

Summary - Parents, Stress and Coping with Mitochondrial Disease Brenda Senger, RN, MA

Brenda Senger is currently a PhD student at Washington State University, working on her dissertation titled: *The Parent Experience of Stress and Coping when Caring for a Child With Mitochondrial Disease* (slide 3). Please note that the survey is no longer available because the research has concluded*. Full research findings can be found at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2794030/>.

Goals for this research are threefold:

1. Identify stress and coping in parents of children with mitochondrial disease (Mito).
2. Educate health care professionals.
3. Provide support to parents of children with Mito.

Objectives include (slide 4):

1. Describe what is known about stress and coping when caring for a child with a chronic illness.
2. Describe what is known about the needs of parents caring for a child with Mito.
3. Discuss the importance of identifying the specific needs of stress and coping for parents of children with Mito.

Chronic Illness in Children: (slides 5-10)

- Increased prevalence of chronic illness today as compared to the incidence in the past.
- Larger population of children with special needs today.
- Better medical care (medication, diagnostic, and therapeutic advances) is helping these children grow into adulthood with increased functioning and a better quality of life.
- Chronic illness in children is especially complex, often with an unpredictable trajectory. For example, acute illness may be followed by remissions in unpredictable patterns, playing havoc with typical growth and development milestones, especially with neurodegenerative diseases like mitochondrial disease.
- Parental Stress: Challenges for these caregivers are often overwhelming, causing physical, emotional, financial, social, and spiritual stress. Anxiety and uncertainty accompany this stress. Discussions of diagnosis, prognosis, and each crisis and deterioration adds stress on the caregiver and family unit.
 - Higher parental stress often translates into stress for the child, and vice-versa. Stressed parents are less available to their child, hampering their ability to care for the child, again creating more psychological distress. Anxiety, fear, and a decreased quality of life for both the parents and child grow, with some crossover from normal levels of stress, anxiety, and coping to mental health issues. Parental maladjustment is dependent upon the length of illness, functional impairment of the child, and the severity of illness.
 - A parent's ability to function is historically a predictor of a child's adjustment. As children with chronic illnesses mature into teenagers, issues become even more

complex. As uncertainty around illness increases, stress increases in both the parents and child.

- Patient and family needs - Parents of children with multiple chronic illnesses have more unmet needs, directly proportional to the severity and complexity of the child's illness, when compared to children with a single chronic illness. Mito is a complex disease, affecting multiple body systems, creating higher unmet needs. Identifying unmet needs and intervening to meet those needs will decrease stress levels for the family unit.

Visible needs:

- medical care and treatment
- finding a skilled provider
- experience fragmentation of care
- getting referrals
- traveling for care/appointments
- financial burdens & insurance coverage
- becoming the medical care and educational coordinator for child
- organizing home health care
- Activities of Daily Living (ADL)

Invisible Needs - which are less often addressed and not understood

- worry
- fear
- uncertain future for self and child
- public reaction to disability tolerance and understanding versus stigmatization

What do parents seek? (slide 11)

- A “normal life” for themselves, as well as for their children even if a “new normal.” Parents seek this stability and predictability.
- Certainty, which is difficult with multisystem, chronic illness in children.
- Control over stressors. A chronic illness, however, is often both unpredictable and uncontrollable.
- Information - from providers, Internet, social media groups, etc.
- Partnership with the health care providers as part of a trusting relationship with all working to help their child.

Parental Stress and Coping (slide 12-13)

Caring for a medically fragile child creates increased psychosocial stress, anxiety, and fear for the entire family across all cultures and socioeconomic lines. Stress management depends on the parent’s ability to cope, and coping is influenced by the ability to resolve the uncertainty surrounding the illness. Better disease understanding often yields better coping skills and decreases stress.

The literature reports that parental coping is related to disease rarity, child's age at diagnosis, degree of functional losses, impact on mobility, degree of cognitive impairment, communication ability, and visibility of the disease. The most important

factor in family coping is the emotional support the parents receive to help their psychosocial adjustment to the disease.

