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Guidelines for Managing Dysautonomia Dysfunction

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This is to certify that the doctoral study by

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has been found to be complete and satisfactory in all respects,
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Walden University
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Abstract

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Project Submitted in Partial Fulfillment

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Abstract

Dysautonomia dysfunction (DD) is a disorder of the autonomic nervous system. Over 70 million people suffer from some type of DD, and the average length of time from symptoms to diagnosis is 6 years. Most facilities and providers choose not to treat DD due to the number of symptoms and the difficulty of being able to diagnose correctly. The purpose of this project study was to create guidelines for the diagnosis, treatment, and management of DD. The research question addressed the effectiveness of these guidelines to help nurses and providers caring for patients with DD provide better care. Watson's theory of human caring. The AGREE II was used to research the literature and grade the strength of evidence with the assistance of an expert panel. Descriptive statistics were used for data analysis of the expert panel's survey responses. There was 95% approval of the guidelines. The approved guidelines were presented to major stakeholders and end users including the director of nursing. The guidelines for managing DD may provide an evidence-based clinical framework for providers to treat individuals with this disorder.

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Section 1: Nature of the Project

Dysautonomia dysfunction (DD) affects approximately 70 million people around the world (Dysautonomia International, 2019). This equals 10% of the total population that is affected by a disease without a cure. DD occurs in all genders, races, ages, and cultural groups. There are at least three primary conditions of DD and hundreds of other diseases that can cause DD to become apparent. "It has been noted that the average length of time from symptoms to diagnosis is six years" (Freeman et al., 2015, p. 30). The length of time waiting on an appropriate diagnosis leads to poorer quality of life including increased anxiety and prolonged symptoms without a known cause. DD is difficult to diagnose, and treatment can be frustrating to both the provider and the patient. Development of a practice guideline has the potential to improve diagnostic speed and treatment effectiveness.

Problem Statement

Most facilities and providers choose not to treat DD due to the vast number of symptoms and the difficulty of being able to diagnose correctly; in addition DD diagnosis can become very overwhelming (Cleveland Clinic, 2016). At the time of the current study, there was no effective cure, and symptom management was the best way to treat DD. Providers normally choose not to treat DD or undertreat the patient. However, many providers are unaware of the fact that symptom management is the key to treating DD. According to Freeman et al, (2015), DD is rarely taught in medical school. One provider shared that he had received only one short lecture. There are no published guidelines for providers to use to treat individuals with DD.

DD is defined as a disorder of the autonomic nervous system (National Institute of Neurological Disorders and Stroke, 2019). DD can be used interchangeably with the term "autonomic dysfunction." This could "occur alone or with another disease" (National Library of Medicine, 2021). According to the Cleveland Clinic (2016), there are hundreds of symptoms, the most common being "postural hypotension: lightheadedness, dizziness, fainting; urinary dysfunction: frequency, urgency, incontinence; sexual dysfunction: erectile dysfunction, vaginal dryness; gastrointestinal: intermittent diarrhea and constipation, nausea, vomiting; impaired sweating; exercise intolerance; and paresthesia's: numbness or tingling in various body parts". There are many different forms of DD. One of the most common forms of DD is postural orthostatic tachycardia syndrome (POTS; Newman, 2017). POTS is a disorder of the autonomic nervous system that is underrecognized by health care professionals (Busmer et al., 2012). The signs and symptoms of POTS include tachycardia, palpitations, and a sense of anxiety on standing. POTS is a debilitating chronic health condition that is poorly understood and probably underidentified (Busmer et al., 2012).

There are many different ways a provider will attempt to treat DD, but no true guideline exists. Because of this, the results of these different methods vary. Some patients have great results, and others have minimal to no results and remain suffering. The best treatment is multifocal. A provider will begin with patient education. Much of the treatment involves the patient implementing certain interventions such as increasing fluid intake to 3 liters of water a day, wearing prescription compression stockings to promote blood flow, and others. There are also pharmaceutical interventions including

medications. A guideline may help providers treat these patients in the same way to attain optimal results for all patients.

The target population for this practice guideline would be providers in the Appalachian region of the southern United States. Primary care providers, cardiologists, neurologists, and nurses working in specialty areas with interest in DD would be included. The field of nursing may be advanced by having these guidelines in place. There will be order sets that will include blood work and testing that the registered nurses can implement when a patient presents for evaluation of DD. Most of the testing can be completed by nurses within their scope of practice, and they will be able to perform testing independently once the guideline order set has been initiated. These guidelines may help nurses manage the treatment of patients with DD and lead to better patient outcomes.

Aubin et al. (2015) evaluated the implementation of guidelines that focused on complications that occur with the lower urinary tract complications in individuals with DD. After guidelines were implemented at one urology office, the results showed that 50% of patients had improved subjective and objective data such as improved voiding symptoms. This study indicated that guidelines result in a better quality of life that would not be possible without the creation of the guidelines. Grigoriou et al. (2014) shared two case studies that addressed how patients were given lifestyle modifications to improve DD symptoms. These modifications were part of a guideline used to treat patients with DD in their facility. Both cases studied revealed a decrease in symptoms and increased patient satisfaction regarding how they feel. To have similar outcomes at the current

project facility, treatment guidelines are needed. Without it, patients with DD will continue to suffer. The closest facility to treat patients with DD is a 5-hour drive away from the facility.

