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Electronic Support Groups: An Open Line of Communication in Contested Illness

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Abstract

Background—Patients with functional somatic syndromes are often difficult to treat. The relationship between doctors and patients can be strained, which limits communication. Instead, patients often communicate with each other over the Internet in electronic support groups.

Objective—This perspective summarizes studies of patient-to-patient communication over the Internet and uses the concept of contested illness to provide insights into the experiences of patients with functional somatic disorders.

Discussion—Conflict between a patient and their physician is a key feature of functional somatic syndromes. Physicians and patients do not have a shared understanding or appreciation of the patient's experiences. Patients with functional somatic syndromes often value their own embodied experience over medical knowledge. At the same time, they remain deeply invested in finding a “good doctor” who believes that the patient is suffering, agrees with their conception of the cause, and assents to the treatment as directed by the patient. Electronic support groups reinforce these beliefs.

Conclusion—Patients may benefit from a compromising, collaborative approach that is realistic about the limitations of medical knowledge. However, physicians should not engage in unsafe treatment practices. Electronic support groups exist for a wide range of illnesses and the issues that rise to the surface in functional somatic syndromes likely occur to some extent with almost every patient.

Keywords

somatization; Consultation-Liaison psychiatry; health; internal medicine; quality of life

INTRODUCTION

Patients come to see physicians for many reasons. Most patients come to seek help with symptoms that trouble them. As part of this interaction, the physician accepts the patients' experience and may recast a collection of symptoms as a disease or syndrome that is amenable to medical treatments.^{1,2} The physician assures the patients that their progress

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through this condition would be a shared journey with an interested and invested partner. Alternatively, the physician may provide reassurance or normalization. Although on the face of it, this is a harmonious process that leads to a negotiated agreement, disagreements can arise at just about every phase.³ Patients and their physicians almost always disagree on some aspect of treatment, diagnosis, or even the nature of symptoms. A healthy relationship between the doctor and patient can help navigate disagreements. A fraught or tenuous doctor-patient relationship, on the contrary, it is a serious impediment to a negotiated, mutually agreed upon solution and a barrier to good care. These latter conditions are commonly encountered when dealing with functional somatic syndromes.⁴

Treaters have created multiple psychologic models of the development of functional somatic syndromes in an attempt to understand their etiology and ultimately provide effective treatment based on the presumed etiology and mechanisms. Many of these models propose that there is a direct link between traumatic experiences during childhood and the subsequent development of somatic syndromes.⁵ Epidemiologic studies have found an association between childhood trauma and later reporting of medically unexplained symptoms.⁶ In psychodynamic theory, these traumas may lead to maladaptive patterns of dissociation or conversion.⁷ In a disassociation model, the distressing physical symptoms are unconsciously used to distract attention from a hidden psychologic stressor, although in a conversion model, the psychologic stressor is translated into physical distress. Attachment theory proposes that cognitive schemas created during interactions with childhood caregivers influence interpersonal relationships in adulthood.⁸ In this framework, childhood trauma leads to the development of insecure attachment styles. Fearful and preoccupied attachment styles are strongly associated with somatization.⁵

Anthropologists, on the contrary, refer to functional somatic syndromes as “contested illnesses.” In this view, the defining characteristic of these conditions is not a possible psychologic origin for the symptoms, but rather the adversarial relationship between doctor and patient.⁹ Clinicians also recognize the importance of the doctor-patient relationship in these syndromes and have produced a large literature on how to preserve it, in the (somewhat unproven) hope that doing so might produce better outcomes.¹⁰ This literature typically calls upon expert consensus, but rarely invokes qualitative data obtained from studies of sufferers of contested illnesses. Even when qualitative data are included, it is most often data communicated to a physician that is less useful than data obtained from patients who are disengaged or feeling alienated from their physicians.

However, just because patients and physicians are not communicating effectively with each other, it does not mean that they are not communicating. Patients use the Internet to communicate with each other about their experiences with bringing contested illnesses to the medical system.^{11,12} Online communications are potentially a rich source of information that could enhance our care of patients. The frame of contested illness may be useful when studying patient-to-patient communication in online Internet communities. In this article, we examine qualitative studies of online Internet communities for patients with functional somatic syndromes and interpret these results through the theoretical framework of contested illness.^{9,11–21} We note several recurring themes across studies including: conflict

between medical knowledge and embodied experience, the dangers of therapeutic “emplotment,” and the ambiguities inherent in operating at the limits of medical knowledge.

