



Lessons learned from a Rhode Island academic out-patient Lyme and tick-borne disease clinic

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PATIENT CHARACTERISTICS, N=218

Female	58.7%
> 50 years old	55.5%
Prior antibiotics	87.0%
> 6 months of symptoms	62.5%
Top symptoms reported	
Fatigue	66.5%
Joint pain	58.2%
Brain fog	32.1%
Headache	27.9%

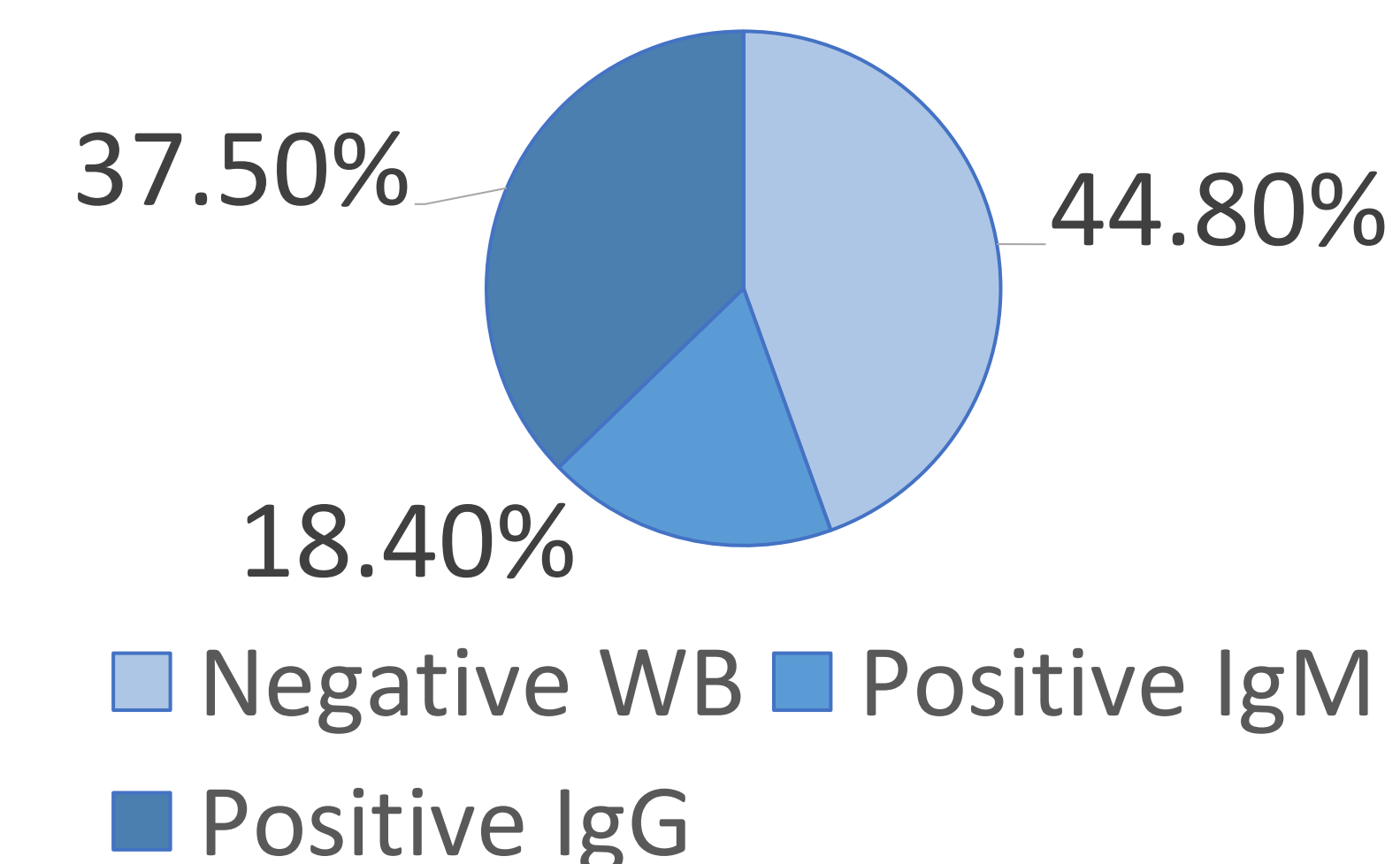
OBJECTIVE 1: to characterize the **types of patients** seen at an academic center for Lyme and other tick-borne diseases

➤ Retrospective chart review, all new patients seen March —November 2018

OBJECTIVE 2: to evaluate the **experiences and perspectives of patients** who have experienced long-term (> 6 months) symptoms from Lyme disease (i.e. Post-treatment or "chronic" Lyme)

➤ Phone survey, subset of 25 patients

Serology Results in Patients with Symptoms > 6 months (N= 136)



CONCLUSIONS

- Patients come to our clinic with a **large range** of symptoms, serologies and experiences related to Lyme disease treatment.
- **Shared decision making** with a **patient-centered approach** even in the absence of curative therapy may be beneficial
- Further research is needed to **establish best practices for the management of** common symptoms of fatigue, joint pain, cognitive difficulty and sleep disturbance.

MAJOR THEMES OF PHONE SURVEY, N=25

Significant frustration regarding delays in Lyme disease diagnosis/treatment	<i>"didn't realize that I had Lyme until 2 years after symptoms started, literally asked to be tested for bone cancer because I was in so much pain"</i>
Dismissive attitudes by medical providers	<i>"I was laughed out of the office at a different practice"</i>
Lack of confidence in doctors/medical system	<i>"the more experience you get with other doctors, the more confused you get; every doctor I've gone to has had a different interpretation"</i>
Appreciation for reassurance/validation provided by doctors (even in absence of curative therapy)	<i>"Was immensely helpful, just knowing [the doctor was] there for me was really reassuring to have someone to talk to" throughout recovery</i>

COMMONLY REPORTED MODES OF SYMPTOM MANAGEMENT

- Diet modifications
- Use of herbal supplements, from extensive herbal regimens from naturopaths to more informal approaches supplements or multivitamins
- Over-the-counter NSAIDs (oral and topical, e.g. Diclofenac)
- A significant minority of patients described using marijuana and/or CBD cream
- Physical therapy
- Support groups for people with chronic conditions