Purpose Statement

The purpose of this project was to develop a clinical practice guideline for providers to diagnose, treat, and manage DD. Most individuals with DD do not obtain adequate treatment because the disease is difficult to diagnose and manage. Due to the lack of care, patients become frustrated because they cannot perform their daily activities, leading to a poorer quality of life. Because of the many symptoms, there has not been much research on this subject. The goal of the created guideline was to help providers give the necessary treatment to patients and decrease the time to treatment. There is not a cure for DD, but patients can live a normal life if treated properly.

Nature of the Doctoral Project

The setting for this project was a local hospital in the Appalachian area and its related cardiology clinic. Currently, the cardiology clinic receives all referrals for patients with DD and will be the primary site to implement the guidelines. However, referring providers need to understand DD, so all providers throughout the health care system will need to be included in the project implementation. To develop the practice recommendations and guidelines, I used the Walden University Library to identify appropriate scholarly resources. In order to provide additional information about DD, I will host webinars so attendees can obtain the most up-to-date information. “Autonomic dysfunction is a very prevalent health problem that remains underdiagnosed,

undertreated, and underappreciated across healthcare systems" (Sánchez-Manso, et al., 2021). The guidelines will be used in management of patients in the outpatient cardiology office who present with symptoms of DD. This could lead to a diagnosis, and the guidelines may also be used to develop the direction of treatment and management. An expert in DD associated with the site facility will be a valuable resource to assist the development of the guideline.

Significance

The average time of DD symptom onset to diagnosis is 6 years, and 84% of people will be misdiagnosed the first time (Freeman et al., 2015), resulting in a poorer quality of life. There are many lifestyle modifications that can be made to help with the treatment of all forms of DD, but education of both the provider and the patient is key. Without the proper education and guidelines to assist the provider, patients will not receive the adequate treatment and will continue to have symptoms associated with DD, which is life limiting. Once correctly diagnosed, a combination of lifestyle changes and pharmacological interventions can improve quality of life, although some patients suffer a lifetime of chronic disability (Busmer et al., 2012). The symptoms make it difficult for a person to live a normal, uninhibited life. An understanding of these symptoms and use of a guideline has the potential to lessen symptoms resulting in a higher quality of life.

Summary

DD can be debilitating if a patient does not find a provider educated in treating it. Out of the millions of individuals affected, few are able to live a mostly normal life because there is a lack of education to the providers, leading to a lack of understanding to

the patients. Guidelines may enable providers to treat patients more effectively. The purpose of the current guideline was to aid providers in recognizing the signs of DD, making the diagnosis, and guiding the treatment.

Section 2: Background and Context

Patients with DD are a complex part of the medical and nursing world and can be difficult to treat due to the variety of symptoms. Due to the complexity, it can take numerous visits to help a patient feel better. Lifestyle modifications by the patients are the basis of treating DD, and this takes education by the provider to the patient. This education requires more time than a normal routine visit and also close follow-ups. Multiple areas of medicine and nursing are drawn in during these visits to give the patient the best care possible. The education received by the patient will be instrumental to their success in managing this disorder. Education is an integral part of the guidelines, but only a small part. The bulk of the guidelines will consist of interventions that will help the patient live a better quality of life. Doctors, mid-levels, and nurses will work together to ensure the patient has the needed education, management skills, and improved quality of life.

Concepts, Models, and Theories

Nursing Concept

One of the most important nursing concepts is quality of life. When DD is uncontrolled, it leads to a poor quality of life for the patients who suffer from it. For all types of DD, the ultimate goal is to give patients an improved quality of life. The Centers for Disease Control and Prevention (2020) defined quality of life as a broad multidimensional concept that usually includes subjective evaluations of positive and negative aspects of life. POTS is one of the most common forms of DD (Dysautonomina International, 2019). An estimated 500,000 Americans suffer from this disorder

(Kauffman & Freeman, 2015). Cutitta et al. (2017) explained that "the diagnosis of POTS may be difficult to arrive at because many of its symptoms are somewhat vague and overlap with symptoms that are seen in many other diseases". This leads to anxiety, depression, and frustration. Patients with DD have a poorer quality of life because their symptoms become overwhelming if left untreated. By having guidelines in place for the treatment of DD, patients may have a better quality of life.

