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# Can the Social Model Explain All of Disability Experience? Perspectives of Persons With Chronic Fatigue Syndrome

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**OBJECTIVE.** The social model of disability has had a major influence on the academic field of disability studies and on contemporary understandings of the causes and experience of disability. The purpose of this study was to examine the adequacy of the social model for explaining the disability experience of persons with chronic fatigue syndrome (CFS).

**METHODS.** This qualitative study examined the experiences of 47 adults with CFS participating in a research project that aimed to evaluate a participant-designed rehabilitation program. Data were aggregated from focus group interviews, open-ended questionnaires, progress notes, and from a program evaluation questionnaire. Data analysis was based on a grounded theory approach and used triangulation of multiple data sources and member checks to assure dependability of findings.

**RESULTS.** Four themes emerged from the analysis: (1) minimization and mistrust of the disability; (2) negative experiences of impairment; (3) lack of identification with the disability community; and (4) the focus on advocacy as a quest for legitimacy. These themes varied in the extent to which they conformed to the principles set forth by the social model.

**CONCLUSIONS.** Although the social model has important contributions to lend to occupational therapy practice, it is important to recognize that it may not capture the full reality of disability. In particular, the social model has serious limitations in describing the disability experience of individuals with disabilities who do not have visibly obvious disabilities and whose impairments do not conform to the traditional viewpoint of disability.

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**M**edical conceptualizations of disability used in most health care practices and in research tend to view physical or cognitive impairment as the primary cause of disability (Oliver, 1996; Rioux, 1997). The field of disability studies has criticized these conceptualizations for erroneously locating disability in persons who have impairments and for pathologizing disability. The social model of disability (Charlton, 1998; Finkelstein, 1980; Hahn, 1990; Oliver 1990; Pfeiffer 1998; Young, 1990) was put forth as a response to the medical and rehabilitation definitions of disability. It represents one of the most important contemporary conceptualizations of disability, and its influence is felt throughout the disability studies literature. This qualitative study examined a cohort of persons with chronic fatigue syndrome (CFS) in order to ask whether their experiences of disability can be adequately explained according to the social model of disability.

## The Social Model of Disability

The social model argues that disability is created by social oppression, discrimination, and exclusion that are systematically reproduced in major economic, political, and cultural institutions. Most straightforwardly (and admittedly at the risk of overstatement from some perspectives), this model locates disability outside of the body or mind and instead grounds it within society and its environmental barriers, discriminatory acts, and socially stigmatizing attitudes. Accordingly, the social model argues that disability is caused by the limitations imposed on activity, social

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integration, and economic well-being levied by a contemporary social organization that fails to include and accommodate persons whose bodies or minds function differently than others. The social model argues that, instead, individuals with disabilities have been exploited, oppressed, ridiculed, excluded, and disadvantaged by society (Fine & Asch, 1990; Katz, Hass, & Bailey, 1988; Meyerson, 1990).

The social model also rejects traditional medical model notions of professionals as experts and clients as care recipients. Instead, a high value is placed on nonhierarchical relationships, the use of peer mentors in empowerment-oriented support efforts, and the reliance on peer-based social advocacy networks, such as Centers for Independent Living, in solving problems. According to the social model, the main objective of persons with disabilities is to break down societal barriers and integrate themselves fully into the community as equals. Within this model, the services of health care professionals such as occupational therapists are valued only to the extent they aim to facilitate empowerment, access to resources, and social justice. In some cases, however, the services provided by rehabilitation professionals, when approached more traditionally in an impairment-focused and hierarchical way, are viewed as oppressive, stigmatizing, and largely irrelevant to the needs of individuals with disabilities (Charlton, 1998).

The pride, acceptance, and sense of power owned by persons with disabilities that embrace the social model have contributed to the creation of a disability culture (Johnson, 1987) and have fostered positive constructions of integrated identity among persons with disabilities (Gill, 1997). The social model has also led to large-scale disability advocacy efforts such as the Disability Rights Movement (Charlton, 1998; Oliver, 1996). For this reason, the social model of disability has been a central force shaping the intellectual landscape of disability studies as well as informing collective action within the disabilities community.

