Small Wins Matter in Advocacy Movements: Giving Voice to Patients

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Abstract In this article, the various players are delineated in a story of a contested illness and patient advocacy, played out within the corridors of federal power. It is suggested that the mistreatment and negative attitudes that health care providers and others have towards those with chronic fatigue syndrome (CFS) is possibly due to the social construction of this illness as being a “Yuppie flu” disease. Institutional factors are identified that created these norms and attributions, as well as the multiple stakeholders and constituent groups invested in exerting pressure on policy makers to effect systemic change. This article also provides examples of how the field of Community Psychology, which is fundamentally committed to based on listening to and giving voice to patients, is broadly relevant to patient activism communities. This approach focused, over time, on epidemiological studies, the name, the case definition, and ultimately the change in CFS leadership at the Centers for Disease Control and Prevention. Keys to this “small wins” approach were coalition building, use of “oppositional experts” (professionals in the scientific community who support patient advocacy goals) to challenge federal research, and taking advantage of developing events/shifts in power. Ultimately, this approach can result in significant scientific and policy gains, and changes in medical and public perception of an illness.

Keywords Social change · Patient advocacy · Community coalitions · Chronic fatigue syndrome · Myalgic encephalomyelitis

Background

Patient advocacy movements draw on the examples of the women’s health, environmental health and occupational health movements to achieve legitimization of a particular illness, direct resources to research and patient care, and influence public policy. For Freire (1970), change begins by helping people identify the issues they have strong feelings about, then helping them search for solutions to their problems in an active way. Following the social justice tradition, these movements present arguments for fairness and rights, but they also draw on the language of science to make their claim (Moritsugu et al. 2009). Typically responses entail “removing scientific, technical, and medical forms of expertise (and sometimes one or two experts) from traditional institutions and locating them in local, communal fields of action” (Couch and Kroll-Smith 2000, pp. 286). While there have been excellent descriptions of these movements within the chronic fatigue syndrome (CFS) field (Johnson 1996), some reports tend to be dated (e.g., Aronowitz 1992) or several others do not provide an inside look at the changing coalitions and tensions that have emerged over time.

Fundamentally, this article will describe a misunderstood illness and organized patient advocacy in collaboration with researchers that was able to impact policy makers at the national level. One of the primary focuses of patient advocacy movements is to give a voice to patients. As noted by Wandersman and Florin (1990), citizen participation emphasizes democratic processes to insure that community members have meaningful involvement in decisions that affect them. When patient activists insisted on obtaining a community-based sample to determine accurate prevalence figures, community research removed the filter of the physicians so that studies could directly
access the voice of the patients. When patients complained about the stigma in the CFS name given to this illness, community researchers listened to patients and developed research tools that more keenly represented what patients said and felt. When Centers for Disease Control and Prevention (CDC) officials substantially broadened the CFS case definition to possibly include those with purely psychiatric disorders, community research was mounted to challenge the new criteria. Finally, community researchers supported patient demands for a change in leadership at the CDC’s program of CFS research. This patient advocacy effort used a “small wins” approach at multiple levels to change the way CFS was perceived by the medical community, policy makers and the general public.

The events unfolded in an incremental fashion and change agents were well positioned to take advantage of opportunities to value the patient’s voice and providing amplification, which is a basic focus of patient advocacy movements. This account represents my own perspective about this complex matter which has been informed not only by my direct experience of it but by what I learned about it from individuals with CFS, CFS patient advocates, and family members.

A Contested Illness

CFS is a highly incapacitating illness, with patients often more functionally impaired than those suffering from Type II diabetes mellitus, congestive heart failure, multiple sclerosis, and end-stage renal disease (Anderson and Ferrans 1997; Buchwald et al. 1996). In an attempt to assess CFS-related mortality, Jason et al. (2006) analyzed a national CFS foundation Memorial List containing the names of individuals with CFS who had died. They found the mean age of death for heart failure (59 years), cancer (48 years), and suicide (39 years) among those with CFS was considerably younger than the mean age of deaths in the general population from heart failure (83 years), cancer (72 years), and suicide (48 years), suggesting that CFS might have increased the risk of death for at least this sample. In addition, the total direct and indirect costs due to CFS range from $18.7 to $24 billion dollars per year (Jason et al. 2008).

