Webinar Q&A Report:

Postural Orthostatic Tachycardia Syndrome – Overview and Focus on Non-Pharmacological Approaches

Q: Did you use any specific compression stocking brands?

[S. Raj / K. Bourne] We do not recommend any specific brands. We do recommend "panty hose" style stockings that provide some abdominal compression. We do recommend a pressure rating or 20-30 mmHg or 30-40 mmHg. Athletic style compression tights may be an option if the brand provides a pressure rating.

Q: Did you perform the compression garment analysis on healthy patients as well?

[S. Raj / K. Bourne] In this study we did not look at compression garments in healthy participants.

Q: What do you think of the use of Midodrine in POTs patients?

[S. Raj / K. Bourne] Yes, midodrine can be used in POTS patients (2.5-15mg every 4 hours up to 3 times per day). Midodrine will most likely benefit patients with a tendancy towards hypotension. Midodrine may be less effective in patients with a hyperadrenergic phenotype, based on some data from Julian Stewart's group. Patients should take midodrine before upright activities. Midodrine may cause supine hypertension.

Q: Have blood volume assessment altered your clinical management? Would a low blood volume assessment make you more likely to prescribe fludrocortisone, for example?

[S. Raj] Yes, I would use blood volume assessment to figure out how hard to push, for example with a medication like fludrocortisone. These tools are not currently available to me in Calgary, but we are working on it.

Q: What was the hydration status of those who was undergoing compression? Were they drinking 2l and taking ample salt?

[S. Raj] Hopefully. Our standard advice involves 3L of water intake and a lot of salt intake.

Q: Will patients get better over time with POTS?

> [S. Raj] I think that the majority of patients that I see do improve in their symptoms and functioning, although I rarely "cure" anyone. It is worth treating POTS patients!

Q: Can you elaborate a little bit about type of exercise that is most useful for POTS?

> [S. Raj / K. Bourne] POTS patients should participate in a graduated exercise program beginning with recumbent exercise 4 times a week (30 minute sessions). Non-upright exercises are recommended, at least initially. Rowing machines, recumbent cycles and swimming are good starting points. Light strength training exercises (especially targeting the thigh muscles and core) are beneficial. This is in addition to the aerobic training, and not a replacement for it. Note that most patients will feel worse before they feel better and should be encouraged to stick with the exercise program. It may take 4-6 weeks for patients to feel any improvement. Not easy to do, but a very important part of the treatment.

Q: Is there some possibility of highly trained endurance athlete having higher chance of having postural hypotension and POTS? Maybe due to higher vagal tone?

> [S. Raj / K. Bourne] Not usually POTS, but some very highly trained athletes can be very prone to vasovagal syncope.

Q: What is your idea about Tilt training? Is that a good option for the treatment of POTS?

> [S. Raj / K. Bourne] It is important that patients do not engage in bed-rest for most of the day, but there is no data for "tilt training" in POTS.

Q: Can you speak to sleep disturbances in POTS and investigations/treatments for same?

> [S. Raj / K. Bourne] Sleep problems are very common. Obstructive sleep apnea is quite rare. The problem seems to be mainly insomnia - both sleep onset and the variant where one wakes in the middle of the night and can't get back to sleep. There may also be some with Restless Leg Syndrome. More work is needed in this area.

Q: What role does dietary sodium have in POTS? Is there an association?

[S. Raj] We recommend high salt diets to almost all of our POTS patients. There is data from an acute crossover study coming out soon from Vanderbilt showing that it can be helpful in POTS.

Q: Is there standard classification for patients who display signs indicative of POTS such as a tachycardia response of more than 40 bpm on upright tilt, and yet also an SBP drop that is greater than 20 mm of Hg? Such pts do not meet strict criteria for POTS. However, they may display signs or report its symptoms.

[S. Raj / K. Bourne] If the SBP drops by >20 mmHg, even with a profound reflex tachycardia, then they have orthostatic hypotension, and by definition do not have POTS. However, they still require treatment, and some of the approaches may be similar. These can include attempts at blood volume expansion with increased dietary salt and water intake, and the use of compression garments.

Q: What percentage of your POTS patients has frequent bouts of mild temperature increases?

