

POTS Patient Perspectives

DYSAUTONOMIA INTERNATIONAL



AWARENESS



ADVOCACY



ADVANCEMENT

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Disclosures

No conflicts.

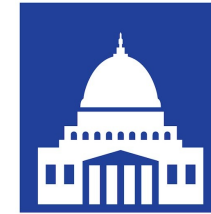
I might discuss off-label use of medications.

10 Things POTS Patients Want You To Know

1) It's not just “a teenage syndrome.”



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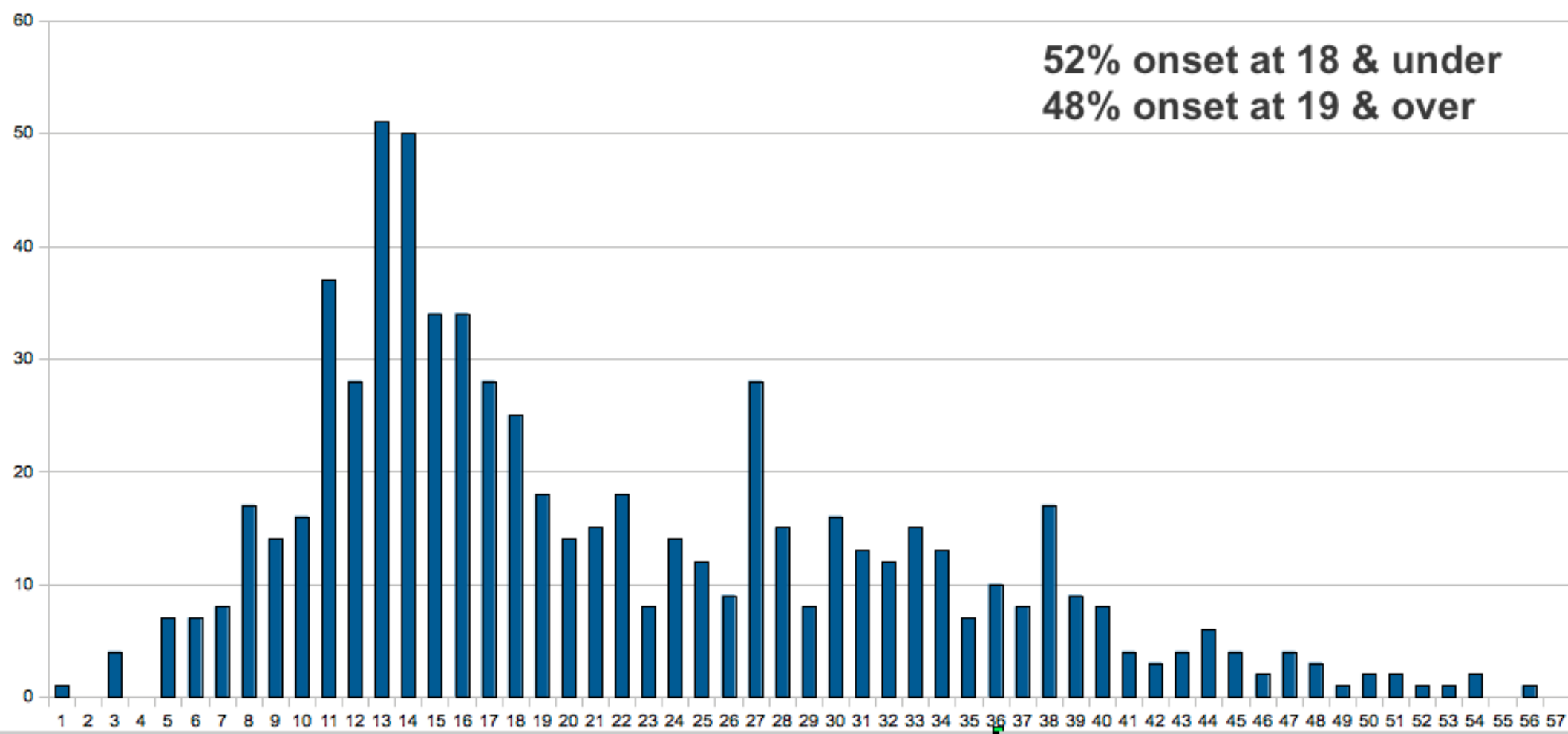
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Patient Reported Age at Onset of POTS Symptoms