Theory

Watson's theory of human caring is a caring science approach used to guide nursing practice, education, and research (Wei et al., 2019). The purpose of this theory is to transform patient care from a treatment-centered repair to a holistic mind–body–spirit healing perspective. "The first of these two main domains in holistic nursing related to professional knowledge and expertise and the second to psychological and spiritual consideration of clients" (Pajnkihar et al., 2017). Caring is imperative to all of health care because "when caring is not present, non-caring consequences and dissatisfaction with care, where the person feels like an object, can occur" (Pajnkihar et al., 2017). Caring has to be done in practice and research (Watson, 2009) because lack of caring is a major threat to health care quality. Patients with DD are usually frustrated with their disorder due to the fact it takes up to 6 years to diagnose and there are usually many misdiagnoses before the correct one is reached. With DD, there are multiple body systems that are involved and affected, including physical and cognitive systems. Dysautonomias happen for a range of reasons, and they are often linked to another condition (Newman, 2017). A provider treating DD is not able to treat a single symptom and have improvement; they

will have to treat holistically with set guidelines for the patient to improve. The theory of human caring states that a "human being cannot be healed as an object. It argues, on the contrary, that he/she is part of his/her self, environment, nature, and the larger universe" (Ozan et al., 2015). When caring for a patient with DD, the provider cannot rely on treating individual symptoms. The entire patient including their environment must be taken into consideration in relation to the underlying factors that can cause problems with DD such as the environment, stress, and weather. Watson's theory of human caring has been used many times to help with guideline creation. One example was discussed by Ozan et al. (2015) about how dealing with infertility in women is so much more than a physical condition. DD is the same in that aspect. The symptoms of DD are more difficult when the patient is under stress or other environmental factors and DD becomes more difficult to deal with psychologically.

Relevance to Nursing Practice

DD is a common disorder that goes undiagnosed for many years. There are many forms of DD, the most common being POTS. Nurses working in this area may encounter potential POTS sufferers and therefore need to gain an understanding of this condition (Busmer et al., 2012). Nurses have an important role in educating POTS patients regarding appropriate lifestyle changes, supporting them through the process of finding appropriate medication, and offering psychological support throughout to help them come to terms with this chronic debilitating condition (Busmer et al., 2012). Cardiac nurses have an important role in helping to identify potential POTS patients and providing support to help patients come to terms with the diagnosis (Busmer et al., 2012).

As with POTS, nurses will need basic education on all forms of DD in order to give the best care possible. Due to the fact nurses will be educating patients as part of the guideline, nurses should have a clear understanding of the disorder and interventions from that guideline.

Local Background and Context

The chosen site facility was a hospital in a rural Appalachian area. The closest facility that is known for treating DD is a 5-hour drive away. Due to the fact there are so few centers in the United States that are known for treating this disorder, the process of getting to an appointment is extensive. The patient must have a referral and then fill out paperwork to determine whether they qualify to be scheduled at the specialty center. The waiting period after approval is around 8 months. At the current facility, there are two individuals skilled in treating DD. Due to the complexity of DD, one of these providers has chosen not to routinely treat these patients. With the creation of guidelines to diagnose, treat, and manage DD, more providers may be available to see this type of patient and effectively treat them.

Role of the DNP Student

For this project, I searched literature pertaining to DD. The end goal was to develop a clinical practice guideline to be used at the site facility that will help a provider diagnose, treat, and manage DD. I recruited individuals to review and evaluate these guidelines and provide final recommendations. These individuals were professionals who were educated in DD, had the ability to take a proposal to a committee for approval, and had the authority to approve the use of these guidelines. The individuals associated with

this process would evaluate and grade each part of the guidelines and give recommendations for alterations as needed. The guidelines would then be developed to help guide the diagnosis, treatment, and management of DD. This guideline would include how to diagnose in terms of knowing the symptoms and needed testing, the best ways to begin treatment, and the most effective ways to have follow-ups and to manage the care of these patients. The American Association of Colleges of Nursing (2020) stated that "the changing demands of this nation's complex healthcare environment require the highest level of scientific knowledge and practice expertise to assure quality patient outcomes". As a DNP student, I acknowledged the need to address those changing demands and provide that highest level of scientific knowledge and practice expertise. The guideline creation required scientific knowledge and practice expertise to develop.

Role of the Project Team

The role of the project team involved a partnership for input on guideline creation. An expert panel was also used to review the guidelines and give suggestions as needed. The project team also completed the survey for content validity.

Summary

DD is a complex disorder. Without proper treatment, a patient will have a poorer quality of life. Through the creation of a guideline for providers that will help with the treatment of DD, patients may feel better quicker and be able to live more normal lives. These guidelines will take all areas of nursing to give the patient the best opportunities to live fuller lives. The consequences of continuing the current treatment without a

guideline include poorer quality of life, physical and mental distress, and patient safety issues.

Section 3: Collection and Analysis of Evidence

Although DD affects more than 70 million people worldwide, it is a disorder that is not well understood. There are no guidelines in place for the diagnosis, management, and treatment of DD. By gathering scholarly evidence, I endeavored to develop a guidelines that would help these patients live a better life with fewer symptoms. DD can affect every body system if left untreated, leading to a poor quality of life. DD, or autonomic dysfunction, is a general term used to describe the failure or malfunction of the autonomic nervous system (Aubin et al., 2015). Aubin et al. (2015) also stated that although there is no cure, symptom treatment may improve quality of life.

Practice-Focused Question

A clinical practice-focused guideline on treating patients with DD did not exist at the project site. Many diseases can be easier to treat, such as high blood pressure or high cholesterol. DD is not easy to treat because medication can only help in certain cases; the main focus involves testing and patient lifestyle modifications (Cleveland Clinic, 2016). There was a gap in medical practice to treat patients with DD appropriately and thoroughly because these patients appear to be healthy but they are not. A guideline may help providers such as doctors, nurse practitioners and physician assistants be able to identify and treat patients with DD. At the time of the current project, there was no guideline available to assist providers with diagnosing a patient with DD. The developed guidelines will focus on how to properly diagnose and treat these patients.

