Giving Legs to Restless Legs: A Case Study of How the Media Helps Make People Sick

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The Policy Forum allows health policy makers around the world to discuss challenges and opportunities for improving health care in their societies.

What Is Restless Legs Syndrome?

The diagnosis of restless legs syndrome requires the presence of the following four criteria [4]:

• An urge to move the legs due to an unpleasant feeling in the legs.
• Onset or worsening of symptoms when at rest or not moving around frequently.
• Partial or complete relief by movement (e.g., walking) for as long as the movement continues.
• Symptoms that occur primarily at night and that can interfere with sleep or rest.

The severity of disease is judged by the frequency of these symptoms, which can range from less than once a month to many times a day. Recommended treatments include stretching exercises and less caffeine for intermittent disease and various prescription drugs (e.g., benzodiazepines and dopamine agonists) for daily symptoms [5].

The Case of Restless Legs Syndrome

To get a sense of how the media works in the context of a major disease promotion effort, we examined news coverage of “restless legs” (see sidebar). In 2003, GlaxoSmithKline launched a campaign to promote awareness about restless legs syndrome, beginning with press releases about presentations at the American Academy of Neurology meeting describing the early trial results of using ropinirole (a drug previously approved for Parkinson disease) for the treatment of restless legs [6,7]. Two months later, GlaxoSmithKline issued a new press release entitled “New survey reveals common yet under recognized disorder—restless legs syndrome—is keeping Americans awake at night.”

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Abbreviation: FDA, Food and Drug Administration

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### Key Elements of Disease Mongering and How the Media Could Do Better

| Key Elements of Disease Mongering | When the Media Can Get Co-opted | Suggestions for Doing Better |
|-----------------------------------|---------------------------------|------------------------------|
| **Exaggerate the prevalence of disease** | Uncritically accepts disease definition. | Learn exact definition of disease and question whether it is appropriately specific. Determine whether the prevalence estimate is credible: Are the “gold standard” diagnostic criteria being used as designed? Does the sample truly represent the general population? |
| Create a broad disease definition based on vague and prevalent symptoms. | Uncritically repeats a broad prevalence estimate. | |
| Publicize a large prevalence estimate. | Highlights the important physical, social, and emotional consequences of severe disease; only telling anecdotes of people with very severe disease. | Be clear about the spectrum of disease. When describing important consequences or personal anecdotes, provide the appropriate prevalence estimate by stating proportion with disease this severe. |
| Blur the distinction between mild and severe disease. | |

**Encourage more diagnosis**

| Highlight that doctors fail to recognize disease. | Quotes an “expert” about how doctors miss the diagnosis; provides anecdotes of people whose diagnoses were missed. | Acknowledge the problems of overdiagnosis (e.g., downside of labeling people with disease or medicalizing healthy people). |

**Encourage people to see themselves as sick.**

| Presents anecdotes or descriptions of people who are unaware that they are sick; encourages self-diagnosis (e.g., symptom checklist). | Same as above. |

**Promote disease awareness** (e.g., disease awareness week, screening clinics, support groups, disease foundations).

| Publicizes disease awareness activities without noting industry involvement (e.g., “nonprofit” foundation). | Learn and state whether disease awareness activities are industry sponsored. |

**Suggest that all disease should be treated**

| Exaggerate the benefits of the drug for everyone with disease. | Overstates the benefit by providing only qualitative descriptions (e.g., only stating “significant improvement” or telling stories of dramatic benefit). | Objectively report benefit by quantifying how well the drug works (e.g., present the proportion with clinically important symptom improvements in the drug and comparison group). Be clear about the populations studied (i.e., acknowledge that the benefit is much smaller for people with mild disease). |
| | Overstates the benefit by using miracle language to describe the benefit. | Avoid miracle language. |
| | Overstates the benefit by quoting a strong claim of benefit from researchers with strong industry ties. | Learn and state industry ties of researchers who make strong claims about a drug’s benefit. |
| | Minimizes the harms by not mentioning the possibility of them or by only telling stories of people who did not experience any harms. | Quantify side effects (e.g., present the proportion with side effects in the drug and comparison group). |
| | Ignores concerns about duration of clinical trials (e.g., not mentioning length of follow-up). | Caution readers that although treatment is generally long term, the longest study was x weeks. So, the long-term benefits and harms are unknown. |