[S. Raj] I have certainly had patients complain of a low grade temperature with a "POTS flare up", but I do not have data on how common this is. Might ask in the Big POTS Survey follow-up.

Q: How to increase the sensitivity of POTS diagnosis?

[S. Raj / K. Bourne] Standing HR and orthostatic tachycardia are highest in the morning and decrease by midday. Assessment of orthostatic vital signs in the morning can optimize the sensitivity.

Q: Is there a variance from day to day? On one day the patient fulfill the diagnostic criteria but not on the other?

[S. Raj] There can definitely be variations in symptoms, and probably hemodynamics, from day to day. There is variation with the menstrual cycle in many patients. Adequacy of hydration, temperature, and other variables could also play a role. If the increase in HR is just below or just above the threshold on a given day, it could end up on the other side on a different day. In most patients, there is not a huge change from day to day.

Q: A lot of patients describe a feeling of sudden energy loss together with a sudden craving for carbohydrate. What is the mechanism behind it?

[S. Raj / K. Bourne] This is not sure. A lot of our patients can feel worse with carbohydrate loading. Sudden loss of energy sound more like a vasovagal reaction than POTS per se.

Q: What is the link between EDS and POTS?

[S. Raj / K. Bourne] There is an association between EDS and POTS. The reasons are not known. In the Diagnosis and Impact of POTS survey we saw that about one-quarter of POTS patients also reported a diagnosis of EDS. This is consistent with other literature. One theory linking POTS and EDS is that EDS patients have increased blood vessel distensibility leading to increased venous blood pooling and orthostatic intolerance. However, there is no research that confirms this theory, and more research is required to understand this relationship.

Q: Could you please provide the URL for the Big Pots Survey Results?

[S. Raj / K. Bourne] B. H. Shaw, L. E. Stiles, K. Bourne, E. A. Green, C. A. Shibao, L. E. Okamoto, E. M. Garland, A. Gamboa, A. Diedrich, V. Raj, R. S. Sheldon, I. Biaggioni, D. Robertson, S. R. Raj. (2019). The face of postural tachycardia syndrome – insights from a large cross-sectional online community-based survey. *Journal of Internal Medicine*. 286(4), 438-448. https://doi.org/10.1111/joim.12895

Please visit: https://onlinelibrary.wiley.com/doi/10.1111/joim.12895

Q: How to do Blood volume assessment?

[S. Raj] Most clinical blood volume tests are done in Nuclear Medicine labs. We used the DAXOR technique using 131-I-Albumin (FDA Approved). Chromium labelled RBC can also measure red cell blood volume. There are some approaches using a small amount of carbon monoxide, but in North America I think that this is a research approach.

Q: Is there a danger that abdominal compression or upper thigh compression increases problems with swelling of legs/feet?

[S. Raj] This has not been a complaint that I have heard. I suspect that it is because that compression is not "complete".

Q: Is BP oscillation suppressed by compression?

[S. Raj / K. Bourne] Yes, we saw that low-frequency blood pressure oscillation was significantly lower with full compression compared to no compression.

Q: You did not mention pain in your symptoms. I have a few patients with POTS and unexplained pain in their extremities. What is your experience with this?

> [S. Raj] Patients can have pain, and it can take multiple forms. A significant sub-group of POTS patients also have Ehlers-Danlos Syndrome or Joint Hypermobility Syndrome, and they can have very severe around their joints (not typically in the joint itself). Some patients have a small fiber neuropathy that can especially involve the extremities (longer nerves) - and these nerves tend to carry autonomic and pain fibers. Then there are patients with other disorders, including, but not limited to fibromyalgia.

Q: Are you concerned with an adverse reaction of high salt? Do these patients need ongoing monitoring?

> [S. Raj / K. Bourne] Most patients have low to normal BP. That could change over time (decades) as physiology changes. The advice might need to be reconsidered if that happens. Not usually a problem in the short term (few years).

Q: Do you find much use of salt tablets? I saw a study looking at 24 hour sodium and salt benefits for POTS patients. What dose do you use and what determines your dose decisions?

