

**ILLNESS WITHOUT A CAUSE—PATIENTS WITH
A CAUSE: ONLINE SELF-HELP/MUTUAL AID
ORGANIZATIONS FOR FUNCTIONAL SYNDROMES
IN THE UNITED STATES AND GERMANY***

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ABSTRACT

This article examines the goals and purposes of internet-based self-help/mutual aid organizations (SHOs) for people afflicted with functional syndromes. Online SHOs for functional syndromes in the United States and Germany are analyzed and compared. The analysis is guided by a distinctive conceptual framework combining medical sociology and self-help/mutual aid literature. The article contributes to the literature on online SHOs and health social movements by showing that online SHOs are dual purpose organizations: they assist sufferers and engage in advocacy. The SHOs also contribute to health social movements. The SHOs demand a biomedical explanation and treatment of the functional syndromes and use the Internet extensively to pursue their advocacy and educational goals. The particular perspectives and activities of the SHOs in Germany and the United States result from different concepts of health and disease as well as different advocacy venues. However, the American SHOs' viewpoint dominates.

*The article is based on the author's Ph.D. research.

INTRODUCTION

I couldn't accept that I had CFS. My condition was so grave that it was incomprehensible to me. Then, when I began to talk about it to colleagues and medical professionals, the injustice of not being believed and the stigma attached to CFS, , made me howl with rage (Vivian; The CFIDS Association of America, 2008).

Vivian suffers from chronic fatigue syndrome (CFS)—a functional syndrome. Other examples of functional syndromes are fibromyalgia (FM), irritable bowel syndrome (IBS), and tension headaches. These chronic conditions manifest themselves in a variety of subjective physical and psychological symptoms. The high prevalence of psychiatric problems among patients with functional syndromes supports the hypothesis that these diseases are “all in your head.” Vivian describes her symptoms as severe; yet, the legitimacy of the disease is contested because there are no known causes nor apparent pathology and many doctors reject biomedical interpretations of functional syndromes.

Vivian has particular needs stemming from the uncertainty and invisibility of the condition, and the skepticism of many doctors and social networks. She wants a meaningful explanation for her suffering. By exchanging her experiences with others, she may affirm the “reality” of her own experience in a self-help group.

Across the Atlantic, Andrea M. has similar experiences:

My fate—misdiagnoses in the beginning, an equally useless and tiring journey through physician's offices, insurmountable obstacles with insurance and bureaucracies—can hopefully be avoided for future CFS-patients. My advice for sufferers: get informed early and thoroughly . . .—and last but not least—contact a CFS- self-help organization (Translation by author) (Andrea M; Fatigatio, 1999).

This article examines the goals and purposes of internet-based self-help/mutual aid organizations (SHOs) for people afflicted with functional syndromes and compares online SHOs for functional syndromes in two similarly developed industrialized countries with different health care systems and different advocacy mechanisms. The analysis is guided by a distinctive conceptual framework that combines medical sociology and self-help/mutual aid literature. The internet pages of leading self-help organizations in Germany and the United States for patients with CFS, FM, and IBS were observed over the period of 1 year and analyzed for concepts of illness, purposes, and goals. This article seeks to answer the following questions:

- What purposes do online SHOs in Germany and the United States serve? How do they fit into the traditional classification schemes in the (self-help/mutual aid group) SHG/SHO literature?
- What kind of advocacy do online SHOs in Germany and the United States engage? Does the SHOs advocacy contribute to national level health social

movements which pursue recognition, increased research, and improved medical care of “their diseases”?

- What views of functional syndromes do the SHOs promote? Do the SHOs challenge the prevailing biomedical views in their respective countries?
- What are the differences between American and German SHOs for functional syndromes?

We first review the relevant literature on SHGs and SHOs, health social movements, and the role of the Internet in self-help/mutual aid in order to develop an appropriate conceptual framework. We then describe the societal context for German and U.S. SHOs—in particular, the health care system, cultural views of health and disease, and self-help/mutual aid. After a description of the methods, findings of the analysis of three German and six American online SHOs for functional syndromes are presented and compared. The article concludes by examining how the findings contribute to the literature on SHOs and to health social movements in medical sociology.

LITERATURE REVIEW

SHGs/SHOs: Single Purpose or Dual Purpose Organizations?

Self-help/mutual aid groups range from informal gatherings to more formalized self-help/mutual aid organizations (SHOs). SHOs are defined as charitable non-profit organizations which operate with a sizable budget to pursue the typical goals of self-help/mutual aid (Borkman, Karlsson, Munn-Giddings, & Smith, 2005). The special competence of the self-help/mutual aid groups is the sharing of first-hand experience of personal crises and coping with those crises. Often, the groups help to gain and deepen knowledge, complementing professional help; but SHGs can also generate alternative views, replacing professional help. SHGs and SHOs play an important role in cost containment in healthcare (Hurrelmann, 2003).

In their general overview of SHGs, Katz and Bender (1976) classified self-help groups in terms of their primary focus as either:

1. self-fulfillment or personal growth;
2. social advocacy;
3. alternative patterns of living; or
4. “outcast” haven or rock bottom groups.

More recently, SHGs are often classified as either member-oriented or social advocate groups. Self-help/mutual aid literature tends to focus on what participants gain from being in a SHG (see for example Humphreys, 2004; Rappaport, 1993; Wuthnow, 1994) rather than on their effects on the broader community.

