Early Onset Symptoms in ME/CFS

A survey was conducted by Massachusetts CFIDS/ME & FM Association March 30 – April 18, 2015, to which 800 individuals responded. The intent of the survey was to find out how well the diagnostic criteria identified by the Institute of Medicine in its recent report, which were based on published evidence largely drawn from patients who had been ill for a long time, matched the symptoms that patients remembered as being present in the early months of their illness. Although this is in no way a scientific study, the results show that the earliest symptoms (as remembered!) were quite heterogeneous.

This was an informal survey. Scoring was done by hand, and judgment was required when assigning individual symptoms to categories or interpreting open-ended answers. Nevertheless, the results are quite interesting and suggest many questions for future research.

Results are shown below. The raw data (800 individual responses, many with comments) is very rich and could be analyzed further.

Question 1: What symptoms did you describe to the doctor during your very FIRST visit after becoming ill?

Symptom group (per CCC)		**% of pts. reporting symptom**
Fatigue	541	76%
Pain	297	42%
Immune	265	37%
Autonomic	197	28%
Neurocognitive	145	20%
Sleep	96	14%
Neuroendocrine	84	12%
PEM	63	9%
Muscle weakness	63	9%

No. of responses scored 800

No cluster analysis was done. Impressions (common combinations):
Fatigue alone
Fatigue and pain
Pain and immune symptoms
Immune and autonomic symptoms

Question 2: How long did it take for you to have a substantial decrease in function (loss of job, education, social or personal life, etc)?

Immediately	264	33%	
1-2 months	91	11%	63%
3-6 months	155	19%	
1 yr	90	11%	
2 yr	66	8%	
3-5 yrs	63	8%	
6-10 yrs	22	3%	
10+ yrs	19	2%	
Don't know or vague	20	3%	
Skipped	10	1%	
TOTAL	800	100%	

Some people gave only the time when they became totally disabled/unable to work.

Question 3: How long did it take for you to notice a pattern of PEM ("Post-Exertional Malaise")?

Immediately	234	29%	
1-2 months	101	13%	61%
3-6 months	155	19%	
1 yr	88	11%	
2 yr	51	6%	
3-5 yrs	56	7%	
6-10 yrs	25	3%	
10+ yrs	13	2%	
Don't know	69	9%	
Don't have it		0%	
Skip	8	1%	
TOTAL	800	100%	

Many mentioned they didn't know the pattern; it took a while to figure out.

Suggested if the doctor had asked questions about it, they would have recognized it earlier.

Question 4: Did you have Orthostatic Intolerance in the early months of the illness?

yes	418	52%
no	255	32%
don't know	96	12%
Skipped	31	4%
Total	800	100%

Many who said "no" for the early months mentioned it had developed later on.

Some said they couldn't tell because they were so fatigued they could barely move or were bedbound.

Lots of "don't know" are because they did not know what the term "orthostatic intolerance" means

Question 5: Did you notice any Cognitive Impairment in the early months of the illness?

yes	598	75%
no	174	22%
don't know	20	3%
Skipped	8	1%
TOTAL	800	100%

"Demographic" questions

Question 6: How long did it take to get a diagnosis?

Immediately	11	1%	
1-2 months	28	4%	21%
3-6 months	124	16%	
1 yr	154	19%	
2 yr	132	17%	55%

3-5 yrs	150	19%	
6-10 yrs	78	10%	
10+ yrs	43	5%	
20+ yrs	37	5%	
Still waiting	27	3%	
Don't know	12	2%	
Skipped	4	1%	
TOTAL	800	100%	

Some said they got a tentative diagnosis earlier, but the doctor was reluctant to say for sure.

Question 7: How many different doctors did you see before getting a diagnosis?

1	81	10%	
2-3	209	26%	
4-5	189	24%	50%
6-10	143	18%	
11-15	47	6%	
16-20	10	1%	
Lost count	58	7%	17%
Can't remember	6	1%	
"Many"	17	2%	
Still waiting	6	1%	
Skipped or N/A	34	4%	
TOTAL	800	100%	

Some needed multiple doctors to rule out other illness before the original doctor was willing to make a diagnosis.

Question 8: How long have you been ill?

up to 6 months	1	0%	
1 yr	23	3%	7%
2 yr	29	4%	
3-5 yrs	140	18%	
6-10 yrs	185	23%	41%
10+ yrs	175	22%	
20+ yrs	154	19%	
30+ yrs	60	8%	30%
40+ yrs	22	3%	
can't tell or too vague	7	1%	
Skipped	4	1%	
TOTAL	800	100%	

Question 9: Where do you live (U.S. state, country)?

US (incl. AK, HI)	341	43%
Canada	48	6%
UK (England Scotland Wales)	251	31%
Ireland	31	4%
Scandanavian countries	51	6%
Other Europe	28	4%

Australia/NZ	46	6%	
Other	2	0%	
Skipped	2	0%	
TOTAL	800	100%	

Question 10: Averaging your best and worst days, what is the state of your health now?

"Recovered"	41	5%	
Mild	176	22%	
Moderate	403	50%	
Severe	143	18%	68%
Skipped	37	5%	
TOTAL	800	100%	

Definitions as given in the survey:
"Recovered" (people who don't know me well may not realize I am still sick)
Mildly impaired (with careful planning, I can function almost normally for at least half the day)
Moderately impaired (may be house-bound all or part of the time; can do some basic tasks but not all)
Severely impaired (house or bed-bound almost all the time; need assistance with basic tasks)

Many questioned the definition of Mild and Moderate; thought the description represented a more severe condition than the term implies.