



MASSACHUSETTS PAIN INITIATIVE **PAIN SURVEY EXECUTIVE SUMMARY**

This survey was commissioned by the Massachusetts Pain Initiative (MassPI) to identify the amount of pain experienced by Massachusetts residents and the impact of that pain. An additional major objective of this research was to quantitatively assess how minorities in Massachusetts experience pain versus the non-minority population.

INTRODUCTION:

Chronic pain is a major healthcare problem not just in Massachusetts, but in the entire country. The Massachusetts Pain Initiative was interested in discovering: how many people experience chronic pain; what ways do they find relief from pain; how have they accessed care; ways pain has impacted their lives; perceptions about pain and pain management as well as the role that health insurance plays in managing chronic pain effectively. The Massachusetts Pain Initiative was also interested in identifying key differences between segments of the population, specifically minorities and non-minorities.

METHODOLOGY:

Fisher College, in conjunction with Strategic Opinion Research, Inc., conducted a telephone survey with people experiencing chronic pain. People were screened for their chronic pain by answering our initial question, “*Within the last two years, have you or anyone in your immediate family experienced pain on a fairly regular basis for at least three months*”. If they answered yes, the interviewer asked to talk to the person with the pain. If the person was not available, a callback time was arranged. Since previous studies have shown that minorities experience with pain is distinct from that of non-minorities, we decided to examine the minority/non-minority populations closely. As a result, we conducted two major components of this study: 1) a 500 sample representing the general population of Massachusetts adults living with chronic pain as defined above; and 2) an additional 100 interviews with minorities who suffer chronic pain to ensure there was a large enough sample for detailed statistical analysis across multiple dimensions.

We used a random digit dial protocol for our general population sample and screened for pain with an initial screening question. In order to compare the sub-groups of minorities and non-minorities, we needed to oversample minorities by conducting the additional interviews with minorities who suffer chronic pain. To aid in the efficiency of data collection for the oversample, we pulled numbers from areas that had high concentrations of minorities based on census tract information. For the oversample, people were screened for minority status and chronic pain status. During the interviewing process, the general population data set was kept separate from the oversample.

The “All” as identified in the reporting of the marginal results refers to the 500 general population sample. This sample was also used to create the base cross-tabs, segmenting the pain population by key demographic and geographic sub-groupings. In this 500 general population survey, we yielded 55 self identified minorities. In order to compare minorities and non-minorities, the minorities from the general population sample were added to the oversample which resulted in a sub-grouping of minorities of $n=152$. This allowed us to compare non-minorities with minorities. Data analysis was done looking at the data in two distinct ways: 1) the general pain population ($n=502$), and 2) comparing minorities ($n=152$) with non-minorities ($n=431$). Our incidence rate among the general sample was 24%, and for the minority population, our incidence rate was 42%.

Interviewing was conducted using a professional interviewing facility where all calls were made from a centrally located and monitored phone bank that adheres to stringent quality control standards. Interviewing took place from February 3rd to February 12th. The margin of error for the general population sample was +/- 4% at the 95% confidence level. All comparative data was analyzed using a standard two-tailed t-test and a 95% confidence level.

This study is not directly comparable to previously conducted studies, whether in Massachusetts or elsewhere in the country, due to differences in study methodologies, target respondents, and the specific questions asked.

MAJOR FINDINGS

General Population Data

- Chronic pain is a significant problem in Massachusetts – this includes untreated pain and undertreated pain.
- People with chronic pain report living with high levels of pain much of the time.
- A substantial number of people living with persistent pain have sought medical care for their pain in an emergency room, the most expensive form of care.
- Most of the respondents’ pain had been diagnosed, but this did not result in receiving adequate pain relief as evidenced by the high reported pain scores.
- People living with chronic pain report that it has a significant negative effect on their quality of life, some report that it affects their relationships with family and friends, and most indicate that it interferes with their work productivity.
- Respondents rely predominantly on their primary care providers for pain care, although a substantial number also use other medical specialists, including some pain specialists.
- Chronic pain sufferers have tried several different types of pain therapies, including exercise, physical therapy, medications, and several types of complementary therapies such as massage, chiropractor, relaxation, etc.