Even though the statistics and findings above indicate that CFS is extremely debilitating and costly to society, many studies indicate that patients with this illness have experienced disrespectful treatment by the health care system (Jason et al. 1997). For example, Anderson and Ferrans (1997) found that 77% of individuals with CFS reported negative experiences with health care providers. Green et al. (1999) found that 95% of individuals seeking medical treatment for CFS reported feelings of estrangement, and 70% believed that others uniformly attributed their CFS symptoms to psychological causes. In addition, many patients report experiencing condescending attitudes from many friends, work associates, and even some family members (Johnson 1996). There have been reports of children with CFS being taken away from their parents after those parents were accused of not meeting their medical needs (Ryan Baldwin Returned Home 2010) and individuals with CFS being deprived of basic medical care and even being institutionalized in mental hospitals (Lost Voices 2008).

Johnson (1996) and others suggest that some early scientific research, which strongly emphasized psychogenic factors at the exclusion of other more biological causal factors, has limited the exploration of the pathophysiology of CFS. A number of prominent scientists within the US and Europe initially described CFS as primarily psychologically based and opposed characterizing CFS as a physiological illness. For example, Abbey and Garfinkel (1991) wrote: “chronic fatigue syndrome will meet the same fate as neurasthenia—a decline in social value as it is demonstrated that the majority of its sufferers are experiencing primary psychiatric disorders or psychophysiological reactions and that the disorder is often a culturally sanctioned form of illness behavior” (p. 1638). Richman and Jason (2001) argued that the social construction of CFS as a psychogenic illness of neurotic women, similar to earlier depictions of multiple sclerosis, may have contributed to the negative attitudes that health care providers and others have towards those with this syndrome.

These results also need to be interpreted within a context where psychiatrists and physicians have regarded fatigue as one of the least important of presenting symptoms (Lewis and Wessely 1992). More recently, many within the research community have adopted a biopsychosocial approach for understanding fatigue and CFS (Johnson 2008). While such an approach attempts to integrate both biological and psychological aspects of illness, patients have continued to be concerned that the emphasis on many of the proposed models has a strong psychogenic emphasis. For example, one research group from the Netherlands (Vercoulen et al. 1998) has maintained that individuals with CFS attribute their symptoms to physical causes, are overly preoccupied by their physical limitations, and do not maintain regular activity. According to this model, these factors cause individuals with CFS to be functionally impaired, implying that the central problem with patients experiencing this condition is a psychosomatic preoccupation with one’s fatigue. As a consequence, some investigators have endorsed a treatment approach that focuses on convincing patients to recognize that their illness is not biologically based but, rather, a phobic avoidance of exercise due to psychological problems. Other studies have
emphasized a CFS etiology related to inappropriate reactions to dealing with childhood life stressors and implicating childhood trauma as a possible cause of CFS or "chronic unwellness" (Heim et al. 2006). Few other illnesses have had such antagonism between these opposing "psychological" versus "biological" views (Jason et al. 1997).

It is beyond the scope of this article to describe the dozens of individuals and organizations involved over time in this controversy but suffice it to say there is strong reason to believe there is a biological basis for CFS that needs to be pursued in research (Jason et al. 2011). However, in the sections below, the interactions over a 20 year period between two critical norm creating organizations, the CDC and a CFS patient organization will be profiled. The outcomes of the, at times conflictual, exchanges had significant implications for how CFS has been portrayed and understood by the scientific community, the media, and the general population. As will be clearly indicated, the interactions between these two gatekeepers were marked by contradictions, mixed allegiances, changing alliances, and complexities.

