

Chronic pain: public understanding of a public health crisis

Gregory Carbonetti¹, Ruobing Li², Christopher Volpe³ and Laura Lindenfeld^{1,2}

¹School of Communication & Journalism, State University of New York at Stony Brook, Stony Brook, NY, USA; Alan Alda Center for Communicating Science, State University of New York at Stony Brook, Stony Brook, NY, USA.

²School of Communication & Journalism, State University of New York at Stony Brook, Stony Brook, NY, USA.

³ScienceCounts, ScienceCounts Inc., Washington, DC, USA.

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Executive Summary

This report summarizes the key findings from a nationally representative survey (and associated focus groups) exploring the current American public's perception and opinions of chronic pain.

The goals of this study were to:

- 1) Acquire new insights regarding the American public's understanding of chronic pain.
- 2) Assess the American public's attitudes concerning chronic pain management and their personal experience of pain.
- 3) Learn about the American public's willingness to support chronic pain research and organizations that assist those in pain.
- 4) Determine ways to more effectively activate the American public to engage with the issues of chronic pain using narratives and test messages.

Key findings

Raise awareness and visibility of chronic pain – this is the first step to public engagement and will make those with pain feel less isolated.

Chronic pain is a relatable condition, and the pain-free public expresses a lot of empathy, however, it is not a top tier health concern. Connections to loss of productivity, quality of life and depression are the most top-of-mind impacts of chronic pain for the pain-free public and they respond to statistics about the prevalence of the problem.

Use expert voices to help make the case that existing options are not sufficient, and more research/new treatments are needed – this element helps create a sense of need around the issue.

Public attitudes are more complex below the surface and reveal judgements about causes, treatments and whether people in chronic pain “do enough” to manage their pain. Some of these judgements are also shared by those in pain themselves. The issue of chronic pain does not need a further sympathy push – it needs a push toward greater understanding that management or effective treatment can be elusive.

Rebrand chronic pain to “unresolved pain” or “persistent pain” to create more urgency and help undermine existing assumptions or judgements about those in pain.

The language around chronic pain needs to be changed. Words like “persistent” and “unresolved” show promise in moving the image away from a “chronic” condition that should be manageable with treatment and lifestyle changes.

Do not focus on convincing people that pain can happen without a cause or underlying condition – it’s a harder conversation to have and not necessary to create interest in engagement.

Belief that pain can happen without a cause or without an underlying condition is not necessary for empathy and engagement. Regardless of the protagonist or narrative, talking about pain without a solution increases the sense of urgency around finding new solutions for pain treatment and management.

Increase training, knowledge and access to specialists in pain treatment and management among the medical community with the goal of giving patients a better, more personalized care experience.

Both people in chronic pain and the pain-free public agree that the current healthcare system does not provide an experience in which patients feel options are explored or concerns heard. When discussing treatment, the idea of “personalized medicine” is appealing, especially for those in pain. It speaks to the idea that people experience pain differently and need a collaborative approach to find a solution.

Change the approach to prescribing options that include more conversation about benefits, risks and expectations to give patients greater confidence, agency and buy-in to available treatments.

There is a gulf between acceptable treatments and perceptions of efficacy. The conversation around opioids is especially fraught for both people in pain and the pain-free public. Current options appear as a laundry list of things to try rather than a set of options that patients fully understand or buy-in to. Medical professionals could do a better job talking about options with people in pain. There needs to be time to talk through benefits, risks and questions, as well as to manage expectations about the experience of treatment along with consideration of how and when treatments work.

“Frontline fighters” and “pain-free populists” are two groups that may be ready to be activated to engage with the issues of chronic pain.

Nearly half of all caregivers who responded to our survey are people who experience chronic pain themselves and have a unique perspective on pain. This demographic, coupled with younger people in chronic pain, form a group we call “frontline fighters” and possess important traits that make them potential candidates to activate the pain audience. They are younger, possess a greater sense of urgency regarding pain and are the most willing to engage on the issues. In terms of activating the broader public, we identified a group we call “pain-free populists” that appear primed to engage on the issues. This group consists of those who are already giving to health-related causes and are more health conscious themselves, possesses the ability to empathize more with the impacts and nuances of chronic pain and does not tend to “blame the victim” like other segments.

Introduction

Chronic pain (defined as persistent or recurrent pain lasting longer than three months) is a public health crisis that affects nearly one-third of American adults and is more prevalent than diabetes, coronary heart disease, stroke and cancer combined¹. Chronic pain can be caused by a variety of traumas, injuries and medical conditions and can even present in the absence of a distinct visceral cause. In addition to the physical challenges of living with chronic pain, these individuals who experience chronic pain are increasingly susceptible to a myriad of comorbidities that both exacerbate the pain condition and impede recovery^{1,2}. For example, people in chronic pain suffer from significantly elevated levels of depression, anxiety, hypertension and high cholesterol¹.

Clinically, chronic pain is difficult to manage and there exist significant equity issues; women are treated less aggressively than men³, racial and ethnic minorities are less likely to receive appropriate treatment in comparison to their white counterparts⁴, and older, poorer and less-educated people are disproportionately affected⁵.

Chronic pain also presents a massive economic burden. The combined expenditure of direct medical costs, lost wages, lower worker productivity and absenteeism costs the United States national economy an estimated \$635 billion a year⁶. All of these issues are further compounded by the ongoing opioid epidemic, which claimed approximately 450,000 lives over the last two decades and negatively stigmatized people who utilize prescription pain medication⁷.

Despite the magnitude of the chronic pain crisis, basic science/clinical research funding, institutional scrutiny and public engagement have not risen commensurately. In 2018, NIH funding for common conditions included ~\$6.6 billion for cancer, ~\$1.5 billion for heart disease, ~\$1.2 billion for diabetes and only ~\$500 million for pain⁸. Additionally, there exist institutional, bureaucratic and organizational challenges that impede progress. Chronic pain researchers do not possess a dedicated NIH institute, only recently formed a comprehensive domestic scientific society (the United States Association for the Study of Pain) and seek private support from a

plethora of decentralized philanthropies and organizations that do not efficiently leverage their potential collaborative strength.

Underscoring all of these problems is the greater public understanding and discourse regarding chronic pain itself. Chronic pain is, “invisible,” and those who suffer can struggle to show and/or effectively convey to clinicians and the general public the debilitating consequences of their lived experiences. Resolving the chronic pain crisis will require new and innovative treatments that arise through a commitment to research and institutional changes, however, this necessitates the type of public support that will only manifest through a transformation of the current public discourse related to pain.

At this moment in time, there is a lack of understanding about the public’s perception and opinions of chronic pain. This lack of knowledge impedes the ability to develop, test and assess science communication strategies based on their ability to increase chronic pain awareness, engagement and advocacy among the American public. The objective of the following study was to acquire new insights regarding the current public’s understanding of chronic pain, their personal experience of pain, their attitudes concerning chronic pain management and their willingness to support organizations that assist those living with chronic pain. Additionally, we sought to understand how to more effectively activate the public around pain and identify targets for future research through the use of chronic pain narratives and test messages. To accomplish these goals, we utilized two exploratory focus groups (to inform the composition and language of our survey), a nationally representative survey (to acquire quantitative data) and two follow-up focus groups (to gather further qualitative data).

Gaining a more nuanced understanding of the current American public’s perception and opinion of chronic pain is necessary to inform the development of the scientific communication strategies that will transform the current public discourse related to pain. This is a necessary step toward ameliorating the biopsychosocial aspects of chronic pain that have led to immense physical/psychological consequences for those who suffer and begin to mobilize support (and nurture existing support) for the necessity of increased research and resources for people affected by chronic pain in the United States.

Study Methods and Administration

Prior to the initiation of this study, we conducted a thorough landscape evaluation to assess current and previous communication strategies used to shape the public discourse regarding chronic pain. This was accomplished through an extensive literature review coupled with semi-structured interviews conducted with 38 different key opinion leaders, researchers, clinicians and advocates in the chronic pain field.

Once we completed this landscape evaluation, we initiated a collaboration with Edge Research (a leading marketing research firm in the United States) to assist us with the development of research instrumentation and data collection. Working with Edge Research, we conducted two exploratory focus groups to inform the composition and language of our survey on January 27th and January 28th, 2021. The first group consisted of seven people with chronic pain and the second group consisted of seven pain-free individuals (and not caregivers of those in pain). These focus groups were recruited to include a mix of participants across: gender, age, race/ethnicity, employment, health status, geographic location, household income and education level.

The nationally representative survey was fielded from March 16th through March 30th, 2021, and reached 1,564 American adults, including: 389 self-reported people in chronic pain, 1,062 pain-free adults and 224 caregivers (111 who suffer from chronic pain and 113 who are pain-free). A blended online and mobile sample methodology was used. 1,281 completed surveys were obtained from *Paradigm* (an online research panel developed and maintained through online intercepts), social networks such as Facebook, exclusive partnerships and offline techniques for audiences with lower digital penetration. All recruits went through a double opt-in process in order to join the panel. 283 completed surveys were obtained through TapResearch (a sample provider that embeds surveys into mobile apps that respondents use), reaching a diverse sample of people who cannot be reached through other methods.

