

Changing Tide

Reappraising Cognitive Behavior Therapy in CFS

BY ELEANOR STEIN, MD, FRCP

Cognitive behavior therapy (CBT) has caused turbulence in the CFS community for good reason. But what's beneath the surface of this contentious issue? Is avoiding CBT risking throwing out the proverbial *baby* with the *bathwater*?



AT-A-GLANCE ▶▶

- **Some** research on using CBT for CFS is couched in the false assumption that CFS is the result of dysfunctional illness behaviors.
- CBT used responsibly to help manage valid illness challenges *can* help CFS patients cope and function more easily.

In the almost 20 years that I've been affected by CFS, it has been an ongoing intellectual and practical challenge to integrate my medical training (which was in progress when I became ill) with my illness experience and the experiences my patients share with me.

In my medical practice I use cognitive behavior therapy (CBT) and know it to be a very effective tool both inside and outside of psychiatry. CBT is used as an adjunct to medical treatment in heart disease, arthritis, multiple sclerosis and cancer to help people cope with the uncertainty, anxiety and life changes those conditions cause. And in many psychiatric disorders, CBT is often considered the treatment of choice.

In CFS however, the use and misuse of CBT is one of the most emotional and divisive issues in the field. Let's take a deeper look at the issue.

What exactly is CBT?

CBT is the joining of two of the major psychological movements of the 20th century: cognitive therapy and behavior therapy.

Cognitive therapy was developed by psychologist Aaron Beck to assist people with depression. Rather than uncovering and resolving deep emotions in order to change negative thoughts, Beck introduced the novel idea that it could work the other way around. A person could change negative feelings by adjusting beliefs. Unlike psychodynamic (depth) therapy, cognitive therapy is a directive, time-limited, structured approach that guides a patient to identify underlying beliefs and assess whether they are helping or hindering life goals.

Behavior therapy developed from the observations of Ivan Pavlov and was furthered by B.F. Skinner who showed that manipulation of consequences (reward or punishment) results in changes in behavior.

In modern psychotherapy, behavior therapy employs the development of an individual behavioral plan based on a patient's observations of his/her own behavioral symptoms and patterns.

Cognitive behavior therapy joins these principles to focus on a person's unique beliefs and behavior patterns in

order to bring about change. In its purest form, CBT involves careful self evaluation under the guidance of an impartial and trained therapist. The therapist has knowledge of common attitudes and behaviors that can go awry in certain conditions (like negative expectations in depression), but each patient is unique and not everyone conforms to illness norms.

In respectfully administered CBT, the patient is in charge of identifying problem areas and goals for change. The therapist makes suggestions as to how this could be achieved. The patient tries the suggestions and reports back on how well they worked. The treatment plan is then altered based on the feedback.

As with any form of therapy, if the therapist pushes his or her own belief system on an unwilling patient, the therapeutic relationship will be adversely affected and therapy is likely to be unsuccessful.

What's the controversy about?

The contentious issue when it comes to CBT and CFS is the implication that CFS is perpetuated by dysfunctional attitudes and behavior. The *attitudes* commonly targeted as dysfunctional are the belief that CFS has a physical cause,

a fear of symptom exacerbation due to activity and a preoccupation with symptoms. The primary *behaviors* considered dysfunctional are avoidance of activity, doctor shopping and attending patient support groups.

There are two contentious issues here. The first is the assumption that the majority of people with CFS have these traits to begin with. The second is that whether these beliefs and behaviors, if present, are actually dysfunctional or are an understandable response to having a complex and disabling physical condition in which the primary defining characteristic is that symptoms increase with activity.

Research does not support the assumption that a majority of CFS patients hold dysfunctional illness beliefs. It has also been proven that patients with CFS generally do not have a clinical fear of activity (kinesiophobia).

In terms of behaviors, some researchers and therapists have also argued that people with CFS inappropriately

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cling to *acute illness behaviors*. Acute illness behaviors are biologically driven by immune and inflammatory chemicals to help people recover from short-term illnesses such as an infection or trauma. These behaviors include: increased attention to symptoms, avoidance of activity and increased sleep. They play a role in sickness and healing.

Why anyone would want to maintain these life-limiting behaviors over the long term puzzles most CFS patients who are desperate to return to their role of provider, parent, worker, volunteer or friend—roles that often provide definition and self esteem, not to mention the money to pay rent and buy food.

Another source of contention is the assertion that CBT can somehow *cure* CFS. This notion, whether overtly stated or covertly embedded in the therapeutic construct, minimizes the physical symptoms experienced by patients and leaves them feeling understandably invalidated.

What does research say about CBT?

On the one hand, there are several published studies that conclude that CBT and graded exercise lead to improved function in patients with CFS. However, a careful reading of some of these studies reveals methodological concerns. Some don't use the accepted 1994 international CFS case definition to select subjects and/or use patients with relatively good pre-intervention functioning and high psychiatric symptom levels. In other words, the subjects in these studies may not be reflective of the severely ill CFS patients who report getting worse from attempts to increase activity levels.

