

Increasing Efficacy of the CDC's ME/CFS Educational Program

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INTRODUCTION

The Centers for Disease Control (CDC) is revising and creating new educational materials for its Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) educational program. The hope is that this fourth try at producing ME/CFS educational materials will result in equality of care for ME/CFS patients and they will, for the first time, experience appropriate care throughout the gamut of our healthcare system: from primary care provider to subspecialty care. According to the CDC, the revisions will reflect the content and recommendations of the 2015 Institute of Medicine (IOM) ME/CFS report.¹ That report found the name, Chronic Fatigue Syndrome, stigmatizing to the illness. Comments expressing that sentiment occur throughout the document. Thus, the view of the IOM's ME/CFS Authoring Committee is that the illness currently known as ME/CFS has been stigmatized. That stigma affects healthcare delivery and, in consequence, patient quality of life.

To fulfil the CDC's mission of *improving the healthcare provided to ME/CFS patients* and thereby improving patients' quality of life, the CDC should go beyond the information contained in the IOM ME/CFS report. More recent, relevant documents and information, as well as the advice gleaned from professional healthcare educators warrant consideration. Specifically, the information and recommendations contained in the National Research Council and Institute of Medicine jointly sponsored report on stigmatized illnesses² should be included. The information and recommendations contained in that report are consistent with and even an extension of the IOM's ME/CFS report.

The CDC's ME/CFS educational program revision seems focused solely on the revision of its educational material. The CDC has not indicated a willingness to consider alterations in the methodology it will use to deliver its revised information or changes in personnel who will convey it. Experienced healthcare educators know that educational content is but part of a successful transmission of information from expert to student. The packaging of the message, the mechanism of its delivery, as well as who delivers it are as important, if not more important, than the content of the message itself. For the message to be received, its relevance to the recipient needs to be manifest, and its importance to the recipient apparent. These considerations are recommended in the NRC/IOM Stigmatized Illness Report.

The CDC's Stated Revision Process

According to the CDC, the process by which the new ME/CFS educational materials will be produced involves holding a technical development workshop at which participants will, *"help identify needs and priority topics for ME/CFS information and educational materials...We would like to invite your organization to participate in this collaboration by nominating a representative to serve as a member of the Technical Development Workgroup (TDW). ...The process for designing these materials must be a transparent collaboration that involves healthcare professionals, patients and advocates, medical educational organizations, and federal agencies"*³

Concerns with the CDC's Stated Revision Process

The purpose of the CDC's ME/CFS educational material revision is stated in a one-page overview sent to invitees of the Technical Development Workshop: *"The purpose of this project is to update the Centers for Disease Control and Prevention's educational materials and web content on ME/CFS, informed by the IOM report's findings and recommendations and the perspectives of patients, providers, researchers and federal partners."*

#1: While the original intent of this project might have been to incorporate the latest ME/CFS findings from an authoritative source, the stated purpose of this project prevents consideration of newer, relevant material that has been published subsequently to the announcement date.

#2: The CDC announcement makes no mention of seeking the opinion of experienced healthcare educators whose advice would be similar to the recommendations contained in the NRC/IOM Stigmatized Illness Report which has yet to earn inclusion in the CDC's ME/CFS knowledge base.

#3: The one-page project overview indicates that the intent of the CDC is to develop one set of educational materials which will be shared among, *"a variety of audiences."* The strategy of developing one set of educational materials to be shared among audiences holding different perspectives is at odds with the recommendations of the NRC/IOM Stigmatized Illness Report. The latter suggests educational materials be tailored to the specific backgrounds and interests of each, specific, target audience; be delivered in a manner that sustains their particular interests; and be presented by personnel who command the respect of each, specific target audience.

#4: Limiting the knowledge base to the IOM's ME/CFS report excludes considering the reasons why the CDC's previous, three ME/CFS educational programs did not achieve their goals of increasing healthcare coverage for ME/CFS patients. Since 2003, the CDC has launched three ME/CFS educational programs: the Trained Trainer Program⁴, the Spark Awareness Campaign⁵ and several continuing medical education courses delivered via the internet.⁶ A recent study,⁷ as well as the IOM ME/CFS report itself, reveal that these efforts have had little impact on ME/CFS patient access to care, or referral to specialized care. The 2014 survey⁷ gathered data from 998 patients throughout the U.S.A. Patient dissatisfaction with medical care was rated high in comparison to a control group. Multiple census regions within the United States were identified which lacked patient accessibility to any specialized care.