Sample invitations to the survey were controlled to replicate census distributions for demographics characteristics of the population 18 and older. Additional quotas were put in place

for age, gender, region, race and ethnicity to adjust for variable response rates and estimated completion rates for particular demographics. The final data were weighted to correct proportions of men and women within the age groups of 18-34, 35-54 and 55 and older. Weights were also applied to correct the proportion of Black/African-American respondents and White-only respondents in the sample. The method for weighting was iterative proportional fitting, also called raking. A set of variables where the population distribution is known is selected and then the procedure iteratively adjusts the weight for each sample case until the sample distribution aligns with the population for those variables.

Two follow-up focus groups to gather further qualitative data to augment our survey were fielded on May 19th, 2021. The first group consisted of seven, “frontline fighters,” or people in chronic pain and primary caregivers and the second group consisted of seven, “pain-free populists,” or pain-free adults who empathize more with the impacts and nuances of chronic pain. These focus groups were once again recruited to include a mix of participants across: gender, age, race/ethnicity, employment, health status, geographic location, household income and education level.

Institutional review board approval for this nontraditional market research study was unnecessary as all information for individual subjects was coded. At no time did any of this study’s investigators obtain, receive or possess any identifiable private information.

Data Analysis

Statistically significant differences between subgroups of the whole sample are reported at the 95% confidence level. Statistical significance was determined using the z-test. Z-test is a univariate test based on the standard normal distribution and is used in order to determine whether two samples means calculated are different in cases where the standard deviation is available and sample is large.

Study Limitations

As with any study that utilizes survey instrumentation, there are limitations to the data collected. Survey results are generalizable but lack the depth to fully explain the meaning behind the responses. Open-ended questions provide supplementary detail, but additional literature analyses, focus-groups and interviews were needed to complement this data. Additionally, only adults (18+ years old) participated in this study and therefore our findings do not capture the perception or opinions of children experiencing chronic pain.

Results

Description of participants

An unweighted base total of 1,564 respondents participated in this survey and was comprised of 389 people in chronic pain (self-reported as having experienced or been diagnosed this past year and for greater than at least three months) and 1,175 pain-free people. Upon weighting this base total, they form a nationally representative sample of the continental United States accounting for gender, age, race/ethnicity, social ideology, geographic region, area type, household income and education level.

Gender and age

Group	Gender		Age		
	Male	Female	18-34	35-54	55+
Chronic Pain	42%	58%	14%	37%	48%
Pain-Free	51%	49%	35%	32%	34%
Gen. Pop.	49%	51%	30%	32%	37%

Bold green/red indicates significantly higher/lower values at a 95% confidence interval.

Percentages represent the weighted base total of respondents.

Race/ethnicity and social ideology

Group	Race/Ethnicity			Social Ideology		
	Black	Latinx	White	Conservative	Moderate	Liberal
Chronic Pain	10%	16%	69%	27%	28%	39%
Pain-Free	16%	20%	57%	30%	32%	33%
Gen. Pop.	14%	19%	58%	30%	31%	32%

Bold green/red indicates significantly higher/lower values at a 95% confidence interval.

Percentages represent the weighted base total of respondents.

Geographic region and area type

Group	Region				Area Type		
	Midwest	Northeast	South	West	Urban	Suburban	Small Town / Rural
Chronic Pain	22%	15%	40%	23%	27%	46%	26%
Pain-Free	21%	18%	38%	23%	30%	50%	21%
Gen. Pop.	21%	17%	39%	23%	29%	49%	22%

Percentages represent the weighted base total of respondents.

Household income and education level

Group	Household Income			Education			
	< \$40K	\$40K - \$100K	> \$100K	HS or Less	Some College / Vocational	College Degree	Postgrad
Chronic Pain	47%	42%	11%	27%	40%	21%	12%
Pain-Free	40%	41%	16%	25%	33%	26%	16%
Gen. Pop.	41%	41%	14%	25%	35%	25%	15%

Bold green/red indicates significantly higher/lower values at a 95% confidence interval.

Percentages represent the weighted base total of respondents.

Based upon our survey findings, chronic pain affects approximately 25% of adults in the United States (~50.2 million) and those currently suffering with chronic pain are most likely to be older (55+) and poorer (household income < \$40K) white females (69% and 58%, respectively).

Another demographic we were keen to explore was that of the caregiver, or those who support or care for a loved one who is experiencing chronic pain (including both physical support such as wellness checks and transportation, and emotional support). Within the unweighted base total of 1,564 survey respondents, 224 identified as caregivers. Interestingly, 111 of these caregivers self-reported as people in chronic pain, while 113 of these caregivers reported as pain-free. These disproportionately female caregivers represent nearly 14% of adults in the United States (~29.3 million) and, hereafter, those caregivers who identify as people in chronic pain will also be included among the chronic pain population and those caregivers who do not live with chronic pain will be designated as caregiver-only.

Caregiver profile

Group	Pain Status		Gender		Age		
	Pain-Free	Chronic Pain	Male	Female	18-34	35-54	55+
Caregiver	52%	48%	42%	58%	30%	37%	34%
	Race/Ethnicity			Household Income			
	Black	Latinx	White	< \$40K	\$40K - \$100K	> \$100K	
	10%	20%	63%	39%	43%	18%	

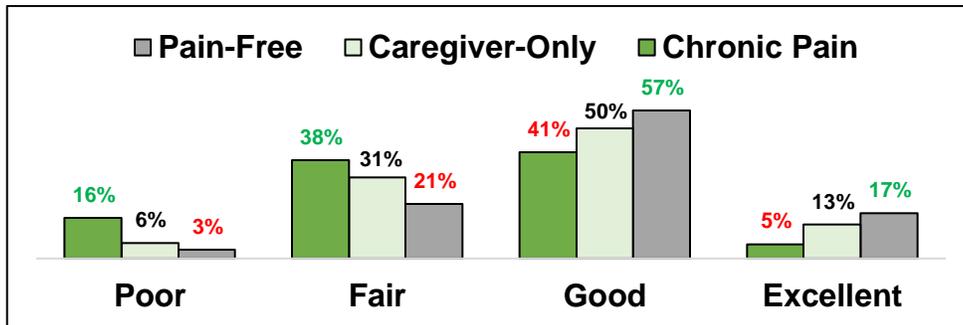
Bold green/red indicates significantly higher/lower values at a 95% confidence interval.

Percentages represent the weighted base total of respondents.

Baseline of overall wellbeing, health and experience of pain

Prior to assessing respondents' awareness, understanding and perception of chronic pain, it was pertinent to evaluate the baseline of their overall wellbeing, health and experience of pain:

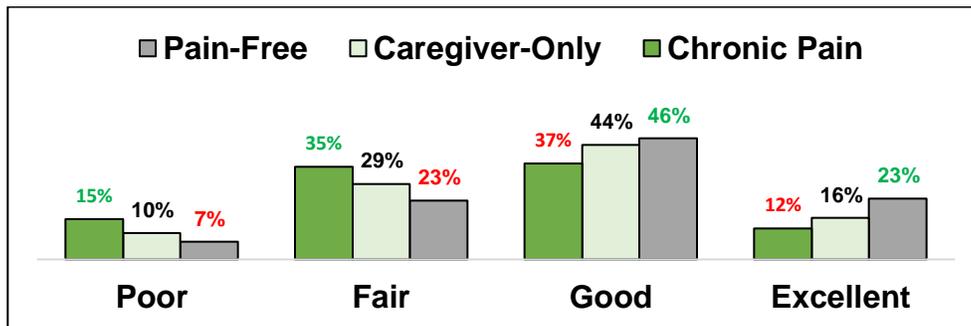
Current physical wellbeing



Bold green/red indicates significantly higher/lower values at a 95% confidence interval.

Percentages represent the weighted base total of respondents.

Current mental wellbeing



Bold green/red indicates significantly higher/lower values at a 95% confidence interval.

Percentages represent the weighted base total of respondents.

As expected, people in chronic pain as well as caregivers rate the wellbeing of their physical and mental health lower than the pain-free public.

Diagnoses and/or experiences (current or within the past 12 months)

Diagnosis/Experience	Group		
	General Population	Chronic Pain	Pain-Free
Chronic Pain	25%	100%	1%
Depression	28%	40%	23%
Hypertension	26%	37%	22%
High Cholesterol	21%	27%	18%
Diabetes	12%	18%	10%
Dermatology Issues	10%	17%	7%
Respiratory Issues	7%	14%	4%
Endocrine Issues	5%	10%	3%
Cardiac Issues	5%	9%	3%
Cancer	3%	5%	2%
Lymphedema	2%	4%	1%
Other	8%	8%	5%

Bold green/red indicates significantly higher/lower values at a 95% confidence interval.

Percentages represent the weighted base total of respondents.

As anticipated, these findings support the heightened prevalence of comorbidities among people in chronic pain, highlighted by significantly elevated levels of depression, high blood pressure/hypertension and high cholesterol. Interestingly, depression was found to be the highest reported shared condition among all groups surveyed.

Duration of pain

Group	Duration of Chronic Pain				
	3-6 months	6-12 months	1-2 years	2-5 years	> 5 years
Chronic Pain	5%	6%	14%	16%	56%
Caregiver with Chronic Pain	1%	6%	10%	18%	63%

Percentages represent the weighted base of respondents.

The vast majority of respondents have been managing their chronic pain longer than five years.