Minority Data

- Chronic pain among minorities surveyed is a substantially larger problem than among non-minorities and there are many disparities in the care they receive.
- More minorities suffer from chronic pain, their pain is significantly more severe, they are less likely to have had their pain diagnosed by their health care provider, they are much more likely to have sought treatment for their pain from an emergency room, and they are more pessimistic about finding relief from their pain.
- Minorities reported that chronic pain had just as significant negative effects on their quality of life and work productivity as reported by non-minorities.
- Minorities were much more likely to report not getting the treatment they needed for their pain due to not being able to afford it – this is consistent with minority pain respondents reporting significantly lower annual household income than non-minorities.
- Economic issues are reflected across many aspects of minorities' attempts to find pain relief – they are much less likely to rely on specialists for their primary pain care, they tend to use treatment approaches that are covered by insurance or are no/low cost (e.g., prescription pain medications, prayer, support groups), while relying less on potentially beneficial treatment therapies that are not covered by insurance (e.g., physical therapy, relaxation, massage), and they are considerably more likely not to have had health insurance in the past and some still report not currently having insurance.
- Even when minorities have health insurance, they are significantly less likely to believe they are covered for key items related to their pain care, particularly routine and advanced diagnostic testing.

DETAILED RESULTS:

The only comparative data reported in this Executive Summary is statistically significant at the 95% level of confidence, unless otherwise noted. Given the substantial study sample sizes, all of the comparative data reported here (minorities vs. non-minorities, and gender, income, and age demographic subsets) are statistically significant. Non-significant trend data is not reported unless specifically noted.

Incidence of Chronic Pain

Chronic pain is a significant issue in Massachusetts. Approximately 24% of the Massachusetts general population experiences chronic pain. That is to say, within the last two years, they have experienced pain on a regular basis for at least three months. Among minorities, the incidence of chronic pain increases to 42%.

Severity of Pain

Not only does a large percent of the Massachusetts population experience chronic pain, the severity of the pain is also striking, with more than three quarters (77%) rating their pain as a 5 or higher on a 0-10 scale. Almost half of the respondents (48%) reported their pain was severe with a rating of 7 or higher, and ten percent rated their pain a 10—the worst imaginable pain.

- Significantly more minorities rated their pain as severe, with 60% assessing their pain a 7 or above compared to 45% for non-minorities. Minorities reported pain skewed even more significantly to the most severe levels of pain with 43% reporting pain at an 8 or greater compared to only 28% for non-minorities.
- The average reported pain rating of 7 for minorities exceeded the average pain rating of 6 for non-minorities.

Diagnosed Pain

Nearly nine out of every ten respondents (86%) said that their pain had been diagnosed.

- However, nearly thirty percent (28%) of all minorities interviewed reported that they did not have a diagnosis for their pain.
 - ♦ Minorities were more than twice as likely as non-minorities to say that the cause of their pain had *not* been diagnosed by their health care provider (only 11% undiagnosed pain for non-minorities).
- Health insurance status, having private health insurance, MassHealth or no insurance within the past five years, does not seem to play a role in whether or not pain has been diagnosed.

The most common diagnosed pain was arthritis (29%) followed by back pain (21%).

- Arthritis was more likely to be reported by respondents over the age of 55 compared to those under 55 (34% vs. 19%).
- Back pain was more of a problem for lower income respondents with 28% of those with incomes below \$25,000 reporting having back pain compared to just 16% of those with incomes above \$75,000.

Pain Management

The majority of respondents (56%) say that they typically wait a couple of days before going to the doctor in hopes that the pain will go away on its own. However, a large percent, nearly a third (29%) admit to trying to avoid going to the doctor and often times wait until it's an emergency situation.

Emergency Room Utilization

Within the last two years, pain has forced nearly one in three respondents (31%) to go to the emergency room.

- Interestingly, older respondents were less likely to use the emergency room (24% of those over 70 compared with 30% of those between 55-70 and 39% of those under 55 years old).
- 47% of minorities have ended up in the emergency room in the last two years, compared to 29% of the non-minorities.

Health insurance coverage seems to play a role in emergency room utilization.

