



## Staying Positive:

Women's illness narratives and the stigmatized vernacular

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## Abstract

This article uses the stigmatized vernacular (Goldstein & Shuman, 2012) as a conceptual framework for examining the public construction and reception of women's illness narratives. I begin by making the case that personal illness narratives – a genre that works to translate the subjective illness experience to a public audience – are rich sites for exploring how discourses of veneration and repudiation can become inextricably intertwined. Discussing illustrative examples of the construction and reception of women's illness narratives shared in contexts of breast cancer and fibromyalgia, I show how popular understandings of emotions, particularly *positive* emotions like happiness, play a major role in the regimes of value shaping how women's illness experiences become tellable or untellable, and thereby valued or devalued. Integrating scholarship on illness narratives, stigma, and happiness, I aim to contribute to a richer and more multifaceted view of the illness narrative genre and the discursive contagion of stigma.

**Keywords:** *illness narrative; emotion; breast cancer; fibromyalgia; stigmatized vernacular*

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### I. Introduction

In a recent special issue of the *Journal of Folklore Research* entitled “The Stigmatized Vernacular: Where Reflexivity Meets Untellability,” editors Diane Goldstein and Amy Shuman introduce “the stigmatized vernacular” as a useful conceptual framework for studying stigmatized individuals and communities.<sup>1</sup> They explain, “The phrase the stigmatized vernacular is intended to capture not only the emic experience of stigmatization, but also the contagion of stigma—the way it spills over beyond the topic into the means of articulation” (2012, 116). Grounding this concept within folklore studies, a discipline that focuses attention on the perspectives of the people being studied and the aesthetic and expressive resources at their disposal for sharing these perspectives, they offer the stigmatized vernacular as an analytical tool for attending to the vernacular experience of the stigmatized, the performance of stigma, and the process of stigmatization (2012, 116).

As part of their introduction, Goldstein and Shuman identify a dialectic relationship between the *stigmatized* and the *venerated* vernacular, highlighting the importance of looking at the “relationship between vernacularity and value” (2012, 117). By vernacularity, they refer to the contrasts invoked by the idea of the vernacular, including high and low culture, expert and lay knowledge. Amy Shuman and Carol Bohmer elaborate on this relationship between vernacularity and value later in the same special issue, noting that “the study of the stigmatized vernacular is part of a tension between the repudiated and the celebrated” (2012, 201). They continue, “The repudiated and the venerated rarely exist in isolation; rather, they are connected to each other through processes of valuation, devaluation, and revaluation” (Shuman & Bohmer, 2012, 201). In essence, both discourses can play a role in marginalizing groups and individuals by marking them as “other.”

Since folklorists often collect and analyze narratives to better understand the perspectives of the people they study, Goldstein and Shuman also draw from narrative scholarship to bring the study of the stigmatized vernacular in conversation with the concept of tellability (Labov, 1972; Sacks, 1992). Identifying tellability as a crucial requirement for competent narration, they explain how it “addresses audience expectations, newsworthiness,

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<sup>1</sup> As they note in their introduction, over a period of several years, a number of linked panels at the American Folklore Society Meetings have been organized under the title “The Stigmatized Vernacular.” This special issue grew out of one of these panels. Goldstein and Shuman situate this special issue, the first publication dedicated to this topic, as just one part of this ongoing multi-layered conversation currently taking place within the field of folklore studies.

uniqueness, relevance, importance, and humor but also—and perhaps just as centrally—appropriateness, contextualization, negotiation, mediation, and entitlement” (2012, 119). Thus, when working with stigmatized individuals and communities, it behooves us to pay attention to how *they* articulate their understandings of what is tellable and untellable, as well as how they negotiate these categories in their presentation of self. Understanding how certain narratives and experiences get marked as *untellable* can offer further insight into, in the words of bell hooks, who is deemed “worthy to speak and be heard” (1992, 176; cited in Goldstein and Shuman 2012, 120) and, by extension, the process of stigmatization.

While Goldstein and Shuman direct their introduction of the stigmatized vernacular primarily to an audience of folklorists, they make clear that the issues central to it are not just relevant to the discipline of folklore studies; rather, they see their introduction, and the rest of the articles in that special issue, as “opening up a conversation broader than the discipline” (2012, 123). Building upon this foundational work on the dynamics of valuation/devaluation and tellability/untellability in contexts of stigma, this article uses the stigmatized vernacular as a conceptual framework for looking at the public construction and reception of women’s illness narratives. I begin by offering an overview of the genre of illness narratives more broadly, calling attention to the dialectical discourses of celebration and repudiation shaping how they are composed and how they are heard/read. In the process, I will make the case that personal illness narratives – a genre that works to translate the subjective and emotional aspects of the illness experience to a public audience – are productive sites for examining the interrelationships between emic perspectives of stigmatization and the discursive contagion of stigma.