Critics who have argued that SHGs tend to ignore the social, economic, and physical context that “caused” the afflictions of their members (for a summary see: Borkman, 1999) are not deeply knowledgeable of the goals of SHGs. For example, 12-step anonymous groups like Alcoholics Anonymous explicitly refrain from voicing opinions on external issues related to their affliction. More sophisticated researchers such as Riessman and Carroll (1995) claim that even purely member-oriented SHGs contribute to social change through the development of empowered individuals who reclaim some control of their lives through skepticism toward expert authority, and the communal support of the SHG.

SHGs and SHOs for health issues have grown dramatically since the late 1970s, primarily because of change in attitude toward medical authority, declining healthcare resources, and the increasing prevalence of chronic diseases. These groups pursue the interests of “consumer-patients” who become informed and actively participate in their treatment in order to control the disease process, their daily life, and their environment (Hurrelmann, 2003). By acquiring knowledge, these patients become experts and initiate change not only within their own lives but in the broader community. The AIDS epidemic is an example wherein lay people often had more scientific knowledge than “experts,” which enabled them to dramatically impact the political and social status of the disease and the priorities of the scientific community (Epstein, 1996).

Medical Sociology Analysis of Health Social Movements

SHGs and SHOs engaging in political activism to seek changes in health related issues are considered part of “Health Social Movements.” Brown and Zavestoski (2004) define “Health Social Movements” as collective challenges to existing medical practice, research, health policies, and values governing healthcare. Health social movements include a variety of groups, organizations, and networks which typically deal with issues such as health disparities, contested illnesses, disability, access to healthcare, and the experience of illness. Classic examples are the Women’s Health and the AIDS movements. “Embodied Health Movements” are a particular type of health social movements which arose in response to bio-ethical debates and increased public awareness of the limitations of medical knowledge. Embodied health movements address “contested illnesses”—medically unexplained illnesses or illnesses with disputed environmental explanations (Brown & Zavestoski, 2004). They emphasize the individual illness experience and critique the medical and scientific authority structures typically fighting for improved treatment and research.

Functional syndromes are “contested illnesses.” Zavestoski et al. (2004) and Millen (2001) argue that activism in the case of medical uncertainty could lead to a different conceptualization of medicine. On the other hand, Barker (2008) suggests that patients with Fibromyalgia seek “physician compliance” in order to have

their ailment defined as a biomedical disease. These patients “self-medicalize” their suffering—framing a condition or problem as a biomedical disease.

In this article the medical sociology interest in patient advocacy is considered by examining online SHOs for functional syndromes in the United States and in Germany. Until recently, medical sociologists who study social movements changing laws and cultural viewpoints have rarely been interested in SHGs (Borkman & Munn-Giddings, 2008; Brown & Zavestoski, 2004; Epstein, 1996; Kroll-Smith & Floyd, 1997) and the self-help/mutual aid literature tends to be separate from the social movement literature and, less understandably, has paid little attention to SHOs (Borkman et al., 2005).

The Role of the Internet in Advocacy and Social Change

New media, like the Internet, play an important role in social movements (Arns, 2002; Gillet, 2004; Leggewie, 2002; Slevin, 2000). With the help of the internet, information can be quickly and efficiently disseminated; public images can be created; scientific information can be filtered and translated into lay language; and geographically dispersed groups can be connected. The Internet is a particularly important medium of communication for sick, disabled, and socially isolated people (Slevin, 2000). Virtual communities furnish advice and emotional support for sufferers; patients with multiple sclerosis, AIDS, or CFS are frequent users of online self-help groups (Fetto, 2000).

The Internet can also affect the doctor-patient relationship. Patients use the Internet to gather health information in preparation for doctor visits, to locate doctors, and to get doctor ratings and second opinions. Doctors use the Internet as a medical technology and a means of communication. It has been argued that the Internet could undermine the relationship of trust between doctors and patients, ultimately leading to a further split between patients and doctors (McClellan, 2004).

This article will contribute to the literature on SHGs/SHOs by:

1. examining the goals and purposes of online SHOs within an innovative conceptual context that combines medical sociology literature and self-help/mutual aid literature;
2. providing some empirical evidence to the literature on online SHOs;
3. examining the role of the Internet for SHOs;
4. providing comparative findings on online SHOs for functional syndromes in similarly developed industrialized countries with different healthcare systems and different advocacy mechanisms; and
5. examining whether SHOs for diseases plagued by medical uncertainty challenge or conform to biomedical interpretations.

SOCIETAL CONTEXTS: UNITED STATES AND GERMANY

Self Help/Mutual Aid in Germany and the United States

Specific historical, social, and cultural processes influenced the development of German self-help/mutual aid groups and organizations. Despite initial resistance from medical professionals, self-help/mutual aid found increasing acceptance in the 1980s in response to growing consumerism and rising healthcare costs. Today, SHGs are partially funded by the German sickness funds and supported by state-funded clearinghouses (*Kontaktstellen*; Matzat, 2001). Just as in the United States, there is a proliferation of different types and forms of groups covering disability, disease, and psycho-social issues such as relationships, family, marriage, life crises, and social integration. It is estimated that 70,000 to 100,000 SHGs exist in Germany and that 5% of the adult population attend a self-help/mutual aid group. In addition to SHGs, 355 nationally operating SHOs and about 270 self-help clearinghouses (*Kontaktstellen*) exist in Germany. The central national clearinghouse for SHGs, SHOs, and local and regional clearinghouses is the *Nationale Kontakt-und Informationsstelle zur Anregung und Unterstützung von Selbsthilfegruppen* (NAKOS; NAKOS, 2008).