### *Impairment Within the Social Model*

A distinguishing and increasingly debated feature of the social model is its consideration of impairment as human difference rather than as pathology (Oliver, 1996). The social model aims to challenge medical and rehabilitation models of normalcy that position the disabled body as a tragic deviation. As such, it considers persons with disabilities as complete or whole individuals, not “broken” or “abnormal” and therefore not in need of rehabilitation or cure (Shreve, 1994). Importantly, the image of a healthy individual with disabilities derived from the social model has attempted to correct false stereotypes that individuals with disabilities are somehow damaged or broken, globally incapacitated, inadequate, or excessively dependent on

medical care (Amundson, 1992). It has helped to rid some individuals with disabilities of stigmatization involving images of the weak body or frail psyche.

However, it is important to note that much of the social model perspective on impairment is based on the experiences of individuals with relatively stable and specific impairments, such as spinal chord injury or blindness (Amundson, 1992). In the case of individuals with more tangible and widely understood disabilities, it has been argued that isolated and specific impairments are a matter of neutral difference and are not problematic except when the person who has them encounters environmental barriers.

### *Challenges to the Social Model*

Despite its importance, a number of challenges to the social model of disability have been raised, particularly from the feminist (Morris, 1991; Thomas, 1997; Wendell, 1996) and critical realist (Williams, 1999) perspectives. In part, these criticisms have been raised by individuals with perspectives that differ from those with more apparent disabilities. Accordingly, the thematic underlay in this study involves comparisons between the experience of a commonly misunderstood fatiguing disability and more traditional, relatively better-understood disabilities. One criticism shared by both the feminist and critical realist perspectives involves failure of the social model to acknowledge the full reality of impairment. That is, critics of the social model argue that the frequent reality of disability involves illness, suffering, pain, or generally experiencing one's bodily or mental processes in a negative way (Morris; Wendell). They argue that casting impairment as only a neutral human difference ignores this reality. In so doing, some argue that the social model draws too narrow a conceptualization of disability (Amundson, 1992). Moreover, it denies important truths of personal experience faced by all individuals with disabilities, regardless of the nature and extent of the disability (Wendell). Although there have been criticisms of the social model from theoretical perspectives, there is limited empirical literature that examines how adequately the social model captures disability experience of persons with disabilities. This study examined the disability experiences of a cohort of persons with CFS in order to test the adequacy of the social model to capture their experiences.

## **Chronic Fatigue Syndrome**

CFS is a highly debilitating condition characterized by 6 or more months of medically and psychiatrically unexplained, persistent fatigue accompanied by at least four of the following symptoms: impaired short-term memory or concentration, sore throat, tender lymph nodes, muscle pain,

multijoint pain without swelling or redness, new-type headaches, unrefreshing sleep, and postexertional malaise lasting more than 24 hours (Fukuda et al., 1994). CFS is characterized by substantial losses in functional status across all domains, including physical, cognitive, social, and occupational functioning (Buchwald, Pearlman, Umali, Schmalung, & Katon, 1996; Christodoulou et al., 1998; Herrell et al., 2002; Komaroff et al., 1996). It has been recognized as a diagnostic category by the U.S. Centers for Disease Control and Prevention (Fukuda et al., 1994). It is considered a disability under the Americans with Disabilities Act (ADA; Banks & Prior, 2001). Finally it has been legitimized as a medically determinable condition by the Social Security Administration (Social Security Ruling 99-2p, 1999).

Individuals with CFS offer a unique opportunity to examine the relevance of the social model because CFS is not a traditional disability characterized by a relatively stable and discrete level of impairment. CFS symptom severity and level of impairment fluctuate dramatically (Taylor, Friedberg, & Jason, 2001). This fluctuation occurs between and within individuals, making it difficult to gauge when a given individual might consider him- or herself disabled (Wendell, 1996). For example, a person who must remain in bed most of the day on a “bad day” may feel well enough to leave the house, take short walks, and converse with others on a “good day.”