As part of this discussion, I will highlight the rhetorical work accomplished around discourses of emotion. According to Geoffrey M. White, “Discourse-centered definitions of emotions have the effect of decoupling emotions from their essential interiority, broadening the focus of emotional research to include the public arenas of communicative action and shared understanding” (1993, 31). This broader focus allows us to move beyond psychological and cognitive understandings of emotion to see how talk about emotion can work “to create or reproduce social identities and relationships” (White 2000, 39).<sup>2</sup> In particular, I will focus on how gendered understandings of emotions (Lutz 1990), particularly *positive* emotions such as happiness, play a major role in how women’s illness narratives – and by extension women’s experiences of illness – are deemed to be tellable or untellable by others. This attention to positive emotions differs from much of the recent work on illness and emotion, which has looked more at experiences of emotional distress – depression, anxiety, fear, frustration, and anger – and its causes (e.g., Dow et al., 2012; Lavie-Ajayi et al., 2012; Ryan & Räisänen, 2012). While it will become clear that discursive framings of positive emotions like happiness overlap greatly with discursive framings of emotional distress, my focus on happiness will foreground the ongoing interrelationships between the categories of the stigmatized and the venerated.<sup>3</sup> Offering illustrative examples of women’s illness narratives shared in contexts of breast cancer and fibromyalgia (and the responses they receive once they enter the public realm), I aim to show how the analytical framework of the stigmatized vernacular makes visible some of the regimes of value influencing the construction and reception of these narratives.

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<sup>2</sup> See also the work of Derek Edwards, who similarly points to the importance of recognizing “the rhetorical design and use of emotion categories” (1997, 171).

<sup>3</sup> Kirsi Hänninen (2007) also examines the intersections between emotions, personal narrative, and stigma, though her work focuses more on the narrative construction of self in contexts of stigmatization and less on the role of personal narrative in the process of stigmatization.

## II. Veneration, Repudiation, and Women's Illness Narratives

As sick individuals find themselves dehumanized and stigmatized by institutional health care and society at large, personal experience narratives provide an outlet through which they can assert their sense of self, and experience offers the authoritative grounding of these narratives. In the second edition of her study of pathographies, personal accounts of illness, Anne Hunsaker Hawkins uses the concept of experience to draw explicit connections between the domain of identity politics and the domain of illness:

Lifewritings give voice to the voiceless and insist that this voice be heeded, hence the importance attached to autobiographies of women or African Americans, present and past. Such writing focuses attention on groups who have been marginalized or oppressed, articulates not only their special experience but also their special values and perspective, and reminds us of what they contribute to the culture as a whole...In much the same way, though on a smaller scale, pathography gives voice to the patient and calls attention to the importance of his or her experience. (1999,189)<sup>4</sup>

When personal narratives are shared in contexts of illness in particular, speaking (or writing) from experience provides individuals a way to contest potential stigmas attached to their illness and assert identities beyond that of their sick bodies.

The sharing of personal narratives always occurs as part of a rhetorical project, whether these stories are meant to construct a coherent sense of self to oneself or to others (Becker 1998; Linde 1993) or to “moralize the events they recount and seek to convince others to see some part of reality in a particular way” (Mattingly and Garro 2000:11).<sup>5</sup> “Narrative,” Byron Good writes,

[...] is a form in which experience is represented and recounted, in which events are presented as having a meaningful and coherent order, in which activities and events are described along with the experiences associated with them and the significance that lends them their sense for the persons involved. But experience always far exceeds its description or narrativization. (Good, 1994,139).

Personal experience narratives should not be read, then, as pure reflections of the experiences they recount. Sharing narratives is rather a process of reduction and translation, whereby one's experiences can take tangible form to become accessible to others. Viewing personal narratives in this way, we become equipped to examine critically what kind of work these narratives accomplish through their telling.

The personal illness narrative has become a recognizable genre in public discourses about health and illness, found in forms ranging from brief testimonials in popular magazine articles about health to published book-length autobiographical accounts. The rise of the Internet and new media technologies has increased people's abilities to create and distribute their illness narratives, most visibly in weblogs, discussion forums, and online

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<sup>4</sup> G. Thomas Couser expresses a similar idea when he writes, “One of the most fundamental functions of illness narrative is to validate the experience of illness” (1997, 293).

<sup>5</sup> See Langellier (1989) for an overview of different approaches scholars have taken to the study of personal narratives.

support groups.<sup>6</sup> As the genre of illness narrative has become a highly visible mechanism for humanizing – and thereby honoring – the experience of sickness, it has clearly been shaped by discourses of veneration. Very often the stories gaining the most positive reception adopt heroic plotlines, forming what Arthur Frank calls quest narratives (1995), thereby connecting the structure of the narratives to the celebration of the person whose experiences are recounted.

While not using the same terms, Judy Segal has looked extensively at how these same discourses of veneration are inextricably intertwined with discourses of repudiation, focusing in particular on breast cancer narratives. Looking at the epideictic rhetoric of the genre of illness narratives, she argues that “Pathography is generically epideictic when its repeated gestures enunciate values preferring certain sorts of accounts over others but also, for the same reasons, *preferring certain sorts of experience*” (Segal 2005: 69, emphasis added). In other words, certain narratives are more tellable than others. Segal shows how breast cancer narratives do more than merely document experience; they reproduce a hierarchy of values that honor some types of experiences while delegitimizing others. Segal elaborates upon this idea in her later work, building on Barbara Ehrenreich’s critiques of a breast cancer culture where “Cheerfulness is more or less mandatory” (2001, 50), by highlighting the role of the illness narrative genre in the “brightsiding” of women’s breast cancer experiences. Bringing attention to emotion in her discussion of the genre conventions shaping the “correct” or tellable breast cancer story (and, by extension, the narrator worthy of veneration), she builds upon existing scholarship on women’s health and the gendered politics of happiness.

