

Stigma in Adults with Fibromyalgia Syndrome: A Comparative Analysis of Perceptions of Invalidation

Carroline Lobo, MS¹; Andrea Pfalzgraf, MPH, PhD²

¹ Graduate School of Public Health, University of Pittsburgh; ² Duquesne University Mylan School of Pharmacy, Pittsburgh, PA

BACKGROUND

- Fibromyalgia (FM) is a pain disorder associated with a variety of symptoms which include fatigue, sleep disturbance, depression, anxiety, cognitive disturbance, muscle stiffness, irritable bowel syndrome and other conditions (1, 2).
- FM patients have reported experiencing distrust, doubt, non-acceptance, rejection, frustration and stigmatization from family, health care providers, workplace, and their other social environment (3-5). These experiences are collectively described as 'invalidation' and measured using the 'Illness Invalidation Inventory' (3*) (3-5).
- The 3*I measures two factors: 'Discounting' and 'Lack of Understanding' (5). Patients may experience 'Discounting' and 'Lack of Understanding' from five sources: spouse/partner, family, health care professionals, workplace, people in social services (5).
- Invalidation of symptom experience in chronic pain patients may lead to distress, frustration, dysfunctional relationships, and withdrawal from society (3, 4, 6).
- According to Howell's model of chronic non-malignant pain, experiences of invalidation in women may result in unmitigated and continuous pain with no motivation among patients to work toward effective symptom management (7). Invalidation of pain may thereby act as a barrier in achieving symptom relief.
- Studies in the past have compared invalidation in FM patients to conditions well-accepted by the medical fraternity and society due to the relative ease in identification, diagnosis and treatment (e.g. rheumatoid arthritis, osteoarthritis, gout, systemic lupus erythematosus etc.). By contrast, most FM symptoms are invisible.
- Migraine is another chronic pain condition analogous to FM in that both disorders are the result of central sensitization and hyperalgesia with mainly invisible symptoms (8-10).
- According to the best knowledge of the researchers, there was no study that compared invalidation in FM to invalidation in migraine.
- The aim of this study, therefore, was to identify and differentiate the experiences of invalidation between two groups of people with chronic pain with inherently invisible symptoms, namely FM and migraine.

METHODS

Study Participants

- This study was approved by the Institutional Review Board at the University of Pittsburgh. An online survey was conducted for a period of two months, from March 1, 2013 to April 30, 2013.
- Due to the non-availability of a well-defined sampling frame, participants were recruited through non-probability based sampling techniques. The surveys were advertised by the following organizations on their respective websites: National Fibromyalgia and Chronic Pain Association, Health Central's Chronic Pain, Pro Health, National Headache Foundation, Migraine.com, and social networking websites. Screening questions were incorporated into the surveys to only allow respondents with FM or migraine to participate. No personal or identifying information was collected in each of these surveys.