Sources of Evidence

Obtaining the sources needed for development of guidelines consisted of an extensive literature search and reviews, as well as attending virtual conferences and meeting with experts in the area of DD. The information available was scarce and sometimes difficult to review because it was outdated. Sources were obtained through internet searches, scholarly articles, live seminars and symposiums, and the preceptor to obtain data. An evidence table was used to gather my information and keep it organized. The resources were less than 10 years old, and the information focused on the diagnosis, treatment, and management of DD. The Walden University Library was an excellent starting point and a valuable resource to gather information. I used available sources such as librarian assistance, webinars, and databases. My local library was also a valuable resource for manuscripts and medical documents that had been published. Search terms included *dysautonomia*, *dysautonomia dysfunction*, *autonomic*, *autonomic dysfunction*, *POTS*, and *orthostatic hypotension*. Inclusion criteria included all disorders associated with DD, which included those listed in the search terms. Exclusion criteria were any documents that were more than 10 years old.

Analysis and Synthesis

I synthesized the literature and summarized it into a practice guideline so providers could access it and use it to provide a better treatment plan. The evidence from the literature was appraised using Grading of Recommendations, Assessment, Development and Evaluations (GRADE). GRADE is a transparent framework for developing and presenting summaries of evidence and provides a systematic approach for

making clinical practice recommendations (BMJ Best Practice, 2020). This tool is the most widely adopted for grading the quality of evidence and making recommendations. The GRADE criteria can give four different ratings: very low, low, moderate, and high. This grading tool also addresses bias, imprecision, inconsistency, indirectness, and publication bias. For this project, evidence was collected into an evidence table, and the GRADE tool was used to evaluate the strength of each source.

After the recommendations were developed, an expert panel used the Appraisal of Guidelines, Research and Evaluation (AGREE II) instrument. AGREE II () is a tool that helps in selecting articles to assess the quality and reporting of practice guidelines (Brouwers et al., 2010). Dr. Muhammad Ahmad assisted with the review, as well as his colleague Dr. Bill Harris. Both of these physicians are skilled and knowledgeable in the management and treatment of DD but choose not to routinely treat it due to the complexity of the diagnosis. The AGREE II has three functions: to help assess methodological quality of guidelines, to guide the development of guidelines, and to inform users on what information ought to be reported in guidelines (National Collaborating Centre for Methods and Tools, 2013). AGREE II is used to assess 23 items grouped into six domains. These domains are scope and purpose, stakeholder involvement, rigor of development, clarity of presentation, applicability, and editorial independence. Dr. Ahmad and Dr. Harris reviewed and graded the evidence. After the evidence that met the inclusion criteria was determined, recommendations were developed. The recommendations focused on the needed testing and subjective data to

diagnose DD, the known treatment modalities and the needed education for patients, and the needed interventions for patients to live a better quality of life.

Summary

By using the sources, I developed a guideline for the diagnosis, treatment, and management of DD. It is difficult to help these patients without knowing the evidence and why each intervention is important. For example, there are different types of treatment that include nonpharmacological measures and medications (Kauffman & Freeman, 2015). The nonpharmacological measures are more important than prescribing a medication, but many providers do not know where to start with these interventions. The lack of appropriate guidelines for the treatment of DD leads to poorer patient outcomes and lower quality of life. The cardiology practice at the facility site did not have a set guideline to help with patient care, and most providers choose not to treat because of the complexity. These guidelines were reviewed by the expert panel of three doctors and then analyzed.

Section 4: Findings and Recommendations

To diagnose dysautonomia dysfunction, a thorough history and physical must be completed (Sanchez-Manso et al., 2021).

First Visit

- patient symptom onset date
- symptom triggers
- treatments to date
- ineffective
- effective
- medical history

The patient will also undergo physical examination to include blood pressure and heart rate readings. According to the Centers for Disease Control and Prevention (2017) the proper way to do this is as follows:

1. Lie for 5 minutes on the examination table uninterrupted and with no distractions (cell phone use, talking, etc.) and have blood pressure and heart rate measured.
2. Patient will immediately stand and measurements will be repeated after 1 minute and 3 minutes.

A drop in blood pressure of 20 mmHg or more, or in a diastolic blood pressure of 10 mmHg or more, or experiencing light-headedness or dizziness is considered abnormal.

Types of Testing

The next step in diagnosing a patient with DD is to undergo testing.

Tilt Table

The tilt table test is often the standard method used for detecting types of dysautonomia (Carew et al., 2009). The patient will lie on a bed with safety straps, and the bed will be elevated to almost a standing position of around 60 degrees. During this time, the blood pressure and heart rate will be monitored closely for changes (Johns Hopkins Medicine, 2021).

Sudomotor Axon Reflex

Quantitative sudomotor axon reflex testing is used to measure stimulated sweat output in the affected and unaffected limb (University of Pittsburg, 2021). A small electric current and acetylcholine is applied to the skin on the chosen limb, stimulating the sweat glands, and a capsule is placed on the skin and measured by the machine. In DD, there is usually a decrease in stimulated sweat output.