Contested Illnesses

Contested illnesses are chronic conditions with non-specific, but quite distressing, symptoms and limited or controversial physical signs.^{2,9} There are opposing ideas of how to fit these conditions into a diagnosis-oriented medical framework that relies on objective signs, laboratory findings, or professionally mainstreamed consensus descriptions. Illnesses are “contested” because conflicting views exist between and among physicians and patients about their nature, causes, and treatment. They include systemic exertional intolerance disorder, fibromyalgia syndrome, irritable bowel syndrome, multiple chemical sensitivity, Morgellons disease, and many more. Sufferers (and some physicians) explicitly connect their experiences to specific underlying biologic causes. Many physicians reject these explanations and instead offer psychiatric diagnoses. Psychiatric interpretations are often poorly received by patients.²² Other disagreements occur when sufferers request treatments that go against medical standards of care.

Contested illnesses have been described as “illnesses you have to fight to get,” with the battleground often lying between doctors and patients.^{8,9} All too often, a fundamental and bidirectional breakdown of the doctor-patient relationship occurs, with doctors seen as invalidating and patients as dismissive of the medical establishment. This misalignment is particularly troubling given that a robust and caring doctor-patient relationship is linked to improved outcomes.²³ Much has been written about how to improve this state of affairs; for example, physicians are often counseled to avoid blaming the patient for their condition.²³ Less attention has been paid to where patients find gratification of their relational needs. Indeed, there is a great deal of communication about contested illnesses that is occurring outside the doctor’s office.

Electronic Support Groups

Electronic support groups (ESGs) such as patient-moderated online message boards, e-mail listservs, social media, and chat rooms are widely used by sufferers of contested illnesses.^{9,14,18,19,24,25} ESGs have several features that make them appealing when compared to traditional, in-person groups. ESGs are not limited by geography or time; a message board posting by a member can be read weeks or even years later by members from other states or even other countries. Joining an ESG can be as simple as searching the Internet and sending an e-mail. Further, participants in ESGs enjoy greater privacy than they would in an in-person group composed of members of their local community. Users of ESGs are demographically similar with the larger population of sufferers.¹⁴

The effects of ESGs on participants are an area of active research. Qualitative data from several studies suggest that members of ESGs feel more empowered, more hopeful, more socially supported, and that their self-rated quality of life is improved by their participation.^{11,12,26–28} However, studies have found no clear effect of ESG participation on clinical and functional outcomes in a variety of illnesses.^{12,29–31}

Several possible negative influences of ESGs have been proposed including propagation of false information, facilitation of feelings of hopelessness, and accidental or intentional privacy breaches for both patients and their treaters.^{12,20} Negative outcomes remain largely hypothetical, as the current research has produced little evidence that they are occurring.²¹ Nonetheless, it is important for physicians to listen to what is being said in ESGs, because patients use them to create shared models of disease that through repetition, online “publication,” and sheer need create an illusion of validity to the claims made. These claims demonstrate, and perhaps further fuel, deficiencies in doctor-patient relationships and the medical system.

THE DOCTOR-PATIENT RELATIONSHIP IS DIFFICULT FOR PATIENTS WITH CONTESTED ILLNESSES

Qualitative studies have focused primarily on the lay-run majority of ESGs.^{9,11,13,14,17,20,25} Although physician moderation could potentially act as a counterbalance to the nonorthodox medical views propagated on these forums, it is unlikely that a physician moderated ESG would be experienced as a safe or worthwhile space by sufferers who have difficult relationships with their own physicians. In particular, a physician might be seen as a gatekeeper to the sick role that patients seek to assume. More broadly, the absence of physician moderation may allow less restrained communication between users.

By examining the characteristics of the users of ESGs and analyzing the nature and content of their postings, we identified important themes in the doctor-patient relationship experienced by patients. This information is rarely directly communicated with providers. Its uncomfortable emotional valence may be difficult for patients to express and for physicians to accept.

This impediment to productive communication can sabotage extant, nascent, and even future doctor-patient relationships. Patients with contested illnesses enter the examination room prepared to do battle with their physicians.⁹ They complain of being intimidated and invalidated by their doctors.^{17,32} Patients write in ESGs about switching from provider to provider, seeking one who is acceptable.^{9,17,33} Psychiatry and psychiatrists are especially scorned—not only do psychiatrists represent the most direct challenge to patient’s views of etiology and treatment, but patients also argue that psychiatry is used to relegate contested illness to the realm of psychiatric illness, with negative effects on insurance access and disability benefits.⁹

Many patients search for years and at significant financial cost to find a doctor with whom they feel satisfied.¹⁴ At best, this leads them to physicians with effective “bedside manners”; at worst it leads them to human versions of their ESGs.³⁴ A better understanding of why patients are unsatisfied with their physicians, coupled with an understanding of what characteristics of “acceptable” physicians can be widely adopted without compromising standard medical care could lead to improved outcomes. Although this idea informs much of the writing around functional somatic syndromes, in this article we draw attention to what patients say to each other safely out of earshot of what they perceive to be an oppositional and withholding medical establishment.