The sections below will also illustrate the power of patient advocacy movements (Kroll-Smith and Gunter 2000), which can build coalitions and take advantage of developing events/shifts in power to bring about policy changes. Ultimately, for change to occur with influential norm-setters, it is critical to mobilize coalitions involving multiple stakeholders, particularly at critical times. "Small wins" can often help motivate an advocacy community to both stay committed to a social justice cause and to strive to accomplish even larger changes over time. Giving voice to patients is a fundamental part of the Community Psychology field, and I will describe how this occurred through research activities in collaboration with the broader patient activism community.

Epidemiologic Studies

Among the different CFS patient organizations, the largest and most influential has been the CFIDS Association, with Kimberly McCleary serving as the CEO for over 20 years. Representing the patient community, she and her organization had a number of confrontations with the CDC over the nature and emphasis of their CFS research program at the CDC. For example, in the 1990s, investigators at the CDC published epidemiologic research that portrayed the illness as being relatively rare, affecting about 20,000 people, and further characterized patients as being European-American and middle to upper-class women (Reyes et al. 1997). These findings supported the belief that CFS was a "YUPPIE flu" disease. And as long as scientists and the public perceived CFS as rare, the CFIDS Association and other patient activists realized CFS would be unlikely to receive the needed federal attention and community resources to develop a better understanding of this illness or provide patient services. Tensions between community organizations and government scientists are not uncommon, as Brown (2000, pp. 365) affirmed: "In their popular epidemiological efforts, community activists repeatedly differ with scientists and government officials on matters of problem definition, study design, interpretation of findings, and policy applications."

The CDC epidemiologic studies were based on a method that relied on physician referral of patients with CFS (Reyes et al. 1997). However, if the physicians did not believe the illness existed, or if patients did not have a physician, many people with CFS would not be referred to researchers or counted in prevalence surveys. In the early 1990s, with financial support from Kim McCleary and the CFIDS Association, my research team conducted a prevalence study whereby a randomly selected group of individuals were telephoned and screened for symptoms of CFS. Those that were identified in the telephone screen as having several CFS symptoms were then provided a complete medical and psychiatric examination to determine whether they actually had CFS. This study differed from the methods used in the CDC study whereby physicians determined who was referred (and thus evaluated) as a possible CFS case. These pilot data from Jason et al. (1995) suggested that CFS rates were much higher than the CDC had previously estimated. These data were extremely helpful in securing a large multi-disciplinary NIH community-based epidemiological grant, which found that over 800,000 people in the US had CFS (Jason et al. 1999) and, contrary to prior beliefs, ethnic minorities had higher CFS rates than European-Americans, and CFS rates were not higher among those with high incomes.

The CFIDS Association used this research to counter the myth that CFS was either rare or a "YUPPIE flu" disease. Eventually, the CDC endorsed these community-based epidemiological methods and published comparable CFS prevalence rates (Reyes et al. 2003). This example suggests that by focusing on specific scientific areas that are manageable or capable of changing, social activists can adopt a "small wins" approach. In other words, while community organizers and researchers are often confronted with overwhelming, seemingly intractable problems, by focusing on one small piece at a time, a success that has the potential to gain new opportunities and possibilities for change can be achieved (Weick 1984).

By the late 1990s, the CFIDS Association again had confrontations with the CFS program at the CDC. This time, this patient organization accused program directors of diverting 12.9 million that Congress targeted for CFS
research into other areas at the CDC. Ultimately, these diverted funds were reclaimed and used to fund CFS research in the 2000s.

Changing the Name

The name given to this illness by the CDC was perceived by patients and activists as belittling the seriousness of the condition (the illness was previously called Myalgic Encephalomyelitis before the CDC renamed it CFS in 1988). Many patients argued that the name CFS placed too much emphasis on the symptom fatigue, when, in fact, the illness is typified by many severe symptoms in addition to fatigue, such as memory losses, flu-like symptoms, and post-exertional malaise. Fatigue is generally regarded as a common symptom experienced by many, otherwise healthy, individuals in the general population. A number of patients used the analogy that if bronchitis or emphysema were referred to as chronic cough syndrome, those illnesses too would be trivialized. Patient groups including the CFIDS Association were united in wanting the name changed.

