

Complementary and Alternative Medicine among Patients with Mitochondrial Disorders

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Mitochondrial diseases are a group of disorders that relate to the impaired function of the mitochondrial respiratory chain. Manifestations of these disorders may be limited to one organ or tissue type, such as optic neuropathy, limited to nervous system and skeletal muscle, or may be multisystemic and affect neuromuscular function and extraneural organs, such as liver, kidney, blood, and gastrointestinal tract. Current treatment for mitochondrial diseases is limited and focuses on management of symptoms, healthy lifestyle, avoidance of certain drugs, vitamin and cofactor supplementation, and prevention and treatment of acute physiologic stresses. No known study to-date investigates the use of complementary and alternative medicine (CAM) in individuals with mitochondrial disorders. Given the limited available treatment and variable presentation, patients may use various CAM modalities to treat their disease-related symptoms. This study investigated the treatments and therapies, including both conventional and CAM, utilized by individuals with mitochondrial disorders. A 57-item web-based questionnaire was developed through SurveyMonkey and distributed through the Massachusetts General Hospital (MGH) Mitochondrial Disease Registry, patient support foundations, and the National Society of Genetic Counselors (NSGC) listserv. Responses were downloaded to an excel file and analyzed using descriptive statistics. Surveys were completed by 271 participants from across the United States and 12 other countries. Overall, CAM use among individuals with mitochondrial disorders was 79%. The most commonly used natural products were fish oil/omega 3/DHA, prebiotics or probiotics, and melatonin. The most commonly used treatments included prayer/spiritual healing, massage therapy, and deep-breathing exercises. Conclusion: Individuals with mitochondrial disorders are using CAM to treat their disease-related symptoms. Further study is needed to investigate effectiveness. Physicians should be aware of the use of CAM to assess for possible contraindications and side effects and possibly provide alternative treatment approaches to their patients.