Another factor that differentiates the experience of CFS from that of a more traditional disability is its invisibility. Not only is CFS not immediately apparent to the casual observer in persons who have it, but also research demonstrates that between 10%–54% of health care professionals do not accept the existence of CFS (Denz-Penhey & Murdoch, 1993; Fitzgibbon, Murphy, O’Shea, & Kelleher, 1997; Ho-Yen & McNamara, 1991; Steven et al., 2000). Since these studies involved self-selected samples, it is possible that acceptance of CFS was even lower among nonresponders (Stein, 2001). As a consequence of professional misinformation and denial, individuals with CFS consistently report negative experiences with health care providers characterized by disbelief, lack of knowledge, misunderstanding, minimization of symptoms, overemphasis on psychological explanations, and a general lack of responsiveness or treatment planning (Anderson & Ferrans, 1997; Banks & Prior, 2001; David, Wessely, & Pelosi, 1991; Green, Romei, & Natelson, 1999; Taylor & Eisele, 2003). Individuals with CFS also face interpersonal stigma related to misunderstanding or denial by family, friends, colleagues, and others. For example, Anderson and Ferrans found that 95% of individuals reported friends’ negative responses to their illness, including outright disbelief by close others.

The nature of CFS impairment and its invisibility are two variables that suggest that the disability experience of persons with CFS might differ from persons with traditional disabilities and thereby not be adequately explained by the social model. This study sought to determine: (a) what aspects of the disability experience of persons with CFS are explained by the social model, and (b) what aspects of disability experience fall outside or contradict central tenets of the social model.

## Methods

Data for this study emerged from a federally funded research project that developed and evaluated a participant-driven program for individuals with CFS (Taylor, 2004). The project was implemented at a center of independent living. Centers for independent living are organized based on principles that incorporate the social model (Oliver, 1996). One aspect of the project was an attempt to integrate persons with CFS into the disability culture represented by the center for independent living and at the same time educate staff in the center for independent living about CFS, which is not widely understood within the disability culture.

The study was a participatory research project in which clients actively identified their service needs, shaped the services they received, and decided the criteria by which the services would be evaluated (Taylor, Braveman, & Hammel, 2004). The research design and services of the project (e.g., use of peer mentors and consumer driven goals and service content) were largely influenced by concepts from the social model. As part of this project, data were collected on persons’ experiences of CFS-related disability as well as their experience of services reflecting ideals of the social model.

### *Participants*

Forty-seven adults meeting the Fukuda et al. (1994) criteria for CFS participated in the study. They were recruited from local CFS self-help organizations, physicians specializing in the treatment of persons with CFS, and advertisements posted in CFS newsletters, local newspapers, on CFS Web sites and listservs, and on a local cable TV station. Prospective participants underwent informed consent by receiving and signing a consent form, receiving a follow-up phone call to clarify all procedures in the study and answer any questions, and returning the form in the mail. Table 1 presents the sociodemographic characteristics of the sample.

### *Data Collection Procedures*

For each client, qualitative data were collected over a period of 12 months. Data were drawn from the following sources:

**Table 1. Sociodemographic Characteristics of Participants With Chronic Fatigue Syndrome**

	Frequency	Percentage
Work Status		
Full-Time Work	7	(15%)
Part-Time Work	7	(15%)
Not Working	33	(70%)
Socioeconomic Status		
Low	12	(25%)
Middle	26	(66%)
High	9	(19%)
Gender		
Female	45	(96%)
Male	2	(4%)
Marital Status		
Never Married	11	(23%)
Married	16	(34%)
Divorced, Widowed, Separated	20	(43%)
Minority		
Minority	8	(17%)
Non-Minority	39	(83%)
	Mean	(SD)
Age	46.9	(10.4)

Note. SD = standard deviation.