- 50% of those who have been without health insurance in the last five years have used the emergency room, compared to 30% of those who have had health insurance for the past five years.

Impact of Pain on Quality of Life and Productivity

Nearly three quarters of respondents, including minorities and non-minorities alike, reported that their pain has negatively impacted their quality of life and interferes with their productivity.

- 78% say that their pain has interfered with their sleep.
- 73% say that their pain causes them to feel anxious, irritable or depressed.
- 68% say that their pain interferes with their ability to do everyday things such as driving a car, walking, grocery shopping or cooking.
- 73% say their pain has interfered with their ability to work productively.

Although not as pervasive an effect on quality of life as the measures discussed above, a sizeable minority of people living with chronic pain reported affecting their personal relationships.

- 37% reported they were reluctant to talk about their pain with family and friends.
 - ◆ This was most significantly experienced by those with incomes below \$25,000 (43% compare to 23% for those with incomes above \$75,000).
- 27% felt their pain had negatively affected their relationships with loved ones and friends
 - ◆ This was most often reported by those younger than 55 (37% versus 17% for those older than 70).

It is interesting to note that elderly respondents (over 70 years old) were less likely to report their pain negatively impacting their quality of life across most dimensions, were more likely to report having their pain diagnosed (93%), and were less likely to end up in the emergency room than younger respondents.

Role of the Primary Care Provider

Most people suffering chronic pain have strong relationships with their primary care providers.

- More than half (60%) say that they depend most on their primary care provider for the management of their care, with minorities and the elderly (over 70 years old) most dependant on their primary care provider.
 - ◆ 76% for minorities compared to 58% for non-minorities
 - ◆ 67% for those over 70 years old compared to 55% for those under 55 years old and 56% for 55 – 70 years old
- 89% have tried using a primary care provider to manage their pain, but only four out of every ten have found the primary care provider to be very helpful.
- Eight out of ten do not believe that their pain has been taken less seriously because of their age, gender or race.
 - ◆ Respondents over 70 years old, compared to their younger counterparts, were more likely to believe that their pain has been taken less seriously (25% compared to 15% of those under 55 years old).
 - ◆ Women were more likely than men (23% vs. 15%) to believe that their pain has been taken less seriously.
 - ◆ There were no significant differences between minorities and non-minorities.
- The desire to be a good patient sometimes inhibits pain sufferers from fully communicating the extent of their pain.
 - ◆ 37% agreed with the statement “I don’t complain about my pain too much because I don’t want to bother my health care provider.”
 - Lower income pain sufferers were more likely to agree. 42% of those with incomes less than \$25K agreed, versus just 28% with incomes above \$75K.
 - Minorities were almost twice as likely to “strongly agree” with this statement as non-minorities (15% compared to 8%).
 - Women agreed nearly three times as often as men (11% compare to 4%).

Role of Specialists

Medical and pain specialists provide the primary pain care for one-quarter (26%) of those with chronic pain

- 19% of people with chronic pain depend primarily on medical specialists (e.g., a rheumatologist, neurologist, orthopedist, oncologist, etc.) to manage their pain.
- Only 7% of chronic pain respondents report depending primarily on a pain specialist.
- Non-minorities are more than 3 times as likely as minorities to report receiving their primary pain care from a medical or a pain specialist (30% compared to 9%).

Interestingly, more people with persistent pain report depending primarily on themselves for their pain care (8%) than depend on a pain specialist (7%).

Methods Used To Relieve Pain

The most common ways respondents have tried to relieve their pain are: primary care providers (89%); exercise (83%); over the counter medications (83%); prescription medications (67%); physical therapy (60%) and prayer (60%).

- Minorities were just as likely to have tried using primary care providers to treat their pain (88% versus 90% of non-minorities), but they were much more likely to depend on them for care (76% versus 60% of non-minorities), less likely to have had their pain diagnosed, and they have higher emergency room utilization rates.
- Minorities are more likely than non-minorities to rely on prescription drug medications (77% vs. 67%) and prayer (78% vs. 59%).
- Minorities are much less likely to have tried physical therapy (48%) compared to non-minorities (63%).

