Two Takes on Fibro: Public Perceptions and Private Realities

Executive Summary
March 2012

For more information visit theACPA.org and FibroTogether.com
The studies were conducted by StrategyOne and fielded by the Harris Interactive Service Bureau. The fibromyalgia sample of respondents was recruited online by Harris Interactive through the company’s proprietary opt-in Chronic Illness Panel. The Chronic Illness Panel was created by screening members of the Harris Poll Online® Panel.

The General Population sample of respondents was recruited online by Harris Interactive through The Harris Poll Online® Panel, which consists of individuals from throughout North America and Western Europe who have double opted-in and voluntarily agreed to participate in various online research studies.
The general public is not fully aware of the realities of living with fibromyalgia

Results from two national surveys comparing the perceptions of people who are living with fibromyalgia to those of the general population reveal striking differences between public perceptions and the private realities of this chronic condition.

92% of the general population has heard of fibromyalgia, but many people in the general public do not fully understand the difficulties people with fibromyalgia experience performing simple everyday tasks, such as driving, sitting for long periods and doing household chores.

HOW FIBROMYALGIA SURVEY RESPONDENTS DESCRIBE IMPACT OF CONDITION

<table>
<thead>
<tr>
<th>Question</th>
<th>% Total Agree</th>
<th>% Total Unsatisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q18: Ability to do the things that I enjoy has been limited</td>
<td>84%</td>
<td>16%</td>
</tr>
<tr>
<td>Q24: Unable to enjoy dancing, sports, or other activities</td>
<td>69%</td>
<td>31%</td>
</tr>
<tr>
<td>Q18: My confidence has been affected</td>
<td>65%</td>
<td>35%</td>
</tr>
<tr>
<td>Q24: I was unable to enjoy gardening, hiking, or hobbies</td>
<td>65%</td>
<td>35%</td>
</tr>
<tr>
<td>Q18: I cannot be spontaneous</td>
<td>55%</td>
<td>45%</td>
</tr>
<tr>
<td>Q19: It’s become more difficult to be physically intimate with my partner</td>
<td>50%</td>
<td>50%</td>
</tr>
<tr>
<td>Q15: Ability to carry out normal routine</td>
<td>67%</td>
<td>33%</td>
</tr>
<tr>
<td>Q15: Ability to take care of others</td>
<td>52%</td>
<td>48%</td>
</tr>
</tbody>
</table>

FM Q18, 19, 24: Please indicate to what extent you agree or disagree with the following statements. Please select one answer for each statement. If a statement does not apply to you, select “Does not apply.” Strongly Agree, Agree, Disagree, Strongly Disagree, Does Not Apply

% Total Agree is a summary of Strongly Agree and Agree.

FM Q15: When you were experiencing symptoms of fibromyalgia that had not yet been diagnosed by a healthcare professional, how satisfied were you with each of the following aspects of your life? Very Satisfied, Satisfied, Unsatisfied, Very Unsatisfied.

% Total Unsatisfied is a summary of the percentages for Unsatisfied and Very Unsatisfied.
One in three people knows someone who has been diagnosed with fibromyalgia, yet they don’t understand the impact of the condition on daily routine.

<table>
<thead>
<tr>
<th>Activity</th>
<th>General Population Total n=1,022</th>
<th>People with Fibromyalgia n=1,215</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keep up with exercise</td>
<td>71%</td>
<td>23%</td>
</tr>
<tr>
<td>Vacuum, do yard work, clean apartment or house</td>
<td>68%</td>
<td>71%</td>
</tr>
<tr>
<td>Lift and carry a bag full of groceries or take out trash</td>
<td>67%</td>
<td>58%</td>
</tr>
<tr>
<td><strong>Walk continuously for 20 minutes</strong></td>
<td><strong>65%</strong></td>
<td><strong>30%</strong></td>
</tr>
<tr>
<td>Climb one flight of stairs</td>
<td>65%</td>
<td>57%</td>
</tr>
<tr>
<td>Change bed sheets</td>
<td>53%</td>
<td>44%</td>
</tr>
<tr>
<td>Shop for groceries or run errands</td>
<td>52%</td>
<td>51%</td>
</tr>
<tr>
<td><strong>Drive a car</strong></td>
<td><strong>41%</strong></td>
<td><strong>61%</strong></td>
</tr>
<tr>
<td>Prepare a meal</td>
<td>40%</td>
<td>33%</td>
</tr>
<tr>
<td>Wash, brush or comb hair</td>
<td>39%</td>
<td>27%</td>
</tr>
<tr>
<td><strong>Watch a movie</strong></td>
<td><strong>18%</strong></td>
<td><strong>75%</strong></td>
</tr>
</tbody>
</table>