(1) *Focus Groups*. During these groups, participants were educated about the social model and were asked about their experiences with CFS within social contexts of home, work, and community. Participants were asked about their interactions with health care providers, family, friends, and peers with and without disabilities. Participants were educated about four concepts relevant to the social model, and they were informed that they would be asked to reflect upon these four concepts throughout the program. These concepts were (a) the independent living philosophy (that people have the right to self-determination and independent functioning), (b) empowerment (self-reliance and reliance on peer networks in solving problems), (c) advocacy (self-advocacy may involve efforts to better direct one's medical care, recruit assistance, or achieve equal employment rights or accommodations under the ADA. Advocacy for the CFS community as a whole may involve direct efforts to change the way larger systems and organizations respond to the needs of individuals with CFS), and (d) sense of community (a supportive network and stable structure that one can identify with and rely on for support and life meaning).

(2) *End-of-Group Reflections Form*. This questionnaire was distributed at the end of each group meeting that occurred during the rehabilitation program (i.e., following the focus groups) to facilitate participants' reflections about social model aspects of the CFS experience. An example of a question that was included on the *End-of-Group Reflections Form* is "Was there anything in particular about the independent living philosophy, advocacy, empower-

ment, or sense of community that you learned in today's group?" Participants were asked to respond to the questionnaire in writing and to share their responses with the group.

(3) *Progress Notes*. Peer counselors and researchers wrote individualized progress notes following each contact with each participant. Progress notes included information regarding each participant's work toward his or her rehabilitation goals, information about current health-related, social, and psychological issues that the participant reported, and information about issues related to the participant's experience of CFS from a disability studies perspective. Informal observations and notes regarding participants' interactions with each other and with project staff were also made.

### Data Analysis

Analysis of the data followed a qualitative comparative method (Glaser & Strauss, 1967; Polkinghorne, 1986). This type of analysis involves going back and forth between the emerging data findings and ongoing data collection. This process allows for the themes that emerge from the findings to be checked for counter instances, more fully explored, and further developed. The emphasis in the analysis was to grasp the experience of disability from the perspectives of the participants and to link this understanding to both the nature of their impairment and to environmental influences.

Several strategies were used to achieve confidence in the findings. Data were triangulated by comparing information within and across data collection methods, across participants, and across time. Member checking with the participants was done to assure that the evolving understanding of their disability experience accurately reflected their views. Because this was a participatory study, the participants actively shaped not only the researcher's evolving understanding of the CFS disability experience but they also shaped their own understanding of themselves as individuals with disabilities. Participants educated both the staff and each other about their individual and collective experiences and advocacy needs. In the process they also clarified their own ideas about what resources they required to maximize independence and how they could best cope with their disability and its consequences for their lives. In the end, the findings were shaped by intimate knowledge of and dialogue with the participants.

### Findings

The four major themes that emerged were (1) minimization and mistrust of the disability by others; (2) negative experiences of impairment; (3) lack of identification with the disability community; and (4) the focus on advocacy as quest to gain legitimacy from others.

## *Misinformation and Mistrust of Chronic Fatigue Syndrome as a Disability*

The social model emphasizes the extent to which persons with disabilities face

- the tendency to overpathologize the person with disabilities and focus on impairment as the central reality of disability, and
- societal attitudes that treat disability as a personal tragedy and stigmatize the person with a disability.

For participants in this study, the experience was quite different. It was dominated by minimization and mistrust of their disability by health care providers, family, friends, and colleagues.

*Health Care Providers.* The participants in this study consistently reported that when they sought help for their condition from health care providers, most health care professionals were either relatively ignorant or incredulous of CFS. Consequently, most participants reported experiences characterized by:

- Outright disbelief in the legitimacy of CFS as a medical entity
- Lack of validation of participants' described impairments and symptoms
- Lack of knowledge about CFS
- Absence of treatment planning and treatment recommendations
- Tendency to overemphasize psychological and social variables as possible causes of the symptoms
- Tendency to overprescribe psychotropic medications
- Tendency to view exercise and psychotherapy as the only nonpharmacological treatments for CFS

Most participants described long and frustrating histories of their attempts to access necessary information and services to help them address the consequences of their impairment. Participants reported that they sought treatment for their CFS symptoms and impairments from an average of six physicians before they were ultimately diagnosed with CFS. After being diagnosed with CFS, most participants reported continued and ongoing dissatisfaction with their treatment, particularly when it was administered by a physician that did not specialize in CFS. Along the way they encountered misinformation, misdiagnosis, and inappropriate treatment recommendations. Finding a physician who could provide appropriate services was often tricky for participants. One participant characterized the kinds of challenges faced in the following words:

I think that is a good thing when a doctor makes inappropriate comments, like, that CFS does not exist. It then becomes obvious you need a new doctor. It's much more dangerous when the doctor keeps his beliefs silent. In this case you are probably not going to get the level of care you

need but you won't know why. . . . I think it's important to find out what your doctor believes.

