

RESEARCH LETTER

Virtual patient workshops: A tool for education, community, and empowerment in patients with postural orthostatic tachycardia syndrome



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Nonpharmacologic interventions for postural tachycardia syndrome (POTS) have been proven to be effective in reducing symptoms and increasing quality of life.^{1,2} However, many patients find it difficult to implement these intensive lifestyle changes, such as exercise, increase in sodium and fluid intake, and use of compression garments, as evidenced by the high (~50%) rate of patient dropout in community-based lifestyle intervention studies.² Other quality-of-life interventions, such as accommodations in the workplace or school and talking effectively with loved ones about POTS, are rarely discussed in the literature. Many patients report low health-related quality of life comparable to that of other disabling chronic health conditions such as congestive heart failure.³ In turn, healthcare providers caring for individuals with POTS often find themselves with insufficient time and financial resources to support these often high-need individuals.

We completed a feasibility study of a virtual, interactive, empowerment-based small-group workshop for patients with POTS. The workshop consisted of 4 hour-long sessions created and presented by a partnership of physicians and patients. Each session was structured as a 30-minute didactic PowerPoint presentation followed by a 30-minute community discussion. Participants had the option to remain anonymous and/or turn off video. The sessions were free to participants, easy to implement, and reproducible, with pre-prepared materials on each topic. We repeated the 4-part workshop twice with 10–15 patients in each group.

The session topics were as follows: (1) “Introduction to POTS,” which covered the diagnosis and physiology of POTS as well as an overview of treatment; (2) “Nutrition, Salt, and Compression,” which covered specific strategies for modifying diet, fluid, and sodium intake and the use of

How likely would you be to recommend this workshop to a friend or family member with POTS?

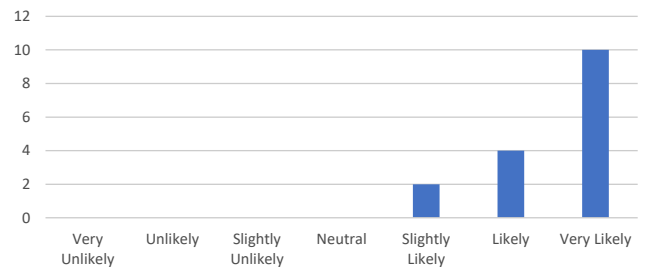


Figure 1 Likelihood that workshop participants would recommend the workshop to a friend or family member with postural tachycardia syndrome (POTS).

compression garments; (3) “Exercise,” which covered the research behind exercise and how to create and maintain an exercise routine to improve symptoms; and (4) “Living with POTS,” which covered common comorbidities, accommodations in school and work, and how to talk about illness with friends and family.

The workshop was well received by participants. When surveyed, all participants responded that they would recommend the workshop to a friend with POTS (Figure 1). Patients reported that they received a more thorough understanding of their illness, learned about clear action items that can be incorporated in their daily life to improve symptoms, felt empowered to make changes, and formed a community with other POTS patients with whom they could share struggles, tips, and successes. The provider responses were also overwhelmingly positive; they felt that small-group sessions were an effective and efficient way to educate patients about POTS. Providers also commented that they learned strategies from the participants that informed future patient care. Limitations included the small sample size, the homogeneity of the groups (composed primarily of young white females), and difficulty quantifying the subjective measurement of the impact of the intervention on health outcomes.

KEYWORDS Postural orthostatic tachycardia syndrome; Patient education; Lifestyle interventions; Virtual health; Group education; Empowerment (Heart Rhythm 0² 2022;3:211–212)

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KEY FINDINGS

- A 4-part virtual educational workshop, held by Zoom, was offered to patients with postural tachycardia syndrome in a Boston cardiology practice.
- The workshop was well received by patients, who felt supported and empowered by the facilitators (MDs and medical student) and participating peers.
- The workshop was well received by the physician facilitators, who felt it was an efficient and effective method of educating and supporting this often high-need population.

Empowerment-based group education invites social interaction, peer support, and modeling, and has been shown to improve outcomes in chronic health conditions including diabetes.^{4,5} Extending this concept to the virtual platform allows greater accessibility to those with health conditions such as POTS that can be unpredictably disabling. During the COVID-19 pandemic, the virtual platform offered a welcoming, safe space to gather with peers and providers. The virtual workshop can be used on a small scale within practices to provide additional support to patients and/or on a larger scale through online support groups to distribute helpful information to the POTS community. It is a cost-effective and efficient way for providers to educate and

empower patients, while encouraging patients to learn from and support one another.

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Patient Consent: Patients provided consent to participate in the workshop and complete surveys electronically via REDCap at the start of the study.

Ethics Statement: This was a noninterventional study with minimal risks. It was reviewed by the Harvard Medical School institutional review board (IRB) and determined to meet the criteria for IRB exemption per the regulations found at 45 CFR 46.104(d) (1)(2). All aspects of this study were conducted in compliance with Health Insurance Portability and Accountability Act of 1996 (HIPAA) regulations and the HIPAA Omnibus Rule of 2013.

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