Feminist critiques of breast cancer culture have made some of the greatest contributions to our understanding of the relationship between women’s experiences of health and illness and the politics of happiness. Ehrenreich, for example, illuminates the central expectation of an upbeat tone in breast cancer narratives, citing the common occurrence of participants in online discussion forums expressing sentiments like “I can honestly say I am happier now than I have ever been in my life--even before the breast cancer” (2009, 28). As part of her critique, she recounts submitting a list of complaints about breast cancer under the heading “angry” on the Komen.org message board, and receiving the following responses:

- “I really dislike saying you have a bad attitude towards all of this, but you do, and it's not going to help you in the least.”
- “Barb, at this time in your life, it's so important to put all your energies toward a peaceful, if not happy, existence. Cancer is a rotten thing to have happen and there are no answers for any of us as to why. But to live your life, whether you have one more year or 51, in anger and bitterness is such a waste [ . . . ] I hope you can find some peace. You deserve it. We all do. God bless you and keep you in His loving care. Your sister, Mary.”
- “You need to run, not walk, to some counseling [ . . . ] Please, get yourself some help and I ask everyone on this site to pray for you so you can enjoy life to the fullest.”

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<sup>6</sup> By focusing on personal illness narratives shaped intentionally for public audiences, the present discussion does not address the alternate, sometimes therapeutic, functions illness narratives can serve for their tellers (Frank 1995). See Hydén (1997) for an overview of alternate approaches scholars have taken to the study of illness narratives.

Ehrenreich asserts that this expectation of a positive tone has become so pervasive, “that unhappiness requires a kind of apology, as when ‘Lucy,’ whose ‘long term prognosis is not good,’ starts her personal narrative on [breastcancertalk.org](http://breastcancertalk.org) by telling us that her story ‘is not the usual one, full of sweetness and hope, but true nevertheless’” (2009, 26).

Audre Lorde offers one of the most highly cited critiques of the *political* implications of the ideals of happiness shaping the individual experience of cancer in *The Cancer Journals*. She criticizes the expectation that being happy is the primary responsibility of the individual, and she raises questions about what political struggles are being obscured by the imperative to deny one’s anger (or other negative emotions) and to look “on the bright side of things” (1980, 74). Others engaging with the politics of happiness highlight how this expectation of positive thinking, or the “tyranny of cheer” (King, 2006, xxxiii), can be linked to cultural ideologies of “good women” (Mason, 2009). Rita Bode, for example, points to historical precedents and explains:

The breast cancer culture of cheer is unmistakably female [...] A culture of cheer hints disturbingly at the nineteenth century’s angelic and true ideal woman, who was expected to submit unquestioningly to adversity; to suppress rather than express justifiable anger [...] Following a pattern familiar in women’s history, the breast cancer culture of cheer operates as another mode of negating the full spectrum of female experience. (2010, 96)<sup>7</sup>

In other words, breast cancer culture works to make certain experiences untellable, by extension deeming certain voices as unworthy to speak or be heard.

Understanding that the “correct” (i.e., tellable) breast cancer experience is one in which the (female) patient keeps her negative emotions under control, we can begin to see that the discourses on emotion shaping the genre conventions of breast cancer narratives, like the genre of illness narrative itself, can serve as a mechanism of both celebration and stigmatization. Catherine Lutz’s (1990) work on the gendered nature of emotion in American discourse helps to make further visible the regimes of value structuring the construction and reception of women’s breast cancer narratives. According to Lutz, emotion holds two seemingly contradictory meanings in the West. One the one hand, equated with the irrational rather the rational, the chaotic rather than the ordered, the female rather than the male, emotion is seen as a dangerous force that needs to be controlled. For Lutz, “This network of associations sets emotion in disadvantaged contrast to more valued personal processes, particularly to cognition or rational thought, and the female in deficient relation to her male other” (1990, 69). On the other hand, emotion also stands in opposition to cold alienation:

Emotion, in this view, is life to its absence’s death, is interpersonal connection or relationship to an unemotional estrangement, is a glorified and free nature against a shackling civilization. This latter rendition of emotion echoes some of the fundamental ways the female has also been ‘redeemed,’ or alternatively and more positively, construed” (Lutz, 1990, 69).

The discussion of breast cancer culture above has made clear that both of the perspectives on emotion identified by Lutz shape the public perception of breast cancer narratives; narrators communicating anger or

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<sup>7</sup> Of course, breast cancer affects men as well, though it is much more common among women and is highly visible in public discourse as a “women’s disease”.

depression are seen as problematic (even dangerous), while narrators focusing on positive emotions are celebrated and normalized. Viewed within the conceptual framework of the stigmatized vernacular, these seemingly contradictory understandings of emotion, particularly the way they are gendered, help us to see a clear relationship between the veneration and repudiation of women experiencing illness.