Most participants found information on CFS outside medical care (through the Internet or self-help groups) and then took the information to their physicians. As one participant indicated, "I know I am not alone, feeling frustrated, when I have to try to explain CFS to a doctor or therapist." Another reported that she took articles to her doctor to convince and inform him about CFS.

Many participants talked about how they had to screen and select their health care providers based on their willingness to recognize their condition. For instance one woman noted:

Because my rheumatologist relocated her practice, I will be interviewing two new doctors in the next couple of months. During the first appointment I will ask each how he feels about me bringing in information and suggestions. This could be a deciding factor in which doctor I chose.

Participants not only reported difficulties getting professional services, they also reported that, as a result of their negative experiences, they sometimes limited their own help seeking to avoid negative encounters with providers. Therefore, the lack of ready services was often compounded with their reluctance or wariness to seek acknowledgment and help. Even when participants found health care providers specializing in CFS that were willing to acknowledge and address their conditions, they often reported extensive self-doubt and shame related to seeking help. One participant expressed concern about consulting her current providers about problems with shortness of breath because she felt she was already pushing the boundaries of their acceptance and responsiveness: "I am already getting a lot of free phone time and sample medications. I'm scared but I just don't want to annoy them anymore."

An important aspect of service access for the participants was the relative absence of any rehabilitation services. For instance, none of the subjects in this study had received occupational therapy within the past 12 months. Partly, this reflects the lack of physician referral for appropriate energy conservation, activity pacing, and other services that occupational therapists might provide. Partly, it reflects the fact that there is very little knowledge in occupational therapy about CFS. Aside from this author's work, only three refereed articles were found in a search of the past 10 years of occupational therapy literature. This is despite the fact that approximately 800,000 persons in the United States have CFS (Jason et al., 1999). One participant reported:

I'd be afraid to go to a physical therapist because the one I saw told me that my muscle strength was within normal range . . . she inferred that I was depressed and out of shape . . . and that exercise would take care of most of my symptoms. . . . I'd be afraid to go to an occupational therapist

because I don't want to be put in a work hardening program again—the last time my company insisted that I do this it sent me into a severe relapse that lasted for almost 2 weeks. I basically had all the symptoms of a severe flu and couldn't even cook for myself.

In addition to difficulty locating appropriate health care, participants reported problems acquiring disability income, concerns about requesting workplace accommodations, and difficulties accessing community-based resources (such as meal delivery programs and specialized transportation options). These problems occurred because the participants had difficulty convincing their physicians of the need for such resources, because they were unaware of these resources, or because their health care professionals lacked knowledge of how and why they might benefit from such resources.

*Family, Friends, and Coworkers.* The participants reported that family members, friends, and coworkers viewed them as individuals that had no obvious manifestation of the disability and who often had extreme variability in symptoms and impairment. These realities, combined with a lack of medical validation of the person's reported experiences, meant that family members, friends, and coworkers tended to feel confused, and were prone to question whether the symptoms and impairments were real. The participants were also typically unsure as to how to respond to their family members' or friend's requests for understanding or help.

For instance, one participant expressed distress over an upcoming family dinner. She was experiencing an increase in her fatigue and wondered if she would be able to manage the preparation and be able to socialize during the dinner. Although she was concerned over whether she could actually do the work, the more distressing concern for her was the reaction she would receive from her relatives if she was exhausted, nauseous, dizzy, or had to lie down when they arrived.

