Published in final edited form as:

Chronic Illn. 2018 March ; 14(1): 3–12. doi:10.1177/1742395317703175.

A content analysis of chronic fatigue syndrome and myalgic encephalomyelitis in the news from 1987 to 2013

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Abstract

Objectives—The aim of this study was to analyze the content of American newspaper articles ($n=214$) from 1987 to 2013, in order to understand how the public digests information related to Chronic Fatigue syndrome, a controversial and misunderstood illness.

Methods—A novel codebook derived from the scientific literature was applied to 214 newspaper articles collected from Lexis Nexis Academic®. These articles were coded quantitatively and frequency tables were created to delineate the variables as they appeared in the articles.

Results—The etiology was portrayed as organic in 64.5% ($n=138$) of the articles, and there was no mention of case definitions or diagnostic criteria in 56.1% ($n=120$) of the articles. The most common comorbidity was depression, appearing in 22.9% ($n=49$) of the articles. In 55.6% ($n=119$) of the articles, there was no mention of prevalence rates. In 50.9% ($n=109$) of the articles, there was no mention of any form of treatment for the illness. A total of 19.4% ($n=42$) of the headlines mislabeled the name of the illness.

Discussion—Based on descriptive statistics of all 214 coded articles, media communicated mixed messages for salient variables such as the name of the illness, its etiology and treatment.

Keywords

Chronic fatigue syndrome; myalgic encephalomyelitis; content analysis

Modern society is increasingly dependent on mass media as a source for information on health and medical issues. Some political science scholars^{1,2} have compared the mechanism of contemporary mass media to that of a “conveyor belt,” transmitting the views and opinions of a select few who hold power over the passively receptive public. As a result, this transmission of knowledge and power from media gatekeepers has the potential to affect public perceptions in political, medical and scientific domains.³ Given the controversies that surround myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS), illnesses

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Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

rife with opposing views on prevalence, etiology, diagnosis, and name, mass media may play an especially significant role in the public's perceptions of ME and CFS.

For over 30 years, ME and CFS have retained a controversial presence in the media. For instance, when there was an outbreak of CFS in Lake Tahoe, Nevada during the mid-1980s, it became a cover story for a popular magazine called *Hippocrates*.⁴ The title of the feature was "Raggedy Ann Syndrome," which seemingly dismissed fatigue and weakness as core symptoms felt by those afflicted. This was not an isolated incident. Early epidemiologic studies, which relied upon flawed sampling methods, found the illness to primarily occur in middle- to upper-class white women, which led to use of the stigmatizing term "yuppie flu" to describe CFS.⁵ This marks a clear instance of the "conveyor belt" phenomenon, wherein highly reputable outlets like *Newsweek* and *The Washington Post* wrote pieces with stigmatizing headlines such as "Yuppie Flu – The Fatigue That Never Ends."⁶ These headlines were then recycled by several other media outlets, thus influencing public opinion of the illness, perpetuating the notion that people with CFS are weak-willed or suffering from psychosomatic illness.

Since its first media coverage, CFS has been socially constructed as an illness of the mind, psychogenic in its etiology. The name chronic fatigue syndrome has had a controversial history since its coining by the Centers for Disease Control and Prevention in 1988. A recent study demonstrated that 96% of surveyed participants disliked the name CFS, and that 55% preferred myalgic encephalomyelitis (ME),^{7,8} which had been used in the UK since 1956.⁹ This is analogous to multiple sclerosis in its infancy, when it was termed "hysterical paralysis" brought on by "oedipal fixations," until subsequent investigations found it to be an immunological disease.¹⁰