SHGs for the functional syndromes CFS, FM, and IBS can be found throughout Germany: websites list 75-88 SHGs for FM (Deutsche Fibromyalgie-Vereinigung, 2008; Fibromyalgie-arbeitsgemeinschaft.de, 2008), 12 SHGs for IBS (Helpster.de. Das Gesundheitsnetzwerk, 2008; Kommitt.Netzwerk Selbsthilfe, 2008; Selbsthilfe-bei-Reizdarm, 2008), and 14 SHGs for CFS (CFS-Info, 2008; Fatigatio, 2008). These numbers do not accurately reflect the actual number of SHGs in Germany as many SHGs tend to be informal gatherings and might not be included in formal samplings (Matzat, 2001).

In the United States, self-help groups for patients with chronic diseases, psychiatric diseases, disabilities, and for relatives of patients have existed since the 1940s (Powell, 1990). In addition to SHGs, self-help centers and national clearinghouses were established in the 1970s. It is estimated that 8 to 11 million people, comprising 3% to 4% of the American population, visited self-help groups in the United States in 2000 (Fetto, 2000). Most states in the United States have local SHGs for functional syndromes. In 2004, 186 SHGs for CFS, many of which also supported FM sufferers, existed in 41 states (Centers for Disease Control, 2004). The National Fibromyalgia Association lists 171 local FM SHGs, some of which include CFS sufferers, in 40 states (National Fibromyalgia Association, 2004). The states without SHGs were typically rural areas with a low population density (e.g., Montana, Wyoming), or small states (e.g., Rhode Island) whose neighboring states offer a number of SHGs. SHGs for IBS are less common. The International Foundation for Functional Gastrointestinal Disorders only knew of 10 SHGs in eight states (IFFGD, 2004); the Irritable

Bowel Syndrome Self-Help and Support Group lists nine local SHGs, most of which are in large metropolitan areas, in six states (IBS Self Help and Support Group, 2004a).

Health Care in Germany and the United States

The United States and Germany have quite different economic and political structures. Americans tend to value a free market economy and mistrust government whereas Germans have higher esteem for government and its bureaucracy. While the United States and Germany developed different styles of medical practice, there has also been a considerable reciprocal influence (Starr, 1982). The technological and pharmaceutical standard is comparable (Roghman, 1989). The German population is more homogeneous has a lower fertility rate, and a higher proportion of older people than the United States.

In the past few decades, demographic trends, inflation, new disease trends, technological progress, and the increased use of diagnostic and therapeutic interventions led to a cost explosion in healthcare in both countries. America has the most expensive healthcare system in the world, but Germans have better health as based on a cross-national comparison of several health indicators which places America well below Germany. The poorer health of Americans is the result of gross inequalities in healthcare, lack of health insurance coverage, and differences in health between population groups. Low-income populations, minorities, immigrants, rural populations, and inner-city populations in large metropolitan areas have poorer health than other groups (see Table 1).

Views of Health and Disease

In both Germany and the United States, science-based allopathic medicine dominates. The American view of disease is predominantly mechanistic and based on the belief that external forces cause disease which, paired with American pragmatism and a “can-do” attitude, results in an aggressive approach to diagnosis and treatment. In Germany, a more holistic view of disease prevails. Emotions are believed to play a pivotal role in health and disease, and internal processes are often seen as causing disease. This leads to a more open attitude toward alternative approaches and an emphasis on the psychological factors of disease (Payer, 1988). There are some scholars who argue that a psychosomatic model of disease currently dominates healthcare in Germany (Ortmann, 2001).

The Interpretation of Functional Syndromes in the German and the U.S. Medical Literature

The more holistic view is evident in the German medical literature on functional syndromes. While the American diagnostic criteria are often applied, it is supplemented by other criteria developed by German doctors (Häuser & Lempa, 2004;

Table 1. Characteristics of U.S. and German Health and Healthcare Systems

Dimension	United States	Germany
Total population	302,841,000	82,641,000
Life expectancy at birth m/f	75/80	77/82
Probability of dying under age 5 (per 1000 live births, 2005)	8	5
Total expenditure on health per capita (Intl.\$, 2005)	6,347	3,250
Total expenditure on health as % of GDP (2005)	15.2%	10.7%
Percent of uninsured (2006)	15.8%	0.2%
Leading cause of death	Ischemic heart disease	Ischemic heart disease
Nature of healthcare system	Mixed: free market/government insurance	Mixed: free market/government insurance
View of health and disease	Mechanical	More holistic

Source: Payer, 1988; WHO, 2008; U.S. Census Bureau, 2006.