GP Q4: Do you know anyone who has been diagnosed with fibromyalgia by a healthcare professional? Please select all that apply.

<table>
<thead>
<tr>
<th>Total</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>33%</td>
<td>30%</td>
<td>35%</td>
</tr>
</tbody>
</table>

GP Q12: Please indicate which of the following activities, if any, you think people with fibromyalgia might find difficult to do. Please select all that apply.

FM Q16: When you were experiencing symptoms of fibromyalgia that had not yet been diagnosed by a healthcare professional, which of the following activities, if any, did you find it difficult to do? Please select all that apply.
One-third of people said fibromyalgia affects older women, but the condition can impact men and young women as well*

<table>
<thead>
<tr>
<th></th>
<th>Total n=1022</th>
<th>Male n=489</th>
<th>Female n=533</th>
</tr>
</thead>
<tbody>
<tr>
<td>Older females</td>
<td>34%</td>
<td>26%</td>
<td>41%</td>
</tr>
<tr>
<td>Younger females</td>
<td>20%</td>
<td>16%</td>
<td>24%</td>
</tr>
<tr>
<td>Older males</td>
<td>16%</td>
<td>18%</td>
<td>13%</td>
</tr>
<tr>
<td>Younger males</td>
<td>8%</td>
<td>9%</td>
<td>6%</td>
</tr>
<tr>
<td>I don’t know</td>
<td>47%</td>
<td>50%</td>
<td>44%</td>
</tr>
</tbody>
</table>

* 271 men with fibromyalgia and 416 young women, 18-34 with fibromyalgia were surveyed

Majority in the general population said they don’t know who fibromyalgia affects

GP Q8: Based on what you know right now, who does fibromyalgia primarily affect? Select all that apply
People with fibromyalgia inaccurately believe the public views them negatively

**People with fibromyalgia are...**

- Courageous: 41%
- Strong: 25%
- Weak: 18%
- Confident: 11%
- Complainers: 9%
- Lazy: 4%
- Other: 34%

**Society views people with fibromyalgia as...**

- Complainers: 66%
- Weak: 57%
- Lazy: 51%
- Courageous: 17%
- Strong: 15%
- Confident: 7%
- Other: 18%

Percentage based on a total of 1,215 fibromyalgia respondents and 1,022 in the general population.
Fibromyalgia prevents many from enjoying key aspects of their lives

"Because of my fibromyalgia symptoms..."

- I was unable to enjoy dancing, sports, or other activities: 69% Total, 68% Male, 74% Female
- I was unable to enjoy gardening, hiking, or hobbies: 65% Total, 67% Male, 64% Female
- I was unable to volunteer or engage in community work: 47% Total, 55% Female
- I missed a loved one's special event: 40% Male, 44% Female
- I missed important events in my children or grandchildren's life: 29% Male, 37% Female
- I put off becoming a parent: 16% Male, 15% Female
- I put off my wedding: 6% Male, 5% Female

FM Sample: 1,215
GP Sample: 1,022

FM Q24: Please indicate to what extent you agree or disagree with the following statements. Please select one answer for each statement. If a statement does not apply to you, select "Does not apply." Strongly Agree, Agree, Disagree, Strongly Disagree, Does Not Apply

% Total Agree is a summary of Strongly Agree and Agree.
People with fibromyalgia find maintaining relationships difficult