PATIENTS VALUE EMBODIED EXPERIENCE OVER MEDICAL EXPERTISE

Doctors and their patients possess overlapping, but distinct knowledge about contested illnesses.^{2,14} Physicians can refer to biomedical or psychologic explanations of illness by invoking their medical expertise. This expertise comes from a long line of clinical and scientific work. It is a shared expertise, especially given the recent emphasis on evidence-based medicine, which is deindividualized. Physicians are trained to encounter the patient's experience, extract out the most salient information, integrate the patient report with information from the physical examination and laboratory findings, and use all of this data to assign the patient an explanation or diagnosis.³⁵ It should be noted that this is never an exact fit, as individuals vary in myriad ways.³⁶ Patients, on the contrary, are experts in their own stories and the distinct topography of their own embodied experience.

Through ESGs, patients with contested illnesses encounter others who report similar experiences. This leads to the creation of a new body of knowledge, which exists in opposition to medical orthodoxy, as a reminder of orthodoxy's failures, and as a symbol of even these patients' yearnings for deindividualized explanation for their suffering (Figure). When patients first began using an ESG, they often write about their experiences and express both surprise and relief that other group members have shared them.¹³ Many explore ESGs seeking relief from invalidation and isolation.²⁶ This is not surprising given that many members report interacting with physicians who seem to deny the meaning, treatability, and even the reality of their suffering. By finding other sufferers with similar stories, ESG users create an alternative knowledge base that draws its legitimacy from shared and reinforced embodied experiences. Patients who express doubts about this knowledge are often "corrected" by reference to the authority of its shared status among large numbers of sufferers.¹⁴ Furthermore, this knowledge is used to develop and affirm models of etiology and treatment that are not supported by mainstream medical practice. Patients would use ESGs to make approving references to biomedical expertise, but only if it is in agreement with their experiential knowledge.¹⁸

Collectively shared experiences are not the same as rigorously derived data but still guide medical beliefs and expectations in ESGs. Thus, in Barker's fibro-myalgia ESG study, one of the most common complaints about doctors was that they were "ignorant."¹⁴ This source of disagreement is a tremendous barrier to an effective doctor-patient relationship, because it casts into sharp relief the power differential between doctor and patient. No matter what the patient experiences or believes, only one person in the room carries a prescription pad and the authority to legitimize suffering with a diagnostic label or prescription.^{9,33}

Another common narrative thread that appears in ESGs is the eventual discovery of a good or at least acceptable doctor. To these patients, an acceptable doctor either shares the patient's explanatory model of their suffering or is persuaded of its validity by the patient. The good doctor also agrees with patient suggestions and grants requests for treatment.¹⁴ The good doctor may marshal some pieces of biomedical evidence to support the patient's ideas, but more commonly aligns with the patient against a corrupt and unfeeling medical establishment.

This underscores an ongoing problem in much of the literature around treatment of patients with contested illnesses; physicians have been repeatedly told to be better listeners, but not been told that patients want physicians to believe them.³⁷ Demonstrating this belief may require the physician to offer treatments, which are at best unsupported scientifically and at worst unsafe.³⁸ Indeed, there is an important distinction to be made between believing and validating the patient's suffering and agreeing with the patient's explanatory model. On one hand, participants in ESGs express delight and relief when they encounter a physician who gives them what they want, whether this is a diagnostic label, desired medication, or therapeutic intervention.¹⁹ On the contrary, the medical uncertainty that accompanies contested illnesses can prompt physicians to use treatments that are unlikely to be helpful and may even be unsafe.

For example, many people believe that they suffer from a chronic infection with *Borrelia burgdorferi*, the spirochete that causes Lyme disease.³⁹ They seek out so-called "Lyme literate" doctors who agree with their assessments and often prescribe very long courses of antibiotic medication. Such treatment is not effective and is linked to serious negative sequelae including death.⁴⁰ These physicians nonetheless remain popular with their patients. Patients and "Lyme literate" physicians have even created parallel organizations such as the International Lyme and Associated Diseases Society, which exist in opposition to mainstream medical organizations and propagate treatment recommendations that are unsupported by science.^{34,39} This example is a powerful reminder that however important the doctor-patient relationship may be, it only exists as a means to an end of decreased patient suffering and improved health. It also underscores the extremely high value that some patients place on their explanatory model.