**Uncritically accepts disease definition.**

| |

**Learn exact definition of disease and question whether it is appropriately specific.**

| |

**Determine whether the prevalence estimate is credible:** Are the “gold standard” diagnostic criteria being used as designed? Does the sample truly represent the general population? |

**Learn and state industry ties of researchers who make strong claims about a drug’s benefit.**

| |

**Quantify side effects (e.g., present the proportion with side effects in the drug and comparison group).**

| |

**Be clear about the spectrum of disease.** When describing important consequences or personal anecdotes, provide the appropriate prevalence estimate by stating proportion with disease this severe. |

**Exaggerate the prevalence of disease**

Table 1. Key Elements of Disease Mongering and How the Media Could Do Better

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**Newspaper Coverage of the Restless Legs Syndrome**

To identify media coverage related to this campaign over two years (November 2003–November 2005), we did full-text searches of “major newspapers” in Lexis-Nexis and ProQuest databases and found 187 unique articles with the phrase “restless legs.” We excluded articles not about the syndrome (e.g., “Elvis’s restless legs”), nonnews stories (e.g., health advice columns, notices of restless legs health screenings/support groups), and articles with only passing mention of restless legs (most of these were about sleep disorders, another “new yet largely unrecognized problem”). We analyzed the remaining 33 articles (all focused on restless legs syndrome) using an explicit coding scheme organized around the key elements of disease mongering, as outlined in the first column of Table 1: exaggerating the prevalence of the disease (e.g., uncritically accepting a broad prevalence estimate), encouraging more diagnosis (e.g., doctors fail to recognize it), and suggesting that all disease should be treated (e.g., overstating the benefits or minimizing the harms of treatment).

**Exaggerating Disease Prevalence**

Figure 1 shows that the news articles often included elements exaggerating disease prevalence. Only one article questioned the disease definition at all (and portrayed the act of questioning the definition as insensitive: “[the patient] knows it can sound trivial. That’s one of the problems with restless legs. Radio show host Rush Limbaugh, for example, has mocked it as a pseudoillness” [10]).

Almost two-thirds of articles provided an estimate of disease prevalence (most commonly, statements such as “at least 12 million Americans suffer from the syndrome” [11] or “it affects 1 in 10..."
adults in the United States” [12]). No article questioned the validity of the prevalence estimates. In fact, there are reasons to believe the estimates overstate the prevalence of clinically meaningful disease. For example, the frequently cited 10% estimate came from a study that used a single question to identify restless legs syndrome rather than the four standard criteria [13]. The less stringent definition inflates the estimate because people with other causes of leg symptoms (e.g., leg cramps or diabetic neuropathy) are counted incorrectly as having the syndrome.

In a recent large study, only 7% of respondents reported all four diagnostic criteria, and only 2.7% reported moderately or severely distressing symptoms two or more times per week (i.e., the group for whom medical treatment might be appropriate) [14]. Even the 2.7% estimate is probably too high, because of bias inherent in the study sample. The authors claimed an implausible 98% response rate to their random-digit dial survey (typical response rates are 50%–70% [15]). Most likely, the authors meant that 98% of individuals who agreed to participate completed the survey. But respondents agreeing to participate in a restless legs study are more likely to have leg-related symptoms than nonrespondents.

Nearly three-quarters of newspaper articles highlighted the potentially serious physical, social, and emotional consequences of restless legs: “…the condition sounds like a joke, but its consequences can be devastating. Driven to despair by years of sleepless nights, patients have become suicidal” [16]). While over 40% of the articles provided anecdotes about people with severe disease, no article provided anecdotes about people who did not find their symptoms especially bothersome.