Despite more sophisticated methods exploring ME and CFS as organic illnesses, with many biomarkers being investigated,^{11–13} stigma remains a prominent issue for individuals with this illness. Patients with ME and CFS often experience negative encounters with healthcare providers, during which they are met with skeptical attitudes and psychiatric treatment suggestions such as antidepressants and cognitive behavioral therapy (CBT).^{14,15} Even with ongoing immunological, viral, and pharmacological lines of research, there remains debate among healthcare providers over whether it is "all in the patient's head" resulting in an ongoing struggle for the illness to obtain mainstream legitimacy.^{16,17} Most recently, the American Psychiatric Association has grouped CFS, now sometimes called systemic exertion intolerance disease, with other Somatic Symptom Disorders like fibromyalgia.¹⁸ In contrast, the National Institutes of Health (NIH) published a position paper in 2015 which states that ME and CFS are not primarily psychological in nature, and argued for increased biological research.¹⁷ While controversy remains around the etiology of ME and CFS, the trend of both research and NIH funding point toward a building consensus for these illnesses to be considered organic rather than psychosomatic as evidenced by the Institute of Medicine's recent comprehensive report on these illnesses.¹⁹ Such mixed messages coming from various academic fields will inevitably lead to mixed messages in the media, as evidenced in Knudsen and colleagues' content analysis.²⁰

Knudsen and colleagues analyzed the content of Norwegian news articles specifically looking at the valence associated with different kinds of CFS treatments.²⁰ Treatments were categorized into either evidenced-based or alternative methods. Because evidenced-based treatments such as CBT imply a psychological etiology, Knudsen and colleagues were interested if such treatments would be reported in a negative light. Their analysis showed 22.1% of news articles that mentioned graded exercise therapy (GET) and CBT portrayed them negatively. However, Knudsen and colleagues only examined articles within a brief timeframe, from 1 January 2008 to 31 August 2009, and only investigated attitudes toward CFS treatments. Thus, there is need for a broader analysis of how ME and CFS have been depicted in the media over time.

Using a content analysis approach, the present study sought to examine how newspaper articles have portrayed ME and CFS across time, and to consider the extent to which this portrayal may impact ME- and CFS-related stigma. We hypothesized that newspaper articles would predominantly portray ME and CFS as psychogenic illnesses, recommend psychiatric treatments, discuss psychiatric comorbidities, refer to the illness as CFS, refer to the Fukuda criteria²¹ as the case definition for the illness, suggest that the illness affects about 1 million US adults, and predominantly utilize quotes or paraphrased opinions of researchers.

Method

We conducted a content analysis of U.S. newspaper articles from 1987 to 2013, an approach described as a quantitative analysis of qualitative data.²² This approach codes text data into explicit qualitative categories, which sought to capture the current scientific climate of the field, and is then described statistically. With this methodology, we intended to concisely show how print media has portrayed this illness over time, and to consider the extent to which this portrayal may impact ME- and CFS-related stigma. The timeframe was chosen because 1987 was the year in which the Lake Tahoe outbreak began to garner mass media attention, signaling the first instance of CFS in the American press. This timeframe also yielded a large enough sample size to examine the totality of American press coverage of ME and CFS, which has never been done before. Lastly, we were able to capture changes in the evolving field of ME and CFS (e.g. illness name, case criteria used).

Search

Using the digitized LexisNexis® Academic archive, we collected newspaper articles from national, regional, and local newspapers. The search string included various names and classifications of the illness: “Chronic Fatigue Syndrome,” “Myalgic Encephalomyelitis,” along with their associated abbreviations “ME” and “CFS.” This sampling technique used broad keywords to retrieve as many articles as possible, allowing for the most thorough analysis. Duplicate articles were discarded along with any articles that came up in the search but were not relevant to the field of ME and CFS.

Coding

A codebook with several variables was developed and applied to each article. Like the Norwegian analysis,²⁰ this study coded for suggested treatments. However, other variables

specific to the subject of ME and CFS were also coded for. These variables were derived from the authors' collective expertise on and understanding of disagreements within current research and advocacy circles and included the etiology of the illness (e.g. psychogenic or organic); any comorbidities mentioned (e.g. depression, fibromyalgia); which diagnostic criteria were used to classify the illness; what treatments were recommended (e.g. CBT, GET, or alternative medicines); what the article cited as the current prevalence of the illness; mentioning of the label myalgic encephalomyelitis (ME); and what illness label the article primarily used. Lastly, variables such as what news organization the story came from, and who was quoted, referenced, or paraphrased, were influenced by standard content analysis methods.²³ The codebook is included as Appendix 1.