<table>
<thead>
<tr>
<th>Statement</th>
<th>% Total Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I spend less time with my friends</td>
<td>60%</td>
</tr>
<tr>
<td>My romantic life has been affected</td>
<td>60%</td>
</tr>
<tr>
<td>I cannot commit to plans</td>
<td>40%</td>
</tr>
<tr>
<td>I do not make plans</td>
<td>20%</td>
</tr>
<tr>
<td>I find it difficult to hug friends &amp; family</td>
<td>80%</td>
</tr>
<tr>
<td>I am apprehensive about entering into a romantic relationship</td>
<td>40%</td>
</tr>
<tr>
<td>I have been unable to make new friends</td>
<td>20%</td>
</tr>
<tr>
<td>I had to end or I lost a relationship</td>
<td>40%</td>
</tr>
<tr>
<td>I no longer have friends</td>
<td>20%</td>
</tr>
<tr>
<td>My marriage has ended</td>
<td>0%</td>
</tr>
</tbody>
</table>

Total Sample: 1,215
GP Sample: 1,022
**Intimacy can be a challenge for men and women with fibromyalgia**

**FM Sample: 1,215**

- **It has become more difficult to be physically intimate with my partner**
  - Total: 50% (Male: 56%, Female: 48%)
  - Male: 33%
  - Female: 32%

- **I am closer to my partner**
  - Total: 33% (Male: 39%, Female: 32%)
  - Male: 32%
  - Female: 31%

- **I am afraid to be more intimate with my partner**
  - Total: 29% (Male: 35%, Female: 28%)
  - Male: 29%
  - Female: 27%

- **I can no longer sleep in the same bed with my partner**
  - Total: 17% (Male: 25%, Female: 15%)
  - Male: 17%
  - Female: 13%

- **I hesitate kissing my partner**
  - Total: 14% (Male: 19%, Female: 13%)
  - Male: 14%
  - Female: 12%

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**FM Q19:** Please indicate to what extent you agree or disagree with the following statements. Please select one answer for each statement. If a statement does not apply to you, select “Does not apply.”