N=697



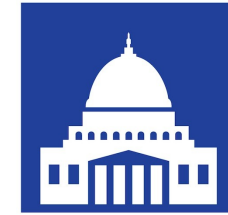
10 Things POTS Patients Want You To Know

2) Everyone doesn't "grow out of it."

Patient reported length of illness in patients reporting POTS symptoms prior to age 19



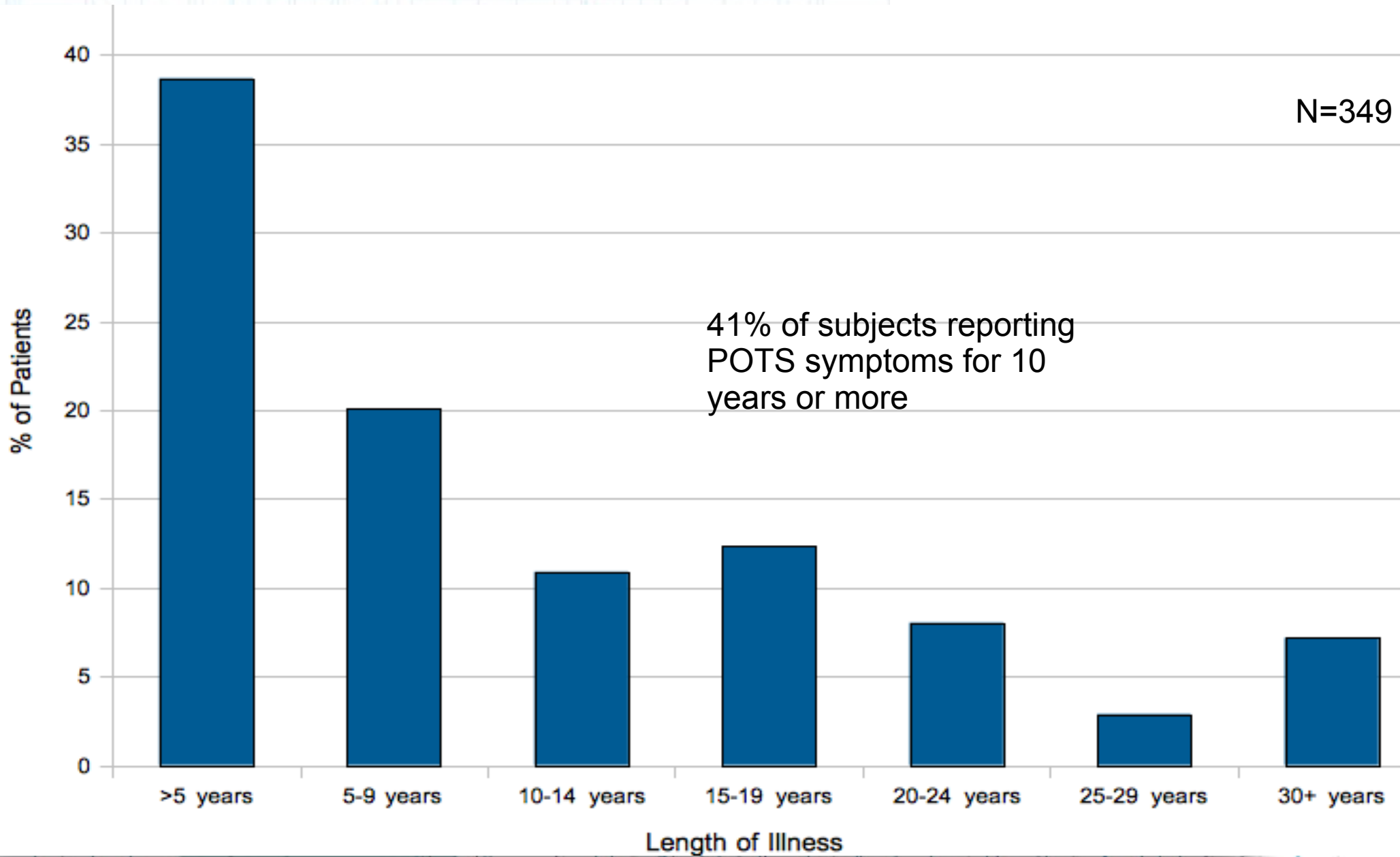
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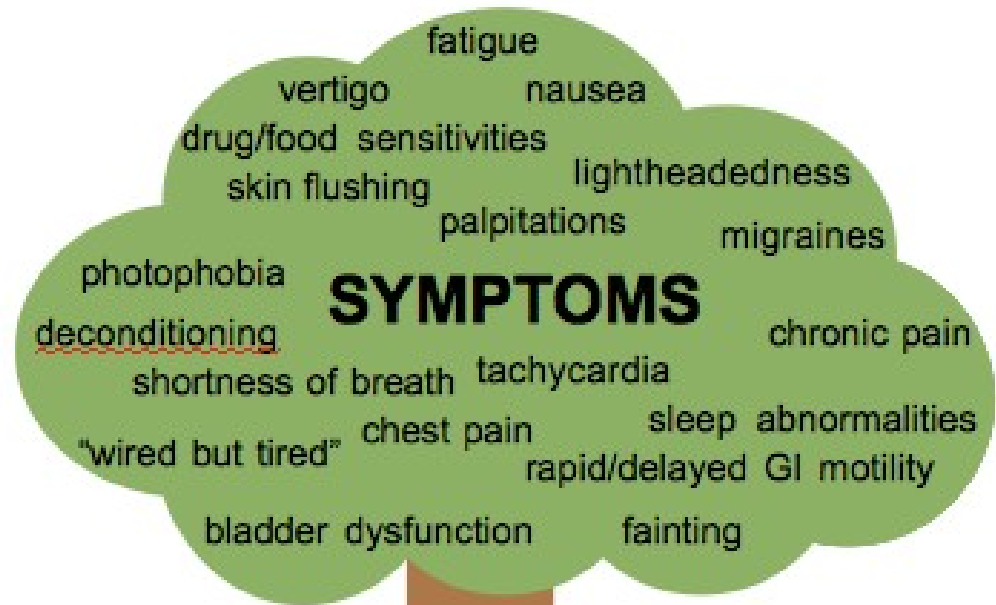