It is, therefore, unlikely that wordsmithing and prioritizing ME/CFS materials contained in the IOM's ME/CFS report, and distributing that revised material without altering the methodologies of distribution, will result in increased access to medical care or increased quality of medical care for ME/CFS patients.

ME/CFS Satisfies the NRC/IOM Criteria of A Stigmatized Illness

The CDC should consider ME/CFS a stigmatized illness because ME/CFS satisfies the definition of a stigmatized illness as defined by the National Research Council/Institute of Medicine Ad Hoc

Committee's Report on Stigmatized Illnesses.² The Report defines a stigmatized illness as, "any condition with no known cause or cure." Cited examples of such illnesses and/or conditions are: cleft palate, epilepsy, tuberculosis, cancer, and HIV/AIDS. The Report observes that, "When cause of illness becomes known, or when a cure is developed, the stigma associated with the condition wains."⁸

Economic Justification For Treating ME/CFS As A Stigmatized Illness

While the NRC/IOM Stigmatized Illness Report acknowledges additional expenses are incurred in educational programs that include activities aimed at reducing or eliminating the stigma associated with illnesses, the authors of this report maintain that the reduction in healthcare costs generated by improved health of patients, and the return of those patients to more productive lifestyles, more than offset the costs of including stigma-reducing activities in educational programming.

Brief History of ME/CFS As A Stigmatized Illness

In 1955, an outbreak of ME/CFS was characterized as, "mass hysteria."⁹ A 1987 article appearing in the *New York Times*¹⁰ quotes one, "expert," as characterizing the illness as, "Yuppie Flu," despite data and expert opinion to the contrary being offered in the same article. That stigmatization persists in recent times as evidenced by: (1) a survey published in 2014, conducted by Dr. Don Baken, a clinical psychologist at the School of Psychology at Massey University in New Zealand who found ME/CFS patients feel misunderstood and stigmatized,¹¹ and (2) the announcement on September 10th of this year, that a panel of, "experts," for the Canadian Institute of Health Research rejected funding of all proposed ME/CFS research because, "there is no evidence that Chronic Fatigue Syndrome is a disease." Rather, evidence suggests that, "psychosocial factors," are, "both a cause and perpetuating factor for CFS."¹² Perhaps *The Guardian's* recently published review of the medical world's treatment of ME/CFS best summarizes contemporary management of ME/CFS: "Yet for much of the past three decades, CFS has been treated as the proverbial skeleton in the closet of the medical world. Potential researchers have been scared off by the stigma associated with the disease, and government funding has been nonexistent. "When I was a medical student in the 90s, we were instructed that CFS patients could not be seen in our clinic," Montoya recalls. "And a letter was sent out to those patients telling them not to come."¹³

To account for the etiology of such stigmatization, Richman, et al.¹⁴ propose that the failure of Western medicine to demonstrate a viral etiology of ME/CFS has led to healthcare practitioners embracing psychiatric and sociocultural explanations of the illness thereby delegitimizing ME/CFS as a biomedical phenomenon.

The Application of Destigmatization Science to ME/CFS Educational Programs

Destigmatization science is relatively new. "Stigmatized illness," is not a Medical Subject Heading (MeSH Term) in the National Library of Medicine's thesaurus of controlled vocabulary used to index articles for MEDLINE although it is currently being considered.¹⁵ Searching the MEDLINE database using, "Stigmatized Illness," as an, "other," term yields 270 papers in the database containing that term, with the earliest paper having been published in 1985. Searching MEDLINE using the terms, "Chronic Fatigue Syndrome," and, "Stigmatized Illness," yields just 2 articles: one dated 2002, the other dated 2008. Hence the consideration of ME/CFS as a stigmatized illness is a relatively recent development.