PHYSICIANS FOCUS ON FORM AND EMPLLOT CONTENT

Most doctors recognize that having an alliance with their patients is important and it is often tempting to try to form an alliance with sufferers of contested illnesses by focusing on amelioration of their symptoms. This is more complicated and problematic than it may initially appear. A strong alliance requires a shared understanding of what patients are experiencing. Note that understanding experiences does not imply agreement on causes. For example, a psychiatrist can maintain a strong therapeutic relationship with a psychotic patient who lacks insight if the patient feels that the doctor understands his or her experiences.⁴¹

However, this understanding may be particularly difficult to achieve when contested illnesses are involved. Physicians are trained to seek forms.³⁵ When a physician sees a patient with a contested illness, the form is that the patient reports multiple medically unexplained symptoms and the specific content of the symptoms is much less important.⁴² This is directly antithetical to the views of the patients who feel that the content of their specific symptoms, that is their own embodied experience, is the key in making the correct diagnosis (Figure).³⁷

Even if a physician is willing to focus on the content of the patient's symptoms, this content still must be successfully communicated to the physician. This means that the agreed upon

conception of what the patient is experiencing is affected by what symptoms the physician is willing to acknowledge as medically, not just experientially, “legitimate.”¹⁴ The collaborative process of symptom identification is at the heart of the doctor-patient interaction. The process plays out in the way doctors phrase their questions to elicit the particular response that they think is appropriate. For example, a doctor might use subtle shifts in tone or language to implicitly direct the patients to deny pain. Therefore, the symptoms as agreed upon in the therapeutic encounter are not exactly the symptoms as the patient experiences them. This process has been called “therapeutic emplotment.”⁴³

It is difficult to establish an alliance around symptoms if there is a fundamental disconnect about what the symptoms are and what they mean. Many patients report that physicians do not understand or appreciate their symptoms.^{9,14} Furthermore, there is a great deal of suffering in having a disease as opposed to and on top of having a particular symptom. Finally, even physicians who are eager to validate their patients’ experiences must remember that patients are variably reliable reporters of their own internal experiences. Striking the right balances between form and content, receptivity and emplotment, and credulity and skepticism contribute heavily to the quality of doctor-patient relationships.

OPERATING AT THE LIMITS OF PHYSICIAN EXPERTISE

One of the main aspects of the role of the healer is that the healer possesses special knowledge that the sufferer does not. This is one of the reasons why the sufferer listens to and accepts the advice of the healer. In the case of contested illnesses, we are operating at the very edge of physician expertise. The etiology remains unknown. Although patients often reference “organic” etiologies and physicians, in the absence of understood “organic” pathophysiology might prefer “psychologic” etiologies to explain these syndromes, the differences in explanations are of mixed importance.⁴⁴ For many patients, merely labeling a collection of symptoms as a somatic symptom disorder provides less explanation than the alternative label preferred by the sufferer. For the provider, the label provides information that helps with prognosis, and promotes the adoption of a medical stance on treatment that reduces cost and iatrogenic harm.⁴⁵ Specific treatments for somatic symptom disorders can be useful, but as seen repeatedly in this article, when “branded” too bluntly they may not ameliorate patients’ suffering and may even worsen it.

SHARED VICTORIES IN CONTESTED ILLNESSES

How can physicians overcome the deep-seated disagreements just described? As doctors, we want to help our patients to live healthy, happy lives. Physicians can try to compromise in conflicts around contested illness to reach larger goals. It is certainly reasonable to do what so many of the users of ESGs ask of us and at least listen to them. However, this is clearly not enough. The act of listening can be improved by greater attentiveness to the difference between focusing on symptoms and enacting emplotment.

Furthermore, we can acknowledge more explicitly that there are real limitations to medical knowledge and there is value in embodied experience. Physicians could humbly acknowledge that they are in a position of power to label patient experiences (including

denying diagnostic labels), even if many of the labels applied to contested illnesses possess little value for patients.⁹ It is more important to focus on common treatment goals than establishing a common label. Some flexibility around treatment is also appropriate. However, at the same time the safety and efficacy of any proposed medical evaluation must be taken into account. For example, providing a topical cream in addition to antipsychotic medication in a patient with Morgellons disease is appropriate, whereas high-dose opioid prescribing for fibromyalgia is not. This is not because the fibromyalgia pain is not real; rather it is inappropriate because the proposed treatment is unsafe in addition to being ineffective.