It's important to note that some of the more recent CFS studies of CBT have used a very different approach than the earlier ones. Focusing on "adaptive lifestyle change" including stress management, cognitive reappraisal and energy and sleep management, they're not based on the assumption that patients demonstrate dysfunctional illness beliefs or activity avoidance. Not all CBT studies are created equal. One needs to read them before judging their credibility.

We can learn from research in *other* medical conditions that patients benefit from education about the nature of their condition and from careful self observation to identify the impact of their thoughts and behaviors on symptoms.

For example, CBT has shown positive results in decreasing depression among patients with multiple sclerosis and decreasing pain among patients with various types of arthritis. Learning not to fear the worst or catastrophize does improve symptom levels presumably through modulation of the stress axis. In arthritis, changes in physiological markers have been noted following behavioral interventions. These studies provide evidence of a strong mind/body connection, suggesting that changing thoughts and behaviors can impact both physical and psychological symptoms.

To date, no change in physiological markers has been reported in any behavioral intervention studies in CFS.

Using CBT appropriately for CFS

The Stanford Self-Management approach to chronic illness is a widely used public health behavioral model in which patients with a range of chronic conditions are provided with a framework to empower them to collaborate with their health care professionals, taking charge of their own health. The model includes: adoption of an exercise program, cognitive symptom management, nutritional change, energy and sleep management, use of medication and community resources, managing emotions (fear, depression) and learning productive communication with health care professionals. It's notable that the Stanford model does not predict that empowerment and behavioral change will cure the underlying condition. Rather it asserts

that with these tools, patients will function better in spite of their medical challenges. The Stanford model is currently being tested in people with CFS.

One solution to the CBT debate, in my opinion, is to treat every patient as an individual. Initiate a

collaborative assessment as to whether there are attitudes or behaviors that could be impairing a patient's ability to function or whether the patient is already functioning maximally given her health status. Patients should not assume that there are no changes they could make, and physicians should not assume that a patient's symptoms are exacerbated by attitudes or behaviors. In both cases, trials of behavioral change may help determine the truth of the matter.

In my clinical experience, once patients realize that I don't have any preconceived assumptions about their function or mental health, they readily identify their own goals

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and discuss change openly. There is almost always something to learn.

Appropriate CBT treatment goals vary considerably depending upon the phase of illness. For example a patient in the crisis of early illness may benefit from learning cognitive skills such as how to accurately appraise symptoms and what makes them better or worse. The priority for a patient who has been ill for many years may be how to reestablish a meaningful, purposeful life within her energy and cognitive limitations.

In practice, most experienced clinicians evaluate each of the major symptom areas in CFS: energy, pain, cognition, activity, immune/inflammatory symptoms, autonomic function, diet/gut function and emotional symptoms. They then suggest interventions to help patients manage these symptoms and maximize their ability to function.

With regard to the contentious issue of activity level, most patients benefit from regular, paced activity. Using tools such as pedometers and heart rate monitors helps patients determine if they're over or under-exercising. The key is to learn what level of activity is beneficial and safe.

Clearly there is an urgent need for more research into the treatment and management of CFS so that patients and their health care providers have a broader range of evidence-based choices rather than one, emotionally charged approach to either embrace or reject.

As for CBT itself, since CFS is a biomedical condition it's unlikely that any behavioral intervention will be curative. Nevertheless, changes in attitudes and behavior can improve coping and function. Given research in other disorders, it would be foolish to disregard the potential usefulness of appropriate cognitive and behavioral interventions in CFS. Figuratively speaking, we shouldn't throw the baby out with the bathwater. ■

Dr. Stein is in part-time private practice as a psychiatrist in Calgary, Canada. Her practice is devoted to CFS and related disorders. Her clinical objective is to help patients navigate the complicated web of the mind-body interface. Her research objective is to develop and implement objective tests to aid in the accurate and timely diagnosis of CFS.

IN THE FIELD: CBT AS A TOOL

Longtime dedicated CFS researcher and clinician Dr. Nancy Klimas has been treating CFS patients for two decades. She considers cognitive behavior therapy (CBT) one of several useful tools at her disposal and says that she uses it frequently.

According to Dr. Klimas, "I use CBT as a supportive treatment, much in the way I use it in other patients with complex chronic illnesses."

She describes studying CBT in HIV-infected men and women for many years and finding that it improves quality of life, helps patients better understand their illness and helps them deal with complicated medical regimens as well as societal and family responses to the illness.

Recognizing that CFS and AIDS pose some similar challenges, Dr. Klimas says, "I think every patient can benefit from this sort of intervention. Societal and family responses and changing medical approaches to the illness can leave a patient feeling out of control. CFS is trickier still, because patients will relapse if they try to push through their pain and fatigue." Her work with CBT for CFS has yielded improvements in quality of life and function—even improvement in immune function. Specifically she notes the benefit of patients learning to understand the concept of a personal "energy bank" and how to assess and manage it effectively day-to-day.

Dr. Klimas' patient Laurie Scop agrees. Diagnosed with CFS in 2001, Scop came under the care of a multidisciplinary team of health care professionals employing a variety of treatments including CBT. She describes using CBT to learn how to identify and disregard unproductive defense mechanisms and to find new ways to participate in life "despite the physiological unknown." Shares Scop, "CBT was therapeutic for me."

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