Hoffmann, 2003; Müller & Lautenschläger, 1990). The commonly used term “somatoform disorder” for functional syndromes points to a tendency also to attribute functional syndromes to psychological problems. The German literature includes descriptions of the “typical” psychological and social characteristics of patients with functional syndromes: neatly dressed, overcommitted women torn between family and paid work, female teachers, or people under performance pressure (Berg, 2003; Brückle, 2004; Riem, 1999). The German medical literature lists *psychosomatische Grundversorgung* (psychosomatic basic care) as one of the main treatment components for functional syndromes. This approach includes psychotherapy and differential diagnoses. Most medical articles suggest a biopsychosocial treatment approach for functional syndromes (Berg, 2003).

American medical textbooks emphasize the plethora of non-objective physical and psychological symptoms, and the absence of apparent pathology. The literature consistently points to the high prevalence of psychiatric problems among

patients with functional syndromes. The preferred treatment option is a combination of anti-depressants, low-grade exercise, and cognitive-behavioral therapy (Braunwald, Fauci, Kasper, Hauser, Longo, & Jameson, 2001). Doctors attribute the causes of functional syndromes to strictly biophysical pathologies, to psychological and psychiatric problems, to the interplay of biological, psychological and social factors, and/or to medicalization (Hearn, 2006).

METHODS

Given the similarities among functional syndromes, a selection of functional syndromes with high prevalence rates and high public recognition seemed justified. Chronic fatigue syndrome (CFS), fibromyalgia (FM), and irritable bowel syndrome (IBS) clearly dominated the scientific and public discussion in 2004 (Medline, 2004; Newspaper Source, 2004).

The cross-cultural comparison of online SHOs for functional syndromes is based on case studies of six American SHOs and three German SHOs. SHOs were included in the analysis if they met the following criteria:

1. the organization is a leading online, national SHO, representing many patients and patient groups;
2. the SHO raises awareness and engages in advocacy; and
3. the organization has been established for 10 years, so the success of its efforts can be evaluated.

To locate the leading online SHOs for CFS, FM and IBS in the United States and Germany, the search engines Google, Lycos, DogPile, and Alta Vista were used to search for the terms “Chronic Fatigue Syndrome and Self-Help Group,” “Chronisches Müdigkeitssyndrom und Selbsthilfe” (Germany), “Fibromyalgia and Self-Help Group,” “Fibromyalgie und Selbsthilfe” (Germany), “Irritable Bowel Syndrome and Self-Help Group,” and “Reizdarmsyndrom und Selbsthilfe” (Germany). The search on Google alone resulted in 182 000 websites for “Chronic Fatigue Syndrome and self-help group,” 125,000 for FM, 84,2000 for IBS (Google.com, 2004). The first hundred results of the 24 different searches, amounting to 2,400 results, were more closely scrutinized. SHOs from foreign countries, organizations for other illnesses, Internet discussion groups, e-mail groups, commercial websites, government websites, and websites posted by individuals were excluded. The most frequently listed and cross-listed organizations were identified. Their existence was verified.

The remaining American organizations were then looked up in the online sourcebook of the “American Self-Help Clearinghouse,” which maintains a databank with national and international online self-help groups (American Self-Help Clearinghouse, 2004). SHOs that were listed in the sourcebook remained in the selection pool. Purely local organizations, organizations less than 10 years old, and organizations not engaging in advocacy and awareness activities were

excluded. The Massachusetts CFIDS Organization was not listed in the source-book but met all selection criteria and was therefore included.

The search for the German patient organizations yielded a high number of support groups led by professionals. Only one organization for CFS, one for FM, and one for IBS fit the selection criteria which eliminated the need to confirm the leading role of the organizations. The German organizations were 10, 8, and 7 years old at the time of the study. To include the German SHOs, the search criteria had to be adapted to “in existence for at least 7 years.” The lower number of online SHOs in Germany can be understood through population and communication statistics: Germany’s population is about one-fourth of the U.S. population (82 million vs. 303 million); in Germany 38.6 million users have access to 200 Internet service providers and 16.494 million hosts; in the United States, 208 million users can access 7,000 providers and 282 million hosts (CIA, 2008). According to a survey, only 32% of Europeans and 43% of American use the Internet to access health information (Eaton, 2002). The German organizations were checked against the databank of NAKOS, the national German clearinghouse for SHGs and SHOs (NAKOS, 2008a).

The online publications of these SHOs are analyzed using a qualitative approach. The documents are also the sites of controversy: they challenge medicine, the public, and the government; and they are disputed by the medical profession. Sufferers, relatives, medical personal, administrators, insurance agents, and politicians have unlimited access to the information posted on the Internet; and they are also targets of the SHOs’ activism (see Table 2).

Table 2. Selected American and German Online Self-Help Organizations for CFS, FM, IBS

Chronic Fatigue Syndrome:

- The CFIDS Association of America (U.S.)
- The Massachusetts CFIDS Association (U.S.)
- Fatigatio e.V. (Germany)

Fibromyalgia:

- The National Fibromyalgia Partnership, Inc. (U.S.)
- The Fibromyalgia Network (U.S.)
- Deutsche Fibromyalgie Vereinigung (DFV) e.V. (Germany)

Irritable Bowel Syndrome:

- IFFGD – International Foundation For Functional Gastrointestinal Disorders (U.S.)
 - Irritable Bowel Syndrome Association/IBS Self-Help and Support Group (U.S.)
 - Deutsche Reizdarmselbsthilfe e.V. (Germany)
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The online publications of the patient organizations were analyzed using a modified grounded theory approach (Strauss & Corbin, 1990)—looking for emergent and recurrent themes, which were organized into categories. Government documents, such as minutes of meetings or public announcements, were used as supporting evidence of the organizations' activities. Information about the history and organization of the SHOs was gathered from publications on the websites. Additional information about the U.S. organizations was found at "Guidestar," a databank of charitable organizations (Philanthropic Research Inc., 2004); further information about the German SHOs was found at the website of Nationale Kontakt- und Informationsstelle zur Anregung und Unterstützung von Selbsthilfegruppen (NAKOS) (NAKOS, 2008b).

