



American Pain Foundation
A United Voice of Hope and Power over Pain

Insurance Barriers to Fibromyalgia Care: The National Experience

Introduction

APF is committed to reaching out to individuals who live with pain and well aware of barriers to effective pain care than can be attributed to insurance companies' policies, no matter the pain problem. Insurance coverage can have a decisive impact on quality of care, available providers, timeliness, etc. APF chose to reach out to their membership to begin gathering more insight using a targeted pain condition.

From December 8, 2008 through February 27, 2009, three online surveys were conducted to identify whether APF members were affected by restrictive insurance coverage policies that delay effective pain management for fibromyalgia. Two surveys, the Mid Atlantic Fibromyalgia Survey and the National Fibromyalgia Survey were launched by the American Pain Foundation (APF). The National Fibromyalgia Association (NFA) partnered with APF and conducted the National Survey to NFA members. A total of 44,813 electronic invitations were sent. 1,363 people affected by the pain of fibromyalgia participated in these three survey efforts.

- APF Mid-Atlantic Survey: 76 respondents out of 2,677 emails sent (2.84% response rate)
- APF National Survey: 806 respondents out of 38,436 emails sent (2.09% response rate)
- NFA National Survey: 500 respondents out of 3,700 emails sent (7.4% response rate)

Note: APF members represent people affected by a variety of pain conditions, not solely fibromyalgia.

Findings

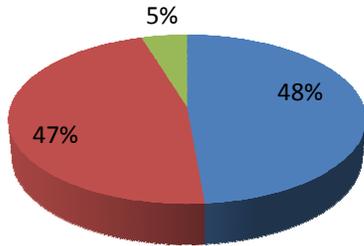
While 96.9% of respondents reported pain related to fibromyalgia, only 92.2% had been diagnosed with fibromyalgia by their healthcare provider. The majority (93.5%) reported that they had some form of insurance coverage.

"Fear of losing coverage is keeping me and my doctor from trying the new medication for fibromyalgia."

"It's the start of a New Year and with that comes paying all of our deductibles"!

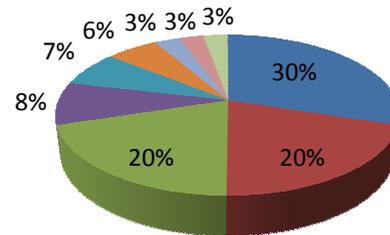
Difficulty with Coverage for Fibromyalgia Pain Treatment

■ Yes ■ No ■ No Response



Health Insurance Plans

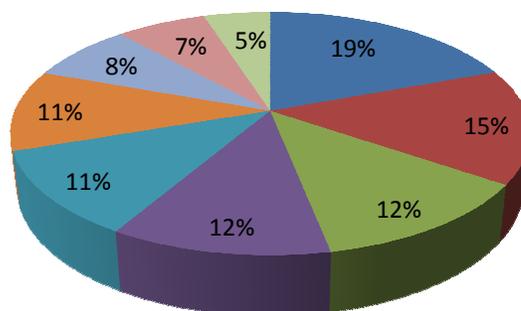
■ Blue Cross/Blue Shield ■ Medicare
 ■ Other ■ United Health Group
 ■ Medicaid ■ Aetna
 ■ VA ■ Kaiser Permanente
 ■ Cigna



"I've been denied by 6 well established insurance companies due to my diagnosis of Fibromyalgia. This situation only adds depression, anxiety, financial hardship, & inability to get needed medication that has helped me in the past."

Problems

■ Incomplete coverage for pain treatment options
 ■ Affordability of co-pays
 ■ Other
 ■ Affordability of premiums
 ■ Delays in pre-authorization process
 ■ Delays in access to FDA-approved medications
 ■ Repetitive denials of covered benefits
 ■ Prolonged appeal process for covered benefits
 ■ No Response



"The doctors do not authorize refills when needed or respond to me so I run out of pain medications for my fibromyalgia and osteoarthritis about 7-10 days before the meds come. I have to make 2-3 calls to get a refill."

Multiple comments about inability to find pain care providers, waiting months to be seen by appropriate providers, recommended medications were not on insurance company drug formulary and poor or non-existent coverage for non-drug therapies, including acupuncture, acupressure, cognitive behavioral therapies, massage therapy, physical therapy, water therapy, chiropractics, vitamins, supplements or special programs for fibromyalgia.

Conclusion

Most respondents with diagnosis of fibromyalgia reported pain. Most of those who participated in the online survey have health insurance, which may be indicative of their economic status. There are common insurance barriers that impede access to pain care for those with fibromyalgia which range to affordability issues to delay in reimbursement or incomplete coverage. While obstacles to appropriate medication management appear to be evident, lack of coverage for non-drug strategies is also reported. Therefore, appropriate and effective multi-modality pain treatment is either delayed or dismantled. These insurance barriers promote undue suffering and untreated, undertreated or inappropriately treated pain. Formal study is warranted.

"Most of my problems were with my insurance company. They had me try all other available medications before approving FDA approved meds."

"My insurance company does not accept the "diagnosis code" for fibromyalgia, so my doctors can't (and won't) correctly code for my treatment."