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10 Things POTS Patients Want You To Know

3) Diagnosing someone with POTS should not be the end of your diagnostic efforts. We want you to help us find the “root cause” if possible.



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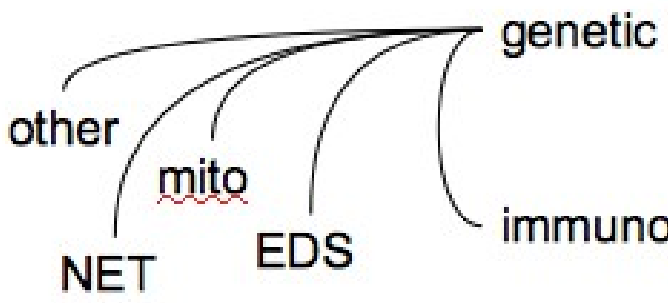
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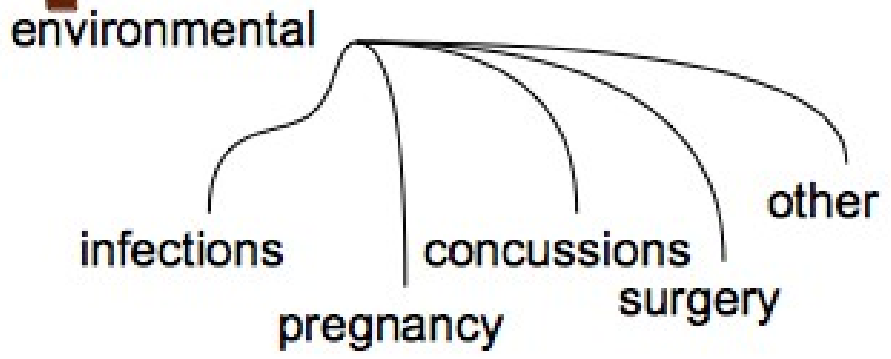
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autoimmunity?