Winning shared victories with patients with contested illnesses requires physicians to reevaluate the way we speak to patients. Patients with contested illness respond positively to shared decision-making models in which physicians and patients explicitly share the authority of making medical choices.⁴⁶ In 2 small randomized controlled trials of fibromyalgia treatment, physicians were either trained in shared decision-making techniques or took a fibromyalgia training course.^{10,47} Both patients and physicians reported better doctor-patient relationships in the shared decision-making group. However, the patients showed no improvement in symptom scores after a year.

It is critical to remember that the significant energy expended in cultivating a healthy doctor-patient relationship goes toward the goal of promoting better outcomes for patients. Indeed, a good doctor-patient relationship that is built on a foundation of unsafe and poor-quality medical care is not worth maintaining; nor is a relationship that seems to perpetuate chronic patterns of incapacity and disease.³⁸ These outcomes are shared experiences but not shared victories.

A limited body of data suggest that some forms of cognitive-behavioral therapy (for somatic symptom disorders) can be helpful in reducing symptom intensity and healthcare costs.^{48,49} A strong doctor-patient relationship could be useful in encouraging patients to try these treatments. In addition, improving the doctor-patient relationship in patients with contested illness is likely to have benefits that extend beyond the management of the contested illness. Patients with contested illnesses often have other comorbid conditions, such as hypertension or diabetes. If patients are distrustful of their doctor or avoiding their doctor because of a damaged doctor-patient relationship around contested illness, the treatment of their other medical conditions is likely to be suboptimal. A potential topic of future research would be to determine whether the use of shared decision-making approaches in patients with various contested illnesses is associated with better health outcomes related to comorbid health problems.

Although we have focused our discussion on interpreting these groups through the lens of contested illness, patients' use of ESGs is also consistent with psychodynamic and cognitive models of functional somatic syndromes. For example, the pattern of moving from treater to treater described by sufferers on ESGs can be understood as a manifestation of the oscillation between approach and avoidance characteristic of patients with fearful attachment styles. Furthermore, the fact that sufferers create and seek out communities online suggests that they are searching for secure attachments.

EVERY ILLNESS HAS A CONTESTED ELEMENT

Although disorders such as fibromyalgia, chronic fatigue syndrome, and multiple chemical sensitivity are commonly labeled as contested illnesses, every illness can be considered to have a contested element. Delusional disorders are an extreme case of a contested illness.⁵⁰ With any illness, patients and their treaters have differing notions about etiology, treatment, and prognosis. For example, in a study of cancer patients, Purkis and van Mossel⁵¹ describe the clinical course of cancer treatment as a series of complicated negotiations between patients and their treaters. The cancer patients in this study have difficult relationships with their treaters similar to those of patients described in this article. Furthermore, the fact that there are ESGs for illnesses like cancer, diabetes, and hypertension suggest that some patients are engaging in online conversations around topics and ideas that are not communicated, accepted, and understood by their treaters.⁵²

In contested illnesses, the areas of disagreement are often obvious and the arguments explicit. In other illnesses, disagreements between physicians and patients are more likely to be subtle. For example, patients who had lumpectomies for breast cancer report being confused about the need for postoperative radiation and wonder why they need treatment for a disease, which has been cured.⁵¹ Even when the doctor-patient relationship is in less obvious jeopardy, it does not mean that the doctor-patient relationship cannot be further strengthened.

CONCLUSIONS

Functional somatic syndromes have an unclear or disputed medical cause and are difficult to treat. In the contested illness framework, the conflict between doctor and the patient and the resulting failure to reach a negotiated agreement is a key component to these illnesses. By reviewing ethnographic studies of ESGs for patients with contested illnesses we can learn what these patients want from their doctors. We can use this information to inform the way we approach patients, to the extent possible. Better understanding of our patients' experiences is useful even with patients who do not have a contested illness.