Sweat

A thermoregulatory sweat test is used to measure how well the body sweats in a warm environment (National Library of Medicine, 2021). A special powder is applied to the skin, and the room temperature is slowly increased to cause the patient to begin sweating. The powder changes colors as the patient is sweating and reveals a pattern to notify whether the patient has an appropriate sweat response.

Comorbidities

A panel of blood work is also completed to identify and rule out causes of DD that can be readily and quickly treated. DD can occur as a primary condition or be secondary to other disorders and diseases. Many comorbidities such as diabetes and

alcoholism can cause DD, as well as neurological disorders including Parkinson's, multiple system atrophy, and familial dysautonomia (National Institute of Neurological Disorders and Stroke, 2019). For these reasons, the blood work will include a comprehensive metabolic panel to evaluate the liver, kidneys, and electrolytes. A complete blood count will be used to evaluate blood disorders; vitamin levels including Vitamin B12, Vitamin D, iron/TIBC, transferrin, folates, and ANA will be measured to rule out rheumatological issues.

Treatment

The treatment of DD will vary depending on the type of DD the patient has. However, the basic foundation is imperative to treating all forms of DD. The treatment of DD is complex. There is usually no cure for DD, but secondary forms may improve with treatment of the underlying disease. In many cases, treatment of primary DD is symptomatic and supportive (National Institute of Neurological Disorders and Stroke, 2019). Patient education is important because they will be unable to reach a higher quality of living with fewer symptoms unless they work hard to make lifestyle modifications.

There are eight types of DD. The first is neurocardiogenic syncope. This is an excessive autonomic response to certain body triggers or stimuli (Earlstein, 2011). These triggers include physical pain, long periods of standing, extreme heat, dehydration, the sight of blood, and intense emotion. This causes an increase in heart rate and a drastic change in blood pressure, causing blood to pool in the legs. This leads to reduced blood flow to the brain and loss of consciousness.

POTS mainly affects a patient's blood flow resulting in light-headedness, fainting, and increased heart rate that usually comes when standing up and is relieved when sitting or lying down. Patients also have symptoms of brain fog, fatigue, intolerance to exercise, migraine, visual disturbance, heart palpitations, tremors, and nausea. Familial dysautonomia affects the development and survival of definite nerve cells in the autonomic nervous system. The symptoms are difficulty with digestion, breathing, and production of tears, and disturbance in regulating blood pressure and body temperature. The sensory nervous system is disrupted and alters taste and cold/hot perception, and worsens pain tolerance.

Multiple system atrophy is a progressive neurodegenerative disorder. This causes issues with fainting spells and problems with heart rate, erectile dysfunction, and bladder management. This can progress to the patient having difficulty with speech and walking. Pure autonomic failure is a neurodegenerative disease of the autonomic nervous system. Orthostatic hypotension is the main problem, with additional symptoms of dizziness, light-headedness, visual disturbance, weakness, lethargy, abnormal sweating, sleep disorders, constipation, and bladder problems. This can be a gateway to Parkinson's disease.

Autonomic dysreflexia is a medical condition manifested by a sudden onset of excessively high blood pressure. This is common in patients with spinal cord injuries who have thoracic nerve damage. Baroreflex failure is a medical condition that results from the damages and disruption of the afferent limb of the baroreflex. Symptoms are acute or fluctuating hypertension and a heart rate that does not respond to some medications.

Baroreflex failure can be the result of surgeries, radiation treatments in cancers, injuries to the nerves, or degenerative neurologic disease. Diabetic autonomic neuropathy is the most serious and common complication of being a diabetic. This causes many issues including hypoglycemic autonomomic failure.

The treatment of DD will vary depending on the type of dysfunction the patient has. However, treatment begins with the same foundation of all of the eight types of DD. These are lifestyle modifications that the patient must adhere to to reduce symptoms and improve quality of life. This takes extensive education by the treating provider to the patient.

The patient must start with drinking 2 to 4 liters of water a day (Earlstein, 2011). The purpose is to increase the amount of fluid in the body, making it easier for blood to get to the head to reduce dizziness (University of Wisconsin, 2022). It is also recommended to begin the day with 8 ounces of water before exiting the bed and before any activities known to exacerbate symptoms. These include shopping, cooking, standing for prolonged periods of time, physical activity, or periods of stress such as blood draws. Education should be given that this fluid intake should not be carbonated drinks such as soda or any kind of alcohol; both of these can exacerbate symptoms (MyHeart, 2022). Alcohol interferes with appropriate vasodilation/vasoconstriction and stops the return of blood to the upper body and head, leading to low blood pressure, dizziness, and syncope.