Given the fast-paced nature of the Internet, a long-term observation of the websites seemed appropriate and the websites were closely observed from May 2003 through May 2004. The contents of the websites changed only minimally over the period of observation, the majority of the changes being in design. The websites vary by size, design, and organization; some contain interactive elements. Most organizations address sufferers, doctors, journalists, and the public separately. All websites were again checked and observed in May 2008. Updates were included in the analysis.

Four of the six selected American SHOs had started as local self-help groups and had developed into leading national patient organizations. The patient organizations differ by size, revenues, and organizational structure. The CFIDS Association, the Fibromyalgia Partnership and the IFFGD are formal organizations with employees, led by a president and a council. The Massachusetts CFIDS Association is staffed entirely by volunteers. The Fibromyalgia Network and the IBS Self-Help Group are run by their founders and are not declared as 501C3 public charities. Revenues and expenses of the organizations run from ten thousands to millions of dollars. The CFIDS Association and the IFFGD have the biggest budgets. The main sources of revenue are membership fees and donations. Revenues pay for the websites, telephone hotlines, publication and dissemination of information materials, the organization of research symposia, awareness campaigns, and lobbying efforts. Some of the organizations fund research projects.

The three selected German SHOs are *eingetragene Vereine, e.V.* (registered organizations), and *gemeinnützige Vereine* (charitable organizations) and were the only nationally active online SHOs in 2004. The organizations were founded by sufferers and activists. A president and a board typically lead the organization; the IBS organization also has a scientific council to advise their leadership. The FM and CFS organizations were funded solely through memberships and donations. The IBS organization also has commercial sponsors. No information was available on the amount of revenues and expenses. The German organizations maintain websites similar in size and design to the American organizations. Information and advice is addressed to sufferers, doctors, and the public, and is provided through newsletters, journals, brochures, online publications, and telephone hotlines.

FINDINGS

What Purposes Do Online SHOs in Germany and the United States Serve?

Vivian and Andrea have debilitating bodily problems and need help, yet the medical profession is reluctant to provide help because medicine has no explanation for their symptoms.

The Association was a lifesaver for me. I discovered that there was a place that offered accurate, reliable information, a place that made me feel like I wasn't alone, a place where people worked every day on my behalf. With every available scrap of energy I had, I used the resources of the Association to read about the research findings, possible causes and treatment options (Vivian; The CFIDS Association of America, 2008).

Most of the SHOs in this study started as local SHGs and still pursue the typical goals of self-help/mutual aid such as assisting and empowering sufferers, and overcoming their isolation. But, the SHOs also fight for insurance coverage, disability benefits, and the introduction of medications to treat functional syndromes. Demands are aimed at physicians, legislators, and the public. Educating sufferers serves the dual purpose of helping sufferers and turning them into advocates. The more formalized organizations also have an advocacy role, raising awareness and fighting for the acceptance and recognition of their diseases. They ask for improved medical care, more patient-oriented and solution-oriented research, and increased research funding.

This IBS Support Group works to educate those who are living with IBS and to increase awareness about this and other functional gastrointestinal disorders. Our goal is to educate and provide support for people who have IBS, to make ourselves more noticeable to the medical profession, and to use our membership to encourage both medical and pharmaceutical research to make our lives easier (IBS Self Help and Support Group, 2004a).

The SHOs give online advice to sufferers addressing medical, social, psychological, and legal aspects of their disease. All organizations post official diagnostic criteria, personal illness accounts, new research findings, and listings of current research grants and trials. A number of free articles can typically be found in the "Archives" and full publications are usually for sale. Much of the information on the websites is accessible to everyone, which is a marked difference from face-to-face SHGs where typically only members receive information. Paid membership usually includes access to addresses of "good" doctors and local self-help/mutual aid groups as well as subscription to the newsletters and journals which report about new research findings, research projects, newly developed treatments, conferences, relevant political actions, and news about the organization.

In contrast to the American online SHOs, much of the information of the German SHOs is only available to paying members. Content tends to be similar though the international orientation of the German organizations is obvious by the number of articles from and about foreign countries in their publications; translations of several American or British publications are posted on the website of the German CFS SHO.

The advice for sufferers is very similar on all websites—some variations are due to the specific symptoms of the particular syndromes. The main advice for patients is to become informed and to stay informed.

Education is one of the most important components in the treatment of CFIDS and FMS and knowledge will empower you (The Massachusetts CFIDS Association, 2003).

Patients are urged to become consumer-patients: to use the online information for educating their physicians; to educate others; and to ask for help and understanding; to join real or virtual communities to overcome social isolation. The websites emphasize the right to “shop” for a doctor and their responsibilities as patients: the need to cooperate; to behave responsibly; to entertain reasonable expectations; and to understand the problems of physicians because of the complex and obscure nature of their diseases.