Survey Instrument

- For the purpose of this study, two surveys were conducted. One was designed for people with migraine and promoted by organizations specific to migraine. Similarly, the other survey was designed for people with FM and promoted by the FM-specific online support groups.
- Both survey instruments used in this analysis included the following sections:
 - Initial consent and screening: The study objectives, survey participation time, and voluntary nature of the survey were explained. Respondents were asked to provide consent before proceeding through the survey. Those respondents not providing consent were directed to the end of survey. Similarly, respondents under the age of 18 years were screened out of participation. The last screening question asked respondents if they had migraine (Do you suffer from migraine?) or FM (Do you currently have fibromyalgia?). Respondents answering 'No' to the screening question were directed to the end of survey.
 - Demographic questions: Information was collected regarding gender, age, highest level of education, current employment status, duration of symptoms, and time since diagnosis.
 - Standardized assessment measures:
 - Pain Impact Questionnaire-6: This is a six-item validated instrument that quantifies pain experienced during the past four weeks (15). The responses for each of the six items are weighted to produce final pain scores that vary from 40-78, with higher scores indicating greater pain.
 - Patient Health Questionnaire (PHQ-4): This four-item questionnaire yields the PHQ-2 depression screener and the Generalized Anxiety Disorder (GAD)-2 anxiety screener (possible range 0-6 for each); recommended cut-offs of ≥ 3 for both the PHQ-2 and GAD-2 scores were used to identify potential depression and anxiety, respectively (16).
 - Illness Invalidation Inventory: This instrument quantifies experiences of 'Discounting' and 'Lack of Understanding' with respect to five sources: spouse/partner, family, medical professionals, people at work, and people in social services. For responses to invalidation (discounting and lack of understanding) from medical professionals, respondents were asked to provide answers based on their experiences with primary care physicians, medical specialists, physical therapists, and other medical professionals. Similarly, invalidation at workplace was measured with respect to boss and co-workers and invalidation from social services was measured with respect to employer's company physician, work-reintegration or vocational rehabilitation staff, unemployment and other government agencies, organizations for care at home, general government workers and health insurance companies (5). For each source, there are eight items; discounting is the unweighted mean of five items representing disbelief, admonishment, dismissal of poor understanding and acknowledgment of disorder, and not giving a chance to explain patient experiences (5). The three items of the lack of understanding are reverse-scored prior to taking the mean; scores range from 1 to 5, with higher scores representing a greater lack of understanding.

Data Analysis

- The survey data were imported into IBM® SPSS® Statistics, version 22.0 (IBM Corp., Armonk, NY). Descriptive statistics were performed to analyze demographic and other disorder-related characteristics. Independent samples t-tests, chi-square analysis were performed to evaluate the study specific aims. All statistical analyses were conducted at a significance level of 0.05.

RESULTS

Table 1. Comparative analysis of demographic characteristics of survey respondents with fibromyalgia and migraine.

Characteristics	Chronic Pain Diagnosis		p value
	FM, n(%)	Migraine, n(%)	
Gender			
Male	56 (4.15)	68 (6.21)	0.38
Female	1292 (95.85)	1027 (93.79)	
Age			
18 to 21	11 (0.81)	22 (2.01)	<0.01
22 to 34	125 (9.25)	259 (23.63)	
35 to 44	310 (22.93)	363 (33.12)	
45 to 54	428 (31.66)	292 (26.64)	
55 to 64	379 (28.03)	129 (11.77)	
65 or above	99 (7.32)	31 (2.83)	
Marital Status			
Single, never married	153 (11.55)	209 (19.75)	<0.01
Married without children	173 (13.06)	164 (15.50)	
Married with children	634 (47.85)	469 (44.33)	
Divorced	181 (13.66)	100 (9.45)	
Separated	40 (3.02)	22 (2.08)	
Widowed	35 (2.64)	10 (0.95)	
Living w/ partner	109 (8.23)	84 (7.94)	
Employment Status			
Employed, Full Time	285 (21.08)	459 (42.19)	<0.01
Employed, Part time	152 (11.24)	174 (15.99)	
Unemployed	327 (24.19)	237 (21.78)	
Retired, due to age	117 (8.65)	43 (3.95)	
Disability or worker's compensation	471 (34.84)	175 (16.08)	
Highest level of education			
Less than High School	27 (2.00)	12 (1.09)	<0.01
High School / GED	232 (17.16)	109 (9.95)	
Some College	455 (33.65)	262 (23.91)	
2-year College Degree	221 (16.35)	139 (12.68)	
4-year College Degree	256 (18.93)	315 (28.74)	
Masters Degree or above	161 (11.91)	259 (23.63)	

Comparisons were performed using chi-square tests at significance level of 0.05, FM=Fibromyalgia

Table 2. Comparative analysis of mood disorders, pain, discounting and lack of understanding among respondents with fibromyalgia and migraine.