The second intervention the patient must be educated about is increasing sodium intake. Most people need 2,300 mg of sodium a day (University of Wisconsin, 2022). People with DD can increase their salt intake to improve their symptoms. The University

of Wisconsin (2022) recommended 1 teaspoon of salt in the morning and 1 teaspoon of salt in the evening. Suggestions will be given to the patient of how to implement increased sodium to their diets:

- ¼ teaspoon of salt with 575 mg of sodium
- adding ¼ teaspoon to the following foods sliced cucumbers or tomatoes, watermelon wedges, sliced apple or banana with peanut butter, scrambled eggs, air-popped popcorn, edamame (soy beans) or kale chips made with soy sauce
- salty drinks such as Powerade, Gatorade, and Propel to help with fluid intake requirements as well as sodium recommendations

Salty snacks include the following:

- baked potato chips or pretzels
- tortilla chips with salsa
- cottage cheese with tomato or fresh fruit
- beef or turkey jerky
- pickles
- olives
- salted nuts or seeds
- raw vegetables with dip

If the patient cannot meet sodium recommendations with dietary changes alone, sodium tablets are also an option. After a 24-hour sodium check, individuals with a value of less than 170 mmol can be supplemented with 1–2 grams of sodium tablets three times

a day (Do et al., 2021). When patients have a higher sodium intake, the systolic blood pressure will increase by 12 mmHg, and patients will have fewer reports of orthostatic intolerance.

The third lifestyle intervention a patient with DD must implement is a healthy exercise program. The University of Wisconsin (2022) recommended to start slowly at 5 minutes twice per day and increase the time by 3 minutes every week. Recumbent exercises are the best for patients with DD, including stationary bike, rowing machine, and swimming. Patients are also taught to do exercises while standing for prolonged periods of time that will assist the blood to return quicker to the abdomen and brain. These include raising up on the toes, clenching the buttocks, and alternating leg raises. This will help to prevent syncope from blood pooling and low blood pressure.

Next is the use of compression stockings. This also helps to return blood upward, preventing pooling in the lower extremities and providing the brain with more blood. The University of Wisconsin (2022) recommended compression stockings to be thigh or waist high, worn during the day, off at night, and with 30 mmHg of pressure. Patients can also use abdominal binders as tolerated to assist with this. The provider should also review the medications currently taken by the patient and withdraw any that can worsen POTS such as norepinephrine transport inhibitors (Sheldon et al., 2015). Finally, patients should try to reduce stress, increase sleep, and avoid triggers such as prolonged standing and extreme heat such as humidity, hot tubs, and long showers.

There are times that lifestyle modifications can completely alleviate symptoms. However, sometimes the provider will have to initiate medications to assist. This depends

on the type of DD. If the DD is related to an underlying disorder, the patient will benefit the most from treating that underlying problem. When DD is thought to be pure autonomic failure or one of the other diagnoses unrelated to an underlying cause and conservative management is not optimizing the patient, medical interventions are chosen. Fludocortisone has be useful for boosting sodium retention and expanding plasma volume (Sheldon et al., 2015). Midodrine constricts veins and arteries and is useful for increasing venous return (Sheldon et al., 2015). Midodrine is administered 3 times a day but not within 4 hours of bedtime due to supine hypertension.

Patients can be infused with 1 liter of normal saline over 1 hour to assist with augmenting blood volume. This will decrease orthostatic tachycardia and improve symptoms for several hours up to 2 days (Sheldon et al., 2015). This is used in more extreme cases and not used as long-term solution, if possible.

Propranolol is used to control sinus tachycardia and palpitations (Sheldon et al., 2015). Propranolol is used low dose at 10–20 mg by mouth daily and lowers standing heart rate, improving symptoms. Higher doses are less tolerated due to causing hypotension, which is already a problem with this patient population. Long-acting propranolol does not improve the quality of life with these patients, and other beta blockers have not been studied for POTS. If the patient is diagnosed with vasovagal syncope, beta blockers have not been found to be beneficial due to the nature of the diagnosis. Ivabradine is used for heart rate control as well and does not impact blood pressure. However, Ivabradine is not yet approved for this use in the United States, and therefore it is difficult for insurance to pay for it.

Pyridostigmine is a “peripheral acetylcholinesterase inhibitor that increases synaptic aceycholine in the autonomic ganglia and at peripheral muscarinic receptors” (Sheldon et al., 2015, p. X). This blunts orthostatic hypotension and improves chronic symptoms but is not used much due to the various gastrointestinal and genitourinary side effects. Clonidine and methyldopa can stabilize hemodynamics in patients with high sympathetic nervous system involvement (Sheldon et al., 2015).

Findings and Implications

The panel consisted of an interventional cardiologist, a second interventional cardiologist who specializes in the treatment of DD, an electrophysiologist, a nurse practitioner who practices at a renowned center for treating DD, a neurology nurse practitioner, and a colleague who has DD. The panel received a copy of the following: consent for anonymous questionnaire form, informative PowerPoint program, and the guidelines. The experts were asked to review the guidelines and appraise the content of the guidelines, then complete the provided nine item 5-point bipolar Likert scale survey. The survey also included an area for the experts to provide additional feedback. Descriptive statistics were used for data analysis of the expert panel’s survey responses. There was a 95% approval of the guidelines (see Table 1). Prior to presenting to hospital education, I had the survey reviewed, and no suggestions were given for alterations. The approved guidelines were presented to the major stakeholders and end users. The guidelines were also given to the director of nursing.