There were a total of four coders who independently read and coded articles. Each article was coded by at least two different coders to establish inter-rater reliability. The inter-rater reliability for all items was assessed with Cohen's Kappa.²⁴ For all items, Cohen's Kappa achieved respectable levels ($.68 < \text{Kappa} < .96$).

Results

A total of 214 articles met our inclusion criteria. Below is a descriptive report of the variables coded for.

Illness label

CFS was the primary label used for the illness, which appeared in 93.9% ($n=201$) of the articles. The next most coded for label was Chronic Fatigue, found in 3.3% ($n=7$) of the articles. A total of 1.4% ($n=3$) of the articles used the label ME/CFS. Only one article explicitly called the illness "ME," though the term myalgic encephalomyelitis was mentioned in 12.6% of the articles ($n=27$). The label Chronic Fatigue Immune Dysfunction Syndrome was used in one article.

Etiology

The etiology of the illness was portrayed as organic in 64.5% ($n=138$) of the articles. Mentions of both psychogenic and organic etiologies appeared in 22.4% ($n=48$) of the articles. Only 2.8% ($n=6$) of the articles portrayed the illness as strictly psychogenic. Etiology was not mentioned at all in 10.3% ($n=22$) of the articles. When coding for etiology, coders operationalized an organic portrayal as an article that did not mention or disputed a psychological cause of illness or psychological treatments for the illness, and instead characterized ME and CFS as diseases, focusing on symptomatology and objective, biological testing. In contrast, an article was coded as a psychogenic portrayal if it emphasized a psychological cause of illness and psychological treatments, and did not mention or disputed ME and CFS as diseases with an organic root.

Case definition

There was no mention of any case definition or diagnostic criteria in 56.1% ($n=120$) of the articles. Vague mentions of symptomatology (e.g. "six or more months of fatigue") were found in 25.2% ($n=54$) of the articles. The Fukuda case definition²¹ appeared in 13.6%

($n=29$) of the articles. The Holmes criteria (1988)²⁵ were mentioned in 4.7% of the articles ($n=10$). The Canadian criteria²⁶ were mentioned once.

Comorbidity

The most common comorbidity mentioned was depression, which appeared in 22.9% ($n=49$) of the articles. Fibromyalgia was mentioned as a comorbidity in 8.9% ($n=19$) of the articles. Various allergies such as to mold were reported in 5.6% ($n=12$) of the articles. Anxiety was mentioned as a comorbidity in 4.2% ($n=9$) articles. Chemical sensitivities were mentioned in 2.3% ($n=5$) of the articles.

Prevalence

In 55.6% ($n=119$) of the articles, there was no mention of prevalence among the general population. An estimated prevalence of one million people was mentioned in 17.3% ($n=37$) of the articles. “Over one million people with the illness” was mentioned in 13.1% ($n=28$) of the articles. Less than one million people were estimated to have the illness in 11.2% of the articles ($n=24$). Lastly, 2.8% ($n=6$) reported that the prevalence of the illness is unknown.

Treatment

In 50.9% ($n=109$) of the articles, there was no mention of any form of treatment for the illness. The most common treatments mentioned were alternative and holistic treatments (e.g. nutrient therapy and meditation), which were found in 12.1% ($n=26$) of the articles. Antidepressants were mentioned as a method of treatment in 11.7% of the articles ($n=25$). Antiviral treatments were mentioned in 8.4% ($n=18$) of the articles. CBT was mentioned in 5.6% ($n=12$) of the articles. GET was mentioned in 4.2% ($n=9$) of the articles. Counseling and or psychotherapy was mentioned in 2.8% ($n=6$) of the articles. Lastly, pacing was mentioned in 2.3% ($n=5$) of the articles.