10 Things POTS Patients Want You To Know

4) Just because “the root cause” can't be identified in the majority of patients at this time, doesn't mean you shouldn't bother to look for one.

A sampling of my POTS friends...

POTS → MS

POTS → LEMS

POTS → Diabetes

POTS → APS

POTS → Sjogren's

POTS → Bechet's

POTS → CDC+ Lyme

POTS → Stiff Man

POTS → Lupus

POTS → AAG

POTS → Celiac

POTS → Crohn's

10 Things POTS Patients Want You To Know

5) After POTS is diagnosed, we often bounce from one specialist to the next because a lack of uniform approach leads to us to think we didn't get “the whole enchilada” work up.



What we want



What we often get

Audience questions...

When should patients stop looking for a root cause and just “accept” that there are no clear answers?

How many doctors are too many doctors for a patient to see?

At what point do you start to think your patient is “attention seeking” or “doctor shopping?”

Don't hold it against patients when they want a second-opinion

National VA study of over 6500 patient initiated second opinions across a range of disciplines:

- 14.8% of second opinions result in a change in diagnosis.
- 37.4% of second opinions result in a change in treatment.

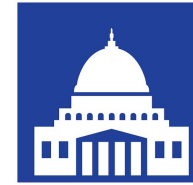
These percentages are probably much higher in poorly understood medical conditions like POTS. Even amongst experts, Dr. A says X, Dr. B says Y and Dr. C says Z.

10 Things POTS Patients Want You To Know

6) POTS patients endure an average diagnostic delay of 5 years and 11 months.