Table 1

Expert Panel's Survey Results

Question	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. The guidelines are clearly stated.	0	0	0	0	5
2. The guidelines define dysautonomia.	0	0	0	0	5
3. Testing is thoroughly explained.	0	0	0	1	4
4. Treatment options are easy to follow	0	0	1	1	3
5. The reader has a clearer understanding of treating dysautonomia.	0	0	1	1	3

Contribution of the Doctoral Project Team

I bore the sole responsibility of researching the evidence; developing, planning, and implementing the guidelines for DD; and collecting and analyzing data for this DNP project. The panel of subject matter experts comprised an interventional cardiologist, an interventional cardiologist who specializes in dysautonomia dysfunction, an electrophysiologist, a nurse practitioner who practices at a renowned center for treating dysautonomia, a neurology nurse practitioner, and a colleague who has DD. The panel received a copy of the following: consent for anonymous questionnaire form, informative PowerPoint program, and the guidelines. The experts were asked to review the guidelines

and appraise the content of the guidelines, then complete the provided nine item 5-point bipolar Likert scale survey. I hope to distribute the DD treatment guideline to the family practice and cardiology offices of the chosen site for easier identification, treatment, and referral, if needed. Results of this project will be disseminated to providers in the cardiology department as well as in family practice, the policies and procedures committee, and hospital education.

Strengths and Limitations of the Project

The strengths of this doctoral project include the knowledge and confidence gained in being able to recognize, diagnose, treat, and manage DD. The results of the survey indicated the panel strongly agreed the guidelines were informative and educational. The results also revealed that the guidelines were beneficial to improving the treatment of DD. The limitations included a small sample size and the project being conducted at one site. It is possible that results may vary at different institutions and with a larger sample size. These results may also vary with nursing shortages and COVID-19. Recommendations include providing education to the nursing staff and providers on a routine basis, such as annually to refresh the knowledge needed to recognize DD and treat/refer as needed.

Section 5: Dissemination Plan

Results of this doctoral project will be disseminated to the cardiology office for the providers and nursing staff, as well as the policies and procedures committee and hospital education. After approval, these guidelines will be available at any time for reference and can be part of an initial education requirement, followed by annual continuing education requirements. Doing this may shorten the time from symptom onset to diagnosis, which is currently 6 years. Patients may have a better quality of life and may be able to have the knowledge to manage their symptoms properly because their providers understand how to treat them more efficiently.

Analysis of Self

During this project, I grew as a DNP student and a clinician. As a DNP student, I was able to research a problem and find a scholarly solution. As a nurse practitioner, I will use these guidelines to assist me in my daily practice. I will be able to provide better quality care due to the knowledge gained during this DNP project.

Summary

After the initial development of guidelines, I created a survey to give to my panel. I was able to use those results to gain a better understanding of the possible issues with the guidelines and make corrections.

References

American Academy of Family Physicians. (2020). *Clinical practice guideline manual*. https://www.aafp.org/patient-care/clinical-recommendations/cpg-manual.html#:~:text=Clinical%20practice%20guidelines%20are%20statements%20that%20include%20recommendations,the%20benefits%20and%20harms%20of%20alternative%20care%20options

American Association of Colleges of Nursing. (2020). *DNP fact sheet*. https://www.aacnnursing.org/News-Information/Fact-Sheets/DNP-Fact-Sheet

Aubin, M. S., Shridharani, A., Barboi, A. C., Guralnick, M. L., Jaradeh, S. S., Prieto, T. E., & O'Connor, R. C. (2015). Lower urinary tract dysfunction in patients with dysautonomia. *Clinical Autonomic Research: Official Journal of the Clinical Autonomic Research Society*, *25*(6), 407–410. https://doiorg.ezp.waldenulibrary.org/10.1007/s10286-015-0320-z

BMJ Best Practice. (2020). *What is GRADE*? https://bestpractice.bmj.com/info/toolkit/learn-ebm/what-is-grade/

Briggers, A. (2017). *What's to know about dysautonomia*? https://www.medicalnewstoday.com/articles/76785

Brouwers, M., Kho, M. E., Browman, G. P., Burgers, J. S., Cluzeau, F., Feder, G., Fervers, B., Graham, I. D., Grimshaw, J., Hanna, S., Littlejohns, P., Makarski, J., & Zitzelsberger, L.. (2010). AGREE II: Advancing guideline development, reporting and evaluation in healthcare. Can Med Assoc J.. https://doi.org/10.1503/cmaj.090449

Busmer, L., Kavi, L., & West, J. (2012). Postural tachycardia syndrome. *British Journal of Cardiac Nursing*, *7*(5), 206.

