Table G3. Evidence table of included studies of harms of diagnosis

| **Author, year** | **Objective** | **N/population** | **Findings** |
| --- | --- | --- | --- |
| Åsbring, et al., 200271 | To investigate whether patients with CFS and fibromyalgia experience stigma and to examine the strategies they use to avoid enacted stigma. | N=25 women (12 CFS, 13 fibromyalgia) were interviewed to the point of saturation of themes regarding stigma. | **Two main aspects of stigmatization were reported** 1) Women experienced their moral character being called into question. 2) They experienced distress from being psychologized by others, especially doctors (decided in advance that problems were ficticious or psychological; and that this experience was deeply violating). |
| Assefi, et al., 200372 | To examine self-reported disability in patients with CFS and fibromyalgia, subsyndromal fatigue, compared with chronically fatiguing but unrelated medical condition. | N=555 (207 CFS, 76 fibromyalgia, 87 CFS+fibromyalgia, 31 sybsyndromal fatigue, 154 medical conditions) of 630 (88%) patients from a university CFS clinic responded to a survey about financial, occupational, and personal consequences of their illness. | **Disability outcomes reported by >20% of CFS (n=207) group** Lower standard of living: 44% (92/207) Significant decrease in social life: 84% (174/207) Lost friends: 38% (79/207) Significant decrease in recreational activities: 90% (186/207) *Of those CFS patients employed (n=119)* Taking a new job requiring fewer skills: 25% (30/119) Took a substantial pay cut: 30% (35/119) |
| Brimmer, et al., 201377 | To evaluate all patients referred to a CFS registry, to diagnose CFS according to CDC (Fukuda, 1994) criteria | N=93 patients referred to CFS registry over the course of 1 year. | **Review of the CFS registry referrals** 33 patients were classified as having CFS, 13 as insufficient fatigue or symptoms and 47 patients as having an exclusionary condition. 24 (65%) of the provider-referred patients and 13 (35%) of the support group referral patients met criteria for CFS. |
| Devasahayam, et al., 201278 | To assess the accuracy of diagnoses made by referrers to a CFS service | N=418 referrals received to CFS service. | **Analysis of referral rejection letters** 52 (36%) of the reasons for rejected referrals were likely alternative pyschiatric diagnosis and 67 (35%) were likely alternative medical diagnosis. |
| Deale, et al., 200073 | To evaluate patient experience with psychiatric diagnoses in CFS patients; evaluate whether psychiatric illness is overdiagnoses in routine clinical practice among CFS patients. | N=68 patients met Oxford criteria (Sharpe, 1991) for CFS completed a questionnaire asking about psychiatric diagnoses or labels given during their illness and then underwent interview to assess for those psychiatric disorders with the DSM III-R. | **Reported psychiatric diagnosis** 46% (31/68) given psychiatric diagnosis (usually depression) 68% (21/31) given depression diagnosis were misdiagnosed 35% (13/37) not given psychiatric diagnosis met DSM III-R criteria for treatable psychiatric disorder, present for ≥6 months |

Table G3. Evidence table of included studies of harms of diagnosis (continued)

| **Author, year** | **Objective** | **N/population** | **Findings** |
| --- | --- | --- | --- |
| Dickson, et al., 200774 | To understand participants’ prioritizations and understandings of CFS. | N=14 people with with self-reported CFS were interviewed about living with CFS. | **Reported difficulties about living with CFS**71% (10/14) experienced dealy in getting CFS diagnosis57% (8/14) were prescribed antidepressants for depression diagnosis instead of CFS diagnosis **Descriptive results**Participants reported that they perceived many medical practitioners to hold stereotypical views of patients with CFS, namely that disease was either psychological or indicative of an affective disorder. Problems with friends and partners centered on the fact that the patient is not visibly ill, and that the symptoms are inconsistent or variable. |
| Green, et al., 199975 | To evaluate stigma among people with CFS. | N=45 of 67 (67%) initially recruited patients with CFS reported perceptions of stigma. | **Reported perceptions of stigma** 95% reported feeling estranged 70% thought others attribute their symptoms to psychological or personality 40% felt need to be secretive about their symptoms in some circumstances |
| Guise, et al., 201076 | To evaluate ME/CFS sufferers’ descriptions of interactions with medical professionals. | N=38 members of an internet-based ME/CFS support group were asked to comment on how they felt about the way medical people treated them. | **Descriptive results** Patients with CFS reported that health professionals lack clinical expertise and empathy; and that they encountered professionals who lacked expectation of treatability, described themselves as fortunate in terms of experiences with medical professionals, and described themselves as able to cope and actively seeking out information and treatment. |
| Jason and Taylor, 200170 | To evaluate perceptions of diagnostic labeling among medical trainees, university undergraduates and practicing mental health practitioners. | N=105 medical trainees (Study 1) N=141 undergraduate psychology students (Study 2) Randomly assigned to being told the case presented to them had CFS, Florence Nightingale Disease, or ME. The case studies were identical.N=93 mental health practitioners (Study 3)Randomly assigned to 1/3 treatments for CFS, and given identical case studies of a woman with prototypic CFS symtpoms, diagnosed by a physician; treatments were 1) Ampligen - IV immmune modulator, 2) CBT with graded activity, or 3) cognitive coping skills therapy. | **Studies 1 and 2: told case was CFS vs. Florence Nightingale Disease vs. ME**Correctly diagnosed: 54% vs. 19% vs. 28%; p<0.01Disease result of as-yet-undiscovered cancer, infection or other illness: 22% vs. 47% vs. 28%; p<0.05Reported patient was likely to improve: 41% vs. 42% vs. 16%; p<0.05**Study 3: Data not shown**Participants assigned to Ampligen were more likely to think that the patient was correctly diagnosed as having CFS (p<0.05) and also thought the patient was signficantly more disabled than did individuals in the CBT with graded activity condition (p<0.05) |