Negative responses from family members were not only distressing, but they also often created tension in the family unit and threatened relationships. For instance, one participant was working on reducing activity levels as a goal of the intervention program. She reported that her husband repeatedly questioned her requests for help with laundry and cooking. In this instance, the wife had been struggling for years with patterns of overactivity that led to relapse. Her husband questioned her sudden request for him to step in since she had been able to manage these chores most of the time. Another subject gave notice at her job because she was no longer able to sustain the energy for working. She expressed concern that her decision was creating tension with her husband to the extent that it was "threatening their marriage."

Every participant reported strained relationships with friends as well as having lost relationships as a result of their friends' lack of understanding of their disability. Some of the kinds of incidents that contributed to strained relationships with friends included the necessity to make last-minute cancellations of planned activities, inability to sustain reciprocity (e.g., having friends for dinner), and ability or inconsistency in continuing participation in activities that had been a central part of the friendship. Respondents noted that friends questioned the legitimacy of these behaviors, or had difficulty understanding the fluctuation in the severity of the impairment. Respondents also reported that friends tended to minimize their symptoms or impairments, which made both parties frustrated or angry. All of these are factors that strained or resulted in termination of friendships. A number of persons in the study reported that they no longer had many, if any, close friends.

Participants faced the same kinds of incredulity and resentment in the workplace. As a result, most participants were reluctant to report their disability status and request accommodations. Instead, they tended to push themselves to avoid negative reactions. Most participants in this study had already left or eventually had to leave their jobs altogether or had to accept less-demanding or less-sophisticated work. Compounding the ambivalence experienced by participants was the fact that friends and colleagues questioned the legitimacy of their leaving jobs and/or seeking disability income when they did so. For instance, one participant related how a coworker had a negative reaction to her "poor choice" to seek disability income. She found it very stressful that the acquaintance had labeled it a "choice" at all since the participant believed she had sought disability income only when she had exhausted every other alternative and saw it as a necessity.

*The Consequences of Misinformation and Mistrust.* Overall, participants felt that they were on a never-ending treadmill trying to manage what others wanted from them. As one participant put it, she felt compelled to "do things till I was ragged." Another male participant summed it up as follows, "Something is wrong with our bodies, but it doesn't stop there. The illness extends into the world and the way it is. . . . Our bodies can't keep up with what's being asked of them."

Despite the recognition that they had difficulty meeting others' expectations, participants were extremely ambivalent about the process of getting others to make allowances for them, setting limits, or asking for help because of the constant disbelief and other negative responses they faced. As one subject expressed, "I am constantly in a 'Catch-22' between always overextending myself to please others and facing people's disbelief and judgment when I can't go on or have to ask for help."

The other problem faced by many of the participants at some point during their illness was self-doubt. They faced so much disbelief and negative reactions that they had periods of doubting their own experiences and the legitimacy of their own condition. For this reason they often found it extremely helpful to be in groups of others with CFS. One participant commented, "It's nice to hear others have similar symptoms and that I am not imagining them all." Another participant reported, "I don't have to struggle, to my own detriment, to be like everyone else around me that are healthy and inflexible or not interested in educating themselves on CFS. I can find support and understanding."

### *Dominance of Negative Experiences of Impairment*

The social model rejects the definition of impairment as a negative situation and emphasizes that disability is a neutral human difference that can contribute to a positive life. By contrast, the participants in this study found their impairments to be uniformly negative. Moreover, they did not embrace their losses in functioning as something that contributed positively to their identity.

First of all, the fatigue that the participants (and other persons with CFS) experience is not simply a functionally limited tiredness, but it is also a feeling of being ill. Moreover, many of the symptoms associated with CFS are highly unpleasant. For this group, they included absolute exhaustion, lack of endurance to activity, chronic nausea, dizziness, fainting, muscle and joint pain, inability to concentrate, loss of short-term memory, chronic headaches, sore throats, painful lymph nodes, gastrointestinal difficulties, and other symptoms. Participants indicated that they truly suffered as a result of their fatigue. One participant reported, "I feel like I got the flu and it never went away."

