

Symptom patterns and Treatment Methods for GWS/MSS Patients

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Approach to the patient with fibromyalgia (or GWS):

- “Practice-based evidence in the absence of evidence-based practice”
- “The challenge is to produce a compassionate and comprehensive treatment program for all aspects of the fibromyalgia patient’s illness.”

--Abeles M et al. Am J Med 2008, pp 555-61

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20 patients who sought me out: who are they?

- Maine patients w/MSS referred by their doctors
- Out-of-state patients seeking a comprehensive evaluation and treatment ideas

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My Main Points

- **My treatment method:** *“No drug or group of drugs has proved to be particularly useful in FMS...”* --Abeles M. 2008. Am J Med. pp 555.
Symptoms: a surprising commonality; new dx's that seem to need attention (sleep apnea, testosterone, thrombosis, DM-BP-Chol); physician-established (NOT self-report)
- **Example of results:** worst and best

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What Do I Offer?

- I have borrowed from a variety of different approaches, and through trial and error use those that achieve good results
- I use “patient-centered care” *
- I address the considerable psychological issues in MSS (and especially GWS)
- I may use narcotics and ritalin, which can provide appreciable benefits
 - * Crossing the Quality Chasm, IOM (2001); GW Veterans: Treating Sx and Syndromes, IOM (2001)

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“You do whatever you can.”

Warren Warwick, M.D.
Emeritus director
Fairview-University Children's Hospital
U. Minn. Cystic Fibrosis Center, with the best
survival statistics for C.F. in the US

--as quoted by Atul Gawande, M.D.
The New Yorker
December 6, 2004

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Demographics of the 20 patients

- 18/20 certain they received anthrax vaccine; 2/20 think it is likely
- 5/20 were Gulf War or Era veterans:
 - 2 Navy/ Marine with almost no land experience
 - 2 Army with ground experience in GW
 - 1 Army vaccinated, sent to school, failed his PT test and was separated before deploying to GW
 - 1 GW soldier became ill, improved, then became quite ill following anthrax vaccinations in 1999

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Comparing the 2 groups

- | | |
|---|--|
| <ul style="list-style-type: none">■ <u>GW</u>■ 2/5 seen at Deployment Health Clinic or Vaccine Healthcare Centers (VHC) (40%) | <ul style="list-style-type: none">■ <u>Non-GW</u>■ 6/15 evaluated by VHC (40%) |
|---|--|

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Comparing the 2 Groups

<u>5 GW Patients</u>	<u>15 Non-GW Patients</u>
1/5 female (20%)	3/15 female (20%)
Avg year of birth 1965	Avg year of birth 1964
Avg age at evaluation 40	Avg age at eval 41 (skewed by older MD and RN)

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How do the 2 groups' symptoms compare?

	<u>GW</u>	<u>Non-GW</u>
Chronic pain	5/5 (100%)	13/15 (87%)
Fatigue	5/5 (100%)	13/15 (87%)
Cognitive disorder	5/5 (100%)	13/15 (87%)
MCS	1/5 (20%)	4/15 (27%)

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Comparing the groups

	<u>GW</u>	<u>Non-GW</u>
Gait/balance	1/5 (20%)	6/15 (40%)
Sleep disorder	4/5 (80%)	15/15 (100%)
Sleep apnea (diagnosed)	2/5 (40%)	7/15 (47%)
Severe N, V, D	2/5 (40%)	9/15 (60%)
Fecal incontinence	1/5 (20%)	3/15 (20%) ₁₁

Comparing the groups...

	<u>GW</u>	<u>Non-GW</u>
Diabetes Type 2	2/5 (40%)	3/15 (20%)
Hypertension	2/5 (40%)	3/15 (20%)
Hyperlipidemia	2/5 (40%)	5/15 (33%)
Pulmonary emboli	1/5 (20%)	3/15 (20%)
Other lung problem	1/5 (20%)	4/15 (27%)
Sexual dysfunction	0/5 (0%)	8/15 (53%)

Comparing the groups...

	<u>GW</u>	<u>Non-GW</u>
Tinnitus	1/5 (20%)	2/15 (13%)
Oral Ulcers, recurrent	1/5 (20%)	3/15 (20%)
Lupus	0/5 (0%)	1/15 (7%)
Inflammatory polyarthritis	1/5 (20%)	0/15 (0%)

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Why review another list of GW symptoms + diagnoses, when there have been multiple papers with similar lists?

1. These diagnoses are firm (physician-established). They are not self-reports, such as Gray et al., 2002; Kang et al., 2000
2. Number (avg 13 each), type and clustering of diagnoses seem important
3. I cannot clinically distinguish between the two groups

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More on treatment

- Multiple Chemical Sensitivity?
- Family relationships?
- Job?
- Educate patient and family
- Remediation: elimination diets, home environment
- Thorough record review
- Every veteran is emotionally wounded

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Questionnaires Help

- Pain questionnaire
- Standard "Review of Systems" questionnaire
- My personal questionnaire, designed to elicit symptoms specific to MSS patients

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In the office

- 1. Get a good feel for the patient and family; can they radically change their diet; get a history of drug and food sensitivities
- 2. Create a complete problem list--this will be a continuing guide to treatment
- 3. Treat pain, sleep, nutrition, GI complaints
- 4. Test for confounders like Lyme (in those who lived in endemic areas), B12 deficiency, thyroid function and other problems unique to each patient; get routine labs
- 5. Treat everything you can
- 6. WRITE EVERYTHING DOWN FOR THE PATIENT, with a carbon copy for you

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Later visits, generally 30 mins.

- How did each intervention work?
- How is the patient, overall? What is most bothersome?
- What can we do about each symptom on the list?
- Should we try an elimination diet?
- How is work going, and family relationships?

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Patient education

1. This is what we know about this disorder
2. We may not understand the cause(s), but the illness is real, and you did not cause it
3. We can treat the symptoms; our goal is improved quality of life
4. I rely on the patient to a) tell me how well the therapies work, and to b) partner with me to find interventions that are successful

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Handouts as appropriate

- Narcotics contract--essential
- Elimination diet
- CDC or national organization brochures on CFS and fibromyalgia, or some written by me
- MCS info
- How GWS relates to other MSS
- Book recommendations

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This treatment is not for everyone

- Some just want a pill, not a “program”
- Some might not trust unusual methods
- Some cannot change their diet
- Some can't afford me, the out-of-pocket supplements or the many drug co-pays
- The treatment may feel as demanding as a job to some (if working on diet and MCS issues)
- Sometimes it doesn't work, but to get no benefit is very rare

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Treatment Guide

- <http://www.anthraxvaccine.org/gulfwar/treatment.htm>

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