Significantly, these seemingly contradictory meanings of emotion overlap with the meanings attributed to illness narratives in public discourse, particularly when we recognize that illness narratives are understood as a mechanism for presenting *lay*, as opposed to expert, perspectives of health and illness.<sup>8</sup> Illness narratives are seen as communicating the experiential aspects of sickness/sickness as it is experienced in everyday life/experiential ways of knowing. At the same time, it sets these subjective experiences in opposition to “expert” ways of knowing, where the expert is the physician whose work relies on transforming the body into an object to be observed, a process that depends upon stripping the body of its subjectivity and seeing how it fits within objective diagnostic criteria. Sometimes, the dichotomy between lay and expert knowledge is invoked to highlight the humanity (i.e., to value) of the patient; other times, this dichotomy is invoked to call into question (i.e., to devalue) the perspectives of the patient. Thus, the illness narrative genre and popular ideas about emotion function similarly as discursive mechanisms of both veneration and repudiation.

By approaching the genre of personal illness narrative as a resource individuals draw upon to make their experiences accessible to broader audiences, in turn opening up these experiences for evaluation, we begin see that this genre plays a key role in the process whereby women’s experiences can be either valued or delegitimized. In addition, we can see that identifying “proper” expressions of (positive) emotions, linked in turn to “proper” gendered roles, can work to value or devalue women’s experiences.

### III. From Breast Cancer to Fibromyalgia: Finding Common Ground

While so far my attempts to make visible the dialectical relationship between the veneration and repudiation of women’s illness experiences have focused on breast cancer narratives circulating in public discourse, it is important to recognize that these issues extend well beyond the specific context of breast cancer. They have certainly received the greatest attention in the existing feminist scholarship on breast cancer because of its high visibility in public discourse – in the words of Ehrenreich, “it’s the biggest disease on the cultural map” (2009, 21); at the same time, they affect women who suffer from *other* illnesses as well, including illnesses that receive far less public attention than breast cancer. At this point, then, I will turn attention to the construction and reception of illness narratives shared by individuals diagnosed with one such illness – fibromyalgia syndrome (FMS).

I have chosen to focus on fibromyalgia for several reasons. First, like breast cancer, while not exclusively affecting women, fibromyalgia is much more common among women than men. Thus, at least in public discourse, it is highly feminized.<sup>9</sup> At the same time, unlike breast cancer, there is no widespread and celebrated “fibromyalgia

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<sup>8</sup> Folklorists have done much work to disrupt the dichotomy of the categories of lay and expert, official and unofficial (Everett, 2009; Goldstein, 2000, 2004; Howard, 2008; Primiano, 1995), and I use the term “lay” here fully aware of its problematic connotations. My goal is using this term is to show some the rhetorical work that gets accomplished when such categories are invoked.

<sup>9</sup> See Kristin K. Barker’s fascinating discussion of the “present absence” of sex and gender in biomedical research on fibromyalgia (2005, 44-63).

culture,” meaning it has relatively low visibility in public discourse. Also, unlike breast cancer, fibromyalgia is a *contested* illness. This sets up fibromyalgia and breast cancer on the opposite end of the veneration/repudiation spectrum. While their experiences and identities *can* be delegitimized by telling the “wrong” kind of story, breast cancer narrators begin from a place of sympathy and, I would argue, veneration. As I discuss in more detail below, the invisibility and contested nature of fibromyalgia sometimes presents difficulties for women seeking to use the genre of the personal illness narrative as a tool for validating their illness experiences. In other words, when women with fibromyalgia share illness narratives, the tellability of these narratives are challenged on multiple fronts, including the validity of the illness itself *as an illness* as well as the tone they use in voicing their experiences. At first glance, breast cancer and fibromyalgia appear to have little in common. In following discussion, though, I aim to show how people draw on the same discursive repertoire on emotion in their attempts to assign positive or negative value to women’s experiences in contexts of both illnesses.

Fibromyalgia, not technically a disease, is a syndrome that refers to a collection of symptoms, including widespread pain, chronic fatigue, headaches, sleep disturbances, cognitive problems with thinking and memory, and irritable bowel syndrome, among others. While these symptoms vary among individuals, distinguishing features of fibromyalgia, like other contested illnesses such as chronic fatigue syndrome, include its elusive etiology, the inability to verify it using any objective measure, and a lack of a standard treatment strategy. Kristin K. Barker situates fibromyalgia within a broader historical framework relevant to the discursive themes addressed in this article by noting the “general symptomatic and epidemiological similarities between hysteria, neurasthenia, chronic fatigue, and fibromyalgia.” She continues:

Whereas each of these disorders has a unique trajectory tied to its specific historical location and the medical specialty with which is most closely associated, their similarities as categories of medical knowledge and patient experience are considerable. Among other similarities, the emergence of each of these diagnoses involves women clinically presenting common, distressing, and ill-defined symptoms and physicians using their available medical knowledge to offer them imperfect explanations of, and even more imperfect remedies for, their distress [...] In short, women have historically filled and still fill the ranks of contested diagnoses that grant them neither full legitimacy of disease nor a meaningful remedy toward health. (Barker, 2005, 55-56).

The uncertainty surrounding this illness adds to the suffering recounted by women who have fibromyalgia, for their experiences of this chronic condition include both significant biographical disruption (Bury, 1982) and having the validity of the diagnosis called into question (Barker, 2005, 64-65). Ultimately, this uncertainty greatly enhances what Åsbring and Närvänen identify as its “stigmatizing potential” (2002, 149), as sufferers commonly come to be viewed as irrational women or malingerers by both physicians and laypeople.<sup>10</sup>

Researchers conducting in-depth interviews with women diagnosed with fibromyalgia and other similar contested illnesses have found that these women often experience doctors feminizing and psychologizing their physical complaints (e.g., Åsbring and Närvänen, 2002; Baker, 2005). Barker, for example, writes that most of the women she interviewed “tell of situations where their complaints are trivialized and they are personally written off as overly emotional, neurotic, or hysterical” (2005, 97). She also quotes her interviewees expressing frustration as they talk about their doctors attributing their complaints to depression or “female” problems.

