

THEory into ACTION

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Advances in Psychological Research on ME/CFS: Turning Theory into Action

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Turning theory into action is essential within the field of Community Psychology. For those of us focused on macro-level empowerment and social change, demonstrating the practical effectiveness of research findings in the field is crucial. Under the direction of Dr. Leonard Jason, DePaul University's Center for Community Research currently hosts a number of projects exemplifying theory in action. One research focus of the Center is Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS).

ME/CFS is currently a hot topic among researchers and physicians. The name "Chronic Fatigue Syndrome" has led to many negative connotations, and in turn research suffered due to lack of funding and disbelief in the reality of the illness. Patients assert, and research supports, that fatigue is only one of many debilitating symptoms associated with this illness. Post-exertional malaise (feeling worse after exertion), memory and attention problems, sleep dysfunction, muscle and joint pain, swollen lymph nodes, and sore throat are all symptoms uniquely characteristic to ME/CFS. Further, the name

“Chronic Fatigue Syndrome” gives the impression that this illness is not to be taken seriously, making way for the colloquial reference to this condition as the “yuppie-flu” by some medical professionals – that is, everyone gets fatigued at some point or another, so what makes this patient group different from others? Currently, many efforts are being put forth to change the name so as to avoid downplaying and insulting the everyday reality of the patient community.

The cause of the illness is not yet definitively known. Research suggests that mold may be one of the possible pathways to developing ME/CFS. Other research suggests viral infections lead to the development of this illness. At the Center for Community Research, one of our current NIH-funded studies, *A Prospective Health Study of CFS Following Infectious Mononucleosis in College Students*, aims to identify possible risk factors and biomarkers that predispose college students to develop CFS.

Previous studies have assessed the prevalence of ME/CFS following infectious mononucleosis (IM), finding that 12% of those who contracted IM develop ME/CFS at 6 months. The current study aims to expand on these findings by comparing baseline data to data collected from students after the development of IM and ME/CFS at 6 and 12 months. Results from this study will provide information on the risk factors (psychological and physiological) and development of ME/CFS in college students.

This study is an excellent example of theory in action in that the results hold implications for ME/CFS prevention and treatment. Committing time to exploring possible physiological causes and trajectories of ME/CFS first validates the experiences

and testimony of patients. It also contributes to the case definition of ME/CFS, which thereby debunks myths and negative connotations associated with the illness (i.e., that it is not a real or serious illness). By assessing biomarkers, symptoms, possible risk factors, and causes associated with ME/CFS, the legitimacy of the illness is established and steps towards awareness, prevention and treatment are made.

Additionally, ME/CFS research has traditionally gathered data from patients within clinics or physician-referred patients, samples of which have been predominantly white, middle-class women. This sampling bias has further encouraged the stigma towards ME/CFS and the use of the nickname “yuppie flu.” In the 1990’s, Dr. Jason and his colleagues conducted a study to determine the prevalence of ME/CFS among adults using a community-based sample and found that despite common misconceptions of the patient population, ME/CFS actually occurs more frequently among minority populations. Other ME/CFS research using community-based samples has yielded similar results. Underserved populations are less likely to have access to or seek out adequate health care, which may explain why they have been under-represented in previous research on physician or clinic-referred samples of patients with ME/CFS. Evidence provided by previous research suggests community-based samples are critical for obtaining unbiased results with higher external validity and may shed light on the needs of underserved populations.

Putting this theory into action, *Pediatric Chronic Fatigue Syndrome (CFS) in a Community-Based Sample*, another NIH-funded study being conducted at the Center for Community Research, aims to determine the prevalence of ME/CFS in youth ages 5-17 from a demographically diverse, unbiased sample of community members. This is the first pediatric ME/CFS study to utilize community-based sampling methods.

Another unique aspect of this study is that it is multi-dimensional, gathering information on children's mental and physical health from assessments by psychologists, physicians, the parent/guardian, and the child, as well as from objective data obtained from an actigraph monitor that measures their activity level over a period of 24-hours. A common misconception about ME/CFS is that its origin is psychological. Patient communities often express their distaste towards this assumption, explaining it makes them feel like their illness is being discounted or that people don't believe their illness is real – that if they *really* wanted to be more active, they could be if they just went to therapy. By incorporating a psychological assessment into participant assessment, we are able to show that the existence of pediatric ME/CFS is not concurrent with psychological disorders.

This study is a collaboration with Lurie Children's Hospital, which allows for a full physical exam to be conducted on the child by a physician. This part of the study includes a blood draw, urine collection, a saliva test, and a heart rate and blood pressure procedure that measures orthostatic intolerance. The blood, urine, and saliva samples are analyzed

to determine whether there are any issues with their thyroid, iron level, organ health, blood sugar, and other common health issues that may cause symptoms similar to ME/CFS. This in-depth examination of a child's physical health further adds to this study's uniqueness because it rules out any exclusionary health conditions.

In a research area that has been cluttered with biased sampling methods, stigma towards patients and the illness itself, confusion among doctors and researchers due to the use of multiple case definitions, and a longstanding chasm between patients and doctors on the origin and treatment of ME/CFS, the studies conducted at the Center for Community Research aim to be unbiased, methodologically sound, and to produce valid and reliable results that continuously exemplify theory into action.

This is one of a series of bulletins highlighting the use of community psychology in practice. Comments, suggestions, and inquiries are welcome. Please direct them to Bill Berkowitz at Bill_Berkowitz@uml.edu.