However, even by the late 1990s, there were no studies providing concrete evidence that the name CFS might negatively influence attributions that others made toward patients. Patient advocates had been interested in a better understanding of how the name of the illness might influence stigma. With input from patient advocates, my research team conducted several studies including one that was funded by the CFIDS Association. In one of these studies, medical trainees were provided a case description of a patient with prototypic symptoms of CFS. The trainees were randomly assigned to several groups, and each group was given a different diagnostic label for the patient (e.g., Chronic fatigue syndrome, Myalgic Encephalopathy, etc.). Results of these studies indicated medical trainees’ attributions about CFS changed as a function of which diagnostic labels were used to characterize the person with this illness (Jason et al. 2001). The more medical sounding term, Myalgic Encephalopathy (ME), was associated with the poorest prognosis, and this term was more likely to influence participants to attribute a physiological cause to the illness. Advocates of a name change cited this study to support their contentions that diagnostic labels can influence attributions, and this study provided scientific justification for selecting a new diagnostic name for this illness.

In the early 2000s, because of the increasing demands among patients for a name change, the US Department of Health and Human Services’ Chronic Fatigue Syndrome Coordinating Committee established a sub-committee called the Name Change Workgroup. Several scientists (I was invited to be part of this group), clinicians, and representatives of patient organizations (McCleary represented the CFIDS Association) were appointed members. The Name Change Workgroup was charged with the responsibility of making recommendations that would require the use of a new term by all federal officials and agencies; these recommendations would later be submitted for approval to the US Secretary for Health and Human Services.

The Name Change Workgroup finally did come up with a set of recommendations to be presented to the CFS Coordinating Committee. However, at the same time, federal officials disbanded the CFS Coordinating Committee. Some patient advocates felt that this committee was terminated because the Name Change Workgroup was actually making progress on changing the name. Concurrently, a new CFS Advisory Committee took the place of the CFS Coordinating Committee and was wholly comprised of new members who were appointed by the Secretary of the US Department of Health and Human Services. When the new CFS Advisory Committee met in 2003, they tabled the recommendations of the Name Change Workgroup, citing more pressing issues needing attention.

Around the time of the defeat of the name change initiative, the CFIDS Association began receiving millions of dollars from the CDC to begin a “CFS Branding” media campaign, designed to help the public better understand the illness known as CFS. Many activists within the patient community were uncomfortable with this close relationship between the CDC and the CFIDS Association, as well as the campaign to brand the term CFS. Even though the efforts to rename the illness had failed at the federal level, many activist groups began using other names for both their organizations and the illness (e.g., ME, ME/CFS, and Neuroendocrine Immune Disorder). In fact, in 2006, the CFS scientific organization changed its name to the International Association of CFS/ME.

These changes in labels could represent second order change (Watzlawick et al. 1974), as a new name might reduce stigma and the mistreatment of patients with this illness. As an example of the importance of these types of labels, Multiple Sclerosis (MS) was initially believed to be caused by stress linked with oedipal fixations, but when the name of the disorder changed from hysterical paralysis (to discredit the legitimate medical complaints of predominantly female patients) to MS, less stigma was associated with this illness (Richman and Jason 2001).

Case Definition

In the mid 2000s, the CDC published an article about how the CFS case definition could be better assessed,
Reeves et al. (2005). This broadened case definition was later used in a community based study. Prevalence estimates based on this broadened definition indicated that more than four million Americans experienced CFS (Reeves et al. 2007). In a relatively brief period of time, the CDC’s characterization of CFS had evolved from the illness being considered a rare disorder, affecting about 20,000 individuals, into one of the more common chronic illnesses in the US.