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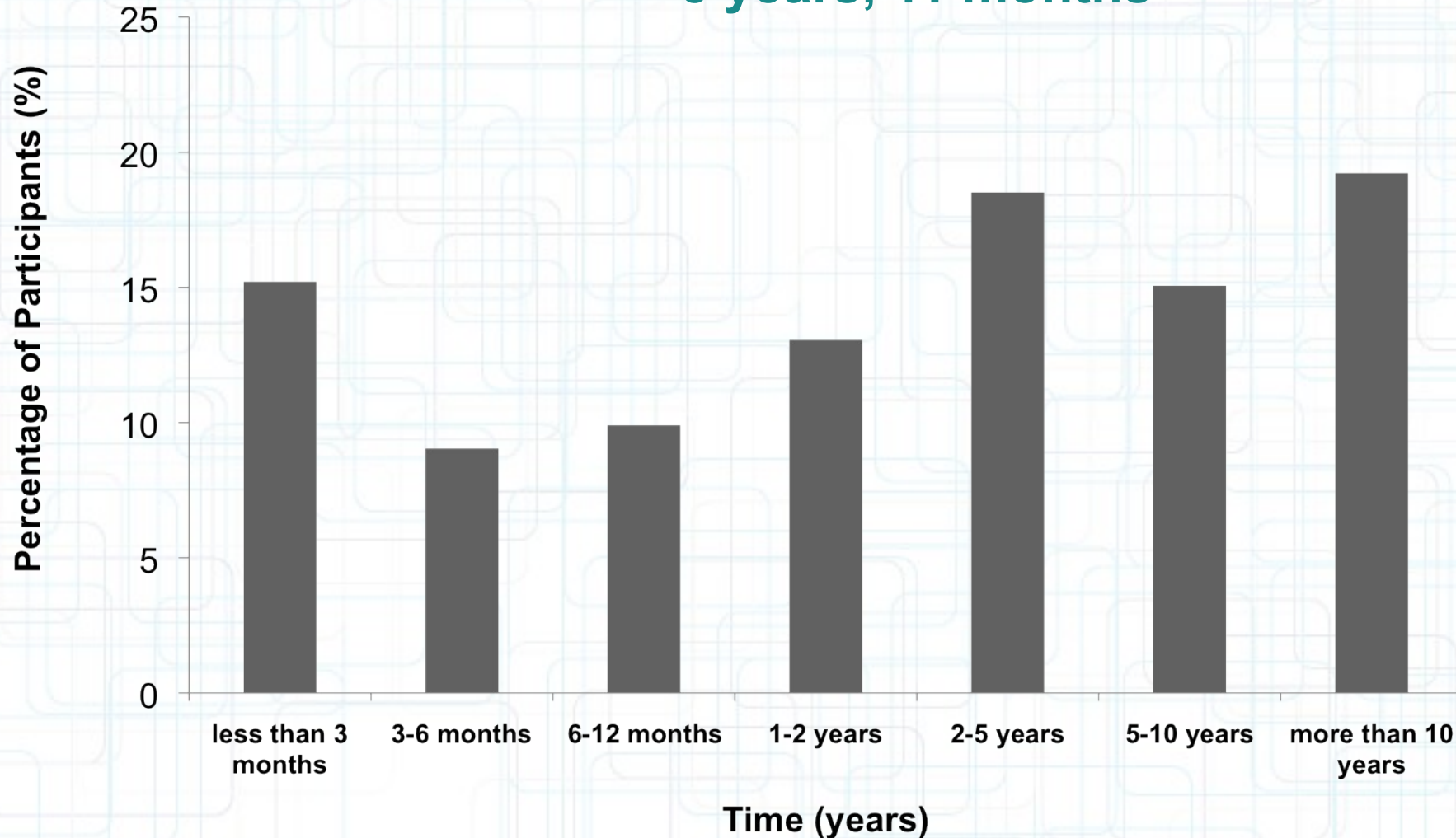