Experience of chronic pain

Experience of Chronic Pain	Group	
	Chronic Pain	Caregivers Reporting on Those Receiving Care
Back Pain	68%	78%
Muscle/Joint Pain	50%	59%
Arthritis	50%	54%
Knee Pain	44%	45%
Arm/Leg Pain	36%	39%
Nerve Pain	34%	42%
Neck Pain	33%	43%
Foot/Ankle Pain	32%	36%
Hip Pain	30%	39%
Migraines/Headaches	29%	37%
Sciatica	27%	34%
Disc Pain	21%	27%
Carpal Tunnel	18%	28%
Dental Pain	16%	24%
Fibromyalgia	12%	16%
TMJ/Jaw Pain	8%	12%
Chest Pain	6%	9%
Other	2%	4%

Percentages represent the weighted base of respondents.

Those who experience chronic pain most highly reported experiencing musculoskeletal pain in line with national prevalence¹. When caregivers were asked to report the experience of chronic pain for those they support, we found a higher rate of prevalence for each type of pain.

Magnitude of pain (typical day)

Pain Score	Group	
	Chronic Pain	Caregivers Reporting on Those Receiving Care
1 - Very Little	1%	1%
2	3%	3%

3	6%	5%
4	10%	11%
5	18%	11%
6	14%	15%
7	19%	18%
8	14%	11%
9	5%	7%
10 - Very High	8%	18%
Mean	6.15	6.73
Median	6	7

Percentages represent the weighted base of respondents.

On a typical day, people in chronic pain report a mean pain score of 6.15 with the majority reporting between 4-8 on a scale of 1-10. Similar to our findings regarding the experience of pain, caregivers reported higher pain scores on behalf of those they support in comparison to people in chronic pain themselves. This is especially pronounced at the highest magnitude of pain (18% vs. 8%, respectively).

Chronic pain management

Management of Pain	Group	
	Chronic Pain	Caregivers Reporting on Those Receiving Care
5- Completely Managed	4%	7%
4	15%	12%
3	41%	44%
2	21%	30%
1 - Not Managed At All	17%	6%

Bold green/red indicates significantly higher/lower values at a 95% confidence interval.

Percentages represent the weighted base total of respondents.

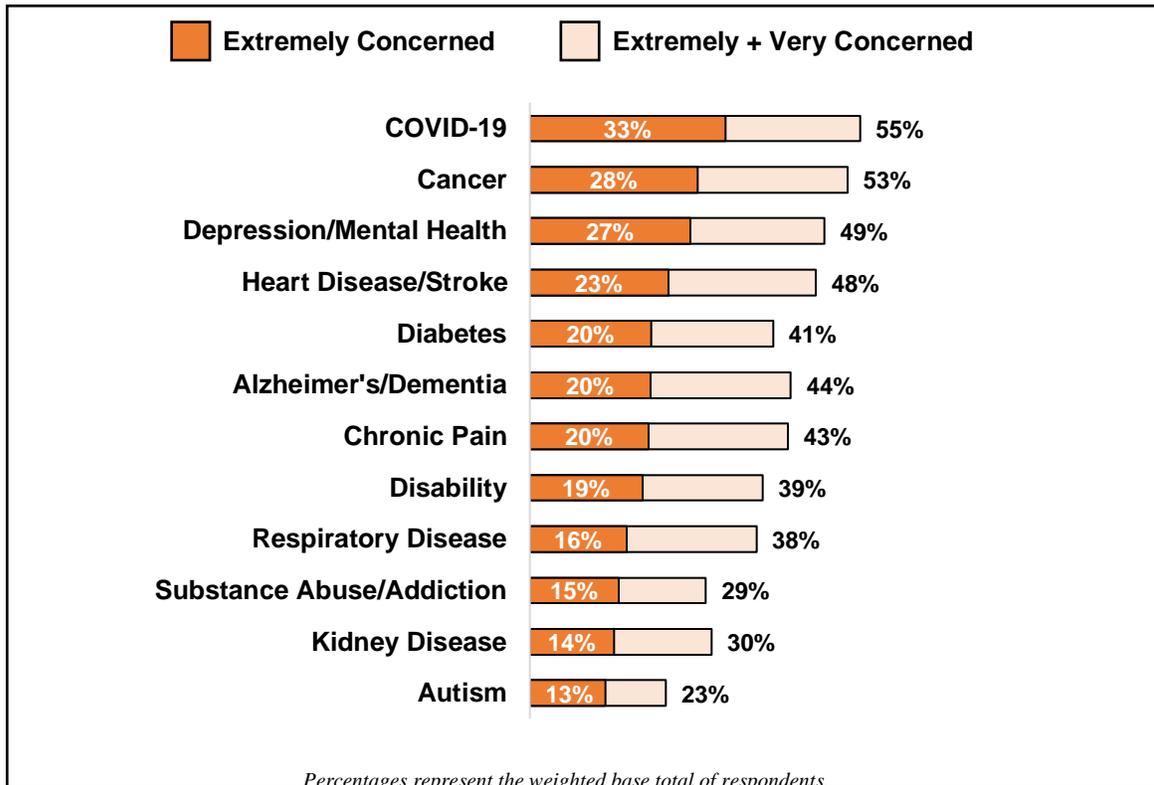
When asked to describe how well their chronic pain is being managed, only ~20% reported their pain as being efficiently managed while the majority reported inefficient management. Among those people in chronic pain surveyed, 91% reported having consulted a doctor or other medical professional regarding pain management.

In summation, the physical and mental wellbeing of people in chronic pain and caregivers are poorer in comparison to their pain-free counterparts. Those in chronic pain experience significantly greater comorbidities than those who are pain-free, although depression is the most common shared experience among both groups. The typical person in chronic pain has been experiencing musculoskeletal pain at a score of ~6 on any given day for longer than 5 years and are not having their pain effectively managed.

Public understanding of chronic pain vs. lived experience

Having gained a more thorough understanding of our survey respondents, we wanted to explore the general public's current understanding of chronic pain in comparison to the lived experience of those who suffer from chronic pain. We were interested to learn whether those in chronic pain and caregivers would report heightened levels of knowledge and empathy for those suffering chronic pain in comparison to the pain-free population. We first asked the general population to describe how concerned they would be at the prospect of themselves or a loved one being affected by chronic pain or other prevalent health issues.

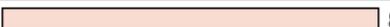
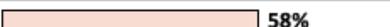
Level of concern oneself or a loved one will be affected by a condition



Given we are currently in the midst of a global pandemic, it was unsurprising the majority of the respondents were most concerned about being affected by COVID-19. When exploring the prospect of being affected by chronic pain, it falls within a middle tier of health worries that Americans have for themselves or a loved one. While 43% of Americans find themselves extremely or very concerned about chronic pain, this figure is mostly driven by those in chronic pain themselves in comparison to the pain-free population (67% vs. 35%, respectively). We sought to understand which segments of pain-free people express the greatest concern for chronic pain and discovered they are young (< 55 years old) minority women (Black/Latinx) who work in physically-demanding low income jobs (< \$25K).

We next explored people’s expectations for how common or rare chronic pain is for particular demographics to try and understand who Americans “expect” to be affected by chronic pain.

Groups in which Americans “expect” chronic pain to be very/somewhat common

	General Population (n=1564)	Chronic Pain	Pain-Free
People who've had a serious injury/accident	 89%	95%	86%
Older people (age 65+)	 87%	94%	83%
Workers whose jobs require physical labor	 85%	89%	84%
People with cancer	 84%	88%	81%
Overweight people	 80%	86%	77%
People with other physical health problems	 80%	84%	77%
People who have had a major surgery	 77%	80%	75%
Professional or competitive athletes	 76%	84%	73%
Military veterans	 73%	76%	72%
People aged 40 to 65	 71%	80%	67%
People with diabetes	 63%	66%	62%
People w/ depression/ mental health issues	 58%	60%	56%
Workers whose jobs mostly done sitting	 47%	49%	46%
People who are otherwise healthy	 26%	24%	27%
Younger people (under age 40)	 26%	26%	26%

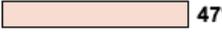
Bold green/red indicates significantly higher/lower values at a 95% confidence interval.

Percentages represent the weighted base total of respondents.

There is a consensus among those in chronic pain and the pain-free population regarding which groups of people they “expect” to be suffering from chronic pain or rather those groups of people they believe are most susceptible to contracting chronic pain, notably older people and those who have had a serious injury or accident. An important observation among both groups is their low expectation that young and otherwise healthy people will suffer from chronic pain, especially among those who suffer from chronic pain themselves.

Having gained an understanding of who Americans view as suffering from chronic pain, we wanted to explore how sympathetic they are towards those living with chronic pain, especially members of the pain-free population.

Americans' views on which aspects of life chronic pain greatly impacts

	General Population (n=1564)	Chronic Pain	Caregivers-Only	Pain-Free
Ability to sleep	 56%	50%	62%	57%
Ability to work	 54%	53%	66%	53%
Overall quality of life	 53%	52%	55%	53%
Mental health	 47%	40%	56%	48%
Activities required for daily life (e.g., getting dressed, preparing meals, etc.)	 44%	37%	46%	46%
Sense of self and purpose	 38%	34%	53%	38%
Physical/emotional well-being of family	 37%	31%	40%	39%
Emotional or mental health of caregivers	 36%	31%	39%	37%
Personal relationships with friends + family	 35%	27%	36%	38%
Hobbies	 34%	30%	42%	35%

Bold green/red indicates significantly higher/lower values at a 95% confidence interval.