In 2006, before the publication of the CDC’s new prevalence data, a press conference had been scheduled in Washington, DC and the Director of the CDC was to preside over this event. The CDC and the CFIDS Association were now working closely together, and both were enthusiastic about publicizing the new prevalence data indicating that over 4 million Americans had CFS. However, I was concerned that the broadening of the case definition might inappropriately lead to bringing in cases that were actually primary affective disorders, such as major depression. If a diagnostic category includes both those with and without an illness, biologic markers of those with the illness will not be consistently found. Illnesses without biological markers are often referred to as unexplained, and then researchers often seek psychogenic explanations of the syndromes (Barsky and Borus 1999).

Some individuals with CFS might have had psychiatric problems before and/or after CFS onset, whereas other individuals may only exhibit primary psychiatric disorders with prominent somatic features. For example, while fatigue is the principal feature of CFS, fatigue does not assume equal prominence in Major Depressive Disorder (Friedberg and Jason 1998). Several CFS symptoms, including prolonged fatigue after physical exertion, night sweats, sore throats, and swollen lymph nodes, are not commonly found in Major Depressive Disorder. Moreover, the onset of CFS is often sudden, occurring over a few hours or days, whereas Major Depressive Disorder generally shows a more gradual onset. Including patients with solely Major Depressive Disorder in the CFS case definition could confound the interpretation of epidemiologic studies, biological markers for the illness, and treatment studies.

By 2006, both the CDC and the CIFDS Association were both in favor of the new criteria to diagnosis patients with CFS as well as the expanded number of people who were thought to have this illness. It is important to note that the CDC’s new estimated prevalence rates for CFS were 2.54%, which is comparable to the prevalence rate of Major Depressive Disorder (Regier et al. 1988). I conducted a study to clarify this situation, and data were collected from two distinct samples, one with CFS and the other with Major Depressive Disorder. The study’s outcome was that 38% of the Major Depressive Disorder group would have been misdiagnosed with CFS using the CDC’s expanded case definition. These findings were released at a CFS scientific conference (Jason 2007) and over the next several years, greater attention was directed at problems with this expanded CFS case definition (Jason et al. 2009).1

Eventually, all patient organizations rejected the CDC’s expanded case definition. Key to this small wins approach was use of professionals within the scientific community to challenge federal research. Community psychologists have the advantage of relying on clinical-individual and community-contextual contexts in understanding dynamics of complex social and diagnostic issues (Sandel et al. 2000). Some scientists perhaps focused too exclusively on particular CFS-like symptoms of individuals out of context, without consideration to the broader ecologic and social environment as well as the history of illness onset, and this failure prevented a thorough appreciation and understanding of CFS. Shinn and Toohey (2003) have coined the term context minimization error that involves ignoring or discounting the importance of the environments or larger context within which individuals live.

### Change in Leadership at the CDC

In the mid 1990s, Congress enacted legislation to create a Chronic Fatigue Syndrome Coordinating Committee within the US Department of Health and Human Services to make recommendations on CFS policy change to the Secretary of the Department of Health and Human Services. As previously stated, in the early 2000s, this group was disbanded, and a new CFS Advisory Committee was formed with a similar purpose.

In 2007, the terms of many of the members of the CFS Advisory Committee expired, and new members were appointed (I was one of the new members appointed to this Committee and asked to chair the Research Sub-Committee). During the Committee’s 2007 spring meeting, the Committee members asked for details of how the CDC was currently using the approximate five million dollars they were receiving annually for CFS research (CFSAC 2007). Despite these requests for information, Dr. William Reeves, the chief researcher for the CFS’s CDC program, was not willing to supply this financial data, and, in turn, tensions began to rise. Finally, after hearing about these problems with accessing this information, two of Reeves’ superiors at the CDC attended a subsequent CFS Advisory

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1 In a response to this, Reeves et al. (2009) brought up a number of methodological concerns regarding this article including our rationale for using a comparison group with Major Depressive Disorder and the fact that we only used eight symptoms to compute our CDC Symptom Inventory. We responded to these critiques in a subsequent article (Jason et al. 2010).
Develop a 5 year research plan, which he presented at the criticism. In addition, the review panel asked Reeves to program at the CDC had a buffer from the increasing not appointed impartial reviewers. However, now, the CFS review, and patient advocates claimed that the CDC had overall conclusions about the CDC's CFS research activi-

ties were generally positive. However, many patient advocates felt that this was not a fair and independent review, and patient advocates claimed that the CDC had not appointed impartial reviewers. However, now, the CFS program at the CDC had a buffer from the increasing criticism. In addition, the review panel asked Reeves to develop a 5 year research plan, which he presented at the next meeting of the CFS Advisory Committee.