CFS and FM sufferers get very detailed information about the necessary documentation for obtaining disability and insurance benefits. (IBS patients in the United States are not entitled to disability benefits.) The organizations stress the importance of a cooperative physician and urge sufferers to be persistent and to systematically document their symptoms and the impacts from the beginning. Moreover, the websites list the symptoms required to “pass” a disability test, legal rights, needed documentation, and helpful addresses, including those of “sympathetic lawyers.”

In What Kinds of Advocacy Do Online SHOs in Germany and the United States Engage and Does Their Advocacy Contribute to National Level Health Social Movements?

Building recognition of CFIDS as a serious, widespread medical disorder; Securing a meaningful response to CFIDS from the federal government; Stimulating high quality CFIDS research; Improving health-care providers’ abilities to detect, diagnose and manage CFIDS; and Providing information to persons with CFIDS and enabling the CFIDS community to speak with a collective voice (The CFIDS Association of America, 2003a).

SHOs for functional syndromes are patient interest groups. Interest groups are permanent organizations deliberately pursuing specific goals and purposes which may be idealistic or material (Alemann, 1989). Service is an important component of contemporary interest groups (Alemann, 1989). The legal status of

the U.S. SHOs is typically that of a 501C3 non-profit organization, a form of tax-exempt charity. German SHOs are organized in similar ways. The groups operate nationally.

Demands are pursued through education about the illness. The SHOs post information on the Internet, publish newsletters, brief the media, and organize public campaigns. Most organizations sell items promoting awareness like posters, pins, or T-shirts. The SHOs organize and coordinate local, regional, and national “Awareness Days” and “Awareness Months.” They educate physicians in the form of online continuing education credits, publications, poster exhibits at medical conferences, or research symposia. Grassroots activities are aimed at senators, representatives, or government officials. The American SHOs take part in “Lobby Days” on Capitol Hill, for which they provide volunteer training sessions. The organizations time letter campaigns to coincide with important deadlines, committee meetings, or congressional sessions: pre-formulated letters and the addresses of legislators and government officials are posted on the websites and sufferers are urged to send in as many letters as possible. Political activism made simple: just fill in the blanks and send off.

The more affluent organizations hire lobbying firms to plan and coordinate their lobbying activities. Members of some American SHOs also sit on government committees and appear in hearings.

The American SHOs claim several accomplishments: increased awareness about functional syndromes among physicians and the public; the establishment of diagnostic criteria for CFS, FM, and IBS; research funding; the shaping of research agendas; and securing disability rights for sufferers. The organizations also claim that they were instrumental in establishing CFS and FM as disease categories in the 10th revision of the International Classification of Diseases (ICD-10). The ICD is the international standard diagnostic classification for epidemiology, clinical use, and health management purposes. The ICD is created and published by the World Health Organization (WHO, 2009). The IBS organizations claim that Lotronex, a medication used to treat IBS, was re-introduced on the American market due to their efforts.

According to information on the websites of the American SHOs and government documents, it is mainly the sufferers and their SHOs that exert political pressure; they have some support from a small group of physicians, medical researchers, and politicians. There is little potential for financial gain for pharmaceutical or healthcare companies and, consequently, none of the powerful interest groups in the United States have shown any interest in their cause. Despite their small size and limited status, the SHOs have succeeded primarily through enlisting support of a few senators or representatives. For example, some activists were former employees of a senator who later agreed to support their efforts. Other fortuitous circumstances have helped patient organizations: in the 1990s, CFS was almost forgotten when news about a mysterious disease among Gulf War veterans emerged and was later identified as CFS. The U.S. Department of

Defense invested funds into CFS research. A few years later, a political scandal brought CFS back into the spotlight when it was exposed that the CDC funds earmarked for CFS had been channeled into other areas of research. The money was refunded, new research programs were developed, and CFS was in the news again (Centers for Disease Control, 2000).

The German SHOs also plan and coordinate lobbying activities. Mailing campaigns and calls for actions are a new feature on the websites in 2008; no such links were posted in 2004. Little information about the mechanisms and targets of the lobbying efforts is available on the German websites; but the goals of the lobbying efforts are very similar in both countries.

What Views of Functional Syndromes Do the SHOs Promote? Do the German and American SHOs Challenge the Prevailing Biomedical Views in Their Countries?

CFIDS is a serious and complex illness that affects many different body systems. No cause or cure has been found yet (The CFIDS Association of America, 2003b).

IBS is not caused by stress. It is not a psychological or psychiatric disorder. It is not, “All in the mind” (AboutIBS.org, 2004).

The SHOs are proponents of a purely scientific biomedical model for functional syndromes. Biomedicine is expected to explain and treat the syndromes. The SHOs strongly reject psychological, psychiatric, or holistic explanations for their diseases; psychological and social problems are considered consequences of the diseases. The only exception is the German SHO for IBS which postulates that IBS is caused by stress and psychological problems (Deutsche Reizdarmselbsthilfe, 2004), an explanation in line with the German medical literature.

The German and American SHOs emphasize the widespread prevalence of the diseases, the severity of the symptoms, and the debilitating effects of the illnesses. The SHOs in each country are clearly connected and collaborate with each other which is obvious from their many cross-references, links, and shared information.