Percentages represent the weighted base total of respondents.

The pain-free public certainly possesses sympathy for the impact chronic pain can have on the lives of those affected (arguably more so than those with chronic pain themselves), and all audiences perceive chronic pain as having a significant impact on productivity, sleep and overall quality of life. Interestingly, caregivers perceive even more significant consequences than are reported by chronic pain sufferers, once again hinting toward a divided reality between those with chronic pain and primary caregivers.

While the pain-free population is able to recognize the hardship of living with chronic pain and express sympathy, we were curious as to how they perceive the relative ease or difficulty of successful chronic pain management. To assess this public perception, we asked respondents which percentage of chronic pain sufferers are able to permanently, “fix, manage or cure,” their chronic pain along with their general thoughts regarding chronic pain management. Chronic pain management was described as using some sort of treatment(s) to reduce pain symptoms enough for people to function in their daily lives.

Views on what % of chronic pain sufferers find permanent pain relief

% "Fixed" or "Managed" or "Cured"	Group	
	Chronic Pain	Pain-Free
0% - 30%	56%	44%
31% - 50%	32%	34%
50% - 100%	13%	22%
Average	34%	39%

Bold green/red indicates significantly higher/lower values at a 95% confidence interval.

Percentages represent the weighted base total of respondents.

Views on ease/difficulty of chronic pain management

Is Chronic Pain Management...	Group	
	Chronic Pain	Pain-Free
Easy	11%	16%
Neutral	15%	16%
Difficult	73%	62%

Bold green/red indicates significantly higher/lower values at a 95% confidence interval.

Percentages represent the weighted base total of respondents.

The pain-free public expresses significantly more confidence that chronic pain can be successfully managed in comparison to those with chronic pain themselves. While we expected that those with chronic pain would likely express a more pessimistic outlook, these findings suggest that the pain-free public believes sufficient chronic pain treatments may already exist.

In our exploratory focus groups, pain-free participants simultaneously expressed sympathy and skepticism regarding chronic pain. For example, pain-free respondents are able to sympathize with the frustration and stress expressed by those in chronic pain, but often feel as though they may not be doing enough to manage their pain (e.g., exercising, eating healthier, etc.). This was also supported by these survey findings in which the pain-free public can recognize the hardship of chronic pain while also expressing more confidence that chronic pain can be effectively managed. To better understand this dichotomy (sympathy vs. skepticism), we asked respondents to offer their judgments on a series of statements regarding the causes of chronic pain, treatments

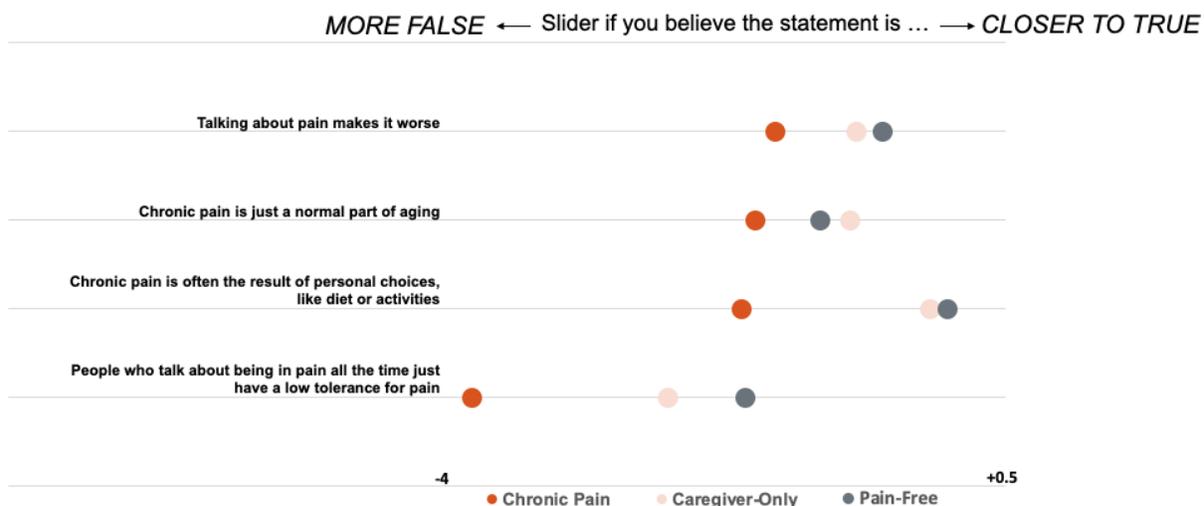
for chronic pain and about those in chronic pain themselves. Respondents were able to characterize their thoughts along a continuum of, “mostly true (+10),” to, “mostly false (-10).”

Chronic pain statements generally viewed as truthful



Scale is from 0.0 through +6.5

Chronic pain statements generally viewed as more false or undecided



The responses to these statements revealed that this issue of sympathy vs. skepticism held by the pain-free public with regard to those in pain may potentially be controlled by a central tenet: the pain-free public’s ability to express sympathy for those in chronic pain requires “proof” that those in chronic pain are actively attempting to manage their pain and exhausting all resources.

All segments agree that we need to get to, “the root cause,” of chronic pain and discover new efficient treatments for pain management, although those in chronic pain and caregivers are more steadfast in these beliefs than the pain-free public. Interestingly, all segments most closely align around the belief that chronic pain can be managed so that it has minimal impact on people’s lives. This presents a dual-reality in which respondents believe we need new treatments for chronic pain, although they seem to believe chronic pain can already be efficiently managed.

Next, there is close alignment between all groups that managing chronic pain with regular opioid use can lead to addiction, which suggests all groups believe their use should be avoided.

Attitudes begin to diverge when discussing other treatment options however, where the pain-free public (in comparison to those in pain) more adamantly believes that non-pharmaceutical options (e.g., physical therapy, meditation, etc.) are better than pharmaceuticals. This is an agreement

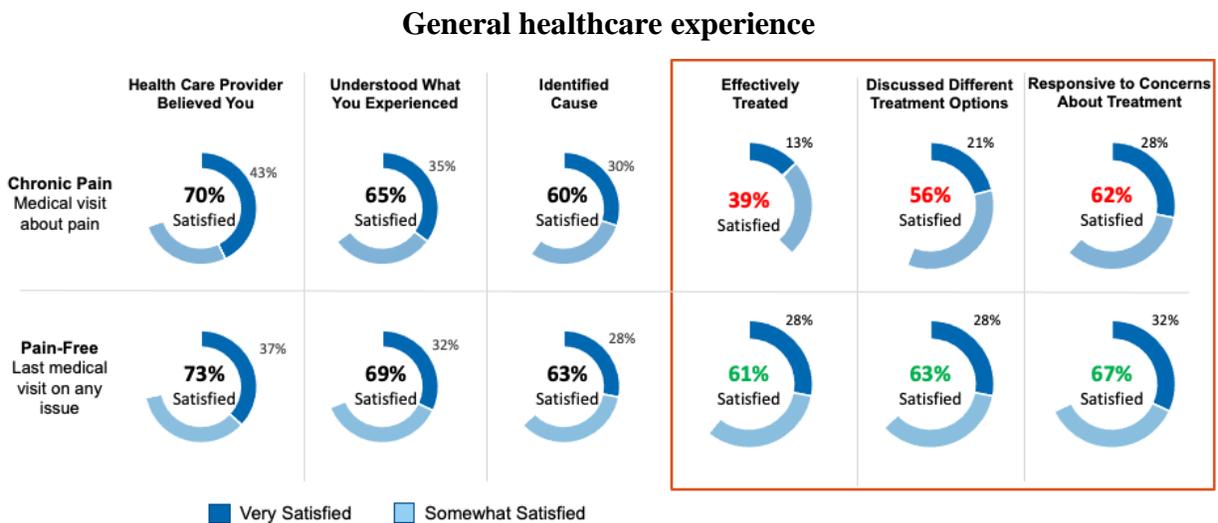
with the belief held most resolutely by the pain-free public that people with chronic pain are not necessarily doing everything they can to manage or fix their pain.

Finally, judgements about why people suffer and how they handle that suffering reveal the biggest divide between those in pain and the pain-free public. The pain-free public finds all of the following closer to true than false: talking about pain makes it worse, chronic pain is a normal part of aging, people who talk about pain have a lower tolerance for pain and, most importantly, chronic pain is often the result of personal lifestyle choices.

All of these findings seem to suggest a similar sentiment among the pain-free public: if people in pain positively changed their lifestyles and found the appropriate balance of treatment options (excluding opioids), they ought to be able to manage their pain. Only when these prerequisites have been satisfied is the pain-free public most likely to express genuine sympathy.

Chronic pain management

Upon learning all segments concur that regular opioid use will lead to addiction, we wanted to further explore the public’s perception of currently available chronic pain treatments as well as their experiences with healthcare providers.



Bold green/red indicates significantly higher/lower values at a 95% confidence interval.

Percentages represent the weighted base total of respondents.

We began by asking respondents to indicate which description best fits their experience with healthcare or with their feelings regarding treatment (people in chronic pain were asked to describe their initial medical consultation regarding pain and pain-free people were asked to describe their most recent medical visit). Our first observation from these findings was the general dissatisfaction expressed by most respondents regarding their healthcare experience. Second, we observed a significantly lower expression of satisfaction by those in chronic pain vs. the pain-free public with regard to the efficacy of their treatment, discussion of different treatment options and the responsiveness of their healthcare providers to concerns regarding treatment.