In 2009, forces were beginning to coalesce among different constituent groups, and there was a growing movement to keep the focus on the need for change, in spite of the CDC’s external review committee’s positive endorse-

ment of the CFS program at the CDC. During public testi-

mony at the CFS Advisory Committee meetings, many patient activists and, in particular, McCleary and Dr. Fred Friedberg, President of the International Association of CFS/ME were extremely critical of the CDC’s leadership. The Advisory Committee then took action, and voted on a recommendation to be sent to the Secretary of Health and Human Services for a change in leadership at the CDC.

During the Fall of 2009, for the next October CFS Advisory Committee meeting, a new group entered the scene. Representatives from the Whittemore-Peterson Institute were invited to present information about their creation of the first private clinic/research facility focusing on the care of patients with CFS. Annette Whittemore and Dan Peterson, in their riveting testimony, told the Advisory Committee, as well as members of the audience (i.e., those at the Hubert Humphrey federal building in Washington and those who tuned in to a live video broadcast; CFSAC 2009), of the success they were having in identifying a retrovirus among patients with CFS and wondered why the CDC’s CFS program of research was continuing to disre-

gard biological markers.

The focused and persistent recommendations from the CFS Advisory Committee, as well as the support from almost all constituent groups, had reverberated throughout the Health and Human Services (HHS) Department and CDC. There was even heightened tension among HHS staff members, and some rumors suggesting that a civil dis-

obedience protest against the CDC might occur at the fall meeting. An announcement was made in January 2010 that Reeves had been placed in a new position at the CDC and he would no longer be in charge of the CFS research program, bringing his approximately 20 year leadership over the CDC research program to an end.

There had been considerable dissatisfaction for years among the patient community with the CDC’s focus of CFS research. Reeves became vulnerable when relations with a number of powerful constituencies were ruptured, including his relationship with the CFIDS Association, the CFS scientific organization, the CFS Advisory Committee members, and the Whittemore-Peterson Institute. There were dozens of patient advocates and organizations who were part of this change effort, many of whom were deeply suspicious of the CFIDS Association due to its opposition to the name change and the millions of dollars worth of contracts the organization received from the CDC. Never-

theless, at a critical time, these organizations focused their activities, worked together, and were effective in changing the CFS leadership at the CDC. We might never
know fully what led to these changes. Sarason (1972) has urged us to focus on what occurred before the beginning of the formation of these coalitions, as individuals and organizations became aware of the problems and began mobilizing actions to bring about change. By recounting events among these patient and government organizations that occurred over the past 20 years, we can gain an appreciation for these early stages of the coalition formation, as they set the stage and often play a shaping influence on efforts to bring about change. Therefore, although a settings history is often filled with contradictions and complicated sets of relationships among key players and coalitions, it is critical to be aware of this history before we intervene in a system.

Discussion

As we have seen, patient advocacy movements have enormous potential for achieving social change (Kroll-Smith and Gunter 2000)—even when those who oppose change are larger, more powerful, and more influential. Critically, doing so requires mobilizing coalitions between multiple smaller groups with similar goals and taking swift advantage of developing events or shifts in power to bring about policy changes. Participating in these types of policy interventions often involves a long-term time commitment, and the process is often unpredictable as alliances emerge and crumble, and even adversaries become allies. This is consistent with Trickett and Mitchell’s (1993) principle of succession, which posits that settings and social systems that encapsulate our community interventions do change over time. This principle of succession alerts us to attend to the unintended consequences of relationship and policy changes, as sometimes they are the most significant outcomes of our interventions.