Furthermore, the participants found their fatigue, along with their cognitive problems (i.e., lack of concentration and memory losses) to interfere with their ability to do things they enjoyed and found satisfying. Since these impairments tended to fluctuate, they experienced them as taking away positive experiences whenever they were exacerbated.

Not surprisingly, the participants put a great deal of effort into seeking ways to alleviate their symptoms. The program in which they were enrolled included elements of how to accommodate to impairments and symptoms. Most participants initially rejected these as strategies for coping with CFS as they still were hoping to find ways to alleviate or remove the symptoms and impairments. Even when they were able to accept that they needed to make accommodations, all participants continued to express a desire to "recover" from CFS. The social model idea that a disabling condition is part of the self did not resonate with this group.

Despite the fact that many participants had CFS for years, all of them preferred to think of CFS as an illness from which they would eventually recover. It should be noted that the hope or expectation of recovery or improvement is not entirely unrealistic, since a majority of persons with CFS do improve somewhat over time and some people do recover. Reports indicate that full recovery occurs in less than 10% of individuals (Joyce, Hotopf, & Wessely, 1997). Though recovery is unlikely, it is not impossible. Participants who had either read about or encountered others who have improved or recovered tend to view this information a reason to hope. For example, one participant noted: "It gave me a lot of hope to see there were people who were healthier than me. I don't know if they reached the depths that I have, but it gave me a lot of hope."

### *Marginalized Disability Identity*

As noted earlier, an important aspect of the social model is the emphasis on a positive disability identity. Many participants in this study found it difficult to view themselves as disabled, much less as members of an oppressed disability community as recommended by proponents of the social model. Two factors accounted for this. First, many participants rejected the idea of accepting a disability identity since, as noted, they hoped or expected to recover. Second, other members of the disability community were not always open to accepting CFS as a legitimate disability.

Even when they were willing to admit they were disabled, most participants insisted on viewing it as a temporary condition. The idea of accepting a disability identity meant to some participants that they were "giving in" to their condition. Many had difficulty accepting the chronicity of the condition. In addition, many did not appear to understand how having a positive, integrated identity as a disabled member of a larger community of persons with disabilities would be empowering. Some had very strong reactions even to the use of the phrase, "CFS as disability." One participant stated, "I hate hearing about these labels! The more you label your self as disabled, the sicker and more dependent you will be."

Although some participants in this study did find some of the social model themes of independent living and empowerment helpful in that they promoted access to resources, they did not find the disability community as a whole welcoming or inclusive of their experience. The participants found reactions of persons with disabilities to their disabling condition similar to that of those who were not members of the disability community. For instance, one participant explained her situation and asked for assistance in calling a cab from a receptionist who happened to be using a wheelchair. The receptionist indicated to the

participant that she looked “perfectly able to run down to the corner and get a cab herself.”

Another participant overheard disparaging comments concerning a person with CFS needing to rest. A specific instance of this occurred when one participant requested a place to lie down and rest before driving home. In another instance an employee with CFS who missed meetings and was unable to keep a consistent schedule despite working part-time was referred to as “a princess” by a coworker with a disability.

Thus participants in this study did not see themselves as members of a larger disability community. When they did emphasize their disability identity it was only instrumental (i.e., to seek disability income or accommodations). This finding is similar to Stein’s (2000) argument that many persons with CFS may have difficulty identifying with disability culture, or to join in disability rights activities—even though they may, with professional support, benefit from disability status through legally mandated accommodations and entitlements.

### *Acknowledgment as the Focus of Advocacy*

According to the social model, the main objective of persons with disabilities should be to break down notions of normalcy and integrate fully into the community in an effort to be viewed and treated as competent and equal members of society. Although many of the participants in this study ultimately agreed with the objective of community integration, it was not their primary concern.

First and foremost, the participants wanted their condition to be recognized by others as legitimate. Thus, the only advocacy (either individual or collective) that the participants took part in was aimed at achieving recognition and legitimacy of CFS. For example, one participant wrote to her congresswomen advocating for more money for medical research to find the cause and treatment of CFS. Others, as already noted, often engaged in activity aimed at informing both health professionals and lay persons about CFS. One participant was very proud for having given a talk about CFS to her church community. In contrast to most disability advocacy efforts that focus away from impairment and instead on removal of community barriers, participants in this study who engaged in advocacy were much more interested in breaking down barriers of misunderstanding and mistrust.