References

1. Aronowitz RA. When do symptoms become a disease. *Ann Intern Med.* 2001; 134(9 II Suppl):803–808. [pii 200105011-00002]. [PubMed: 11346314]
2. Barsky AJ, Borus JF. Functional somatic syndromes. *Ann Intern Med.* 1999; 130(11):910–921. <http://dx.doi.org/10.1016/B978-0-443-07352-6.50023-3>. [PubMed: 10375340]
3. Mik-Meyer N. The social negotiation of illness: doctors' role as clinical or political in diagnosing patients with medically unexplained symptoms. *Soc Theory Health.* 2014; 13(1): 30–45. <http://dx.doi.org/10.1057/sth.2014.15>.
4. Farkas C. The blind men and the elephant: mediating conflicting views of controversial diagnoses. 2014; (4):4–22.
5. Waldinger RJ, Schulz MS, Barsky AJ, Ahern DK. Mapping the road from childhood trauma to adult somatization: the role of attachment. *Psychosom Med.* 2006; 68(1):129–135. <http://dx.doi.org/10.1097/01.psy.0000195834.37094.a4>. [PubMed: 16449423]
6. Barsky AJ, Wool C, Barnett MC, Cleary PD. History of childhood trauma in adult hypochondriacal patients. *Am J Med.* 1994; 3:211–214.

7. Brown RJ. Psychological mechanisms of medically unexplained symptoms: an integrative conceptual model. *Psychol Bull.* 2004; 130(5):793–812. <http://dx.doi.org/10.1037/0033-2909.130.5.793>. [PubMed: 15367081]
8. Ciechanowski PS, Walker EA, Katon WJ, Russo JE. Attachment theory: a model for health care utilization and somatization. *Psychosom Med.* 2002; 64(0033–3174): 660–667. <http://dx.doi.org/10.1097/01.PSY.0000021948.90613.76>. [PubMed: 12140356]
9. Dumit J. Illnesses you have to fight to get: facts as forces in uncertain, emergent illnesses. *Soc Sci Med.* 2006; 62(3): 577–590. <http://dx.doi.org/10.1016/j.socscimed.2005.06.018>. [PubMed: 16085344]
10. Bieber C, Muller KG, Blumenstiel K, et al. Long-term effects of a shared decision-making intervention on physician-patient interaction and outcome in fibromyalgia. A qualitative and quantitative 1 year follow-up of a randomized controlled trial. *Patient Educ Couns.* 2006; 63(3): 357–366. <http://dx.doi.org/10.1016/j.pec.2006.05.003>. [PubMed: 16872795]
11. Josefsson U. Coping with illness online: the case of patients' online communities. *Inf Soc.* 2005; 21(2):133–141. <http://dx.doi.org/10.1080/01972240590925357>.
12. Eysenbach G, Powell J, Englesakis M, Rizo C, Stern A. Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. *Br Med J.* 2004; 328(7449):1166. <http://dx.doi.org/10.1136/bmj.328.7449.1166>. [PubMed: 15142921]
13. Barak A, Boniel-Nissim M, Suler J. Fostering empowerment in online support groups. *Comput Human Behav.* 2008; 24(5):1867–1883. <http://dx.doi.org/10.1016/j.chb.2008.02.004>.
14. Barker KK. Electronic support groups, patient-consumers, and medicalization: the case of contested illness. *J Health Soc Behav.* 2008; 49(1):20–36. <http://dx.doi.org/10.1177/002214650804900103>. [PubMed: 18418983]
15. Burrows, Roger, Brain, Loader, Muncer, S. Virtual community care? Social policy and the emergence of computer mediated social support. *Infor Commun Soc.* 2000; 3(1):95–121.
16. Gage EA. Social networks of experientially similar others: formation, activation, and consequences of network ties on the health care experience. *Soc Sci Med.* 2013; 95:43–51. <http://dx.doi.org/10.1016/j.socscimed.2012.09.001>. [PubMed: 22999229]
17. Hvizdak, E. Master's Thesis. Loyola University Chicago; 2013. I am relieved to discover my symptoms are normal for my condition: an analysis of two irritable bowel syndrome support communities.
18. Lian OS, Nettleton S. United we stand: framing myalgic encephalomyelitis in a virtual symbolic community. *Qual Health Res.* 2015; 25(10):1383–1394. <http://dx.doi.org/10.1177/1049732314562893>. [PubMed: 25488934]
19. Smedley R, Coulson N, Gavin J, Rodham K, Watts L. Online social support for complex regional pain syndrome: a content analysis of support exchanges within a newly launched discussion forum. *Comput Hum Behav.* 2015; 51:53–63. <http://dx.doi.org/10.1016/j.chb.2015.04.040>.
20. van Uden-Kraan CF, Drossaert CH, Taal E, Shaw BR, Seydel ER, van de Laar MA. Empowering processes and outcomes of participation in online support groups for patients with breast cancer, arthritis, or fibromyalgia. *Qual Health Res.* 2008; 18(3):405–417. <http://dx.doi.org/10.1177/1049732307313429>. [PubMed: 18235163]
21. van Uden-Kraan CF, Drossaert CHC, Taal E, et al. Coping with somatic illnesses in online support groups: do the feared disadvantages actually occur. *Comput Hum Behav.* 2008; 24(2):309–324. <http://dx.doi.org/10.1016/j.chb.2007.01.014>.
22. Stone J. What should we say to patients with symptoms unexplained by disease? The number needed to offend. *Br Med J.* 2002; 325(7378):1449–1450. <http://dx.doi.org/10.1136/bmj.325.7378.1449>. [PubMed: 12493661]
23. Lipsitt DR, Joseph R, Meyer D, Notman M. Medically unexplained symptoms: barriers to effective treatment when nothing is the matter. *Harv Rev Psychiatry.* 2015; 23(6): 438–448. <http://dx.doi.org/10.1002/9781119950905.ch18>. [PubMed: 26378814]
24. Fair B. Morgellons: contested illness, diagnostic compromise and medicalisation. *Sociol Heal Illn.* 2010; 32(4): 597–612. <http://dx.doi.org/10.1111/j.1467-9566.2009.01227.x>.