The American SHOs for CFS reject the name “Chronic Fatigue Syndrome” as trivializing. They suggest using the British label, Myalgic Encephalitis, or the name “Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS).” Both terms imply organic problems stemming from infections or auto-immune dysfunctions. According to the German SHO *Fatigatio*, CFS is caused by dysfunctions of the immune system (Fatigatio e.V., 2004).

The biomedical model for functional syndromes is underlined by the extensive use of medical jargon and medical information on the websites. But the information posted on the websites is not always in agreement with the medical literature. For example, the SHOs tend to list more symptoms, symptoms tend to be more severe, and tend to occur more frequently than indicated in the medical literature. The SHOs interpret medical information from their point of view and

use it for their goals, shifting the boundaries between expert and lay knowledge. Lay people become experts (Aronowitz, 1998; Barker, 2008; Epstein, 1996; Kroll-Smith & Floyd, 1997; Zavestoski et al., 2004). The authentic experiences of patients—such as the suffering and the impact of the diseases on daily life—are used to underline the scientific-biomedical explanation.

In order to have their suffering recognized as an organic disease, sufferers need a biomedical diagnosis. Finding a “good doctor” is therefore very important. Patients are also told to scrutinize their physicians. When confronted with “ignorant” physicians, patients need to take initiative.

If your physician does not view these as real entities, you need to correct that view or see someone else (AboutIBS.org, 2003).

But the SHOs also advise patients to stay with their physician. Should patients switch doctors, they would have to start all over again in educating their physician and building a good relationship. Staying with one physician also has the advantage of consistent documentation of the disease process which might be helpful when applying for disability or social security benefits.

Another indication of a deliberately chosen biomedical interpretation is the scant attention paid to alternative treatments on the websites. The consistent advice to sufferers in regard to alternative or complementary medicine is to be open but skeptical and to be under the close supervision by a biomedical physician. Patients with chronic pain syndromes, especially patients with FM, are known to be frequent users of alternative and complementary approaches (Wahner-Roedler, Elkin, Vincent, Thompson, Oh, Loehrer, et al., 2005). The view of the SHOs in regard to alternative medicine is obviously not representative of all sufferers. SHOs might promote an exclusive biomedical disease model for pragmatic reasons such as insurance coverage, research dollars, status as a “disease,” but patients might also display a culturally accepted view of disease. In his historical work on functional syndromes, Shorter postulates that the changing manifestations of functional syndromes are in line with the culturally accepted symptoms of disease in a specific historical era (Shorter, 1993).

The strong rejection of psychiatric explanations is surprising. Psychiatry is a recognized medical specialty providing a disease model, diagnostic labels, and effective treatments for functional syndromes. Patients would be able to receive recognition of their ailments as a disease and adequate medical care. The negative attitude toward psychiatry could be the result of the persistent stigma of psychiatric disorders and/or from the strong conviction of patients that they suffer from an organic illness. Even though the SHOs reject psychological causes, psychological, holistic, and alternative approaches are listed as treatments for functional syndromes on their websites.

It is obvious that the SHOs participate in the medicalization of the experiences of sufferers with functional syndromes. Medicalization is a process in which a

condition or behavior is defined as a medical problem requiring medical treatment (Conrad & Schneider, 1980). Paradoxically, the SHOs for CFS, FM, and IBS challenge biomedicine by conforming to the biomedical model. The SHOs were formed in response to the problems sufferers encountered when they were trying to obtain medical help and many doctors did not agree with a biomedical explanation of their symptoms. Authors have pointed to a tendency among medical doctors to attribute functional syndromes to psychological causes (Aspring & Narvanen, 2003; Banks & Prior, 2001; Barker, 2006), or a variety of explanations including psychological or psychiatric, organic, biopsychosocial, and sociological (Hearn, 2006).

What are the Differences between American and German SHOs for Functional Syndromes?

SHOs in Germany also rely on the Internet for mutual support and for voicing their interests. The German organizations have a stronger international orientation than their American counterparts and networking and communication with patients and patient organizations in other countries is one of the explicit goals of the organizations. The topics, the advice, and the demands of the German SHOs are very similar to the American SHOs. The German SHOs only list the diagnostic criteria for CFS, FM, and IBS acknowledged in the United States, ignoring the other diagnostic options available in Germany. Differences between the American and the German websites can be found in regard to treatment options with the German organizations for FM and IBS listing more alternative treatments, such as relaxation, physical therapy, Ayurveda diet, Feldenkreis, or massages, than their American counterparts. This reflects the greater propensity of Germans to utilize alternative and holistic approaches (Ortmann, 2001). The German SHO for CFS, following the American example, avoids any references to alternative treatments.

The advice for sufferers is very similar: the importance of education is emphasized; the patients are urged to be active consumers; addresses of “good” doctors are exchanged; and detailed information on how to obtain disability and social security benefits is listed. The German SHO for IBS strongly recommends lifestyle changes, including changes in workplace and in personal relationships.

German and American SHOs engage in political activism, but operate in different frameworks. In the US, interest groups have long been a part of the political process. In Germany, the political parties tend to integrate various interests and legislators typically have a strong allegiance to their party. Germany also has a hierarchical system of lobbying: only federal associations, registered as interest groups with the German *Bundestag* (Lower House) and the German *Bundesregierung* (Federal Government), contact legislators. Activists in Germany thus typically address the executive and government departments directly. They also try to exert pressure through public opinion (Alemann, 1989).