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<sup>10</sup> Norma Ware (1992) has identified similar experiences of delegitimation in her work on chronic fatigue syndrome.

In looking at fibromyalgia narratives through the framework of the stigmatized vernacular, my work here overlaps with existing research using interviews to gain access to women's experiences with fibromyalgia and similar contested illnesses. While such research is important for helping us to better understand the emic perspectives of stigmatization, my goal is to look not just at these emic perspectives but at the way stigma "spills over beyond the topic into the means of articulation" (Goldstein & Shuman, 2012, 116). Thus, I will show how experience itself becomes an object of debate in the expressive form of the illness narrative in public circulation. To do so, I will present examples from two different contexts in which fibromyalgia narratives have been constructed for public audiences. In my introduction and discussion of these two contexts, I seek to highlight how the discourses on emotion shaping fibromyalgia narratives make visible broader regimes of value creating an ongoing tension between the veneration and stigmatization of women's illness experiences.

In March 2010, the Health Section of [newyorktimes.com](http://www.nytimes.com) introduced fibromyalgia as part of its ongoing Patient Voices series, a series highlighting the experiences of individuals suffering from a range of conditions, from Tourette's Syndrome to Type 2 Diabetes. As with other conditions covered in this series, this feature presented the experiences of patients representing different ages, races, and professions. Five women and one man were introduced to the audience. As the audience listened to the voices of the individuals describe what it is like to live with fibromyalgia (lasting about 2 minutes for each person), a slideshow of images cycled automatically on the screen, showcasing the individuals in different settings of their daily lives: washing dishes, bowling, sleeping on the couch, walking to school, taking photographs, or holding a beloved pet. Next to each image, the audience was presented with text written in the third person. Taken together, these audio, visual, and textual elements offered a narrative framework for the experiences of each of the six individuals featured.

Viewers of the Patient Voices features were invited to "Join the discussion" by following a link to the *New York Times* Wellness Blog. This link took the viewer to a blog post that summarized the information presented in the interactive feature and opened up opportunities for viewers to post comments of their own. The discussion forum in response to the fibromyalgia stories began with one person, identifying himself as Dr. Hirschberg, communicating his skepticism about whether the majority of people claiming to have fibromyalgia actually have it. As the discussion continued over the next fifteen months, many other people – including both laypeople and self-identified health professionals – posted responses agreeing with Dr. Hirschberg. Interestingly, the emerging discussions in the forum made little reference to the specific narratives in the Patient Voices feature. Instead, they focused primarily on the validity of the experiences of the claims people make about their experiences with fibromyalgia more broadly. The skeptics in the forum pointed to a variety of reasons for their doubts. Some articulated their doubts in terms of the condition itself, pointing to its lack of clear diagnostic criteria. A good number, however, articulated their doubts by pointing to the characteristics of the people diagnosed with fibromyalgia, emphasizing its prevalence among women and the apparent lack of happiness that accompanies the illness. For example:

- I'd have an easier time believing it actually exists if it weren't for the fact that everyone I know that claims to have it is a woman, usually is depressed, and also claims to have various other vague pain disorders [...]<sup>11</sup>

— *Ingrid*

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<sup>11</sup> All direct quotes are presented exactly as they appear in their original context.

- [...] And it is unfortunate that the people (primarily women) that I know who have fibro are very well versed in all their symptoms and they, like others have said here, are not happy people. Failed marriages, children who have gone astray, abuse in their childhood, frustrated in completing goals. And the list goes on and on [...]

— *Laura*

- I will have to go with Hirschburg!! I know someone who says she has Fibro, but I am skeptical of that. All she does is complain about everything, and looks for attention. Stop looking for sympathy and move on with your life, you have a kid and a great husband. Stop complaining about everything that may “hurt” or “bothering” you, it’s annoying!

— *Anthony*

Several posters drew connections between the fibromyalgia patients’ apparent lack of happiness and the failure of these women to fulfill the idealized feminine roles of wife and mother. In the second post listed above, for example, Laura cites failed marriages and distant children as common causes for this lack of happiness. The third poster, Anthony, draws a similar though inverted connection between happiness and social roles, identifying the expressions of unhappiness as disrupting one woman’s relationship with her “great husband’ and child.

These examples illustrate some of the issues Sarah Ahmed explores in her book *The Promise of Happiness*. In this book, Ahmed builds upon existing feminist and queer scholarship on the politics of happiness to look at the types of rhetorical work accomplished by the imperative of happiness. Situating her work within what she calls “the happiness turn,” she shows how the relatively recent emergence of the science of happiness has transformed happiness into a desire that can be found. Identifying marriage as one of the primary happiness indicators within this science of happiness, she explains how the new science of happiness ‘locates happiness in certain places, especially marriage...as well as in stable families and communities’ (Ahmed, 2010, 7). Discussing the implications of such indicators, she writes, “Not only does happiness become an individual responsibility, a redescription of life as a project, but it also becomes an instrument, as a means to an end, as well as an end” (Ahmed 2010, 10). If we view happiness as a kind of cultural capital instead of merely a description of some emotional state, we can see a clear relationship between the desire for happiness and being a good, as opposed to a disruptive, subject. Thus, a visible lack of happiness in women, along with its expression in the form of excessive complaining, becomes evidence for a lack of social responsibility.