While over-the-counter (OTC) pain medications have been tried by a large percent of respondents (83%), just 19% found them to be very helpful compared to prescription pain medications tried by far fewer (67%), but credited with being very helpful to the majority of respondents (34%).

- Over-the-counter and prescription pain medications represented the least and most effective pain therapies, respectively, of the treatment approaches evaluated.

Use of Medications

About a quarter of all respondents take over-the-counter and prescription pain medications on a regular basis to manage their pain.

- One third of the minorities (35%) take prescription pain medications on a regular basis compared to 23% of non-minorities. Minorities are no more likely to take over-the-counter medications on a regular basis (20% vs. 23% of non-minorities).
- While minorities are more likely to take prescription medications, they also are more likely to agree that many people taking prescription pain medications become addicted (73% vs. 60% of non-minorities).

Few (4%) have reported problems finding pharmacies to fill their prescriptions for pain medication and this is consistent among all demographic groups.

- Note: This data is not consistent with multiple previous studies in other urban centers. However, this study's methodology was significantly different, making any comparisons of the data impossible. Further, this study did not ask chronic pain respondents what specific prescription pain medications they used, which could have a significant impact on the availability of those medications.

Attitudes Towards Pain

While more than half (58%) believe that uncontrollable pain is an unavoidable part of many serious illnesses such as cancer, most remain optimistic. Minorities and respondents with lower incomes are less optimistic. Minorities had much higher representation in the less than \$25K income level (39% versus 20% for non-minorities) and much less representation in the high income levels above \$75K (6% versus 28% for non-minorities).

- Overall, just 20% agree with the statement, “I have given up on trying to find relief from my pain.”
 - ◆ 27% of the minorities agree compared to 19% of non-minorities.
 - ◆ 28% of those with incomes under \$25K agree compared to just 14% with incomes above \$75K.
- Almost 30% agree that there is not much that can be done to relieve most pain.
 - ◆ 40% of minorities compared to 26% non-minorities agreed.
 - ◆ 39% of those with incomes under \$25K agree, compared to only 14% with incomes above \$75K.
- Minorities were twice as likely to feel they did not get the treatment for pain that they needed since they could not afford it (33% of minorities experienced this versus 16% of non-minorities)
- Similarities between minority and income data for some dimensions are not surprising given the minority income distribution disparities discussed in the previous section.

Health Insurance

While nearly everyone (97%) of our general population currently has health insurance, differences in coverage exist, and there were even greater differences in the past.

- Minorities were less likely to have health insurance (9% vs. 2% of non-minorities).
- Among minorities who do have health insurance, 44% have MassHealth compared to just 14% of the non-minority population.
- Minorities are more likely than non-minorities to report lack of adequate health insurance coverage for preventative care (87% vs. 76% non-minorities), sick visits (88% vs. 78%), routine (94% vs. 80%) and advanced diagnostic testing (88% vs. 74%).

CONCLUSION:

There is a significant level of undertreated pain in Massachusetts, and this is even more dramatic among the minority population. In this study, almost 1 in 4 Massachusetts adults report substantial chronic pain over an extended period of time (>3 months).

While most respondents feel they have had their chronic pain diagnosed, few are finding relief from their pain, with a majority rating their pain a 7 or more. Nearly a third of respondents have ended up in the emergency room because of their pain, clear evidence that their pain is not being managed effectively. These findings are even more pronounced among minorities, where pain affects more people and the level of pain is even more severe. Finally, most chronic pain sufferers admit that their pain has a substantial negative impact on the quality of their daily lives, and importantly from the perspective of society, pain can negatively affect their work productivity.

The good news is that most, including minorities, have formed positive relationships with their primary care providers. However, it is notable that these positive relationships did not result in better pain diagnosis (for minorities) or adequate pain relief for either the general population or for minorities as evidenced by their high reported ongoing pain levels.

The key difference around pain between minorities and non-minorities seems to revolve around economic issues, which impacts access. Minorities and lower income respondents are less likely to have had their pain diagnosed, are more likely to have been in the emergency room and are less likely to have health insurance. Even those minorities with health insurance report believing they have less adequate coverage than is reported by non-minorities.