25. van Uden-Kraan CF, Drossaert CHC, Taal E, et al. Health-related Internet use by patients with somatic diseases: frequency of use and characteristics of users. *Inform Health Soc Care*. 2009; 34(1):18–29. <http://dx.doi.org/10.1080/17538150902773272>. [PubMed: 19306196]
26. Rains SA, Young V. A meta-analysis of research on formal computer-mediated support groups: examining group characteristics and health outcomes. *Hum Commun Res*. 2009; 35(3):309–336. <http://dx.doi.org/10.1111/j.1468-2958.2009.01353.x>.
27. Zrebiec JF. Internet communities: do they improve coping with diabetes. *Diabetes Educ*. 2005; 31(6):825–836. [PubMed: 16288090]
28. Griffiths KM, Calear AL, Banfield M. Systematic review on internet support groups (ISGs) and depression (1): do ISGs reduce depressive symptoms. *J Med Internet Res*. 2009; 11(3):1–25. <http://dx.doi.org/10.2196/jmir.1270>.
29. Harvey-Berino J, Pintauro S, Buzzell P, et al. Does using the internet facilitate the maintenance of weight loss. *Int J Obes Relat Metab Disord*. 2002; 26(9):1254–1260. <http://dx.doi.org/10.1038/sj.ijo.0802051>. [PubMed: 12187404]
30. Høybe M, Johansen C, Tjørnhøj-Thomsen T. Online interaction. Effects of storytelling in an internet breast cancer support group. *J Soc Interv*. 2009; 17:2.
31. Kaplan K, Salzer MS, Solomon P, Brusilovskiy E, Cousounis P. Internet peer support for individuals with psychiatric disabilities: a randomized controlled trial. *Soc Sci Med*. 2011; 72(1): 54–62. <http://dx.doi.org/10.1016/j.socscimed.2010.09.037>. [PubMed: 21112682]
32. Seeman, A. Master's Thesis. University of New Mexico; 2012. Disruption of ritual: doctor/patient interactions in the era of internet.
33. Barker KK. Listening to Lyrica: contested illnesses and pharmaceutical determinism. *Soc Sci Med*. 2011; 73(6): 833–842. <http://dx.doi.org/10.1016/j.socscimed.2011.05.055>. [PubMed: 21840638]
34. Auwaerter PG, Bakken JS, Dattwyler RJ, et al. Antiscience and ethical concerns associated with advocacy of Lyme disease. *Lancet Infect Dis*. 2011; 11(9):713–719. [http://dx.doi.org/10.1016/S1473-3099\(11\)70034-2](http://dx.doi.org/10.1016/S1473-3099(11)70034-2). [PubMed: 21867956]
35. Sadler, JZ. Diagnosis/Antidiagnosis. In: Radden, J., editor. *The Philosophy of Psychiatry: A Companion*. New York, New York: Oxford University Press; 2004. p. 163–179.
36. Rosenberg CE. Contested boundaries: psychiatry, disease, and diagnosis. *Perspect Biol Med*. 2006; 49(3):407–424. <http://dx.doi.org/10.1353/pbm.2006.0046>. [PubMed: 16960310]
37. Jagosh J, Donald Boudreau J, Steinert Y, MacDonald ME, Ingram L. The importance of physician listening from the patients' perspective: enhancing diagnosis, healing, and the doctor-patient relationship. *Patient Educ Couns*. 2011; 85(3):369–374. <http://dx.doi.org/10.1016/j.pec.2011.01.028>. [PubMed: 21334160]
38. Chew-Graham CA, May CR, Roland MO. The harmful consequences of elevating the doctor-patient relationship to be a primary goal of the general practice consultation. *Fam Pract*. 2004; 21(3):229–231. <http://dx.doi.org/10.1093/fampra/cmh301>. [PubMed: 15128679]
39. Auwaerter PG, Bakken JS, Dattwyler RJ, et al. Scientific evidence and best patient care practices should guide the ethics of Lyme disease activism. *J Med Ethics*. 2011; 37(2):68–73. <http://dx.doi.org/10.1136/jme.2009.032896>. [PubMed: 21097940]
40. Patel R, Grogg KL, Edwards WD, Wright AJ, Schwenk NM. Death from inappropriate therapy for Lyme disease. *Clin Infect Dis*. 2001; 31(4):1107–1110.
41. Kontos N, Freudenreich O, Querques J. Using a medical model with psychotic patients. *Am J Psychiatry*. 2006; 163(11):1466–1467.
42. Wessely, S., White, PD. There is only one functional somatic syndrome; *Br J Psychiatry*. 2013. p. 95–96. <http://dx.doi.org/10.1192/bjp.185.2.95>
43. Mattingly C. The concept of therapeutic emplotment. *Soc Sci Med*. 1994; 38(6):811–822. [http://dx.doi.org/10.1016/0277-9536\(94\)90153-8](http://dx.doi.org/10.1016/0277-9536(94)90153-8). [PubMed: 8184332]
44. Huibers MJH, Wessely S. The act of diagnosis: pros and cons of labelling chronic fatigue syndrome. *Psychol Med*. 2006; 36:895–900. <http://dx.doi.org/10.1017/S0033291705006926>. [PubMed: 16403245]
45. Smith GR Jr, Monson RA, Ray DC. Psychiatric consultation in somatization disorder. *N Engl J Med*. 1986; 314:1407–1413. [PubMed: 3084975]