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Diagnostic Delay in POTS

N = 696

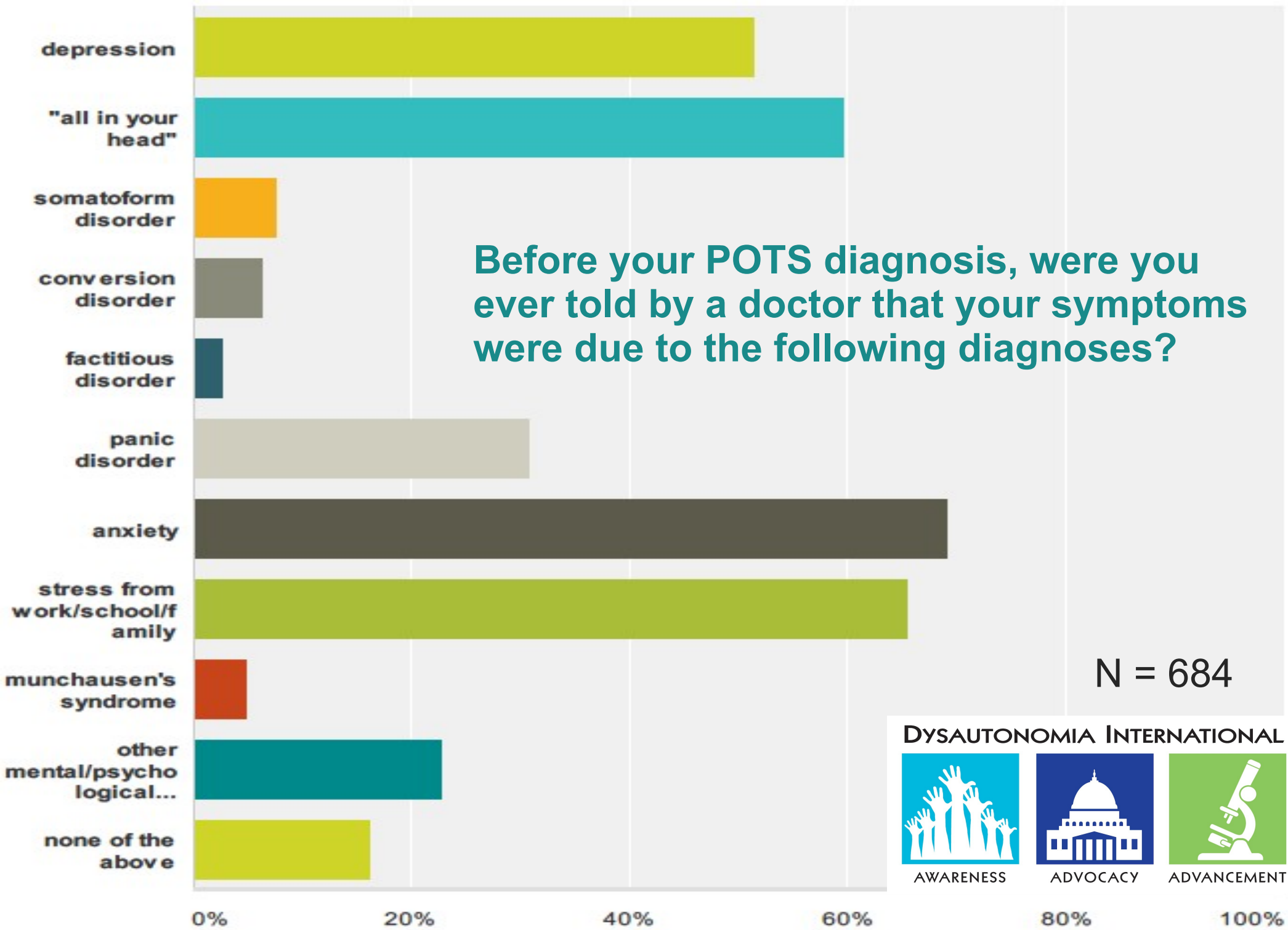
**Average Diagnostic Delay:
5 years, 11 months**



10 Things POTS Patients Want You To Know

7) Prior to being diagnosed with POTS, 59% of us are told it's "all in your head" by a doctor.

Before your POTS diagnosis, were you ever told by a doctor that your symptoms were due to the following diagnoses?



10 Things POTS Patients Want You To Know

8) Patients are often blamed for their symptoms when doctors can't figure out what's wrong.

Patient Blaming 101

Do they offer this course in medical school?

“Maybe you weren't cut out to be a lawyer. Go home and enjoy a glass of red wine to relax.”

“You must be doing this because you're 31 and don't have babies yet, and you're just trying to get attention from your husband.”

“You're deconditioned because lawyers sit at their desks all day.”

Me sitting at my desk all day...



10 Things POTS Patients Want You To Know

9) It helps us when you clarify the difference between a “symptom” and a “disease.”

Too many diagnostic labels can add to psychological burden of chronic illness

Example: “I'm only 15, but I have POTS, dysautonomia, autonomic neuropathy, peripheral neuropathy, sudomotor neuropathy and small fiber neuropathy. It's so hard to live with all of these diseases!”

1 problem, given 6 different names.

Easier for patients to cope if they can visualize their illness as 1 problem, rather than 6.

Explain to patient what these terms mean, and that their SFN is part of their POTS – not a different “disease.” (...unless you find the cause of the SFN)

10 Things POTS Patients Want You To Know

10) Lengthy diagnostic delays and misdiagnoses are devastating to patients and their families, sometimes worse than POTS itself.