These types of references to the emotional states of the women who have been diagnosed with fibromyalgia not only delegitimize those who claim this illness experience, but they also deny access to the genre of illness narrative as a means of personal validation (and potentially veneration). That is, by refusing to recognize these experiences as resulting from a *real* illness, narrators’ claims to the genre of the illness narrative are framed as being, at best, delusional, and at worst, manipulative.

Such discursive framings of emotion put sufferers of fibromyalgia in a bind for how to respond, especially when invoking personal experience as evidence in their counter-arguments that fibromyalgia is real and that its

causes stem from the body instead of the mind.<sup>12</sup> On the one hand, because the condition is invisible, sufferers need to describe the pain and fatigue and illustrate its significance by highlighting the extent to which it stands in the way of living a “normal” life. On the other hand, personal accounts of fibromyalgia that express too much negative emotion run the risk of being interpreted as proving the very points the skeptics are making. For example, as numerous individuals responded to the skeptics in this forum by emphasizing the physical and emotional distress brought by fibromyalgia, one person responded by writing, “A simple analysis of the tone of the previous FM posts will provide insight into the subconscious anguish that is the cause – not the result – of the pain of fibromyalgia. Not to dismiss it! The pain is real. But let’s try not to ascribe physical causes [...]” (*Dr R*).

Framing their experiences in direct response to the challenges exemplified above, many individuals with fibromyalgia chose to focus on characterizing themselves before they fell ill:

When I first had fibromyalgia (FM), my doctors and I were very concerned. I went from being a fit woman who practiced law, ate right, exercised regularly, and had a great life with many friends and a close family. Suddenly I was terribly ill with horrendous pain. My family physician couldn’t understand what was wrong, nor could several other local specialists. Finally I was diagnosed at the Mayo Clinic. I had no idea that FM could be so debilitating. I participate in physical therapy 4 times per week and take medication just to help control the pain. I have found nothing for the crushing fatigue. FM is very real. I have no reason to fake an illness [...]

– *Kristine Lanning*

[...] Prior to succumbing to Fibromyalgia and the many, many accompanying problems and afflictions I am currently struggling to live with, I was a vibrant, driven, optimistic, hard-working and ambitious person — and the fight to preserve those natural personality traits is a battle I wage every day despite the debilitating pain.

I would be willing to bet that I do not know one other person in my life who would have been as tenacious at pushing forward despite the pain and fatigue I have dealt with for many years. I am as tenacious as they come [...]

– *Monique*

When I was diagnosed with CFS and FM, I was a happy straight-A pre-medical student at the best university in U.S. I had a wonderful social life, volunteered, worked, exercised daily, and highly competitive student. I had the world and my finger tips and everything to look forward to.

No one, who had the life I had, would chose to have a chronic illness. Unfortunately, living with CFS and FM, I don’t have the luxury of denial. My life is lived to the fullest my body, pain, and fatigue allow daily! [...]

– *FK*

Notably, emotion served as a rhetorical resource in many of these responses, as the posters highlighted positive emotions in attempts to assert the legitimacy of the diagnosis and, by extension, their illness experiences. For example, Kristene, while not referencing her emotional state directly, calls attention to widely recognized

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<sup>12</sup> This situation resonates with Jane C. Richardson work on how women suffering from chronic widespread pain construct accounts of their experiences to present a positive identity in the face of delegitimation (2005).

happiness-indicators: “many friends and a close family.” Monique and FK make more explicit references to their previous emotional states, identifying themselves as “happy” and “optimistic.”

Making specific references to emotional characteristics (for example by constructing one’s former self as happy and one’s current self as actively trying to be happy) is one way of reconstructing a positive identity and making one’s experiences more tellable in the face of stigma. At the same time, such attempts to make experiences more tellable also work discursively to reaffirm the same imperative of happiness that works to delegitimize their experiences. I call attention to this not to criticize the choices these individual posters made in the face of delegitimation, but to show how the very discursive choices available to them for making their experiences tellable to skeptical audiences enact the discursive contagion of stigma.

Of course, the *New York Times* Patient Voices feature and its accompanying discussion forum stand as just one particular context of illness narrative construction and reception. The fibromyalgia narratives shared as part of the Patient Voices series were constructed primarily for a diverse public audience, including people who had fibromyalgia and people who did not. As a result, since skepticism was voiced very early in the discussion forum accompanying the feature, the personal experiences shared in the forum were constructed defensively – responding both to the doubt surrounding the diagnosis and the stigma attached to the people who were diagnosed. That is, many of the posters with fibromyalgia framed their experiences as part of a rhetorical project of *revaluing* their experiences in the face of delegitimation.