In the context of chronic pain, it is unsurprising that people in pain would report dissatisfaction with treatment efficacy (as evidenced by our previous findings within this survey that only ~20% are having their pain efficiently managed). In an effort to understand why people in pain are dissatisfied with the discussion of different treatment options and the responsiveness of their healthcare providers to their treatment concerns, we asked respondents to describe their general experience with chronic pain treatment, their willingness to utilize particular treatment options and their general insights regarding the efficacy of different treatments.

General treatment experience

	Experience with Each Treatment		Stopped Using	Total Used (Current + Past)
	Currently Using	Have Used in Past		
Over-the-counter pain relievers	60%	94%	34%	
Prescription medication (non-opioid)	30%	74%	44%	
Homeopathic or natural remedies	20%	45%	26%	Age 18-34: 69%
Behavioral therapy (e.g., meditation, etc.)	17%	37%	20%	Age 18-34: 61%
Medical marijuana	14%	23%	8%	Age 18-54: 31%
Local anesthetics or injections	14%	52%	38%	
Physical therapy	12%	74%	62%	
Opioids like morphine or oxycodone	12%	46%	34%	
Physical treatments (e.g., massage, acupuncture)	11%	45%	35%	Age 18-34: 65%
Surgery	5%	33%	28%	
Psychedelic drugs (LSD or "magic mushrooms")	3%	10%	7%	Age 18-54: 15%

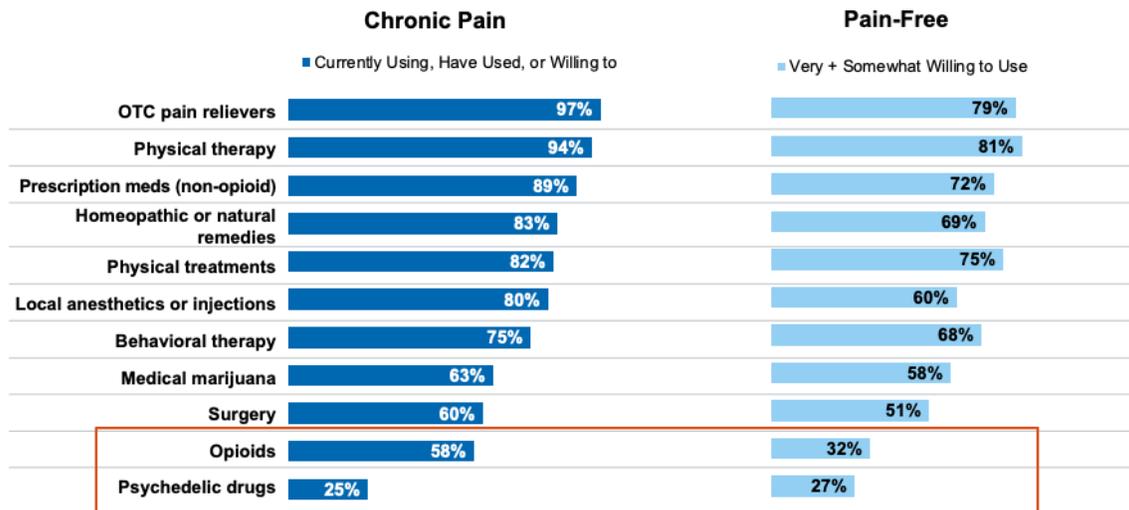
Bold green indicates significantly higher values at a 95% confidence interval.

Percentages represent the weighted base total of respondents.

Our findings regarding the general treatment experience of those in pain begins to reveal a “cyclical” pain management experience wherein those seeking aid will utilize a particular treatment option for a limited time prior to its cessation and the initiation of a new treatment avenue. As an example, 74% reported having utilized physical therapy to manage chronic pain but 62% of these people have stopped pursuing this treatment. Such a trend is present among other treatment options such as non-opioid prescription medications, local anesthetics/injections and physical treatments such as massage or acupuncture, to name a few.

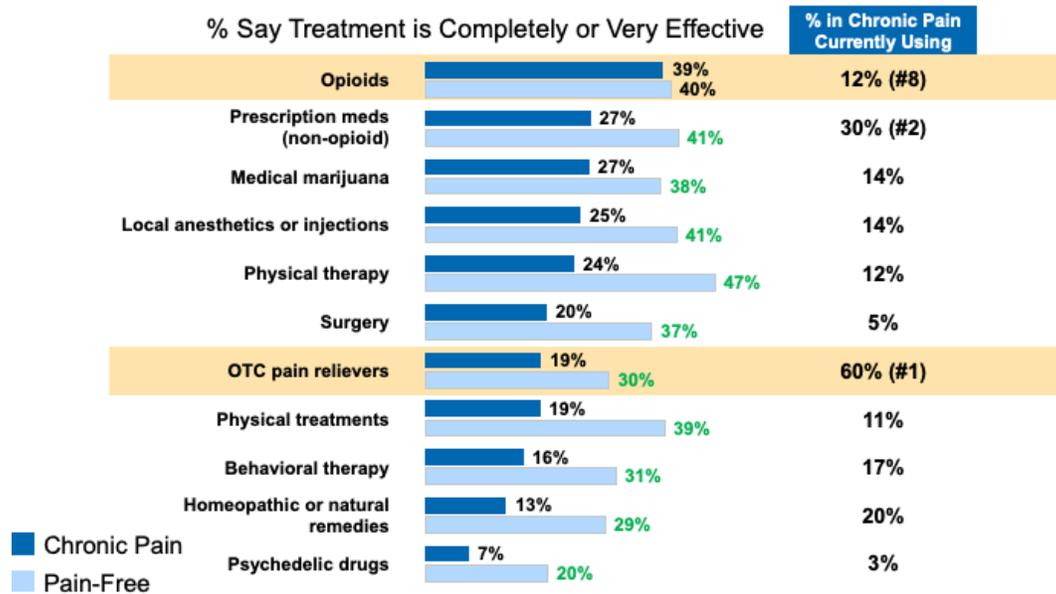
To continue to learn more about these healthcare experiences, we asked all respondents to describe their general willingness to use a particular treatment option as well as their thoughts regarding the efficacy of these treatments.

General willingness to use a particular treatment option



Percentages represent the weighted base total of respondents.

General insights into treatment efficacy



Bold green indicates significantly higher values at a 95% confidence interval.

Percentages represent the weighted base total of respondents.

First and foremost, those in pain and the pain-free public rank treatment options similarly in terms of their willingness to try them, with the exception of opioids which would be very undesirable among the broader public. Next, asking respondents to describe their beliefs regarding the efficacy of particular treatments is often paradoxical. For example, willingness to utilize opioids for pain management is incredibly low, however, opioids are believed to be a very effective means of pain management. Similarly, the vast majority of respondents utilize over-the-counter pain relievers, however, less than 20% of respondents in pain believe they are effective. Interestingly, the pain-free public believes all treatment options are significantly more effective than those in chronic pain do (yet another example that the pain-free public seems to believe sufficient pain management treatments already exist).

These findings, coupled with qualitative data gleaned from our follow-up focus groups, begin to illustrate a similar shared healthcare experience for those in pain who find themselves frustrated. It appears for many people in pain that there exists a level of, “trial-and-error,” as it pertains to their treatment. In these instances, a treatment option is pursued and, if not effective, replaced with another therapy. Adding to the “cyclical” nature of these treatment regimens, people in pain often state that certain treatment options are initially effective before precipitously losing their

beneficial effects. There is also a disconnect between what patients are using/willing to use and what the perceived efficacy of that particular treatment option is. Ultimately, people in pain seem to desire a broader and more comprehensive understanding of what all their treatment options are, while also gaining more in-depth knowledge about the potential effects of such treatments. While it would prove convenient to place this obligation of increasing patient empowerment solely upon the healthcare community, there is certainly a role to be played by organizations and entities that specialize in patient advocacy.

