Emilia A. Ramirez, BS, Marjorie Buchholz, PhD, LMFT, Jesse Allen, LMFT, MedFT, Brian Distelberg, LMFT, PhD, David Puder, M.D.

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In this episode of the podcast, we host a discussion about the MEND program, which serves patients with chronic illness and their families.

Over the last several years, Dr. Puder has worked as the medical director for Loma Linda University Health's MEND program, a hospital-based intensive outpatient program (IOP) and partial program that works with patients who have chronic illness and their families. Jesse has been a lead therapist instrumental to the program's success and Brian Distelberg oversees the MEND program and acts as the Director of Research for the program. During this episode, they come together to discuss the MEND program.

Introduction

There is strong evidence in academic literature indicating that stress places a negative influence on our mental and physical health. Catecholamines, the body's stress hormones, contribute to the development and exacerbation of chronic health conditions. For example, increased levels of catecholamines may cause hypertension, inflammation, and immune suppression, which could contribute to chronic illness progression. The production of the catecholamines epinephrine, norepinephrine, and dopamine is initiated by the body's nervous system; their quantities are influenced by stress and anxiety.

The MEND model assumes that the physiologic stress of chronically ill patients develops in response to, or is at least exacerbated by, psychological, family, and social experiences. Over time, the patient with chronic illness and their family system develop patterns of interaction which trigger the stress response and actively contribute to the illness progression. There is hope and evidence that, by identifying and decreasing the stress response, chronic illness progression can be delayed and health care costs decreased.

Cost Benefit

A retrospective study, by Brian Distelberg, Jesse Allen and David Puder, among other colleagues in 2020, reviewed 107 adult patients, ages 18- to 80-year-old, who completed an average of 25 sessions. The study showed a 12-month total cost savings of \$16,376. This total cost is a combination of costs due to physical health (PH) and behavioral health (BH), but does not include the cost of the MEND program. With each treatment day valued at \$285, the total

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cost of the program over 25 sessions would be \$7,125. Therefore, when accounting for the cost of the MEND program, the 12-month total cost savings would result in a net savings of \$9,251.

Another study performed a cost-benefit analysis of the MEND program to determine if there is cost benefit in the pediatric chronic illness management costs. This study found that 12 months post pediatric MEND completion, families saved \$15,249 in direct medical costs and an additional \$15,627 in indirect costs, saving approximately \$5.74 per dollar spent on the MEND program.

Stress Response

MEND patients are taught to understand the biological processes and negative effects of stress. The mind-body connection is paramount in MEND—specifically, the interaction between a patient's psyche and the sympathetic nervous system. The sympathetic nervous system is what triggers the biochemical fight, flight, or freeze response in the body. Over 1,400 physiological and biochemical changes occur in the body during the sympathetic response. Within these changes are 30 different stress hormones that are released, including adrenaline, noradrenaline, and cortisol, to prepare the body and mind to respond to the proposed threat.

Prolonged secretion of these stress hormones can contribute to the progression of a chronic illness. This can be seen through various effects of stress hormones: suppression of thyroid function, contribution to blood sugar imbalances, higher blood pressure, lower immunity, increased inflammation, and slowed wound healing. Additionally, a decrease in cognitive performance inhibits one's ability to process emotions, which can cause depression and anxiety.

The MEND model also recognizes that the stress response experienced in a patient with a chronic illness is interdependent with the parent-child relationship, larger family system, and social networks (such as school or work). Examples of stressors from these social networks include a sense of isolation, feelings of looking different, or being different from healthier peers. Over time, these stress responses directed by a patient's psyche may develop more frequently and in greater intensity, becoming maladaptive. This maladaptive stress response contributes to chronic disease through the body's physiological response to stress hormones.

To assess the impact of MEND on decreasing a pediatric patient's stress response, a prospective pilot study was conducted. This study expanded its patient population from other studies that focused only on pediatric patients with Type I Diabetes by including pediatric patients with various chronic illnesses who were enrolled in the MEND program at Loma Linda University Health.

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The study found that dopamine levels rose significantly to a normal range at the completion of the MEND program and continued to increase even at 3 months post-MEND intervention (Distelburg et al., 2018). Epinephrine and norepinephrine levels were also found to decrease significantly to normal range at completion of the program and were maintained at the normal range 3 months later. Another outcome evaluated by this study was in mental health (via HRQL) and cognitive functioning. Both were found to have significant improvement at the end and 3 months post completion of MEND among the pediatric population studied.