Persons quoted

In 34.1% ($n=73$) of the articles, a researcher was directly quoted in the article. In 26.2% ($n=56$) of the articles, a patient was directly quoted. In 15% ($n=32$) of the articles, a clinician was quoted. A patient advocate (usually a family member) was quoted in 11.7% ($n=25$) of the articles. Government officials were quoted in 4.7% ($n=10$) of the articles. Lastly, caretakers were quoted in 2.8% ($n=6$) of the articles.

Headlines

A total of 19.4% ($n=42$) of the headlines were coded as stigmatizing or trivializing (see Table 1). Forty of these headlines mislabeled the name of the illness (e.g. chronic fatigue, fatigue, Yuppie Flu) and these were coded as trivializing. Two additional headlines that utilized the correct label of CFS were also coded in this section as being potentially stigmatizing or trivializing due to an emphasis on the word “tired.”

Discussion

This is the first study in which American newspaper articles were analyzed for their portrayal of the controversial illnesses ME and CFS. American media has great potential to

influence the opinions of the general population, which means uncritical reporting on chronic illness may contribute to stigma and other harms for individuals with the illness.

Our hypothesis that newspaper articles from 1987 to 2013 would predominantly portray ME and CFS as psychogenic illnesses was not supported by the data. The illness was most frequently constructed as having an organic etiology, yet 22% of the articles did mention the possibility of both psychological and organic causes. Based on this finding, it is conceivable that laypeople who are trying to understand this complex illness will have a difficult time doing so given the mixed messages found in media reports.

The hypothesis that CFS would be the most widely used label among the articles was supported by our findings; meanwhile, the term ME was only mentioned in 12.6% of our sample. This is an important finding, as the name of an illness has been found to affect how it is perceived. One study involving medical students found that students more often attributed physiological causes to ME while the name CFS was perceived to be psychogenic, thus not requiring medical attention.²⁷ This finding demonstrates that ME, the label preferred by patients and more likely to be attributed to physical causes, has been left out of the print media's portrayal of this illness.

The treatments suggested in the articles represent another limitation of print media reports on ME and CFS. While our hypothesis that psychological treatments such as CBT and other forms of psychotherapy would be most often suggested in the media was not supported, over 50% of the articles mentioned no treatment altogether. That the treatments most often cited were alternative and complementary medicines (e.g. vitamins, meditation, holistic remedies) could further alienate the illness from the mainstream medical community.

We hypothesized that the Fukuda criteria²¹ would be the most prominent case definition cited and this was supported by the data. However, the majority of the articles did not mention any case definition and many times alluded to vague symptomatology, mainly, "a requirement of six or more months of fatigue." Because 15–25% of people in America experience brief periods of fatigue,²⁸ alluding to it as the primary symptom may downplay the illness.²⁹ This portrayal does not highlight other debilitating symptoms such as post-exertional malaise and neurocognitive difficulties, symptoms which most of the general population do not experience in their lifetime.³⁰ Further, the most common co-morbidity mentioned in the articles was depression. While many people with chronic illnesses may eventually go on to develop some depressive symptoms, rarely is depression so often cited as being an important feature of a chronic illness. Due to vague case definitions and overly inclusive diagnostic criteria, people with primary affective conditions may be improperly diagnosed with ME and CFS, but it does not follow that depression is more common in ME and CFS than in other illnesses such as cancer or multiple sclerosis.³¹

There have been epidemiologic studies of ME and CFS which estimate a prevalence of greater than 800,000 Americans.^{32,33} However, the majority of articles did not mention any prevalence rates for ME and CFS. The data supported our hypothesis that articles that mentioned prevalence would estimate around one million people.