Awareness of chronic pain organizations



*Bold green/red indicates significantly higher/lower values at a 95% confidence interval.
Percentages represent the weighted base total of respondents.*

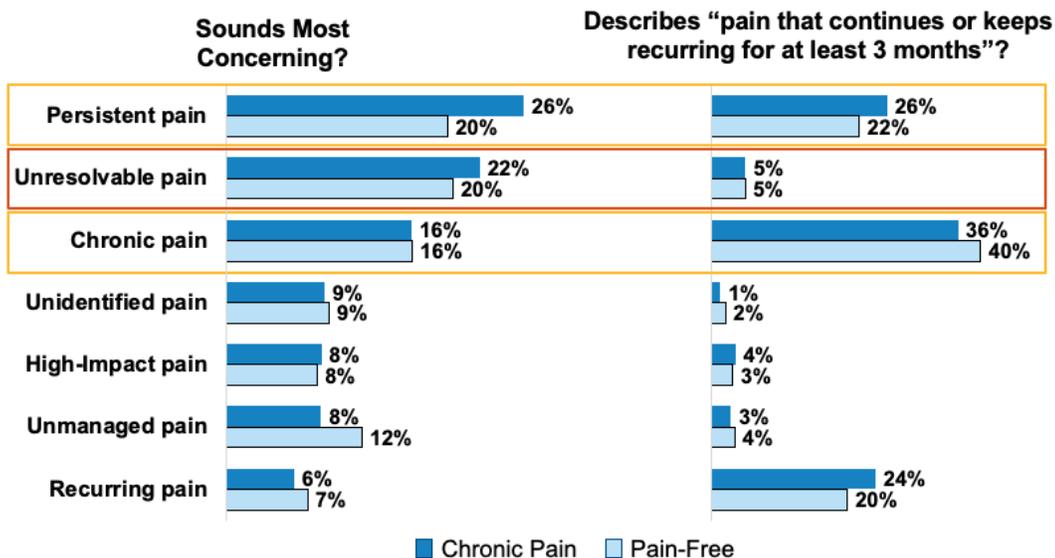
When respondents were asked if they are aware of any organizations or entities that are researching ways to manage chronic pain or provide assistance to those living with chronic pain, the vast majority of respondents were unfamiliar with their operations. Throughout our focus groups comprised of people in pain, respondents expressed relief while speaking to others who shared their experiences. As an example, one respondent stated, “I’ve had the same negative experience everyone is sharing. It’s interesting that we’re pretty much describing [chronic pain] the same way. I never get to talk to other people who have experienced this.” Another participant offered, “The fact that we’re all saying the same thing suggests to me [chronic pain] is universal. Could be anywhere, any situation, any age. More people have this experience than you might

think.” These sentiments and data underscore a need for additional support options and groups for those in pain, as well as increased visibility for research organizations which explore new viable treatment options.

Narrative testing and messaging

Having gained insight regarding the public’s understanding of chronic pain and chronic pain management, we felt it was important to become more knowledgeable about how the public understands the “language” of chronic pain as well as how they respond to chronic pain narratives presented from a variety of perspectives and different contexts. To begin, we presented respondents with a list of terms which included other ways chronic pain can be described and asked them to choose which terms they found the most concerning and/or best describe, “pain that continues or keeps recurring for at least three months.”

How the public responds to other terms for chronic pain



Percentages represent the weighted base total of respondents.

Interestingly, the two terms that respondents found most concerning were, “persistent pain and unresolvable pain.” In our follow-up focus groups, we asked respondents to provide us with their rationale for choosing these particular terms. We learned that participants felt that “persistent pain” creates both concern and seemed to be a good fit with the definition of chronic pain since

pain persists despite treatment. One participant offered, “[persistent pain] - seems more of what it is [than chronic] – it’s just always there, almost insidious at times. Nothing makes it go away.” Similarly, participants felt that “unresolvable pain” has emotive traction since it creates more urgency and hope as a solution hasn’t been discovered yet. As a participant explained, “[unresolved pain] – sounds like there is a solution, but it just hasn’t been found yet. Rather than, “this is it.”” We were also curious as to why “unmanaged pain” tested so poorly and learned that many felt it implied someone in pain was choosing not to manage their pain.

When asked what terms best describe, “pain that continues or keeps recurring for at least three months,” the three most selected terms were, “chronic pain, persistent pain and recurring pain.” We believe that chronic pain (which participants explained as descriptive but lacking the ability to invoke as much concern as, “persistent pain and unresolved pain”) tested highly in this capacity since it had been utilized throughout the entirety of the survey to this point. Similarly, “recurring pain” may have tested highly as the term, “recurring,” was used directly in this question.

In the future, it may be worthwhile to explore the value of rebranding chronic pain to “persistent pain” or “unresolved pain” to create more urgency and help undermine existing assumptions or judgements about those in pain. Although unexplored in our survey, another term which may warrant future evaluation and was well-received by our follow-up focus groups is “personalized pain” for its ability to evoke an identity and individuality for those in pain.

To explore what stories and details might move the needle positively on the public’s understanding of and sense of urgency around chronic pain, we tested five different narratives which can be found in the appendix. Each narrative had a different messenger, pain, cause, primary problem/impact and “call-to-action.” Each respondent saw one narrative and was able to select phrases of text to indicate information or ideas that stood out or made them feel that chronic pain is an issue that needs to be addressed or items that caused them to question or doubt the narrative. After each story, we asked several previous survey questions to measure the understanding and urgency of chronic pain to test for movement on key metrics as a result of exposure to the narrative.

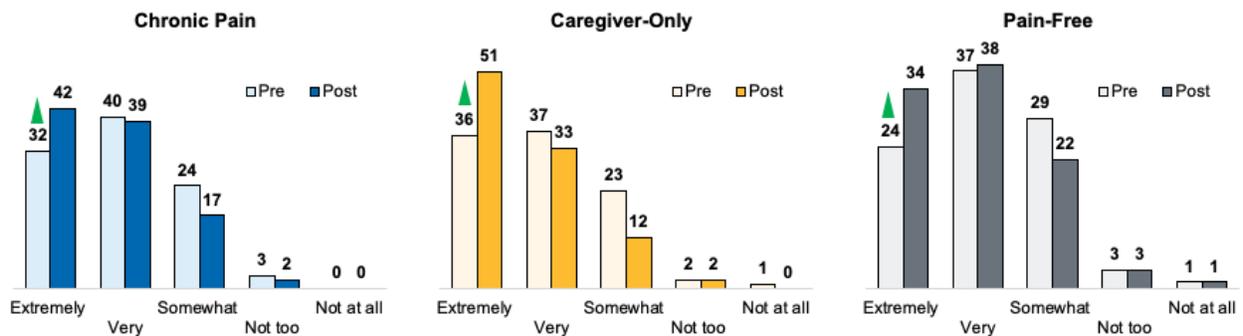
Narrative summary

Story	A	B	C	D	E
Messenger	Pain specialist doctor	Younger woman with chronic pain	Older man with chronic pain	Wife of man with chronic pain	Latina nanny
Cause of Pain	Not specified	None	Accident	Cancer/Chemo	Job/Repetitive Stress
Problem/Impact	Economic impact	Social life	Activities of daily living	Relationship	Limited access to care
Solution	Research	New treatments	Need for organized voices/Support	Advocacy	Recognize chronic pain as a condition
Difficult to Identify Cause	61% (+13)	56% (+15)	34% (-11)	37% (-6)	40% (-3)
Difficult to Manage	69% (+8)	62% (-7)	64% (+1)	67% (+0)	59% (-8)
Urgency of Need for Treatments	77% (+10)	73% (+11)	76% (+12)	76% (+14)	71% (+3)
Believability	79%	75%	80%	79%	75%

Bold green/red indicates significantly higher/lower values at a 95% confidence interval.

Percentages represent the weighted base total of respondents.

Pre- and post-narrative: how urgent is the need for new treatments/solutions?



Percentages represent the weighted base total of respondents.

Following the administration of these narratives, two encouraging observations emerged: the sense of urgency for the issue of chronic pain increases after the narratives (even among those who are pain-free) and respondents find the narratives very believable. This increase in urgency is driven by those who start off with at least some sense of urgency and become more convinced when presented with more information. Other observations of note are that an authoritative voice and a surprising victim moved the needle regarding pain without a cause (stories A and B), the voice of sufferers does not do much to convince the public on the difficulty of pain management

(stories B, C, D and E) and that all stories are able to effectively move the needle on urgency with the exception of the messenger who refused strong medications, claims physical therapy has not worked and may have pain that is too relatable (story E).

These findings validate the use of narratives to increase urgency and understanding with regards to pain and offer an opportunity to draw in diverse groups around a common experience. It is also important to note that even relatively minor details within these narratives can compel or derail the conversation and that even problems related to chronic pain can detract from the more salient aspects of a narrative. As an example, when presented with the information that pain may not be manageable or solved with available options, a follow-up focus group participant offered, “...how many people are even able to try all of the things that are available because of insurance, unemployment...Insurance costs in this country are absolutely deplorable and disgusting.”

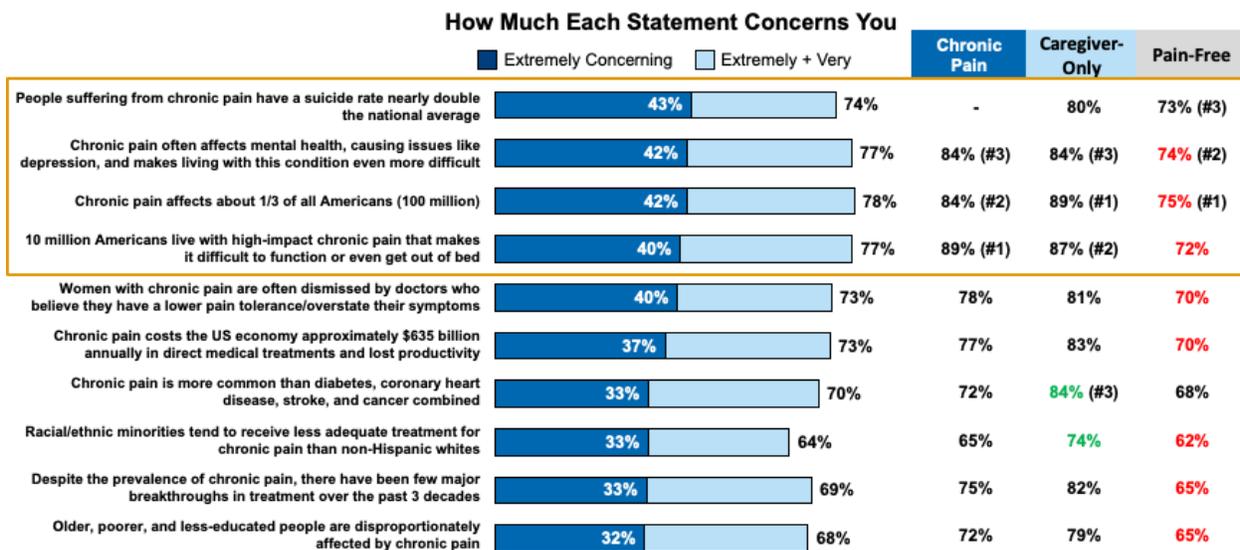
Top testing excerpts across all stories (descending order)