Illness Narratives

The MEND model presupposes that an underlying cause of chronic activation of sympathetic nervous system activity comes from the meaning, or illness narrative, a patient associates with their chronic illness. For instance, if a chronic illness patient believes "I'm a burden," then each time this belief is heard or felt the patient's body interprets it as a real threat and mounts a physiological response to the perceived threat. This belief, "I'm a burden," is a part of their illness narrative. Additionally, the family system may unwittingly become a co-conspirator in the illness narrative and sympathetic nervous system triggering.

For example, there is a heavy burden of financial stress placed on many families of pediatric patients with chronic illness. The parent may miss work and may experience a decrease in their paychecks while trying to afford the costs of care for a child with chronic illness. The financial stress experienced by a family may be observed by the child, contributing to the child's perceived validity of their illness narrative, "I'm a burden." While this is often unconscious, the chronic illness patient lives in a world full of real and perceived threats that trigger the sympathetic nervous system stress response. Based on the MEND model's presupposition that beliefs initiate a stress response and the subsequent physiological responses worsen chronic illness narratives.

For example, a longitudinal cohort study at Duke by Pargament et al. in 2001 was conducted to determine the impact of specific religious beliefs on a patient's mortality risk. The specific beliefs surveyed were that "God has abandoned me," "God must not love me," or "the devil caused this illness to happen to me." This study surveyed 596 hospitalized patients aged 55 and older admitted to Duke's medical inpatient services. The results indicated that all-cause mortality was increased if patients believed that God had abandoned them (risk ratio, 1.28, P=0.02) or questioned God's love for them (risk ratio 1.22, P= 0.05) after controlling for demographic, physical health, and mental health variables. The MEND model proposes that these specific religious beliefs induce a stress response in the patient and contribute to the observed increase in mortality risk. The MEND program can be applied to these patients and proposes to help

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them form healthier narratives that are no longer perceived as threats. MEND provides chronic illness patients and their families with tools to recognize their perceived threats and thus decrease their stress responses.

Reading the Stress Response and Congruency

Many chronic illness patients develop behavioral responses to stress and internal responses to stress as a means of conscious or unconscious communication of their stress. These responses to stress become maladaptive. Some behavioral responses include foot tapping, lack of eye contact, perspiration, smirk, increased speed of speech, changes in breathing pattern, changes in skin color, etc.. These are considered external psychogenic cues of a maladaptive stress response.

Examples of internal responses to stress include immunosuppression, pro-inflammatory process, disruption of regeneration processes (such as sleep and digestion), and they are considered to be internal psychogenic cues of a maladaptive stress response. Identifying the patient's psychogenic cues to the stress response is important to helping a patient begin to decrease their stress response. MEND therapists help patients and their families recognize these internal and external psychogenic cues to identify when the patient's body is experiencing stress.

Additionally, when one's outward expression of emotion, internal emotional process, and physiological response are the same, a patient is said to have psychogenic congruence. When a patient has psychogenic congruence, their stress response decreases. The patient's stress response, as seen through psychogenic cues, becomes a road map to assist the patient toward developing congruence. MEND therapists help chronic illness patients move toward congruency by finding their most congruent modality of communication (art, written, verbal).

Once this is established, the therapist provides a variety of assignments/interventions that help the patient and family recognize when they are congruent and when they are not. The MEND program maintains that working towards psychogenic congruence is imperative for patients and their families. MEND therapists work to accomplish this by developing baseline behavior and identifying areas of stress and incongruence enforced by a patient's illness narrative.

The Family System

Throughout the MEND program, family is considered integral in moving the chronic illness patient toward improved health. These families experience a complex interplay of normal child

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developmental needs and the additional chronic illness needs. Often, families develop a relationship with the illness in addition to, and sometimes in replacement of, their relationship with the child. Thus, the child may be left struggling to develop ways of having their non-illness needs met.

The MEND model helps families learn to express their needs and concerns regarding the illness, improve their listening, develop more adaptive responses to their child's needs, and recognize personal stressors. They are also taught to recognize their child's unique psychogenetic cues of stress. This process allows the family to develop and improve their relationships separate from the illness and its various stressors. This goal is accomplished by creating second order change: meaning, the individual and family have changed the illness narrative and established new patterns of interaction grounded in psychological and physical congruence.

Information: <u>MEND Program Website</u>

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