaper media, in particular the presentation of evidence-based versus alternative treatments as effective interventions for the disorder. Further, we wanted to examine who were quoted as the sources of statements on chronic fatigue syndrome/ME treatment.

Methods

Searches

The digitalized Norwegian media archive Atekst, containing national, regional and local newspapers, was used to search for Norwegian newspaper articles published in the period 1 January 2008 to 31 August 2009 where chronic fatigue syndrome/ME was mentioned and treatment options discussed. This time period was chosen because all major newspapers were represented in the digitalized media archive utilized for the study. Further, it represented a period without any major chronic fatigue syndrome/ME story dominating the news. In particular, it should be noted that the publication and extensive media coverage of a possible link between the xenotropic murine leukemia-related virus (XMRV) and chronic fatigue syndrome/ME¹⁴ occurred after the time period included in our study.

Categorization

For the purpose of this study, treatments for chronic fatigue syndrome/ME were grouped into categories based on their evidence of efficacy. Treatments evaluated as effective in terms of the Cochrane standard¹⁵ were grouped into the category evidence-based treatments, and included cognitive behavioural therapy and graded exercise

process have been provided from Simon Wessely, Ingvard Wilhelmsen and members of the Network for Psychiatric Epidemiology

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treatment.^{4,5} Alternative treatments were divided into two subcategories. The subcategory alternative treatment Lightning Process included interventions related to the training program Lightning Process,⁷ while other alternative treatment included all other types of non-evidence-based treatments. The unique subcategory for Lightning Process was constructed because this intervention has received great attention in Norwegian media in recent years, and is increasingly being recommended by some health professionals as an effective intervention for chronic fatigue syndrome/ME.

Statements regarding the treatments were then categorized as being either positive or negative. A statement was categorized as positive if it gave a clear recommendation of the treatment, if the treatment was described in positive terms, or if a person described that he or she had experienced a beneficial effect of the treatment. Statements were categorized as negative if they gave a clear warning or devaluation of the treatment, if the treatment was mentioned in negative terms, or if an experience of no or adverse effects from the treatment was described. Statements clearly denying the existence of evidence-based treatments, for example 'There exists no acknowledged treatment for chronic fatigue syndrome/ME', were categorized as negative towards evidence-based treatments. Each separate statement was registered as a single unit independent of number of words.

Finally the quoted source for each statement was registered. If the source was a person, his or her role or occupation was registered, and if the source was an institution the name of the institution was registered. When the source was an individual with a statement based on personal experience with chronic fatigue syndrome/ME, this was registered as a 'case subject' or 'interviewees'. The categories were discussed and agreed upon by the Norwegian speaking authors (AKK, ANO, CMSL, LVL and AM), while the coding was performed by ANO.

Analysis

Techniques from content analysis were employed to examine the relative frequency of positive and negative statements. As the newspapers publishing the articles varied in terms of circulation

size, and hence in their potential impact on the population, a secondary analysis weighted for circulation was conducted.

Ethics

The study was evaluated by the Norwegian Regional Ethics Committee, where no objections were raised.

Results

Initial searches revealed 123 articles mentioning chronic fatigue syndrome/ME, of which 44.7% ($n = 55$) contained statements regarding treatment. The total number of statements regarding treatment was 122. The distribution of positive and negative statements regarding each of the treatment categories is visualized in Figure 1 and the distribution among sources are described in Table 1.

The three most frequent categories, which constituted 71% of the statements, were positive statements towards alternative treatment Lightning Process ($n = 32$, 26% [95% CI 18–34]), negative statements towards evidence-based treatments ($n = 27$, 22% [95% CI 15–30]), and positive statements towards other alternative treatments ($n = 27$, 22% [95% CI 15–30]). Only 18 of the statements

Figure 1
Distribution of positive and negative statements regarding treatment interventions for CFS/ME in Norwegian newspaper articles (1 January 2008 to 31 August 2009). Positive statements are marked with +, negative statements are marked with -. LP = Lightning Process

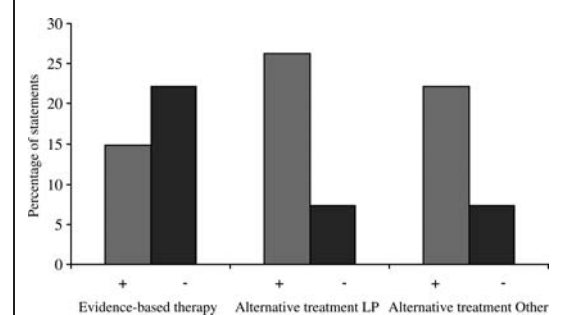


Table 1**Distribution of sources of statements regarding treatment interventions for chronic fatigue syndrome/ME in Norwegian newspaper articles (1 January 2008 to 31 August 2009)**