Turning attention to a different context of sharing personal experiences with public audiences, one that allows for more complexity in the presentation of self, the final example I will discuss is Deb’s Fibromyalgia Blog (<http://debsfibromyalgiablog.blogspot.com/>). A weblog (also known as a blog) is a frequently updated website in which dated entries are displayed in reverse chronological order.<sup>13</sup> While personal illness narratives shared with public audiences are most often composed from a singular perspective in the present recounting and reflecting on experiences in the past, the format of the blogged illness narrative is different in that it allows narrators to present experiences as they are happening. Rather than offering a coherent presentation of self like other forms of personal narrative in the public domain, the structure of the personal blog is both open-ended and episodic, allowing the blogger to offer different presentations of herself at different times. The blog format also allows for reader comments, adding an element of interaction that provides the illness blogger with opportunities to connect with others “to provide or seek support in the form of experience, advice, and encouragement” (Page, 2011, 224).

At the time she started the blog in June 2009, Deb had been diagnosed for just over six years. Married with adult children and grandchildren, she and her husband had been living and traveling in their RV since they retired. Like other bloggers sharing experiences with fibromyalgia and related contested illnesses, she used her blog as a space for recounting specific events in her daily life, reflecting on the experience of fibromyalgia more broadly, offering tips and advice for others suffering from fibromyalgia, and soliciting responses from her readers. Unlike the individuals with fibromyalgia participating in the discussion forum accompanying the Patient Voices featured

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<sup>13</sup> A relatively new form of new media storytelling, the blog has been identified as a form of hybrid genre straddling the border between public and private storytelling, an emergent form indexing other online and offline genres, including emails, personal webpages, diaries, and autobiographies (Herring et al.; 2004, Page, 2008). For scholarship explicitly addressing the relationship between online modes of self-presentation like personal webpages and blogs and other genres, see Kiloran, 2003; Mcneill, 2003; Miller & Shepherd, 2004; and Sorapure, 2003.

above, it was clear that she shared her experiences with the expectations of a receptive and supportive audience that would not question that the tellability of her experiences. This expectation became most visible when, upon reading an anonymous negative comment posted by a reader, she posted an entry entitled “Anonymous Comment,” in which she pasted the critical comment and wrote, “In case you have not noticed, this blog is about MY journey with Fibromyalgia. If you do not have a positive comment, please do not leave one” (May 13, 2012). Over the three and a half year period that she kept this blog,<sup>14</sup> she highlighted how her experiences with fibromyalgia involved not only her struggles to deal with the physical manifestations of the illness (e.g., pain, “fibro fog,” fatigue), but her struggles to deal with her emotions as well. While the experiences presented in this blog are specific to this individual, the way this blogger wrote about emotion reflects patterns that are visible in the fibromyalgia blogging community more broadly. By looking at how she wrote about different types and expressions of emotion, it becomes clear that her reflections on the tellability of her fibromyalgia experiences were highly influenced by the broader discourses on emotion that I have introduced above.

In discussing how blogs differ structurally from more traditional personal narratives, Ruth Page explains that the structure of blogs “would seem to lend itself readily to many of the thematic concerns central to personal accounts of illness,” including ‘radical fragmentation,’ ‘unbridgeable gaps,’ and interplay between ‘continuity and disruption.’” She continues by asserting that such thematic characteristics of typical illness narratives “are echoed in the formal qualities of the blog’s episodic and open-ended post sequences, contained within the coherent framework of the blog homepage” (2008, 155). Making a similar observation in her study of breast cancer blogs, Karen McNamara writes “although the process of storytelling itself may signal a stabilizing of the self, the blog as a form of narrative nonetheless resists such integration. Instead, the blog allows the disrupted and intermittent speech of the blogger to come through in the text” (2007, 4). This open-ended structure, along with the expectation of audience support, gives the illness blogger a great deal of freedom in how she reports and reflects upon her experiences.<sup>15</sup> At the same time, as we see in Deb’s blog, emotion can nevertheless become a discursive site for navigating the competing yet overlapping discourses of stigmatization and veneration invoked by the genre of the personal illness narrative.

For example, Deb dedicated a good number of her posts to expressing negative emotions like frustration, anger, and depression, though like “Lucy” who was cited in Ehrenreich’s work on breast cancer, she often framed these expressions using phrases like “I need to apologize upfront [...] I need a ‘bitch post’” (November 27, 2010) and “Have I bitched enough?” (December 5, 2010). This framing language points to a clear recognition of the untellable nature of negative emotions. The relative untellability of negative emotions is further emphasized by another consistent theme emerging throughout Deb’s blog – the importance of striving for happiness. For example, at the end of one post entitled “How’s Your Attitude,” she wrote, “Always think about your tone of words. Keep a sunny attitude” (November 8, 2009). Implicit in these words is the idea that staying positive is a choice, an idea that resonates with some of the skeptics’ posts in the Patient Voices discussion forum. This idea was expressed even more explicitly in other posts. Sometimes, she communicated this idea by directly quoting others, such as when she quoted a statement she found in a women’s health magazine: “JUST DO IT: Choose to be happy” (January 27,

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<sup>14</sup> As of this writing, the last entry was posted in January 2013.

<sup>15</sup> While the democratizing nature of new media technologies does open up empowering opportunities for individuals sharing their illness narratives, especially those writing from historically marginalized or misrepresented positions (Langellier and Peterson, 2004), Victoria Pitts (2004) and Ruth Page (2008) have cautioned us against assuming an inherently empowering nature in online illness narratives.