> [S. Raj / K. Bourne] Encouraging patients to add table salt to their daily meals is a good way to increase salt intake if patients can tolerate the taste of salt. I ask patients to take 2 tsp of NaCl and put it in a snack bag in the morning, and to get that in throughout the day. I try to avoid salt tablets unless the patient hates the taste of salt. In addition to 3 litres of water per day. Some salt tablets may induce nausea, but others come in buffered capsule form and may be more tolerable.

Q: What do you think of tragues vagas stimulation for hyperadrenergic POTS patients? Any experience?

> [S. Raj / K. Bourne] No, but there are ongoing studies of this at Vanderbilt University and the University of Oklahoma.

Q: Do POTS patients experience episodes of HR elevation that are not accompanied by hypotension?

> [S. Raj / K. Bourne] Yes, this is correct. For the diagnosis of POTS the patient must have a heart rate increase of 30 beats per minute or more without hypotension. If the patient only experiences orthostatic tachycardia in response to orthostatic hypotension, then orthostatic hypotension would be the correct diagnosis.

Q: How do we encourage engagement with non-pharm treatment?

[S. Raj / K. Bourne] Many patients are interested in non-pharmacological therapies to avoid medication side-effects. It takes time to explain the rationales.

Q: How much daily sodium do you recommend in managing POTS? Do you prescribe IV fluids and if yes where is the research? Do you use clonidine in managing hyperadrenergic POTS? Do you recommend full autonomic testing aside from HUTTT in patients diagnosed with POTS?

[S. Raj / K. Bourne] 4-5 grams of sodium (10g of NaCl) is recommended daily in addition to 3 litres of water. I find that clonidine has a short half-life and is associated with significant rebound symptoms. One could use a long-acting clonidine patch, but this is not available in Canada. I use methyldopa for very hyperadrenergic patients. Full Autonomic Function Tests can be useful in some POTS patients (including a Valsalva Maneuver, IOH assessment and hyperventilation, in addition to a HUT).

Q: Is it bad to wear compression if you have coils in veins in your abdomen?

[S. Raj / K. Bourne] No.

Q: What is your experience in POTS in older adults, and their diagnosis and management?

[S. Raj] Less common, but older adults can have POTS. Many times, when an older patient is referred for POTS, the problem is actually Orthostatic Hypotension.

Q: What are your projections with regards to POTS and Long COVID?

[S. Raj] In areas with a lot of COVID infections in the past year, there are quite some patients with post-COVID dysautonomia and some of them have developed POTS. What we need to understand, is what that is and what it means. The AAS is working on a position statement to try to point this out, but much is still unknown. One of the questions is, what potential differences are between post-COVID patients with POTS, compared to other POTS patients? Generally speaking, this topic demands more research and appropriate funding in the upcoming period.

Q: What test can I request to diagnose POTS?

[S. Raj / K. Bourne] The diagnosis of POTS is based on clinical criteria. Orthostatic vital signs (heart rate and blood pressure) are critical to the diagnosis.

Q: What would be the best way to direct physicians who say they know nothing about POTS? Where would you point them first?

[S. Raj / K. Bourne] The Canadian Cardiovascular Society Position Statement on Postural Orthostatic Tachycardia Syndrome and Related Disorders of Orthostatic Intolerance (document available for download) would be a good initial summary.

Please Visit: https://www.sciencedirect.com/science/article/abs/pii/S0828282X19315508

Q: Where all hemodynamic parameters (heart rate, blood pressure, stroke volume) in the POTS compression garment study (Bourne, 2021) measured non-invasively and continuously?

[S. Raj / K. Bourne] Yes, all parameters were collected beat-to-beat and non-invasively, using a small finger cuff.

This hemodynamic data can all be derived with the Finapres NOVA device, combined with Advanced Hemodynamics software (Modelflow). Finapres also offers the recently launched 'Guided Autonomic Testing' application, this provides a guided protocol for several autonomic tests including the tilt table test. This GAT application also supports operator & patient instructions, video recording and automated reporting.

You can also refer to: http://www.finapres.com/pagina/193/Advanced_Hemodynamics/

If you have additional questions for Dr. Satish Raj or Kate Bourne regarding content from their webinar please contact them by email.

If you have questions for Finapres Medical Systems or wish to receive additional information about Guided Autonomic Testing, please contact the Finapres team directly at the email address below.

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