Context of Excerpt Use	Excerpt Verbatim
More chronic pain research is needed.	We need more scientific research into what causes chronic pain.
Attempting to manage chronic pain.	After a few surgeries and a lot of time spent doing physical rehabilitation, I'm alive, and my bones have healed, but the pain in my right arm just won't go away.
Cancer is a relatively well-understood cause that elicits sympathy.	Ever since his second round of chemo, my husband has experienced persistent, chronic nerve pain that makes it hard for him to function...
Relatable experiences that can cause pain over time.	But these years have taken their toll on my body - picking up children, carrying laundry up and down stairs, lifting car seats and strollers in and out of the van, crawling on my hands and knees to play.
Why isn't anybody really talking about chronic pain?	There are many organizations out there that focus on cancer - making sure there is research, providing support for those fighting it - but with all their good work, they don't have much to say or do about the chronic pain that sometimes comes after it...
More chronic pain treatments are needed.	...if people realized that constant pain is not something you should just accept as you get older but something that should be treated like any other disease, there would be more options...
A relatable impact of chronic pain and the loss of one's independence.	Many days, the pain in my right arm is so bad I can't cope, let alone brush my teeth or lift a fork.
Authoritative assertion that the diagnosis of chronic pain can be elusive.	Sometimes when people experience chronic pain, there is a cause or condition we can fix or treat that will help them, but other times, even treating the condition doesn't resolve the pain...
More chronic pain research is needed.	We need to find new, safe treatments for chronic pain so people like me can get back to their lives and to doing the things they love with the people they love...

Activating the public around pain

Aside from the impact that powerfully constructed narratives can have on activating the public, we sought to understand the specific information that audiences find most concerning about chronic pain, what respondents would specifically be interested in doing to address chronic pain and which particular demographics are the most receptive to being activated to engage with the issues of chronic pain.

Chronic pain information audiences find most concerning



Bold green/red indicates significantly higher/lower values at a 95% confidence interval.

Percentages represent the weighted base total of respondents.

When pressed to provide the information they find the most concerning about chronic pain, all audiences described information on the prevalence of chronic pain and its associated impacts on mental health as the most concerning. During our exploration of current medical diagnoses/experiences, depression and associated mental health issues were the most common shared condition among all demographics. These findings suggest that chronic pain, unlike cancer, is less about fear of direct personal impact or death but is very capable of tapping into other shared experiences (such as mental health) so that empathy can be activated.

Near the conclusion of the survey, we presented respondents with a list of actions they could carry out to address the problem of chronic pain and inquired how interested they would be in performing each particular action. Our findings revealed that caregivers are the most likely to take actions to address the problem of chronic pain.

Actions willing to be done to address chronic pain

% Extremely Willing/Definitely Will	Chronic Pain	Caregiver-Only	Pain-Free
Talk to friends/family with chronic pain to learn how you can support them	26%	46%	21%
Do additional research on your own to better understand the problems of chronic pain	24%	31%	15%
Tell public officials that we need to increase funding for research into chronic pain management	19%	20%	14%
Participate in a walk, run, etc. (post-COVID) to raise money for research on better pain treatments	15%	29%	14%
Post information about the issue to your Facebook page or share it with others in your social network	14%	21%	12%
Contact public officials (via phone, email, post) to make sure they are aware of the problem and what should be done	13%	20%	12%
Donate money to an organization studying ways to manage chronic pain	12%	23%	13%
Donate money for support services for people living with chronic pain (e.g., transportation, mental health support)	12%	21%	12%

Bold green/red indicates significantly higher/lower values at a 95% confidence interval.

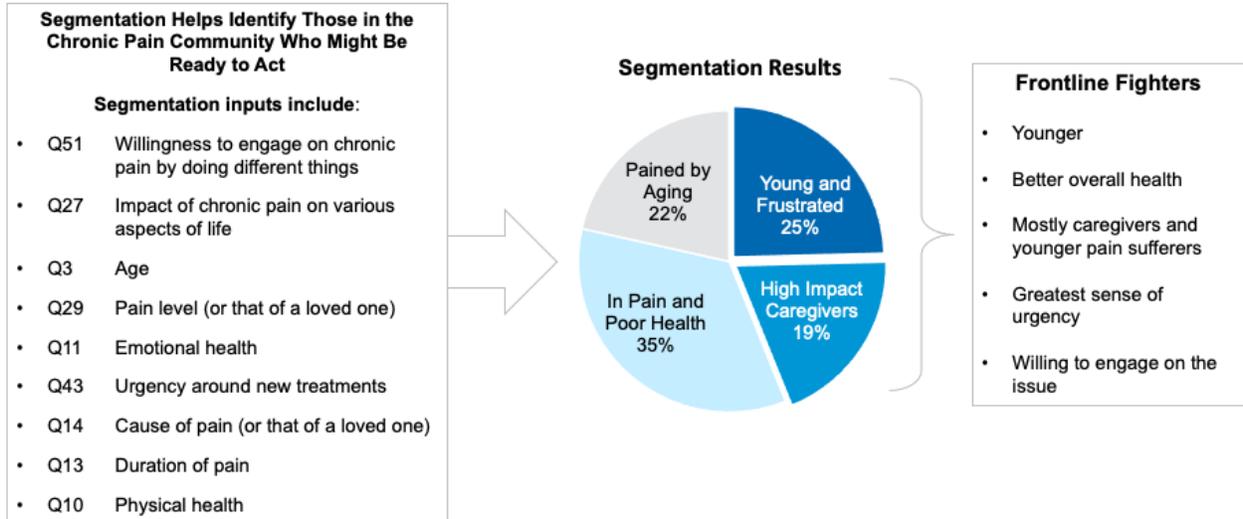
Percentages represent the weighted base total of respondents.

Utilizing all of the data we gathered through this survey, we performed a series a segmentation cuts to determine which demographics would be most receptive to being activated to engage with the issues of chronic pain. First, we sought to understand who among the pain audience can be activated and determined that two key segments, younger people in chronic pain and caregivers, combine to form a segment we have called “frontline fighters” and may be ready to act. These “frontline fighters” are younger, have a better overall quality of physical/mental health, possess a greater sense of urgency around chronic pain and are willing to engage on the issue.

Next, we wanted to learn who among the broader pain-free public can be activated and discovered that two segments, those who are already giving to health causes and people who are

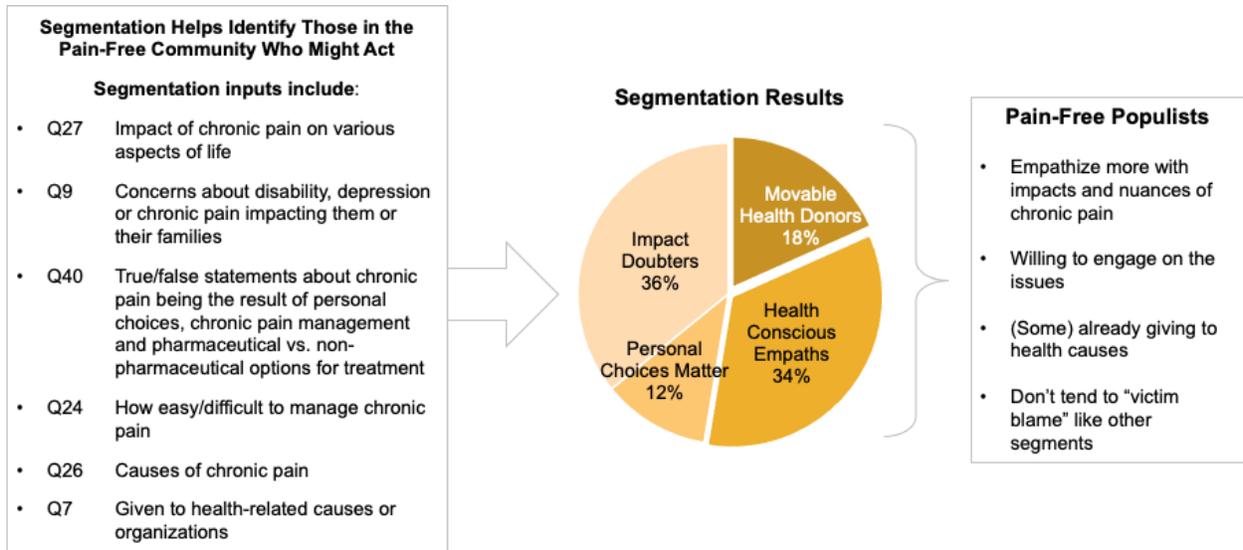
more health conscious themselves, combine to form a segment we have called “pain-free populists” and may also be ready to act. These “pain-free populists” are able to empathize more with the impacts and nuances of chronic pain, willing to engage on the issue and don’t tend to “blame the victim” like other segments.

