

Nurses Can Play Key Role in CFS Management

By Terri Lupton, RN

Chronic fatigue syndrome (CFS), also known as chronic fatigue and immune dysfunction syndrome (CFIDS), continues to puzzle the health care, research and patient communities. The cause of CFS is unknown and universal treatment methods have yet to be identified. Medical and nursing care is a particular challenge as new therapies are invariably a trial-and-error process.

The psychosocial implications are extensive as people with CFS make efforts to keep their lives intact while facing the stigma associated with the illness. Family, work and social relationships are often strained and the financial impact can be devastating when the illness produces significant disability. The side effects of a sedentary lifestyle, hypersomnolence and/or insomnia pose additional health risks.

CFS varies considerably in both symptom expression and severity. Some people may continue to work but must curtail home and social activities. At the other end of the continuum is the person who is disabled to the point of needing assistance in meeting basic needs.

It is estimated that 800,000 or more adults in the U.S. have CFS. Prevalence rates of this magnitude indicate that nurses are likely to encounter CFS in many settings, including the classroom. Prevalence data is not available for CFS in children and adolescents, but it should be noted that the illness has been diagnosed in children as young as age 5 years (rarely)

and in adolescents. In the under-20 population, CFS appears to occur more often in youth ages 11-17. CFS is not particularly selective: it affects blue- and white-collar workers and people of all racial and ethnic groups. It affects females at a rate of about three times that of males. Research indicates that CFS is most widespread in women ages 40-49.

Nursing Approaches

People with CFS are aware that the diagnosis brings with it negative reactions from all segments of society; however, a particularly distressing impact may be felt when rejected by the health care community. It is imperative that CFS patients feel believed and respected. Listening with full attention and accepting the patient's account of the illness experience may be the most important actions that nurses can perform.

Nurses need to equip themselves with accurate facts about CFS. Misinformation about this illness is bountiful. Fact-based information is available from credible sources, including well-respected journals, organizations and websites. *Nursing Spectrum*, the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH) and the CFIDS Association of America are examples of reliable resources.

Fundamental knowledge of the case definition criteria is essential for nurses to help identify people with CFS. The 1994 International Case Definition for CFS was developed to provide a form of standardization for research studies. Lacking a clinical case definition, the



1994 document is used in the clinical setting to offer guidelines for diagnosis as well. However, both researchers and clinicians find the document to be insufficient in some sections. In response to this, a working group of multidisciplinary CFS experts was assembled by the CDC in 2001 to clarify ambiguities in the case definition and make it more applicable in research and clinical settings. In the clinical arena, the focus was to enhance the diagnostic process for health care providers and patients.

Diagnoses with unknown etiology are frequently subject to skepticism. A substantial body of objective evidence points to a physiological basis for the disorder; however, no specific diagnostic marker has been found. There are studies that theorize a psychological basis, yet nothing definitive has been identified in this area. When a physical basis is not readily apparent for chronic illness, there is a tendency to psychologize it. This appears to be true for CFS; attaching a mental health label is a seemingly common occurrence. Reports from CFS patients tell of numerous incidences when they have been told, "It's all in your head."

Lorraine Steefel, a senior staff writer at *Nursing Spectrum* and a core trainer for the CFIDS provider education program developed by the CDC and the CFIDS Association of America, says that even today, "I find that most RNs are unaware that CFS is a recognized disorder by the CDC and that many studies dispute the notion that it is a psychosomatic illness." Nurses can play one important role in managing CFS patients simply by being open-minded and respectful of patients. Considering all patients holistically and without preconceived assumptions is a basic nursing practice that produces benefits for all involved.

The current health care environment, coupled with today's more well-informed patients, is ideal for building a collaborative provider-patient partnership. Nurses can

create a setting in which many patients can actively contribute to their own health management. This can be accomplished by encouraging patient input, guiding patients in self-care education, providing resource information, monitoring treatment compliance and outcomes and acting as a bridge to the medical community. Sharing responsibility for personal treatment options may also decrease patient's feelings of helplessness and hopelessness. The CFS population is an excellent group with which to attempt this type of collaboration because patients are, in general, quite knowledgeable about the illness and related treatment interventions, want desperately to get well and have a sincere desire to be heard and involved.

Nurses can also act as advocates for CFS patients by raising awareness of the complexities and realities of the illness and taking advantage of educational opportunities for nursing groups, legislators and other health care providers. In summary, CFS patients are in need of the compassionate care that lies at the core of nursing philosophy. ♦

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