One of the primary focuses of patient advocacy movements is to give a voice to patients: the work and research described in this article was committed to based on listening to patients. For example, when the CFIDS Association insisted on obtaining a community-based sample to determine prevalence figures, researchers removed the biased filter of the physicians. The new prevalence numbers suggested that CFS was not a rare disorder nor was it appropriate to refer to this illness as a “Yuppie flu” disease. Community research successfully challenged these myths and in the process led to a more accurate and less stigmatized view of patients with this illness. Research was also used to support the patients’ claim that label CFS was stigmatizing, and this legitimized the need to adopt alternative terms. The major scientific organization in the US also changed their name to the International Association of CFS/ME in part due to these efforts to change the name of the illness. At the Oct 2010 meeting of the CFS Advisory Committee, a recommendation was made to the Secretary of HHS that ME/CFS be used across all HHS departments. In 2011, the National Institutes of Health sponsored a State of the Knowledge workshop on this illness and they referred to the illness as ME/CFS rather than CFS.

This small wins approach was used to change the way that CFS was perceived by the medical community, policy makers and the general public. This approach is reminiscent of the “incremental” approach to change described by Lindblom (1979). While the approaches were not part of a coordinated strategic plan, they evolved in response to opportunities and conditions, which according to Lindblom is more often the case. Small wins are often needed in the long campaigns for social justice, as working on small wins can set in motion forces that can lead to increased higher level interventions. Other activist movements have used small wins such as the AIDS/HIV community, where the AIDS Coalition to Unleash Power (ACT UP) mounted protests and had regular demonstrations at the Food and Drug Administration, the National Institutes of Health, and the White House (Gould 2009). These activists forced pharmaceutical companies and the government to develop and disseminate drug treatments against HIV, and were eventually able to serve on the committees they had previously picketed. ACT UP eventually changed the landscape of how patients with HIV are treated in the United States. CFS coalitions are now using small win strategies in their battles for a similar type of legitimacy and recognition.

Valuing the patient’s voice is most compatible with the values of Community Psychology, where professionals can function as “boundary spanners,” and dialogue with multiple stakeholders in order to facilitate information exchange and communication. But there might be times when the views of community researchers might differ from those of the patient advocacy movement. For example, by 2006, both the CDC and the CIFDS Association (as well other CFS activists) felt that the expanded number of people who were thought to have CFS would help generate more positive attention for this illness. But by endorsing that more than 4 million Americans had CFS, they were implicitly supporting a broadened case definition that had been proposed by the CDC. I felt that this broadened case definition had dangers that were not evident, and this included the possibility of a more heterogeneous group of patients being included in research samples. If this group included individuals who did not have CFS, future research would never be able to identify reliable biological markers for this illness.

A decade earlier, I had felt embraced by the patient and scientific community when my expanded prevalence numbers challenged the inappropriately low CDC rates of the 1990s. But now I was in a very different situation, as
the larger scientific and patient communities were endorsing these expanded numbers, and implicitly supporting the new criteria for identifying cases. At the time, I did not have any data to support my position. I still vividly remember in 2006 when Kim McCleary came to a Board meeting of the International Association of ME/CFS, of which I served as Vice-President, and she asked our Board to endorse the new prevalence figures from the CDC. I walked out of the meeting, as my fellow board members were convinced that the larger numbers would help legitimize the seriousness of CFS, and I felt that they were not willing to listen to my objections regarding the changing criteria. That tactic shook up the board, and the next day, rather than endorse the new prevalence numbers, the Board members asked me to write a position paper that was posted to the official website of our organization, representing my opinion about the new criteria but not that of our professional society. I did publish this essay on their website, and it received considerable discussion among patient advocates and scientists. Over the next year, my research team collected data that supported my position about the possibility that the new criteria brought into the new case definition individuals who had a primary affective disorder rather than CFS. Eventually members of the patient advocacy movement, and many leading scientists in the US no longer supported the CDC’s new criteria for diagnosing CFS.