Carew, S., Cooke, J., O'Connor, M., Donnelly, T., Costelloe, A., Sheehy, C., & Lyons, D. (2009). What is the optimal duration of tilt testing for the assessment of patients with suspected postural tachycardia syndrome? *Europace*, *11*(5), 635–637. *PubMed*

Centers for Disease Control and Prevention. (2017). *Assessment: Measuring orthostatic blood pressure*. *https://www.cdc.gov/steadi/pdf/Measuring_Orthostatic_Blood_Pressure-print.pdf*

Centers for Disease Control and Prevention. (2020). *Health-related quality of life*. https://www.cdc.gov/hrqol/concept.htm

Cleveland Clinic. (2016). *Autonomic dysfunction*. 0https://my.clevelandclinic.org/health/diseases/15631-autonomic-neuropathy-or-autonomic-dysfunction-syncope-information-and-instructions/management-and-treatment

Cutitta, K. E., Self, M., & la Uz, C. (2019). Postural orthostatic tachycardia syndrome (POTS) in teens: A guide for behavior change to manage symptoms. *Pacing & Clinical Electrophysiology*, *42*(2), 283–286. https://doiorg.ezp.waldenulibrary.org/10.1111/pace.13571

Do, T., Diamond, S, Green, C., & Warren, M. (2021). *Nutritional implications of patients with dysautonomia and hypermobility syndromes*. www.ncbi.nlm.nih.gov/articles/PMC83451088

Dysautonomia International. (2019). *What is dysautonomia*? http://www.dysautonomiainternational.org/page.php?ID=34

Earlstein, F. (2011). Different Types of Dysautonomia Dysfunction.

Freeman, K., Goldstein, D., & Thompson, C. (2015). *The dysautonomia project*. Bardolf & Company.

Johns Hopkins Medicine. (2021). *Tile table testing*. https://www.hopkinsmedicine.org/health/treatment-tests-and-therapies/tilt-table-testing

Kauffman, H., & Freeman, R. (2015). *Postural orthostatic syndrome*. https://www.uptodate.com/contents/postural-tachycardia-syndrome?search=pots&source=search_result&selectedTitle=1~49&usage_type=default&display_rank=1

Marcum, J. (2016). *Autonomic dysfunction*. https://www.healthline.com/health/autonomic-dysfunction#treatments

MyHeart. (2022). *What POTS patients should avoid*. www.myheart.net/pots-syndrome/things-to-avoid

National Collaborating Centre for Methods and Tools. (2013). How to use the AGREE II Instrument presented by Caroline Zwaal, Health Research Methodologist at the Program in Evidence-based Care at McMaster University. Retrieved from: https://www.nccmt.ca/uploads/media/media/0001/01/0e218ebff042ea98666720cbcbaf62f9e7ea2c73.pdf

National Institute of Neurological Disorders and Stroke. (2019). Dysautonomia

information page. Retrieved from: https://www.ninds.nih.gov/Disorders/All-Disorders/Dysautonomia-Information-Page

National Library of Medicine. (2021). Autonomic Testing. Retrieved from: https://medlineplus.gov/lab-tests/autonomic-testing/

Newman, T. (2017). What's to know about dysautonomia? Retrieved from: https://www.medicalnewstoday.com/articles/76785

Oner, T., Guven, B., Tavli, V., Mese, T., Yilmazer, M., Demirpence, S. (2013). Postural orthostatic tachycardia syndrome (POTS) and vitamin B12 deficiency in adolescents. Pediatrics. 2014 Jan;133(1):e138-42. doi: 10.1542/peds.2012-3427. Epub 2013 Dec 23. PMID: 24366986.

Ozan, Y. D., Okumuş, H., & Lash, A. A. (2015). ORIGINAL PAPER. Implementation of Watson's Theory of Human Caring: A Case Study. International Journal of Caring Sciences, 8(1), 25–35.

Pajnkihar, M., Stiglic, G., Vrbnjak, D. (2017). The concept of Watson's carative factors in nursing and their (dis)harmony with patient satisfaction. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5299993/

Sánchez-Manso JC, Gujarathi R, Varacallo M. Autonomic Dysfunction. [Updated 2021 Oct 9]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2021 Jan-. Available from: https://www.ncbi.nlm.nih.gov/books/NBK430888/

Sheldon, R., Grubb, B., Olshansky, B., Shen, W., Calkins, H., Raj, S., Krahn, A., Morillo, C., Stewart, J., Sutton, R., Sandroni, P., Friday, K., Hachul, D., Cohen, M., Lau, D., MAyuga, K., Moak, J., Sandhu, R., Kanjwal, K. (2015) 2015 Heart Rhythm

Society Expert Consensus Statement on the Diagnosis and Treatment of Postural Tachycardia Syndrome, Inapporpriate Sinus Tachycardia, and Vasovagal Syncope. Retrieved from: www.Hrsonline.org.guidance/clinical-resources/2015-heart-rhythm-society-expert-consensus-statement-diagnosis-and-treatment-postural-tachycardia.

University of Pittsburg. (2021). Autonomic Testing. Retrieved from: https://www.neurology.pitt.edu/clinical-divisions/neuromuscular-disease/autonomic-testing

University of Wisconsin. (2022). POTS/Dysautonomia Treatment Plan. Retrieved from: www.uwhealth.org/files/kids/docs/peds_heart_care/pots-dysautonomia-treatment-plan.pdf

Vanderbilt Heart. (2019). Autonomic dysfunction. Retrieved from: https://www.vanderbilthealth.com/heart/51522

Wei, H., Fazzone, P. A., Sitzman, K., & Hardin, S. R. (2019). The Current Intervention Studies Based on Watson's Theory of Human Caring: A Systematic Review. International Journal for Human Caring, 23(1), 4–22. https://doi-org.ezp.waldenulibrary.org/10.20467/1091-5710.23.1.4