I TOLD YOU I WAS SICK: WHAT PATIENTS WANT HEALTHCARE PROVIDERS TO UNDERSTAND ABOUT ME/CFS

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Seven Recurrent Themes

- ME/CFS is real: believe patients’ experiences
- Don’t confuse ME/CFS with chronic fatigue
- Post-exertional malaise ≠ post-exertional fatigue
- Getting a diagnosis is vital
- Recognize how severe the condition can be.
- Even without a cure, there are many actions clinicians can take to help patient
- Patients (pt.) can offer unique knowledge/ perspectives

1) #believeME: ME/CFS Is Real

You need to:

“find something to do with your time other than sit around and complain.”

“stop being so ambitious.”

“resolve your issues with your dad”
“get a boyfriend” “get married” “have a baby”
“go on vacation.” “drink more coffee.”

“I don’t believe in ME/CFS” “ME/CFS is made up”

“Everyone experiences fatigue”
“You’re just stressed out from work.”
“Are you sure you aren’t depressed?”

95% felt estranged
77% labelled as psychological case by at least one MD.

Clinicians add to disease burden, miss treatment opportunities and diagnoses.

2) ME/CFS ≠ chronic fatigue

- Don’t confuse disease with symptom
- ME/CFS is more than chronic fatigue
- Post-exertional malaise (PEM), problems thinking, feeling sick, etc. more disabling
- Inquire, evaluate, treat, monitor all symptoms


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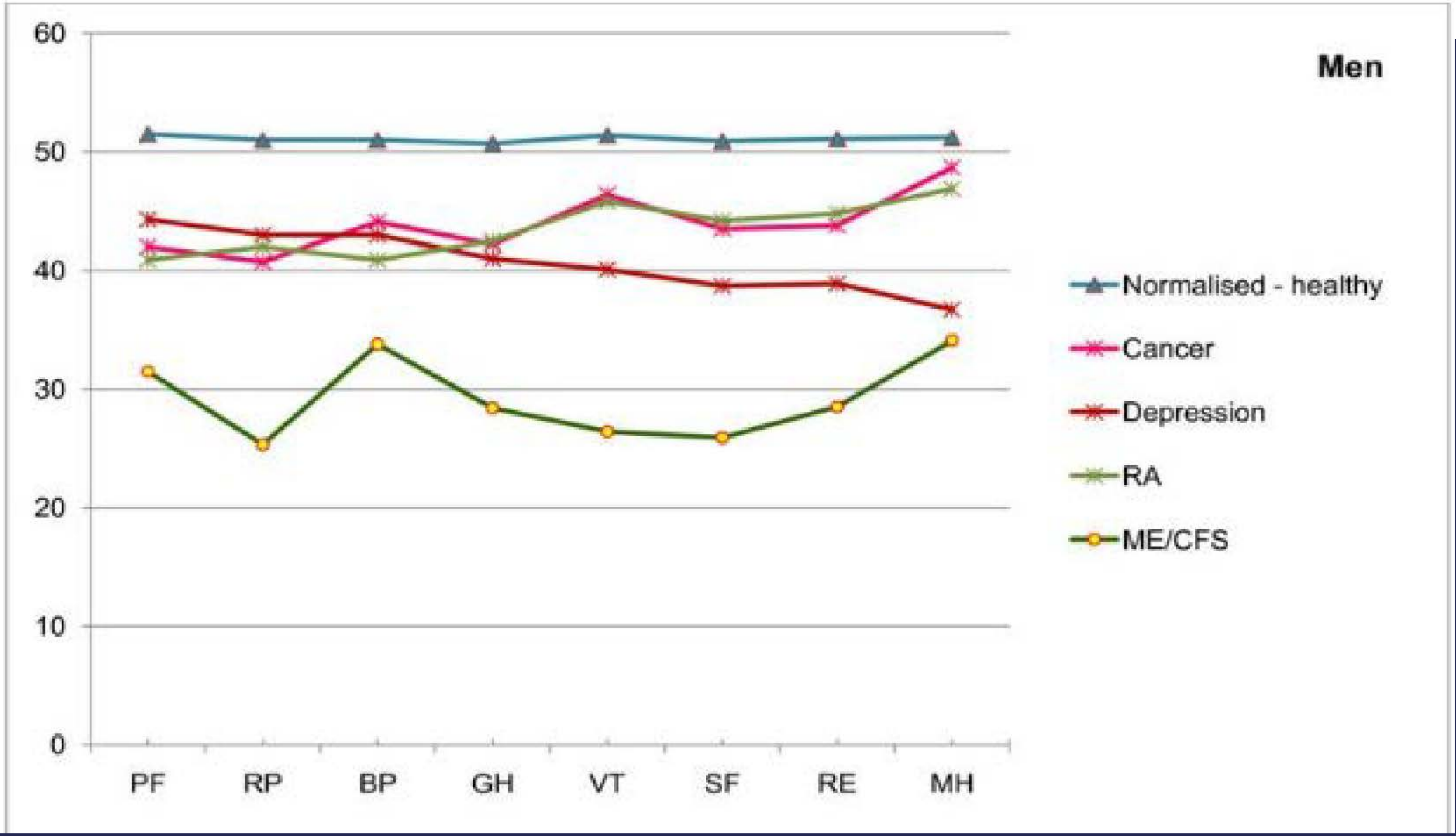
3) PEM ≠ Post-exertional Fatigue