Lastly, no hypotheses were made about the content of the headlines as it was an exploratory variable. Eye tracking studies^{34,35} suggest that headlines are an important feature to be analyzed in content analyses, given when people are reading they spend the majority of their time on headlines. Almost 20% ($n=42$) of the headlines in the present study mislabeled the illness by only referencing the word “fatigue,” which patients may construe to be trivializing the condition, because there are many more debilitating symptoms aside from fatigue. The stigmatizing phrase “Yuppie Flu” was also used in four of the headlines; such inaccurate headlines should be avoided to prevent propelling the social construction of ME and CFS as modern day hysterias.

While outside the scope of this analysis, in October 2015, several similar headlines appeared in major UK publications referencing a follow-up study to the PACE Trial.³⁶ The headlines construed ME and CFS as psychogenic illnesses, which can be conquered by positive thinking and exercise. *The Daily Mail*³⁷ wrote the following headline: “ME can be beaten by taking more exercise and positive thinking, landmark study claims”; *The Telegraph*’s³⁸ headline was: “Chronic Fatigue Syndrome sufferers ‘can overcome symptoms of ME with positive thinking and exercise’.” We felt this was necessary to mention as the field of ME and CFS to this day remains a contentious topic within the scientific community, and this is reflected in such headlines as well as in the critical response, as evidenced by a headline in *The Guardian*,³⁹ “Chronic fatigue sufferers need help and more research- not misleading headlines.” Ironically, this headline encompasses both a move forward for print media, yet still utilizes the inappropriate label of “chronic fatigue.”

The main strength of this study was its breadth. Covering a 26-year-span provided a window through which to interpret the evolution of reporting on ME and CFS as complex, chronic illnesses. However, this study also has limitations. First, blogs and other online magazines, which produce a large portion of American media content, did not make it into our sample, as we kept to print media. That our search strategy involved using only one database, Lexis Nexis Academic, is another limitation. Using the same search string may produce a different sample of articles from which to code depending on what archive is being used. Another potential limitation was the codebook, which perhaps limited the scope of the analysis. Other variables may have been left out, such as the valence of certain variables. For instance, if a certain treatment or comorbidity is mentioned, what is the tone in which it is brought up? Lastly, there was no comparison disorder. The present study cannot compare whether media coverage of ME and CFS is any more mixed and protean than other stigmatized illnesses, such as HIV or chemical dependency. Future content analyses of chronic illnesses in the media should try to compare illnesses to one another.

In summary, our results indicate that media coverage of ME and CFS remains controversial. Where articles portray the illness as biological and worthy of medical attention, others invoke psychogenic etiologies and recommend psychotherapy or exercise as potential treatments. The media in America holds immense power over public opinions on health and science, and such mixed messages being present in the coverage of this illness is potentially harmful for patients and funding of future research. Authors of this study recommend that media relating to ME and CFS continue to be analyzed in future studies.

Acknowledgments

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Funding was provided by the National Institute of Allergy and Infectious Diseases (grant number AI105781) and the Eunice Kennedy Shriver National Institute of Child Health and Human Development (grant number HD072208).

Appendix 1.: ME and CFS content analysis coding protocol

1. **News organization & date of publication:** This variable refers to the name of the newspaper the article appeared in and the year of publication.
2. **Individuals quoted in story:** This variable refers to who is quoted within the story, and how many words are quoted. Multiple categorizations possible.
 - a. **Category of individual:**
 - i. Researcher
 - ii. Clinician
 - iii. Patient
 - iv. Patient advocate
 - v. Caretaker
 - vi. Government official
 - vii. Other
 - b. **No. of words quoted:** Numeric
3. **Individuals referenced or paraphrased:**
 - a. **Category of individual:**
 - i. Researcher
 - ii. Clinician
 - iii. Patient
 - iv. Patient advocate
 - v. Caretaker
 - vi. Government official
 - vii. Other
 - b. **No. of words written:** Written
4. **Etiology:** This variable refers to how the article portrays the etiology of the illness
 - i. Psychogenic