Consequences of diagnostic delay and misdiagnosis

- countless office visits, medical tests, trying new medications that don't help or cause side effects
- may not be believed by medical professionals, family, friends, co-workers
- prolonged suffering without treatment → increased disability?
- may have lost their job or had to drop out of school/transfer to home schooling
- social isolation

“Post-Traumatic Misdiagnosis Disorder”

Consider the psychological impact that could occur after being through months or years of misdiagnosis...

- Physical and emotional stress caused seemingly endless tests, office visits, numerous ER visits & hospital admissions.
- Increasingly hostile medical professionals who accuse the patient of malingering and/or refuse to help.
- Patient becomes desperate.
- Some patients might exaggerate symptoms or complain more than necessary in an effort to be taken seriously and obtain help for the symptoms they really are experiencing – which only makes doctors less willing to help.

“Post-Traumatic Misdiagnosis Disorder”

Misdiagnosis breeds distrust of medical professionals.

- if doctors keep misdiagnosing me, then why should I believe them when they tell me this isn't fatal/there is nothing to worry about/I will recover?

- distrust leaves desperate patients open to quacky theories & treatment ideas

- distrust means patients are less likely to follow good treatment advice

- distrust is another reason patients bounce from one doctor to the next

“Post-Traumatic Misdiagnosis Disorder”

How This Makes the Patient Feel

Feelings of guilt: Is this really my fault? I must be a terrible person if I am causing myself to be like this. I am a burden on my loved ones.

Feelings of self-doubt: Am I losing my mind? Will I ever be the same person I was?

Feelings of hopelessness: I've seen 20 doctors and no one can figure me out. Most of them don't even want to help. I'm worried I might die before we find out what's wrong.

“Post-Traumatic Misdiagnosis Disorder”

Financial strain: inability to work (or caregivers having to take time off or stay home); medical billing and insurance problems (stressful to manage even if you can afford to pay)

Social isolation: family, friends, classmates and co-workers disbelieve you when no diagnosis is found; expectation that you should be better by now; friends eventually stop calling when you can't hang out

Caregiver burnout: caregivers shuffle you from one appointment to the next, and may have to help with food prep, showering, doing your chores around the house

How does overdiagnosis & misdiagnosis change perspectives?

May change a patient's perspective:

- I have 101 diseases and I'm probably going to die.
- There's no hope for me to get better because I have too many problems.
- Illness becomes the patient's identity.
- I hate going to the doctor because I get a new diagnosis each time I go.

May change a medical professional's perspective:

- Immediately suspect that the patient is a hypochondriac or malingering.
- Reluctance to get involved.
- Assumption that prior doctors have already considered everything; no new effort to find a root cause or offer new treatment suggestions.

May change family/friend perspectives:

- Suspect that the patient is hypochondriac or lazy.
- Reluctance to help care for patient; withdrawal of support.
- Resentment towards the patient; blame patient for creating burden on the family.
- Abandonment of friendship/family relationship.

Are We Crazy? (Am I crazy?)

No, but you would have to be brain dead not to be psychologically impacted by years of misdiagnosis coupled with a debilitating chronic illness.

If POTS is autoimmune, depression/anxiety not uncommon in other autoimmune diseases – considered a consequence, not a cause. No one tells MS patients “if you just stopped limping, it wouldn't be a problem.”

Questions to think about...

- Are there antibodies associated with behavioral changes in POTS?
- Could adrenergic antibodies impact brain function/behavioral changes?
- Co-existence of anti-NMDA, PANDAS antibodies?
- Does excessive NE cause behavioral changes?
- Structural brain changes?

Take home points:

Remember that most POTS patients have been through a lot before they see you.

Avoid giving patients a “diagnosis” for each sign/symptom.

- Makes patients think they are falling apart and worsens psychological burden of illness.
- Makes other medical professionals think they are nuts.

Most important... listen to your patients, use your brain and THINK! Don't be a box checking robot.



I'm not a robot