Activating the pain audience: frontline fighters



Percentages represent the weighted base total of respondents.

Activating the public: pain-free populists



Percentages represent the weighted base total of respondents.

Discussion and Recommendations

Resolving the chronic pain crisis will require new and innovative treatments that arise through a commitment to research and institutional changes, however, this necessitates the type of public support that will only manifest through a transformation of the current public discourse related to pain. A lack of understanding about the public's perception and opinions of chronic pain has impeded our ability to develop, test and assess science communication strategies based on their ability to increase chronic pain awareness, engagement and advocacy among the American public. This study has allowed us to acquire new insights regarding the current public's understanding and judgements about chronic pain and also helped to identify potential target demographics to activate around the issue of chronic pain. The following are our research insights and recommendations regarding how to better communicate about pain, how to improve the healthcare experience for those in pain and how to better activate the public around pain based upon the findings of this study.

Communicating about pain

Raise awareness and visibility of chronic pain – this is the first step to public engagement and will make those with pain feel less isolated.

Chronic pain is a relatable condition, and the pain-free public expresses a lot of empathy, however, it is not a top tier health concern. Connections to loss of productivity, quality of life and depression are the most top-of-mind impacts of chronic pain for the pain-free public and they respond to statistics about the prevalence of the problem. Unlike cancer, chronic pain is less about fear of direct personal impact or death. Chronic pain is capable of tapping into a shared experience (such as pain or mental health) so that empathy can be activated. Anecdotally, some of the pain-free populists we spoke with had people with pain in their lives, so an awareness raising message similar to mental health – recognize the signs, chances are you know someone who is dealing with chronic pain, etc. – could be a way to start. This has the added benefit of making those with pain feel less invisible.

Use expert voices to help make the case that existing options are not sufficient, and more research/new treatments are needed – this element helps create a sense of need around the issue.

Public attitudes are more complex below the surface and reveal judgements about causes, treatments and whether people in chronic pain “do enough” to manage their pain. Some of these judgements are also shared by those in pain themselves. The issue of chronic pain does not need a further sympathy push – it needs a push toward greater understanding that management or effective treatment can be elusive. Expert voices, such as the pain specialist in our tested narrative, can help make the case that existing options are not effective for many and therefore not sufficient.

Rebrand chronic pain to “unresolved pain” or “persistent pain” to create more urgency and help undermine existing assumptions or judgements about those in pain.

The language around chronic pain needs to be changed. Words like “persistent” and “unresolved” show promise in moving the image away from a “chronic” condition that should be manageable with treatment and lifestyle changes (“unmanaged” exacerbates this underlying attitude). “Unresolved pain” creates more urgency around pain and speaks to a lack of a solution – something the public needs to be further educated on. For some, “unresolved pain” also includes hope by suggesting a solution is possible. Both “persistent” and “unresolved” give the impression that treatment has been tried but the pain persists or is unresolved, so using this terminology can help subtly undermine the idea that people in pain just aren’t trying everything.

Do not focus on convincing people that pain can happen without a cause or underlying condition – it’s a harder conversation to have and not necessary to create interest in engagement.

Belief that pain can happen without a cause or without an underlying condition is not necessary for empathy and engagement. Regardless of the protagonist or narrative, talking about pain without a solution increases the sense of urgency around finding new solutions for pain treatment and management. Do not focus on convincing people that pain can happen without a cause. Instead, meet them where they are and focus on the prevalence of pain and the current lack of solutions, things they can be convinced of more easily.

Improving the healthcare experience

Increase training, knowledge and access to specialists in pain treatment and management among the medical community with the goal of giving patients a better, more personalized care experience.

Both people in chronic pain and the pain-free public agree that the current healthcare system does not provide an experience in which patients feel options are explored or concerns heard. Even many trusted doctors don't seem to have the expertise to treat pain effectively. When discussing treatment, the idea of "personalized medicine" is appealing, especially for those in pain. It speaks to the idea that people experience pain differently and need a collaborative approach to find a solution. One-size-fits-all approaches or rules (such as, "always start with an over-the-counter medication," or aversion to opioids) have made it harder for people in pain to find relief. Greater knowledge across the medical community and greater access to specialists is needed to achieve this goal of a more "personalized" experience.

Change the approach to prescribing options that include more conversation about benefits, risks and expectations to give patients greater confidence, agency and buy-in to available treatments.

There is a gulf between acceptable treatments and perceptions of efficacy. The conversation around opioids is especially fraught for both people in pain and the pain-free public. Current options appear as a laundry list of things to try rather than a set of options that patients fully understand or buy-in to. Medical professionals could do a better job talking about options with people in pain. There needs to be time to talk through benefits, risks and questions, as well as to manage expectations about the experience of treatment along with consideration of how and when treatments work. With more information, people in pain could have more confidence in the process and feel less like they are in a never-ending cycle of trial-and-error without much hope. Additionally, there is a role to be played for increasing patient empowerment among organizations and entities that specialize in patient advocacy.

Activating targets

"Frontline fighters" and "pain-free populists" are two groups that may be ready to be activated to engage with the issues of chronic pain.

Nearly half of all caregivers who responded to our survey are people who experience chronic pain themselves and have a unique perspective on pain. This demographic, coupled with younger people in chronic pain, form a group we call “frontline fighters” and possess important traits that make them potential candidates to activate the pain audience. They are younger, possess a greater sense of urgency regarding pain and are the most willing to engage on the issues. In terms of activating the broader public, we identified a group we call “pain-free populists” that appear primed to engage on the issues. This group consists of those who are already giving to health-related causes and are more health conscious themselves, possesses the ability to empathize more with the impacts and nuances of chronic pain and does not tend to “blame the victim” like other segments.

Future Directions

These findings (which we collectively refer to as Phase I of this work) have allowed us to gain a more thorough understanding of the public's perceptions, misperceptions and attitudes toward chronic pain. An important next step in shaping a more productive national discussion of chronic pain is to better understand people's responses to specific messaging to address it effectively.

Using this data from Phase I, the Alan Alda Center for Communicating Science plans to design an experiment in which we construct various forms of communication strategies and test the effectiveness of those strategies with a nationally representative sample (which we collectively refer to as Phase II of this work). Such an experiment will allow us to identify the most effective strategy for mass communication regarding chronic pain with various stakeholders. Scientific communication strategies work differently with various audiences and this experiment would allow for an understanding of these nuances and identify the most effective strategy for reaching these different audiences based upon our acquired data. This experiment would also help researchers better understand chronic pain from a social science perspective, facilitate scientific collaborations between social scientists and medical scientists and provide valuable insights for policy making and chronic pain management.

The findings from Phase II of this work could then be utilized to inform a national mass media campaign to increase the public's awareness and understanding of chronic pain (using the science of science communication) and change the discourse surrounding chronic pain among various stakeholders (which we collectively refer to as Phase III of this work). Such a campaign can also be paired with the formulation of a best practices training guideline for science communication trainers and practitioners to help instruct chronic pain researchers, clinicians and advocates. Additionally, Phase III of this work would include ongoing assessment to ensure that communication and engagement efforts are facilitating the type of changes we propose to achieve and include multiple organizations in collaboration to elicit social discussion and conversation around chronic pain to increase social empathy and support on the topic.

There are other considerable findings from this study that would warrant future investigation from social science researchers and science communicators and would help to better facilitate an engagement on-ramp for the public:

Lesson	Action
Identifying a cause of chronic pain undermines the idea that pain sometimes does not have a cause.	Explore in focus groups and/or decide whether this is a key element of chronic pain that we want the public to better understand.
Lack of effective treatments for pain conveys the idea that pain is hard to manage, but lack of access to those treatments does not.	Focus future communications on the trial-and-error aspect of current chronic pain treatments to make an impact.
From this data, credible messengers include doctors, spouses and persons in chronic pain who have taken steps to try to resolve their pain.	In future studies, explore what makes someone a credible source on the chronic pain experience or problem.
Narratives that possess relatable details are compelling and convey impact.	In future communications, use details that anyone can relate to – the inability to do basic tasks, stress in a marriage, the physical toll of caring for a family, etc.
Research into both the causes of chronic pain and related treatments garners attention.	The public is uncomfortable with the concept of pain that comes from nowhere, therefore future communications should address both these aspects of chronic pain research.
Leadership is needed for attention and credibility.	Long-term, there is the need to identify an organization or entity that can lead the charge and organize collaborative efforts.

Appendix

1) Exploratory Focus Groups Discussion Guide:

<https://drive.google.com/file/d/1A1BwxMjnuU-HDytUPMvtvujFDGvlyzPW/view?usp=sharing>

2) Survey Questions:

<https://drive.google.com/file/d/1G5wCrslhVgvIXDvb6UDYARCZSoo1VVxT/view?usp=sharing>

3) Survey Results:

https://drive.google.com/file/d/1_p6nHtudKtWmRvGz4a97nxHbO12933OE/view?usp=sharing

4) Follow-Up Focus Groups Discussion Guide:

https://drive.google.com/file/d/16LoVtD6_UwqfS6jnwYHh52Vw7al4rgd/view?usp=sharing

5) Narratives:

<https://drive.google.com/file/d/1vRWSEmncm8KBhTcZZmKpMBzpGj6IFD3n/view?usp=sharing>

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