Encourage More Diagnosis

The articles also reinforced the need for more diagnosis. About half reported that the syndrome is underdiagnosed by physicians (“…relatively few doctors know about restless legs. This is the most common disorder your doctor has never heard of” [17]) and underrecognized by patients (“…many people can suffer in silence for years before it is recognized” [18]). One-quarter of articles encouraged patient self-diagnosis and suggested people ask their doctor whether restless legs might explain various problems (including insomnia, daytime fatigue, attention deficit disorder in children, and depression). One-fifth of articles referred readers to the “nonprofit” Restless Legs Foundation for further information; none reported that the foundation is heavily subsidized by GlaxoSmithKline. No article acknowledged the possibility of overdiagnosis (the idea that some people will be diagnosed unnecessarily and take medication they do not really need).

Suggest That All Disease Should Be Treated

About half the news stories mentioned the drug ropinirole by name. Only one story quantified the drug’s benefit. By contrast, about half the stories mentioning ropinirole included anecdotes about patients who took the drug (and in most cases noted substantial improvement). One-third of articles used “miracle language” to describe patient response to medication (e.g., “it has been a miracle drug for me” [19]). The actual benefit of the drug is modest. The drug label reports that in a 12-week US clinical trial, restless legs symptom scores (measured on a 40-point scale) improved by 13.5 points for patients taking ropinirole compared with 9.8 points for those taking placebo [20]. In more clinical terms, 73% taking ropinirole responded to the drug (i.e., restless legs scores improved by six points) compared with 57% taking placebo.

The drug label [20] also notes that ropinirole has a number of side effects, including nausea (40% in ropinirole group versus 8% in placebo group) and dizziness (11% versus 5%, respectively). Somnolence and fatigue (ostensibly, the real target of the drug) were also higher in the ropinirole versus the placebo group (12% versus 6%; 8% versus 4%, respectively). Nonetheless,
only five of the 15 articles mentioning ropinirole noted that it could have side effects and just one quantified the chance of any side effect (“nausea was the most common side effect, reported in 38% of patients” [18]). Finally, only one news story noted that the ropinirole trials were “relatively short” in duration (the longest was 36 weeks), despite the fact that many people would use the drug for years or even a lifetime.

Suggestions for How the Media Could Do Better

Unfortunately, there is no obvious way to distinguish information from infomercial. In Table 1, we highlight clues that should alert journalists to the presence of disease mongering, and suggest some things they can do to expose these efforts.

First, journalists should be very wary when confronted with a new or expanded disease affecting large numbers of people. If a disease is common and very bothersome, it is hard to believe that no one would have noticed it before. Prevalence estimates are easy to exaggerate by broadening the definition of disease. Journalists need to ask exactly how the disease is being defined, whether the diagnostic criteria were used appropriately, and whether the study sample truly represents the general population (e.g., patients at an insomnia clinic cannot be taken to represent the general public).

Journalists should also reflexively question whether more diagnosis is always a good thing. Simply labeling people with disease has negative consequences [21]. Similarly, journalists should question the assumption that treatment always makes sense. Medical treatments always involve trade-offs; people with mild symptoms have little to gain, and treatment may end up causing more harm than good.

Finally, instead of extreme, unrepresentative anecdotes about miracle cures, journalists should help readers understand how well the treatment works (e.g., what is the chance that I will feel better if I take the medicine versus if I do not?) and what problems it might cause (e.g., whether I might be trading less restless legs for daytime nausea, dizziness, and somnolence).

Conclusion

The news coverage of restless legs syndrome is disturbing. It exaggerated the prevalence of disease and the need for treatment, and failed to consider the problems of overdiagnosis. In essence, the media seemed to have been co-opted into the disease-mongering process. Although our review was limited to the coverage of a single disease promotion campaign, we think it is likely that our findings would apply to others. It is easy to understand why the media would be attracted to disease promotion stories and why they would be covered uncritically. The stories are full of drama: a huge but unrecognized public health crisis, compelling personal anecdotes, uncaring or ignorant doctors, and miracle cures.

The problem lies in presenting just one side of the story. There may be no public health crisis, the compelling stories may not represent the typical experience of people with the condition, the doctors may be wise not to invoke a new diagnosis for vague symptoms that may have a more plausible explanation, the cures are far from miraculous, and healthy people may be getting hurt.

We think the media could report medical news without reinforcing disease promotion efforts by approaching stories like “restless legs” with a greater degree of skepticism. After all, their job is to inform readers, not to make them sick.

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