Mitochondrial Disease (slide 14-15)

The National Institutes of Health (NIH) categorizes mitochondrial disease as a "rare childhood illness," with the first case documented in 1962. Birth and lifetime prevalence of Mito is changing with some sources quoting a 1 in 3,000 incidence, while others quote a 1 in 5,000 incidence, approximately the incidence of cystic fibrosis. Experts now cite that the incidence may be nearly 1 in 2,000, closer to the prevalence of childhood cancers. Mito is inherited, neurodegenerative, and life-limiting with 80 percent of those diagnosed before the age of 5 not reaching their 20th birthday. Mito has no cure, no definitive treatment, and presents with a variety of clinical symptoms, often with organ failure. Diagnosis is difficult because no identifiable biomarker has been discovered. Invasive muscle biopsies are giving way to genetic sequencing as diagnostic standards. Diagnosis is not always clear, falling into definite, probable, possible, or unlikely categories (slide 19). Treatment is twofold: Mito Cocktail (vitamins, cofactors, and antioxidants) plus symptom-based therapies. The Mito Cocktail has not been proven effective in mitochondrial disease, but rather, is used anecdotally. Current clinical trials, however, are being conducted for novel therapies for Mito, such as EPI-473, Bendavia, and more.

Mitochondrial disease presents a unique challenge as Mito is not a single illness, but rather a spectrum of disorders with hundreds of different genetic variations. The trajectory of the disease is unpredictable and diagnosis difficult. Parents and children are not sure of what to expect regarding day-to-day progression or the long-term prognosis. A child with Mito may appear well, but may be slowly or rapidly internally deteriorating.

Unique Parental Stressors with Mito (slides 16 - 18) relate to the uncertainty of the diagnosis, prognosis, and progression of the disease. High physical, emotional, financial, social, and spiritual demands are involved in caring for the child. The parental role expands to include becoming a medical expert about Mito, a care coordinator, and a Mito educator, spending time and energy navigating the health care system and advocating for their child.

Potential visible demands

- Medical care - office visits, hospital visits, equipment (like wheelchairs, feeding tubes, etc.), and developmental delays.
- Physical care of the child.
- Coordination of care with therapies & educational system.

Potential invisible demands

- Worry, fear, and uncertainty of illness trajectory.
- Variability of symptoms.
- Concerns raised with clinical vs. genetic vs. possible diagnosis.
- Public reaction to child's health issues or disability if an invisible illness.
- Health care providers who understand Mito and child's needs.
- Developmental delays.

Research studies investigating the unique needs of Mito parents are sparse. One study examined parents in the diagnostic phase of the disease found that parents want information about symptoms, prognosis, life expectancy, genetics, coping, and support. Most health care professionals, however, lacked the information to give to parents (slide 20).

"Mito Moms" (slides 21-23)

The literature focuses on mothers because, as the primary caregivers, they experience the greatest degree of stress. The genetic link for Mito is often maternal, also stirring feelings of guilt.

- A study by Catherine Reid found that Mito moms experienced greater psychological strain than mothers of children with Phenylketonuria (PKU), another inborn neurological disease. The Mito family needs more health care services, more specialists, more hospitalizations, carry more financial burdens, and have more stress, strain, and worry.
- In 1999, another study looked at personality profiles of Mito mothers and demonstrated elevated psychological scores for hypochondria, hysteria, paranoia, depression, and anxiety related to both the uncertainty of the disease and the high caregiving demands.
- A Korean study (2010), compared the mothers of children with epilepsy with the mothers of children with Mito, citing that Mito mothers had a higher caregiver burden, higher depression and anxiety, higher guilt from maternal inheritance, as well as a lower quality of life.

Summary of Stress and Coping with Mitochondrial Disease (slide 24 -25)

1. Caring for a child with Mito is stressful, increasing risk for emotional distress and family dysfunction.
2. Parents want information about diagnosis, prognosis, treatment, progression, & inheritance to try to offset the uncertainty associated with Mito.
3. Parents rely heavily on health care providers and seek control over their child's health care through information, coaching, validation, support, and competent health care providers.
4. Parents want support from family and friend (normalcy, control, and support), increasing quality of life.
5. More research is needed to understand the parent's needs.

The Survey

Parents of a living child under the age of 18 were asked to complete the survey. The survey asked about 10 questions per page and took 15-20 minutes. A section asked about parental stress that had occurred within the past 7 days and stress that had occurred within the last 30 days. The survey also asked for demographic data.

***Post Study Addendum:** Parents were warmly thanked for completing the survey and adding to the growing body of knowledge around the issue of parental stress and coping. Validating the extraordinary stress levels associated with the care of a Mito child

can open doors to improved understanding and compassion by medical professions and the community.

Additional Reading

Parental stress coping survey information.

Stress and Coping of Parents Caring for a Child with Mitochondrial Disease, Brenda A. Senger, PhD, Linda D. Ward.

Mitochondrial disease: Needs and problems of children, their parents and family. A systematic review and pilot study into the need for information of parents during the diagnostic phase, G. Noorda, M. Hermans-Peters.