2010). Other times, she voiced this sentiment in her own words, like she did on New Year's Eve in 2010 in a post entitled "Our Future is Spotless": "'Our future is spotless?' I interpret this to mean that the year 2011 is about to begin and what we do with 2011 as a blank slate, is our individual choice. Will you choose to be positive?" (December 10, 2010)

While these excerpts indicate that she was aligning herself with the happiness imperative critiqued by Ahmed and Lorde, among others, the way she used language to qualify this idea problematized the simplicity of the idea of choice and, by extension, the happiness imperative. For example, she began one entry entitled "A Joyful Heart" with a quote from the Bible: "'A joyful heart makes a cheerful face.' Proverbs 15:13"<sup>16</sup> She followed this Bible verse with her own words:

Are you joyful? I have found it difficult to be "joyful" since Fibromyalgia came to stay in my life. When you have continuous pain throughout your body, 24/7, it's hard to be "joyful." On the other hand, I have found "joy" in people, situations and things [...] I hope you can find "joy" in your life...it surrounds you and when you find it, your Fibromyalgia feels better. Purposefully find something that makes you "joyful" today. (January 18, 2010)

This post, while clearly communicating the value of "purposefully" finding joy, also acknowledged the difficulty in such an endeavor when living with the physical effects of fibromyalgia. She further emphasized how difficult it is to seek out happiness in practice by repeatedly placing the word "joy" quotation marks. Throughout her blog, she also employed the language of work as she talks about being positive. For example, in one entry entitled "How Positive R U?" she writes,

I work VERY hard to stay positive during my day. To be honest, by dinner-time my positive attitude is beginning to fade. My patience is short. My fatigue has increased, which increases my Fibro Fog and my pain. If I have an issue that kicks my anxiety into gear prior to dinner-time, I'm in trouble the rest of the day. When I'm feeling really rotten, I'm usually quiet. I need to work harder when I open my mouth to be nice. I'm sure everyone has these experiences that has constant chronic pain and fatigue... (August 8, 2009)

Interestingly, references to happiness as work consistently accompanied references to the importance of being happy for the sake of others (or, to borrow a term from Sarah Ahmed, the importance of being a happiness-object): "I try not to talk about my FM symptoms in a complaining manner. Who wants to listen to me complain every time I open my mouth" (August 8, 2009).

Being a happiness-object is not easy, though – either physically or emotionally – as she communicated in the following post, entitled "I'm Flaring and Thankful":

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<sup>16</sup> This idea is inverted in later posts when she references smiling as a performance, or another type of work:

- "You can [...] smile in the face of pain." (September 3, 2011)
- "You can [...] put a smile on your face when you would rather not." (February 28, 2012)

I have been in a flare for two weeks. My body is racked with pain and fatigue. Depression set in two days ago. I started my "pity party" when the depression started, which makes sense doesn't it? I'm trying hard not to complain much as I don't want to become known as a winner. I just want to feel better NOW! I don't want Fibromyalgia and Chronic Fatigue!" (September 28, 2009)

She then presented a long list of things she was thankful for as she tried to identify the positive aspects of her life before ending the post abruptly with the words, "My wrists are stiff so will sign off for now" (September 28, 2009). While creating a list of what she was thankful for showed an attempt to focus on the bright side of things, the beginning and abrupt ending of the post highlighted her struggle to control negative emotions in the face of the pain and fatigue of fibromyalgia (both in the context of the blog and in her day to day interaction), even as she tried to choose to adopt a positive attitude. In essence, this post, like her blog as a whole, illustrates her ongoing struggles to navigate the contradictory and gendered discourses on emotion.

#### IV. Conclusion

My analysis in this article has developed around two separate yet related questions:

- How can the conceptual framework of the stigmatized vernacular help us better understand the rhetorical power of genre of the illness narrative, particularly the role it can play in processes of stigmatization?
- How do gendered discourses on emotion determine how women's illness experiences come to be recognized as tellable or untellable, venerated or repudiated?

My engagement with these questions has by no means been comprehensive, though by pairing these questions together, I have shown the role that gendered ideas about emotion can play in the regimes of value shaping women's illness narratives. Thus, while the specific experiences of living with fibromyalgia differ from those of breast cancer, and while the specific context of narrative production and reception in Deb's Fibromyalgia Blog differs significantly from the context of the Patient Voices discussion forum, we can see that the broader repertoire of discourses on emotion shaping the various articulations of women's illness experiences do not. At the same time, using the conceptual framework of the stigmatized vernacular, I have called attention to the close relationship between the discursive processes of stigmatization and veneration in the construction and reception of women's illness narratives.

Of course, the relevance of the stigmatized vernacular to the study of personal illness narratives is not limited to women's experiences, though this is one place where the complex dynamics of tellability/untellability and veneration/repudiation are highly visible. Many scholars in the social sciences, humanities, and health care fields are already looking at illness narratives in contexts of stigma, highlighting how these narratives open up opportunities for both managing "spoiled identities" (Goffman, 1963) and speaking back to the stigma itself. While my examination here has focused on emotion discourse as one way that the experiences of social stigma can "spill over...into the means of articulation" (Goldstein & Shuman, 2012, 116) via the genre of the personal illness narrative, I hope others will extend the framework of the stigmatized vernacular to a diverse range of illness and storytelling contexts, contributing to a richer and more multifaceted view of both illness narratives and the discursive contagion of stigma.

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