Just like their American counterparts, the German SHOs for functional syndromes plan and coordinate lobbying activities to pursue increased awareness, research funding and access to benefits.

DISCUSSION AND CONCLUSION

The German and American online SHOs for functional syndromes are similar to SHGs in that they provide support—sharing of information, stories, emotions, and community—but differ dramatically from face-to-face groups in access. Anyone with an interest in functional syndromes can access the websites which are used in both countries for extensive, relentless advocacy as well as support for sufferers. The SHOs are not interested in complementing or replacing professional help: they are *instructing* the medical profession and legislators on *how* to define and *how* to help sufferers with functional syndromes.

The SHOs represent the collective actions of patients who feel neglected by medicine and society and can thus be classified as interest groups of “Health Social Movements” and more specifically of the “Embodied Health Movement” (Brown & Zavestoski, 2004). Despite accusing biomedicine of inadequate recognition, diagnosis, and treatment, the SHOs promote exclusive biomedical interpretations of FM, CFS, and IBS: the diseases are to be understood as serious organic pathologies; modern biomedicine is expected to diagnose and treat these diseases. Once a biomedical explanation for functional syndromes is found, the SHOs will have completed their work. This perspective is not open for further discussion; social, economic, and physical contexts are ignored; the lifestyle in modern societies is not questioned. The German SHO for IBS is an exception and there is greater willingness in Germany to list alternative treatments for IBS and FM.

The SHOs actively medicalize the experiences of sufferers: they pursue the transformation of personal experiences into official disease classifications. The organizations do not agree with new developments in medicine such as the integration of psychosocial aspects and the increasing acceptance of alternative medicine. The findings of this article differ from the findings of Zavestoski et al. (2004) and Millen (2001). SHOs for CFS, FM, and IBS do not broaden the narrow biomedical conceptualization of disease. On the contrary, the SHOs seek “physicians’ compliance” in the self-medicalization of their suffering as Barker (2008) suggested. Reasons for this standpoint might be pragmatism, but the severe symptoms, the organic nature of the symptoms, and the discrepancy between the medical information and the information of the SHOs could be a reflection of the specific experiences of sufferers. A pragmatic reason for the strong rejection of psychological and psychiatric explanations might lie in the spotty and inadequate psychological/psychiatric care in the United States (Weitz, 2004). In the United States, patients with functional syndromes are referred to psychologists or psychiatrists when physicians do not find any legitimate physical disease.

But in order to find adequate help, patients need to be diagnosed with an organic disease. Another interpretation of the purely biomedical model of disease propagated by the SHOs is that individuals today have internalized biomedical concepts of disease and health (Foucault, 2002; Gerhardt, 1991).

Riessman and Carroll's argument that SHGs empower individuals who then contribute to social change can be applied to SHOs for functional syndromes. The SHOs contribute to changes in the patient-physician relationships by providing detailed medical information, and encouraging patients to demand certain tests and treatments, the role of the physician is redefined to "medical consultant." The patients and the SHOs have had impact on physicians as evidenced in the heated debates in medical journals (Hearn, 2006). It also confirms what McClellan (2004) suspected, that empowerment of patients contributes to a further split between patients and doctors—especially with those who do not agree with the patients. The impact on the medical profession is furthered by any and all advocacy successes of the SHOs lobbying efforts through the allocation of research funds, the classification of diseases, the granting of social security benefits, and the planning of research agendas.

The viewpoint of the SHOs is not representative of all sufferers who utilize much more alternative medicine than would be recommended on the websites. However, it can be safely assumed that the organizations have some definitional power over fellow sufferers (Barker, 2002). A "patient elite" might influence the sufferers' understanding of their ailment. Not only are the sufferers influenced: a specific presentation of the disease is seen in medical practice and medical research. The influence of SHOs could thus have far reaching consequences. The interpretations of FM, CFS, and IBS propagated by the SHOs journey from the Internet to sufferers, from patients to physicians' practices, from clinical presentation to conferences and medical journals, and from scientific debate to government agencies, where they are turned into official diagnostic criteria and research programs. Medicine could be biased in favor of a "patient elite" while neglecting the experiences of other patient populations.

Cultural concepts of disease and the organization of the healthcare system influence how functional syndromes are understood and dealt with, but the issues are very similar in Germany and in the United States: there are problems with diagnosis and treatment of functional syndromes, medical uncertainty, the application of evidence-based medicine, and difficult doctor-patient relationships. There are three primary differences when comparing the German and U.S. online communities for functional syndromes. Germany's sites are:

1. much more international in scope with links to sites and information in other countries;
2. more limited to members only; and
3. more open to alternative treatment options—only the CFS avoids reference to alternative treatments.

This article contributes to the literature on online SHOs, SHGs, and embodied health social movements by providing evidence that SHOs are dual purpose organizations; impact and success of these SHOs are mainly due to the extensive use of the Internet. The medicalization of their syndromes gives rise to the paradox that the biomedical model may impede the health and morale of the sufferers. The comparison of U.S. and German SHOs reveals that context has some bearing on the perspectives and the mechanisms of pursuing goals.

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