Symptom	Physical/ cognitive exertion N = 144 (%)	Emotional Distress N = 144 (%)
Median # Sx.	7 ± 2.8	5 ±3.3
Fatigue	135 (94%)	109 (76%)
Problems thinking	106 (74%)	88 (61%)
Muscle pain	106 (74%)	48 (33%)
Sleep disturbance	97 (67%)	95 (66%)
Flu-like feelings	88 (61%)	47 (33%)
Joint pain	77 (53%)	30 (21%)
Headache	73 (51%)	53 (37%)
Sore Throat	60 (42%)	28 (19%)

4) Getting A Diagnosis Is Vital

- Knowledge not the only barrier
- 70% MDs: “disabling self-fulling prophecy” ; “promotes adoption of sick role”; doesn’t impact treatment
- 90% of patients: positive “turning point”
- Relieves anxiety/ fears
- Validates pt. experience: avoid “dustbin of neurotic complainer”
- Helps pt. and family cope/ strategize treatment/ explain
- Needed for supportive care

5) Recognize The Severity of ME/CFS



SF-36 Subscale scores

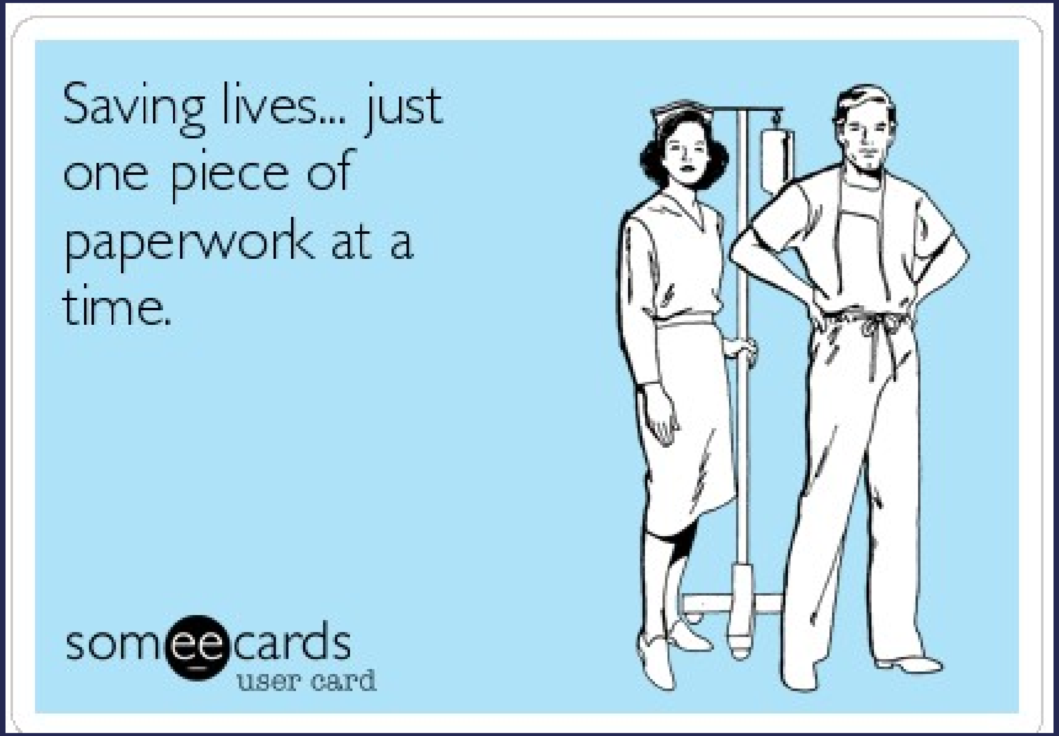
25% bedridden/ homebound

Others must restrict/ reduce/ monitor activities

6X suicide risk

Influences pt. care

6) Actions Clinicians Can Take Now!



Saving lives... just one piece of paperwork at a time.

- Assess function/ needs
- Provide supportive documentation
- Identify/ treat pain and sleep issues
- Be alert for treatable co-morbidities
- Start low, go slow with medications
- Improve pt. health, function, quality of life

7) Incorporate Patients' Insights/ Perspectives

- Patients' lives depend on solving ME/CFS
- Listening would have prevented harm from GET/ CBT
- NAM "Clinical Practice Guidelines We Can Trust"

1. Include patients on development/ reviewer panels
2. Consider patient treatment preferences
3. Take clinical subgroups into account

- Patients' views have been ignored/ dismissed for decades. Yet they often have real-world, time-tested knowledge/ experience to contribute.

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