



Sjögren's Syndrome

Nancy B. Cabelus, DNP, MSN, RN

Founding member, Doctors of Nursing Practice, Inc.
Awareness Ambassador, Sjögren's Syndrome Foundation



ABSTRACT

This poster project is intended to provide education and awareness for advanced practice nurses who may diagnose and/or treat Sjögren's Syndrome patients. Sjögren's Syndrome (SS) is an autoimmune disease that affects nearly 4 million Americans yet it takes an average of 5 to 7 years to diagnose. Sjögren's Syndrome (SS) was discovered in 1933 by Dr. Henrik Sjögren, an ophthalmologist from Sweden. Commonly referred to as a sicca disease with hallmark symptoms of dry eye and dry mouth, SS is a complex disease that can attack several systems within the body and can destroy tissue and organs. Patients with advanced SS may suffer from Raynaud's phenomenon, salivary gland enlargement, swollen lymph nodes, anti-Ro/SSA and anti-La/SSB positivity, central nervous system dysfunction and have 44 times greater risk for developing lymphoma than healthy individuals (Setoodeh, K. & Wallace, D., 2012). In 2011, tennis superstar Venus Williams was diagnosed with SS. Chronic fatigue, joint pain, numbness in the hands and feelings of "not getting enough air" forced Williams to withdraw from the U.S. Open tournament. Until then, media attention had not focused on SS. The Sjögren's Syndrome Foundation, founded in 1983, is the leading organization on research, awareness and education on SS. In 2012, the foundation launched a campaign to reduce the diagnosis time of SS by 50% within 5 years. While there is no known cure for SS, nurses can play a significant role in diagnosis, treatment and prevention of complications related to SS. Further, nurses can join the campaign to reduce diagnosis time of SS by 50% in the next 5 years. The author is a volunteer, awareness ambassador for the Sjögren's Syndrome Foundation and a founder of Doctors of Nursing Practice, Inc.

OBJECTIVES

- ★ Provide awareness about Sjögren's Syndrome to advanced practice nurses
- ★ Describe symptoms commonly associated with Sjögren's Syndrome
- ★ Support the Sjögren's Syndrome Foundation's goal to shorten the time of diagnosis by 50% in 5 years

RESEARCH QUESTION

SS is an autoimmune disease with no known cause or cure. It takes an average of 5 to 7 years to diagnose SS. Can advanced practice nurses with awareness of Sjögren's Syndrome help to shorten the time of diagnosis by 50% in 5 years?

HALLMARK SIGNS & SYMPTOMS

- ★ Hallmark symptoms are chronic dry eye and dry mouth also known as sicca syndrome. Patients may also experience:
- ★ Headaches
- ★ Chronic fatigue
- ★ Swollen salivary glands
- ★ Salivary gland infections
- ★ Requires liquids to swallow
- ★ Dental caries
- ★ Arthritis
- ★ Scleroderma
- ★ Raynaud's Phenomenon
- ★ Vaginal dryness
- ★ Depression
- ★ At risk for other auto-immune diseases, lymphoma or having a family member with an auto-immune disease

DIAGNOSING SS

SS is difficult to diagnose because symptoms mimic other illnesses. Symptoms are similar to those in patients who suffer from viral infections such as HIV or hepatitis. Patients may also present with symptoms characteristic to lupus or rheumatoid arthritis.

Most SS patients are female and middle-aged. SS occurs in approximately 1:70 individuals.

Primary Sjögren's is when a previously healthy individual is tested positive for SS via antibody tests, lip biopsy, and symptoms of dry eyes and dry mouth for three months. **Secondary Sjögren's** is when a patient with a known connective tissue disease such as Rheumatoid Arthritis or lupus later develops complications of chronic dry eyes and dry mouth.

Diagnostic blood studies:

Anti-SSA (Ro antibody): Associated with Sjögren's syndrome, sun sensitivity, neonatal lupus, and congenital heart block.

Anti-SSB (La antibody): Almost always seen with anti-SSA.

Lip biopsy for purposes of examining cells within minor salivary glands

NURSING INTERVENTIONS

Nurses have an important role in educating SS patients and helping them to manage their illness. Regular eye and dental exams are encouraged. Monitoring of physical activities, musculoskeletal pain, medication use, emotional state, impaired concentration or memory, disturbed sleep and discomfort from dry eyes or mouth are important to track progression of SS. Local or topical therapies may provide some relief. The SS Foundation website provides helpful information and resources for patients and providers.

GOAL

REDUCE THE DIAGNOSIS TIME OF SJÖGREN'S SYNDROME BY 50% IN FIVE (5) YEARS THROUGH AWARENESS AND EDUCATION OF ADVANCED PRACTICE NURSES AND HEALTH CARE PROVIDERS

REFERENCES

Setoodeh, K & Wallace, D., (2012). Who develops Sjögren's? In Wallace, D. The Sjögren's Book. Oxford University Press: New York.
Sjögren's Syndrome Foundation. <http://www.sjogrens.org/>
Wallace, Daniel. (2011). The Sjögren's Book. Oxford University Press: New York.

Author's note: This project is dedicated to my mother, Joan Cabelus, a Sjögren's Syndrome survivor for 4 decades who is also fighting her second battle with Non-Hodgkin's Lymphoma.