46. Alghalyini B, Oldfield M. That sinking feeling. *Can Fam Physician*. 2008; 54(8):1576–1577. [PubMed: 19005133]
47. Bieber C, Muller KG, Blumenstiel K, et al. A shared decision-making communication training program for physicians treating fibromyalgia patients: effects of a randomized controlled trial. *J Psychosom Res*. 2008; 64(1):13–20. <http://dx.doi.org/10.1016/j.jpsychores.2007.05.009>. [PubMed: 18157994]
48. Barsky AJ, Ahern DK, Bauer MR, Nolido N, Orav EJ. A randomized trial of treatments for high-utilizing somatizing patients. *J Gen Intern Med*. 2013; 28(11):1396–1404. <http://dx.doi.org/10.1007/s11606-013-2392-6>. [PubMed: 23494213]
49. Allen LA, Woolfolk RL, Escobar JJ, Gara MA, Hamer RM. Cognitive-behavioral therapy for somatization disorder. *Arch Intern Med*. 2014; 166(14):1512–1518.
50. Freudenreich O, Kontos N, Tranulis C, Cather C. Morgellons disease, or antipsychotic-responsive delusional parasitosis, in an HIV patient: beliefs in the age of the internet. *Psychosomatic*. 2010; 51(6):453–457. [http://dx.doi.org/10.1016/S0033-3182\(10\)70736-2](http://dx.doi.org/10.1016/S0033-3182(10)70736-2).
51. Purkis ME, van Mossell C. Cancer as a contested illness: seeking help and treatment. *Contesting illness: processes and practices*. 2008:142–157.
52. Broom A. Virtually healthy: the impact of internet use on disease experience and the doctor-patient relationship. *Qual Heal Res*. 2005; 15(3):325–345. <http://dx.doi.org/10.1177/1049732304272916>.

FIGURE.

Electronic Support Groups and Doctor-patient Interactions Each Create An Explanatory Model for Patient Suffering. In The ESG, A Positive Feedback Loop Enhances As Each Individual's Embodied Experience is Reinforced by Similar Reports From Others. Another Bidirectional Interaction Exists Between The Embodied Experience And Certain Explanatory Models. In The Doctor's Office, An Individual's Embodied Experience is Emplotted Into Symptoms The Doctor Is Willing To Accept. There is an Interaction Here Between The Doctor's Training And Medical Knowledge And These Emplotted Symptoms. The Emplotted Symptoms Are Used To Create The Physician's Explanatory Model or Diagnosis, Which Itself Then Affects How The Patient's Symptoms Are Emplotted. Conflict About Explanatory Models Obscures The Shared Goals of the Physician And Patient.