In mounting an ME/CFS educational program for healthcare providers and/or the general public, the NRC/IOM Report on Stigmatized Illnesses would recommend the inclusion of the elements listed in Table 1 below. For the purpose of providing possible explanations as to why the previous CDC ME/CFS educational programs did not achieve their desired outcomes, the utilization of the stigma-reducing elements by each of the CDC's previous three programs is shown in columns on the right-hand side of Table 1.

Table 1: Elements of An Illness Destigmatizing Educational Program¹⁶

	TtTP	Spark	Online
Planning/Design Elements:			
Long-term support – perhaps for decades	No	No	No
Selection of communication channels and settings of message dissemination	?	Yes	Yes
Planning phase includes formative research	Yes	Yes	Yes
Evaluation and monitoring from planning phase forward	?	No	?
Development of prongs to address each relevant need	No	No	No
Coordination of delivery across states, and economic and social sectors	No	No	?
Identification of attitudes and beliefs of target audiences toward the stigmatized illness prior to launch	No	No	No
Targeting medical students early in their education and training: Medical students’ attitudes tend to solidify as students progress through medical school and residency. ¹⁷	No	No	No
Message Content:			
Presentation contains factual information with the goals of correcting misinformation and contradicting negative attitudes and beliefs	No	No	No
Messages are tailored to the specific audiences	?	No	?
The source of the information delivered is perceived as a credible by the target audience	Yes	Yes	Yes
The source of the information is perceived as relevant, and worthy of trust and respect by the target audience	Yes	?	Yes
Message Delivery:			
The most effective programs are contact-based interventions and contact-based educational programs.	Yes	No	No
Media campaigns should be delivered through both traditional platforms and newer social media.	n/a	?	n/a
The message should be delivered repeatedly to increase the likelihood of attitudinal and behavioral change.	No	?	No
For healthcare workers, provide multiple avenues of message exposure: e.g. workplace informational materials, continuing education, face-to-face contact with people with lived-experiences, billboards near health care facilities and on buses and trains along routes that workers might use to get to work.	No	No	No

Table Legend: The column marked, “TtTP,” contains the scores for the Train the Trainer Program. The column marked, “Spark,” contains the scores for the Spark Awareness Campaign. The column marked, “Online,” scores the results for the online medical education courses. “?” indicates doubt as to whether the program utilized that element. Scoring is the personal opinion of the author based upon knowledge and experience with the programs.

Summary

The three previous CDC educational programming efforts designed to increase healthcare provider knowledge about ME/CFS and increase healthcare provider participation in the improvement of healthcare delivered to ME/CFS patients were not designed to be, nor knowingly included, illness destigmatizing elements. Perhaps the lack of recognition of ME/CFS as a stigmatized illness in these programs, and the lack of stigma-reducing content in these programs contributed to their less than anticipated outcomes. Table 1 lists 16 elements which should be included in the design and implementation of a successful illness-destigmatizing, educational program. The *Train-the-Trainer Program* lacked 8 of these elements, the *Spark Awareness Campaign* lacked 10, and the *online medical education programs* lack 8. Other stigma-reducing elements which these programs may or may not have included are indicated by “?” in the Table. Most likely, each of these programs contained approximately one-half of the suggested stigma-reducing elements which may account for the unanticipated, disappointing outcomes of these programs. Because ME/CFS should now be recognized as a stigmatized illness, educational programming going forward should be designed to include stigma-reducing elements to overcome false beliefs regarding the illness and encourage healthcare providers to provide appropriate care regardless of level: from primary care to subspecialty care.

A final note: It is possible to design an illness-destigmatizing program that fails, despite the incorporation of the 16 elements listed above. According to the NRC/IOM Report, stigma-reducing programs fail for three reasons:

1. The message design was not driven by testing.
2. The message focused on personal consequences but not relevant ones.
3. The argument that was crafted did not fit the desired program outcome.

Thus, the factual or scientific content of an illness-destigmatizing program is not what determines its success or failure. It is the presence or absence of ongoing evaluation, providing programming that is relevant to each specific target audience, and the crafting of the programming so that it compels the desired outcome. None of the destigmatizing illness elements have been considered in the IOM’s ME/CFS report. Hence, to rely solely on that report as the knowledge base for the revised ME/CFS educational program risks another disappointing outcome.

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