The relationship over time between the CFIDS Association and the CDC represented complex behaviors in interaction with its social and cultural contexts (Kelly 1990; Kingry-Westergaard and Kelly 1990). It is important to recognize that individuals at the CDC and the CFIDS Association involved in these events felt that the policies they adopted were legitimate and appropriate, and also within the best interests of the larger community of patients. Reeves, for example, was committed to trying to operationalize the CFS case definition (Reeves et al. 2003), and when he argued for the use of instruments and cut off points that broadened the case definition, he did not recognize that this might inadvertently bring people into the CFS category who did not have this illness. Many people with CFS do experience demoralization and even some psychiatric symptoms after experiencing the trauma of an incapacitating illness and then further after experiencing the trauma of the negative attitudes people have toward their illness. And yet, there are also many people with CFS who never experience any psychiatric conditions, so one cannot conclude that psychiatric conditions are equivalent to CFS. Certainly, how activists and researchers decide what is in the best interests of the patient community is a value laden and challenging task, and as is evident from this article, constituent groups often disagree as to what actions are perceived as victimizing and stigmatizing.

There are certainly implications for community psychology, and this is well reflected in Sarason’s (1976) anarchist insight, which suggests that government interventions for social problems can undermine the sense of community for social change movements. When scientists such as those at the CDC used methods in the early 1990s that underestimated the prevalence of CFS, community researchers worked with advocacy organizations to correct these biases. The revised prevalence estimates were used by community activist organizations and policy makers to advance a more accurate depiction of CFS. When a broadened case definition was later proposed by the CDC, it was critical from a science position to challenge these findings, and ultimately this is critically important from a practice point of view. From these experiences, I realized the importance of staying committed to a content area like CFS for a long period of time and staying true to my values and beliefs, even if they were not popular. It was also clear to me that the CFS patient advocacy movement was very receptive to the role of scientific analysis in better understanding this illness regarding the epidemiologic research on prevalence and issues involving diagnostic definitions.

Patient groups were energized with the change in leadership at the CDC and began organizing anew to demand more research funding for the CFS area. The new CDC leadership has already contacted a number of patient organizations and the leader of the International Association of CFS/ME to discuss ways to work more cooperatively with these different constituent groups. In addition, over the past year, a new coalition of CFS patient organizations formed, called the Coalition 4 ME/CFS, to present a unified voice with common goals and objectives that will improve the quality of life for patients and their families. In addition, ten patient organizations signed a joint letter inviting the CDC to an open dialogue through regular meetings. The letter and a petition contained nine action points calling for change in the CDC’s research into CFS. The efforts to bring about change will continue, but these developments suggest that the patients’ coalitions were strengthened by the patient advocacy that ultimately resulted in changing the CFS leadership at the CDC.

As is argued above, many patients have felt that research conducted by the CDC fueled the stigmatization of CFS and contributed to the climate in which the legitimacy of CFS was questioned. But it is important to recognize that there are multiple sources of such doubt concerning the legitimacy of CFS. Books, articles, and even popular radio talk show physicians continue to discredit the notion that CFS is a real illness. There will continue to be social change efforts in the US and other countries to deal with these forums that trivialize CFS by portraying people with this serious chronic illness as being a form of hysteria (Showalter 1997). As Seidman (1988) has written,
second order change involves changing shared goals, roles and power relationships, and little changes when expectations and policies remain intact. Thus, social justice efforts are needed to focus on systemic change directed toward those responsible for creation of norms or policies that discriminate against or stigmatize marginalized groups such as those with the illness known as CFS.

I was a witness to many of the events described in this article, and gained access to a number of policy settings after engaging in basic research involving epidemiology, the name change, and issues involving the CFS case definition. Such efforts can ultimately provide researchers with credibility among their peers, as well as community activists. For example, findings from the community-based epidemiology study (Jason et al. 1999) provided the credibility needed for me to be appointed to federal advisory panels that made recommendations on CFS to the Secretary of the US Department of HHS, as well as to be elected as a board member of the major CFS scientific organization. Gaining access to those critical constituent gatekeepers can provide unique opportunities to influence public policy.

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