Table G3. Evidence table of included studies of harms of diagnosis (continued)

| **Author, year** | **Objective** | **N/population** | **Findings** |
| --- | --- | --- | --- |
| Jason, et al., 200114 | To reproduce a prior study of labeling, in term of whether different names for CFS prompts different attributions regarding cause. | N=105 medical trainees (Study 1)  N=141 undergraduate psychology students (Study 2) Randomly assigned to being told the case presented to them had CFS, Florence Nightingale Disease, or ME. The case studies were identical. | **Told case was CFS vs. Florence Nightingale Disease vs. ME Mean score of whether correct diagnosis (1-6 scale; 1=not at all and 6=very likely): 4.5 vs. 3.9 vs. 4.0; p<0.01 Proportion that associated “causal factors” with diagnosis: 28% vs. 31% vs. 49%; p<0.01 Mean score of whether diagnosis was associated “organ donorship” (1-6 scale; 1=not at all and 6=very likely): 3.7 vs. 3.5 vs. 3.1; p<0.05** |
| Lawn, et al., 201079 | To quantify the number and nature of comorbid psychiatric disorders in patients with CFS. | N=135 patients participating in the PACE trial. | **Psychiatric interview using the Structured Clinical Interview fo DSM-IV Disorders 102 patients (76%) had a comorbid psychiatric diagnosis; 31% depression, 11% dysthymia, 35% anxiety, 11% social phobia, 15% specific phobia, 6% post-traumatic stress disorder and 2% obsessive compulsive disorder.** |

Table G3. Evidence table of included studies of harms of diagnosis (continued)

| **Author, year** | **Objective** | **N/population** | **Findings** |
| --- | --- | --- | --- |
| Newton, et al., 201080 | To examine the proportion of subjects referred to CFS specialist service who fulfill the CDC (Fukuda, 1994) criteria vs. alternative fatigue-associated diagnoses. | N=260 patients referred to CFS specialist service between 2008 and 2009. | **Reviewed medical notes of patients referrend to CFS specialist service**  Of those referred, 60% were diagnosed with CFS; 40% had alternative diagnosis including other chronic disease (47%), sleep disorder (20%), psychological (15%), idiopathic fatigue (13%), cardiovascular (4%) and other (1%). |
| Reyes, et al., 200321 | To estimate the prevalence and 1-year incidence of CFS in the population, and to report on exclusionary diagnoses identified by telephone interview. | N=3,528 subjects with fatigue >1 month duration (2762 with fatigue >6 months). 3 physicians and 2 psychiatrists independently reviewed each subject’s clinical and laboratory data and classified the individual according to the CDC (Fukuda, 1994) criteria. | **Descriptive results of exclusionary diagnosis identified in the telephone interview** Among 1,155 subejcts who had fatigue >6 months, not relieved by rest with >4 of 8 CFS symptoms, 600 had a medical or psychiatric diagnosis. Of 299 subjects without a medical/psychiatric diagnosis who underwent a clinical examination, 43 had CFS, 112 had insufficient symptoms or fatigue, 141 (47.2%) had a medical or psychiatric diagnosis that had not previously been identified and 3 were not classified. |
| Woodward, et al., 199581 | To describe doctors’ and patients’ perspectives on the risks and benefits of symptomatic diagnosis of chronic fatigue syndrome. | N=20 general practitioners (Study 1) and N=50 patients with diagnosis of CFS (Study 2). | **Descriptive results of interviews** 14/20 physicians reluctant to diagnosis CFS (scientific uncertainties about condition, beliefs about appropriate professional practice and uncertainty about impact of diagnosis on patient’s lives). 45/50 patients stated that diagnosis was the single most helpful event over the course of their illness. Described harms from *not* having a diagnosis (fear, anxiety, confusion, self-doubt, bitterness). Subjects in this study did not appear to endorse harm from labeling, but helpful |

**Abbreviations:** CBT= cognitive behavioral therapy; CDC= Centers for Disease Control and Prevention; CFS= chronic fatigue syndrome; DSM-III-R= Diagnostic and Statistical Manual third edition revised; ME= myalgic encephalopathy; n= sample size; vs.= versus