	Chronic Pain Diagnosis		n	Mean	Std. Deviation	Std. Error Mean	p value
	FM	Migraine					
Mood disorders (PHQ-4)	FM	1325	1325	6.50	3.45	0.09	<0.01
	Migraine	1059	1059	4.87	3.41	0.10	
Anxiety (PHQ-2)	FM	1325	1325	3.22	1.94	0.05	<0.01
	Migraine	1059	1059	2.46	1.88	0.06	
Depression (PHQ-2)	FM	1325	1325	3.27	1.88	0.05	<0.01
	Migraine	1059	1059	2.41	1.89	0.06	
Pain (PIQ-6)	FM	1274	1274	69.31	5.23	0.15	<0.01
	Migraine	983	983	64.86	4.89	0.16	
Discounting from family	FM	1295	1295	3.04	1.06	0.03	<0.01
	Migraine	1001	1001	2.67	1.04	0.03	
Lack of understanding from family	FM	1295	1295	3.02	1.01	0.03	<0.01
	Migraine	1001	1001	2.63	1.00	0.03	
Discounting from medical professionals	FM	1300	1300	2.56	1.01	0.03	<0.01
	Migraine	1015	1015	2.20	0.92	0.03	
Lack of understanding from medical professionals	FM	1300	1300	2.61	1.00	0.03	<0.01
	Migraine	1015	1015	2.32	0.97	0.03	
Discounting from spouse	FM	907	907	2.42	1.12	0.04	<0.01
	Migraine	708	708	2.12	1.00	0.04	
Lack of understanding from spouse	FM	907	907	2.32	1.09	0.04	<0.01
	Migraine	708	708	2.01	0.96	0.04	
Discounting from people at work	FM	512	512	3.01	1.09	0.05	0.003
	Migraine	683	683	2.82	1.07	0.04	
Lack of understanding from people at work	FM	512	512	3.31	0.87	0.04	<0.01
	Migraine	683	683	2.91	0.92	0.04	
Discounting from people in social services	FM	512	512	3.01	1.09	0.05	<0.01
	Migraine	451	451	2.75	1.16	0.05	
Lack of understanding from people in social services	FM	586	586	3.43	1.03	0.04	0.095
	Migraine	451	451	3.32	1.01	0.05	

Comparisons were performed using independent samples t-tests at significance level of 0.05. FM=Fibromyalgia, PHQ-2= Patient Health Questionnaire-2, PHQ-4= Patient Health Questionnaire-4, PIQ-6= Pain Impact Questionnaire-6

DISCUSSION & LIMITATIONS

- In this study, the FM group had significantly greater pain and higher ratings on the mood disorders scales.
- Mean discounting and lack of understanding scores were significantly higher for the FM group from all sources except for lack of understanding from social services, where no significant difference was observed. These findings suggest that FM maybe a relatively less accepted condition than migraine.
- The low regard given to FM by health care providers has been demonstrated previously. A study asked general practitioners to rank 38 common medical conditions, based on each condition's prestige within the medical community (1- low prestige to 9-high prestige). FM was the only medical condition to receive an average score below 3 (8). The top ranking conditions were, in descending order: myocardial infarction, leukemia, spleen rupture, brain tumor, pulmonary embolism, testicular cancer, and angina, with scores ranging from 7.2 to 6.5. Unfortunately, migraine was not included in this study.
- Previous literature suggests that FM may have an effect on marital relationships (6). The respondents (both FM and migraine) indicated they experienced less invalidation (discounting and lack of understanding) from their spouse or partners when compared to other sources.
- Both FM and migraine groups reported greater lack of understanding from social service, although no significant difference was observed. The FM group experienced greater discounting from the workplace, while the migraine group experienced greater discounting from social services.
- This study has some limitations. Due to the use of a non-probability based sampling method, the results of this study are more representative of educated women, who were diagnosed with FM or migraine, and who were members of online support groups.
- Furthermore, the data could be susceptible to self-report bias, as the survey respondents could have provided socially desirable responses

The authors would like to acknowledge the contribution of the late Dawn Marcus, MD in disseminating the online surveys used in this study. This study is supported by the CPNP *Defining the Future Research Grant*.
For a list of all references, please contact the primary author: cpl13@pitt.edu.