This finding is consistent with the advocacy activities of major CFS self-help organizations that are also focused on such things as changing the diagnostic label for the condition in order to achieve better medical recognition of its legitimacy, improving the accuracy of medical diagnosis of the condition, and educating medical professionals about

the condition and its most effective treatments (Taylor & Eisele, 2003). Thus, when the participants did become involved in local or national CFS organizations, as a few in this study did, they were naturally directed toward these types of advocacy efforts.

## Discussion

Unlike those with obvious disabilities who are socially stigmatized, in part because of the visible presence of their disability, the participants in this study faced an opposite reality. Instead of having to battle against the overgeneralization of their impairments and the medicalization of their condition, they experienced barriers to visibility and exerted substantial energy to establish and find persons who would accept its legitimacy. These experiences are consistent with findings from other research indicating that persons with CFS seeking medical services face disbelief, misunderstanding, misinformation, and an overemphasis on psychological explanations (Anderson & Ferrans, 1997; Banks & Prior, 2001; David, Wessely, & Pelosi, 1991; Green, Romei, & Natelson, 1999; Taylor & Eisele, 2003). Despite evidence against the hypothesis that depression is responsible for CFS (Antoni et al., 1994; Friedberg & Krupp, 1994; Ray, 1991), many medical practitioners, as well as friends and families of persons with CFS, continue to believe that the illness is related to psychological dysfunction, and that the symptoms can be attenuated, relieved, or eliminated with psychotropic medications or if the individual would only learn to cope with them more effectively (Conant, 1990).

Participants in this study were also at variance with the social model idea that impairment is a neutral difference and with the idea of taking on a disability identity. Many individuals with CFS do not embrace the notion of taking pride in their disability, but instead struggle with the fluctuating nature of their symptoms and seek diagnosis and care from multiple health care professionals with expectations of symptom relief or cure. It is not surprising that persons with CFS would have difficulty achieving a disability identity on two accounts. First, as already discussed, their experience of the disability is quite at variance with that advocated by scholars in disability studies and by leaders in the disability movement. Second, as persons with an invisible disability, these individuals are not always readily recognized and welcomed into the disability community by other persons with disabilities. This point was underscored in this study. Part of the intervention for these participants involved exposing them to concepts from the social model. Although many of the clients found that those themes related to personal rights were useful to them, for the most part, the themes of disability pride, disability culture, and

positive disability identity simply did not resonate with this group's experience and perspectives.

## Conclusion

Although the social model certainly has profound implications for occupational therapy practice, it is important to recognize that it does not capture the full reality of disability. In particular, the social model has serious limitations in describing the disability experience of individuals with disabilities who do not have obvious disabilities and whose impairments do not conform to the traditional viewpoint of disability. Although CFS is unique in that health professionals sometimes deny its existence, a variety of invisible disabilities carry with them unique circumstances that also differentiate them from traditional disabilities. For example, AIDS carries with it the stigma associated with homosexuality or intravenous drug use, as well as fears about contagion. Such unique, additional characteristics, associated with particular disability conditions, mean that the total concatenation of factors that constitute the disability circumstance are much broader than those offered by the social model. Thus, although the social model has been an important influence on contemporary understanding of disability and certainly offers a way of conceptualizing and approaching the disability circumstances of many people, there are others whose disability experiences fall outside of its explanatory approach. In the end, the implications for occupational therapy are that the incorporation of disability concepts into one's therapeutic approach must also be done with careful consideration of the disability experience of one's client or client group. The social model simply may or may not be relevant to the person's experience depending on the nature of the impairment or the unique history of the person's disability experience. Occupational therapists who seek to inform their practice with concepts from disability studies will need to carefully examine when and how these concepts are relevant to particular clients and, importantly, to recognize other realities of the disability experience that may not be captured by existing or dominant concepts.▲

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