What is Life Like for Patients Living with Dysautonomia?: A Literature Review

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INTRODUCTION
A disease affecting the autonomic nervous system, dysautonomia, while not rare, is rarely known about. Patients living with this condition often struggle to receive a diagnosis and proper treatment due to the complexity of the disease and lack of knowledge within the healthcare system. Raising awareness among healthcare professionals and the general public can greatly impact the lives of patients living with dysautonomia.

OBJECTIVE
• Provide an overview of the autonomic nervous system and dysautonomia
• Identify and discuss five of the most common forms of dysautonomia
• Identify symptoms and treatment methods related to each form of dysautonomia
• Provide an overview of the quality of life of patients living with dysautonomia

WHAT IS DYSAUTONOMIA?
• Malfunction of part of, or all, of the autonomic nervous system
  • Parasympathetic Division: “rest-and-digest”
    • Increased blood flow to digestive, urinary, and reproductive systems
    • Increased heart rate, blood pressure, respiration, blood glucose, muscle contractions
  • Sympathetic Division: “fight-or-flight”
    • Increase in blood flow to cardiac and skeletal systems
    • Increased heart rate, blood pressure, respiration, blood glucose, muscle contractions
• Primary Dysautonomia: related to genetics or a degenerative disease
• Secondary Dysautonomia: consequent of injury or infection
• Five of the most common forms:
  • Neurocardiogenic Syncope (NS)
  • Postural Orthostatic Tachycardia Syndrome (POTS)
  • Multiple System Atrophy (MSA)
  • Autonomic Dysreflexia (AD)
  • Familial Dysautonomia (FD)

WHAT IS LIFE LIKE FOR PATIENTS LIVING WITH DYSAUTONOMIA?
• “The condition can cause marked physical and cognitive impairment that can significantly impact upon activity” (Welford & McKenna, 2016, p. 1).
• Patients experience constant changes and need to be prepared
  • Welford and McKenna (2016): impacts occupation, self-care, employment, education, parenting, social/recreational activities
  • Significant changes seen in motivation, performance capacity, and fatigue
  • Not having control impacts physical and mental health
• 201 participants rated pre- and post-symptom abilities: 76.8% of patients needed assistance with daily activities
• Only 30% were able to work or attend school full-time

TREATMENT METHODS
• Neurocardiogenic Syncope (NS)
  • Increase sodium intake, increase fluid intake, moderate exercise regimen, beta-blockers, fludrocortisone, losartan, captoprile
• Postural Orthostatic Tachycardia Syndrome (POTS)
  • Increased sodium intake, increase fluid intake, compression stockings, gradual exercise program, short-term saline infusions, fludrocortisone, midodrine, beta-blockers
• Multiple System Atrophy (MSA)
  • Physical therapy, occupational therapy, speech therapy, levodopa, BIPAP machine, Botex injection, liquid thickeners, enteral feedings
• Autonomic Dysreflexia (AD)
  • Treat cause of episode first, antihypertensive drug therapy, regular bowel and bladder routines
• Familial Dysautonomia (FD)
  • Thickened formulas, upright feeding position, adequate hydration, increase sodium intake, compression stockings, patient regimen, raise head of bed, assistive walking devices

QUALITY OF LIFE OF PATIENTS
• “Just because you can’t see it, doesn’t mean it doesn’t exist.” (Boris, 2010, Armstrong, 2017, Halstead, 2018)
• Significant changes seen in motivation, performance capacity, and fatigue
• Not having control impacts physical and mental health
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SIGNICANCE
Raising awareness about dysautonomia greatly impacts the lives of many around the world. It brings comfort to patients as healthcare providers have a better understanding regarding treatment. Patients would not have to continuously advocate for themselves in ways that others do not think are necessary. It can increase time between onset of symptoms and time of diagnosis if more healthcare providers recognize symptoms related to dysautonomia. Education can bring acceptance and understanding that patients long for, as the constant challenge to remain healthy, as well as remain social often contradict each other. Dysautonomia International is a non-profit organization that raises awareness, advocates for patients, and makes advancements in research.

(Dysautonomia International, 2019)

REFERENCES