- ii. Organic
 - iii. Both
- 5. **Comorbidity:** This variable refers to any other illnesses mentioned as commonly occurring with the illness
 - i. Fibromyalgia
 - ii. Multiple Chemical Sensitivities
 - iii. Depression
 - iv. Allergies
 - v. Anxiety
- 6. **Case definition:** This variable refers to what case definition the article refers to
 - i. Fukuda
 - ii. Holmes
 - iii. Empiric
 - iv. Canadian
 - v. ME
 - vi. Vague diagnostic
- 7. **Treatment:** This variable refers to any treatments recommended in the article
- 8. **Prevalence:** This variable refers to what the article reports as the prevalence in the US of the illness
 - i. Numeric (xxx people in the USA)
 - ii. Percentage (x.x% of the US population)
- 9. **Use of ME language:** This variable refers to whether or not the term ME, either Myalgic encephalomyelitis or encephalopathy, is mentioned
 - i. Yes
 - ii. No
- 10. **Focus:** This variable refers to the focus of the article
 - i. Discussing new study
 - ii. General interest
 - iii. Personal story
 - iv. Community event
- 11. **Illness Label:** This variable refers to what the illness is primarily referred to as in the article
 - i. CFS

- ii. ME/CFS
- iii. ME
- iv. CFIDS
- v. CF

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Table 1.

Headlines coded as *stigmatizing* ($n = 42$).

Headline	Year
Fatigue ‘Virus’ Has Experts More Baffled and Skeptical Than Ever	1987
Chronic Fatigue Gets a More Precise Definition	1988
Yuppie Flu linked to depression; UW researchers rule out virus as culprit	1990
Depression, not virus, causes fatigue	1990
Muddle over cause of chronic fatigue	1990
Research again finds no link between virus, chronic fatigue; Epstein-Barr appears absolved...	1990
Scientists report link between virus, “Yuppie Fatigue”	1990
Experts Unable to Link Chronic Fatigue to Virus	1991
Fatigue Disorder Linked to Immune Response Overactive T-cells may cause syndrome	1991
Researchers Fail to Trace Fatigue Syndrome to Viruses	1991
Virus, chronic fatigue disorder may be linked	1991
Yuppie Flu-The Fatigue That Never Ends	1991
Chronic Fatigue’s Prevalence Debated	1992
Chronic Fatigue still eludes defining	1993
Chronic fatigue frustrating	1993
Yuppie Flu Not to Be Laughed at But Recognized	1994
Chronic Fatigue Finds Its Way to the Young	1994
Chronic Fatigue Sufferers Have Overactive Immune Systems	1994
Virus Tied to Chronic Fatigue; Testing of a Possible Cure for the Syndrome Could Begin ...	1994
Blood Pressure Disorder Tied to Chronic Fatigue	1995
Chronic Fatigue Changes Lives; Noted Expert on the Illness Addresses Exeter Audience	1995
Chronic Fatigue Sufferers Going Public	1995
Medication, Salt May Combat Chronic Fatigue	1995
Victims Can Get Chronic Fatigue Help	1996
Sick & Tired	1996
Chronic Pain, Chronic Fatigue, Chronic Mystery	1997
A Doctor Tackles the Mysteries of Fatigue	1999
Chronic fatigue is a real problem for many	2004

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Headline	Year
Expert advice: Seeing signs of chronic fatigue	2004
J&J drug won't help chronic fatigue, study says	2004
Chronic Fatigue's Genetic Component...	2006
Chronic fatigue energized by research; Awareness effort sets diagnosis straight	2006
Genetic clues found for chronic fatigue	2006
Always tired? It could be a sign of chronic fatigue syndrome	2008
Hormone levels and chronic fatigue	2008
Lifelong Health; Chronic fatigue's virus link...	2009
Chronic fatigue blood donors barred	2010
Chronic fatigue study points to retrovirus; Findings could alter approach to treatment	2010
Mouse virus may not cause chronic fatigue, study says	2010
Study links chronic fatigue to virus class	2010
One woman's battle with chronic fatigue	2013
Chronic fatigue more than just sleeping in	2013