% Total Agree is a summary of Strongly Agree and Agree.
For some with fibromyalgia, just getting through the day can be difficult

```
FM Q23: Please indicate to what extent you agree or disagree with the following statements. Please select one answer for each statement. If a statement does not apply to you, select "Does not apply."
% Total Agree is a summary of Strongly Agree and Agree.

For some with fibromyalgia, just getting through the day can be difficult

- Completing everyday household chores is more difficult
- I had to spend more of my time indoors
- I had to give up a hobby
- I had to talk more on the phone than visit in-person
- I can no longer participate in outdoor activities
- I had to give up a sport
- I had to stop my leisure travels

"Because of my fibromyalgia symptoms..."

FM Sample: 1,215
GP Sample: 1,022
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The public believes people with fibromyalgia find it more difficult to participate in certain parenting activities

**Fibromyalgia respondents reported differently**

<table>
<thead>
<tr>
<th>Activity</th>
<th>General Population (n=1022)</th>
<th>Fibromyalgia Parents &amp; Grandparents (n=656)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lift their child or grandchild</td>
<td>75%</td>
<td>45%</td>
</tr>
<tr>
<td>Feed or dress their child or grandchild</td>
<td>49%</td>
<td>16%</td>
</tr>
<tr>
<td>Attend their child’s or grandchild’s school or sports event</td>
<td>40%</td>
<td>32%</td>
</tr>
<tr>
<td>Help their child or grandchild with homework</td>
<td>22%</td>
<td>18%</td>
</tr>
</tbody>
</table>

GP Q12: Please indicate which of the following activities, if any, you think people with fibromyalgia might find difficult to do. Please select all that apply.

FM Q16: When you were experiencing symptoms of fibromyalgia that had not yet been diagnosed by a healthcare professional, which of the following activities, if any, did you find it difficult to do? Please select all that apply.
Men, more so than women, feel the impact of fibromyalgia at work

"Because of my fibromyalgia symptoms..."

- I had difficulty completing tasks
- My work life or career has become more difficult
- I had to take more sick & personal days
- My personal income has decreased
- I could not work a full shift or complete a work day
- I am less productive at work
- I did not apply for a new job
- I had difficulty keeping a steady job
- I had to claim disability insurance
- I am no longer physically comfortable going to after-work gatherings
- I had to change to a less demanding job
- I had difficulty completing my academic studies
- I had to change careers
- I did not receive a promotion

FM Sample: 1,215
For many, including young women, fibromyalgia interferes with careers

**BECAUSE OF MY FIBROMYALGIA SYMPTOMS...**

<table>
<thead>
<tr>
<th>% total agree</th>
<th>Young Women - 18-34 (n=416)</th>
<th>Total (n=1215)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I had difficulty completing tasks</td>
<td>68%</td>
<td>70%</td>
</tr>
<tr>
<td>My work life or career has become more difficult</td>
<td>62%</td>
<td>61%</td>
</tr>
<tr>
<td>I had to take more sick and personal days</td>
<td><strong>67%</strong></td>
<td><strong>60%</strong></td>
</tr>
<tr>
<td>My personal income has decreased</td>
<td>44%</td>
<td>56%</td>
</tr>
<tr>
<td>I could not work a full shift or complete a work day</td>
<td>46%</td>
<td>48%</td>
</tr>
<tr>
<td>I am less productive at work</td>
<td><strong>50%</strong></td>
<td><strong>44%</strong></td>
</tr>
<tr>
<td>I did not apply for a new job</td>
<td>37%</td>
<td>40%</td>
</tr>
<tr>
<td>I had difficulty keeping a steady job</td>
<td>37%</td>
<td>38%</td>
</tr>
<tr>
<td>I had to claim disability insurance</td>
<td>22%</td>
<td>36%</td>
</tr>
<tr>
<td>I am no longer physically comfortable going to after-work gatherings</td>
<td>36%</td>
<td>35%</td>
</tr>
<tr>
<td>I had to change to a less demanding job</td>
<td>33%</td>
<td>35%</td>
</tr>
<tr>
<td>I had difficulty completing my academic studies</td>
<td><strong>52%</strong></td>
<td><strong>34%</strong></td>
</tr>
<tr>
<td>I had to change careers</td>
<td>28%</td>
<td>32%</td>
</tr>
</tbody>
</table>

FM Q22: Please indicate to what extent you agree or disagree with the following statements. Please select one answer for each statement. If a statement does not apply to you, select “Does not apply.” Strongly Agree, Agree, Disagree, Strongly Disagree

% Total Agree is a summary of Strongly Agree and Agree.
Unbearable symptoms are the primary motivator for seeking help

- **The symptoms were unbearable**: 36%
- **I was afraid there was something really wrong with me**: 22%
- **I wanted to get back to my daily routine/become active again**: 12%
- **The symptoms caused me to lose my job or stop working**: 4%
- **Someone recommended I get help**: 5%
- **I read about fibromyalgia**: 5%
- **I met someone else with fibromyalgia**: 4%
- **I saw advertisements for a fibromyalgia treatment**: 1%
- **A friend on a social network discussed fibromyalgia**: 1%
- **I came across an online community focus on fibromyalgia**: 1%
- **Someone close to me did not want to hear me talk about my symptoms anymore**: 1%
- **I wanted to become a parent**: 0%
- **Other**: 9%

**FM Sample: 1,215**

FM Q27: What motivated you to seek help for your fibromyalgia symptoms? Please select only one response.
People with fibromyalgia tolerated their pain and delayed seeking help significantly longer than the public would.

**FIBROMYALGIA**

How long symptoms of fibromyalgia existed before seeking help from HCP

- Less than 1 year: 3%
- 1-3 years: 2%
- 4-6 years: 3%
- 7-9 years: 4%
- 10-11 years: 3%
- 12-14 years: 2%
- More than 16 years: 4%
- I don't know: 3%

**GENERAL POPULATION**

How long pain would be tolerated before seeking help from HCP

- A year or more: 4%
- More than one month: 2%
- More than one week: 3%
- 6-7 days: 3%
- 4-5 days: 2%
- 2-3 days: 3%
- 1 day: 3%
- No time: 4%
- I would not seek help: 2%

FM Q7: How long did you have symptoms of fibromyalgia before seeking help from a healthcare professional? Please round to the nearest year. Select one

GP Q25: How much time would you allow yourself to be in pain before you seek help from a healthcare professional? Select one

Total may not equal 100% due to rounding.