The Parent Experience of Stress and Coping When Caring for a Child With Mitochondrial Disease

By:
Brenda Senger
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Introduction

- RN 28 years
- Nurse Educator
- Mother of 4 children
- May 23, 2003
- 4 y/o daughter
- Probable Mitochondrial Disease
PhD program

Goal: identify stress and coping in parents of children with Mito

Educate health care professionals

Provide support to parents of children with Mito

Take this survey

https://wsunursing.qualtrics.com/SE/?SID=SV_cOnqRUyfTTHO5a5
Objectives

- Describe what is known about stress and coping when caring for a child with chronic illness.
- Describe what is known about the needs of parents caring for a child with Mito.
- Discuss the importance of identifying the specific needs of stress and coping for parents of children with Mito.
Increased prevalence
Larger population of children with special needs
Medical assistance is helping these children grow into adulthood with increased functioning and better quality of life
Chronic Illness in Children

- Complex
- Unpredictable trajectory
  - Neurodegenerative disease can deteriorate either within a short period of time or over many years.
- Challenges can be overwhelming:
  - Physical, emotional, financial, social, spiritual
  - Anxiety, stress, and uncertainty
Chronic Illness in Children

- Chronic Illness is a stressor for parents and children
- Relationship between parent stress and child distress
- The higher the parental stress the greater the level of distress in the child
- Parental maladjustment depends on length of illness, functional impairment, severity of illness
Parents of children with multiple and severe chronic illness have more unmet needs than children with a single chronic illness.
Unmet needs are proportionate to the severity and complexity of the child’s illness.
Mito is complex affecting many body systems.
Needs of Parents

- Medical care
- Finding a skilled provider
- Fragmentation of care
- Getting referrals
- Travel for medical appointments
- Organizing home health care
- Financial burdens
- Insurance coverage
- Activities of Daily Living
- Coordinating with schools and other organizations
Needs of Parents

**Visible Demands**
- Medical care
- Treatments
- Monitoring symptoms
- Physical demands
- Activities of daily living
- Developmental delay
- Impaired social skills
- School needs

**Invisible Demands**
- Worry
- Fear
- Uncertainty
- Future for their child
- Public reaction to disability
- Tolerance
- Stigmatization
What do Parents Seek?

- Normalcy
- Certainty
- Information
- Control over stressors
- Partnerships with health care providers
Parenting Stress

- It is stressful to care for a child with a chronic illness
- It is a family affair
- It is cross-cultural
- Successful management of illness is dependent on ability of parent to cope
- Coping is influenced by ability to resolve uncertainty in illness
Successful management of the child's illness depends on the ability of parent to cope

Disease rareness, age of onset, loss of function, impact on mobility, course of illness, cognitive function, ability to communicate, visibility of illness

Emotional support and positive coping influenced psychosocial adjustment of parents
What do we know about Mitochondrial Disease?

- Rare
- Childhood Disease
- Inherited
- Chronic neurodegenerative
- Life Limiting
- No cure
- No biological marker
- No Treatment
- Variety of clinical symptoms
Not a single chronic disease
Spectrum of inherited disorders
Unknown disease trajectory
Unknown prognosis
Neurodegenerative disease may look well at diagnosis, but deteriorate slowly or within a short period of time.
Potential Parent Stressor

- Uncertainty of diagnosis, prognosis or disease progression in a complex health care setting
- Physically, emotionally, financially, socially and spiritually
- Expansion of Parent role
  - Medical experts
  - Care coordinators
  - Advocates
  - Teachers
Potential Visible Demands

- Medical care
  - Office visits
  - Hospitalizations
  - Special medical equipment at home/school
  - Wheelchairs, developmental delays, g-tubes, vision problems
- Physical care of the child
- Coordinating care with social services and the educational system
Potential Invisible Demands

- Worry
- Fear
- Uncertainty of illness trajectory
- Variability of symptoms
- Diagnosis or not?
- Public reaction to child’s disability
- Health care providers understanding needs
- Developmental lags of the child
What We Know About Mito19

- Medical Science is taking lead role
- First documented case in 1962
- Diagnosis is difficult
  - No biological marker
  - Muscle biopsy
  - Genetic sequencing
  - Definite, Probable, Possible or Unlikely
- Treatment depends on symptoms
  - Mito cocktail
What We Know About Parents

Gap in the number of studies done to understand needs of Mito parents

Parents want information about:

- symptoms, prognosis, life expectancy, genetics, coping, and support.
- Health professionals lack information to give to parents.
What We Know About Mito Moms 21

- Usually primary care giver
- Mothers experience greater psychological strain
- Mothers of children with Mito and PKU
  - Need of more health care services
  - More specialists
  - More hospitalizations
  - More financial burden
  - Out pocket expenses
  - Number of work days missed
  - More stress, strain and worry,
Personality profiles of Mito mothers
Elevates scores in
- Hypochondria,
- Hysteria
- Paranoia
- Depression
- Anxiety
Related to stress of uncertainty, and caregiving demands
What We Know About Mito Moms  23

- Study from Korea
- Compare moms of children with epilepsy & Mito
  - Higher caregiver burden
  - Lower quality of life
  - Greater depression and anxiety
  - Guilt with maternal inheritance
Caring for a child with Mito is stressful. Parents want information about diagnosis, treatment, progression, and genetic transmission. Control over the child's health care, support from family and friends, and reliance on health care providers predict quality of life.
Summary

- Risk for emotional distress and family dysfunction
- Uncertainty associated with Mito
- Stress with uncertainty
- More research needed
- Parents want information, coaching, validation and competent health care providers
Please take and complete this survey and contribute to the growing body of knowledge around the needs of parents caring for a child with Mitochondrial disease.

Mitochondrial Disease Parent Survey

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Questions?

Brenda Senger RN, MA, PhD(c)
Brenda.senger4@gmail.com