Sources	Statements						Sum n (% of total)
	Evidence-based treatment		Alternative treatment (Lightning Process)		Alternative treatment (Other)		
	Positive n (%)	Negative n (%)	Positive n (%)	Negative n (%)	Positive n (%)	Negative n (%)	
Case subjects/ interviewees	0 (0)	8 (19)	15 (35)	4 (9)	12 (28)	4 (9)	43 (35)
Physicians	14 (40)	5 (14)	8 (23)	0 (0)	8 (23)	0 (0)	35 (29)
The Norwegian Association of Myalgic Encephalopathy	0 (0)	8 (57)	0 (0)	5 (36)	1 (7)	0 (0)	14 (11)
The Norwegian Directorate of Health*	3 (38)	3 (38)	0 (0)	0 (0)	0 (0)	2 (25)	8 (7)
Journalists	0 (0)	2 (33)	2 (33)	0 (0)	2 (33)	0 (0)	6 (6)
Lightning Prosess	0 (0)	0 (0)	6 (100)	0 (0)	0 (0)	0 (0)	6 (5)
Pasienthåndboka [†]	1 (50)	1 (50)	0 (0)	0 (0)	0 (0)	0 (0)	2 (5)
Clinical psychologists	0 (0)	0 (0)	1 (100)	0 (0)	0 (0)	0 (0)	1 (2)
Others	0 (0)	0 (0)	0 (0)	0 (0)	4 (57)	3 (43)	7 (1)
Total	18 (15)	27 (22)	32 (26)	9 (7)	27 (22)	9 (7)	122 (100)

*The Norwegian Directorate of Health includes the Norwegian Institute of Public Health and the Norwegian Board of Health Supervision.
[†]Online health information site (nhi.no)

were positive towards evidence-based treatments (15% [95% CI 9–21]).

Weighting for newspaper circulation only modestly altered the results. The three most common statements were negative statements towards evidence-based treatment (25%), and positive statements towards alternative treatment Lightning Process (22%) and other alternative treatments (22%) (data not shown).

The most frequently registered sources of the statements were the case subjects ($n = 43$, 35% [95% CI 27–44]), followed by physicians ($n = 35$, 29% [95% CI 21–37]) and the Norwegian Association of Myalgic Encephalopathy (the ME association) ($n = 14$, 11% [95% CI 6–17]) (Table 1). The majority of statements from case subjects were positive to both forms of alternative treatment (63%). Physicians had the most positive

statements towards evidence-based treatments (40%), while the ME association had statements predominantly negative towards evidence-based treatments (57%). There were no registrations of positive statements towards evidence-based treatments from either the case subjects or the ME association (Table 1).

Discussion

The majority of statements regarding treatment of chronic fatigue syndrome/ME in Norwegian newspapers articles were either positive towards alternative treatment or negative towards evidence-based treatment. The majority of statements made by patients were positive towards alternative treatment, while physicians were more positive towards

evidence-based treatment and the ME association were negative towards evidence-based treatment.

The main strength of this study was its comprehensive search strategy covering 56 different Norwegian newspapers. However, this study also has some limitations. The categorization of statements is based on subjective interpretations according to its perceived message. The possibility that diffuse statements may have been misinterpreted cannot be ruled out, and the lack of any formal test on reliability and validity is the major limitation of this study. Further, there is no comparison disorder, thus this study cannot answer whether the skewed interest towards alternative treatment is a particular characteristic of reporting on chronic fatigue syndrome/ME. Finally, the study is limited to the newspaper media, which may attract some segments of the population more than other forms of media.

To the best of our knowledge, this is the first study examining how treatment of chronic fatigue syndrome/ME is presented in the media of any country. The skewed presentation, which is contradictory to empirical findings, may have several explanations. Journalists might be more prone to present novel information, and thus ignore more established forms of treatment.¹⁰ In addition, practitioners of alternative therapies may be more skilled at promoting their services via the media. Even if the results of scientific research or complicated treatment trials are presented to the media, journalists may find them more difficult to summarize into a readable format¹⁰ compared to case stories or strong statements from alternative therapists. Many journalists admit finding it difficult to comprehend some health issues, to place health news in context, and to interpret statistics.¹⁶

Based on the results of this study, it is conceivable that individuals with symptoms of chronic fatigue syndrome/ME will be influenced by the print media to choose alternative treatments rather than evidence-based interventions. Many countries have guidelines for the media aimed at reducing the possible negative effects of journalism, although most do not have any specific codes on how to present health issues and the evidence base for treatment options. Health researchers and health professionals are also responsible for disseminating correct and relevant information concerning treatment options. If the media

presents opinions and pseudo-facts which are in conflict with known evidence, then experts in the field should attempt to provide alternative evidence-based information. Journalists, researchers and health professionals should not underestimate their responsibility when communicating health information to the population and should cooperate more to increase the availability of desirable health information.

In summary, statements regarding treatment options for chronic fatigue syndrome/ME in newspapers are skewed against evidence-based treatment. The media has great potential to influence health behaviour, meaning this unbalanced reporting is potentially very harmful.

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