2021 Pediatric Pain Survey

U.S. PAIN FOUNDATION

PEDIATRIC PAIN WARRIOR
A U.S. PAIN FOUNDATION PROGRAM

Chronic pain affects millions of children in America, but experts seem unable to agree on a single number. This unclear picture is just one small example of our inadequate understanding of and attention paid to pediatric pain.

In fact, while studies increasingly show that pain care is insufficient for American adults, pediatric pain management is often considered even less adequate. This paints a troubling picture for youth diagnosed with chronic pain.

To better understand the challenges faced by children with chronic pain and their loved ones, U.S. Pain Foundation's Pediatric Pain Warrior program recently surveyed 125 families with one or more children living with pain.

The results show that children with chronic pain experience high levels of pain and disability, struggle to control pain with currently available treatments, face serious quality of life and mental health obstacles, and are at risk for insufficient education and social support.

Our hope is that this survey can benefit both children with chronic pain and their families by highlighting the need for better pain management. This includes addressing their physical and emotional needs along with providing improved educational and social support.

Children are our greatest asset as a society; they represent our hope for the future. Improving care for children with chronic pain is essential to helping them meet their greatest potential throughout their lives.

Sincerely,

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IN THIS REPORT:

Key Takeaways

1. Pediatric pain is real and children live with severe pain daily.

2. Pediatric pain is an underserved, underrecognized condition.

3. Comprehensive pain services for pediatric pain are not readily available or easily accessible.

4. The cost of caring for a child with chronic pain is daunting and often leaves families unable to afford much-needed care.

5. The social and psychological impacts of pediatric pain are life-altering and potentially life-threatening.

6. Caregivers of pediatric pain patients want to learn more about medical, rehabilitative, and psychological care options.

Demographics

Between January 31 and March 12, 2021, 125 responses were received to the Pediatric Pain Survey. All respondents, who were typically parents or caregivers, reported having at least one child with chronic pain. Individuals with more than one child with chronic pain were instructed to give an answer for each question that reflected an approximation or average for all of their children.

The age range of responses was from preschool age (less than 5 years old) to 21 years or older. The most common age range was 16-21 years (49%) followed by 11-15 (39%), then 5-10 (22%). Over 21 years and under 5 years of age were relatively smaller portions at 6% and 4%, respectively.

When asked what gender the child with chronic pain identified as: 62% were female, 40% were male, 6% were transgender male, 5% were gender non-conforming, and 2% did not respond. Respondents were able to select multiple options as well.

Survey authors also chose to allow respondents to select multiple races to better reflect individuals who are mixed race. Most respondents identified as white (89%) while 2% chose "Prefer not to answer." A total of 11% indicated they were either multiracial (8%) or BIPOC (Black, Indigenous, and people of color) (3%).

The breakdown of BIPOC by race is as follows: American Indian or Alaskan Native (2%), and then 1% for Black or African-American, and Asian. In another question, 9% of respondents indicated their child is Hispanic or Latino(a). This data suggests a significant need to conduct more outreach to diverse patient communities, who are underrepresented in this survey.

The majority of children have private insurance through a family member's employer (62%), followed by Medicaid (28%). Small segments reported having other insurance such as Cobra or Tricare (6%), self-funded insurance (2%), or not being insured (2%).

While 2% is a seemingly small number, it is alarming that any child with a chronic condition is without medical insurance.

Pain Severity and Causes

When asked about average daily pain level on a scale of 0 to 10, with 10 being the highest pain, the average response was 5. More than half of children (54%) rated their daily pain as a level 6 or above.

When asked how long the child had experienced chronic pain, the large majority —82%— indicated the child had lived with pain for at least 50% of their lives (**see Figure 1**).

When asked about the number of confirmed medical diagnoses per child, respondents indicated: one to two (20%), three to five (41%), six to nine (26%), 10 or more (10%), and zero (3%). This means that more than three-quarters have at least three diagnoses.

The most commonly reported diagnosis was tied between Ehlers-Danlos syndrome and headache/migraine (66%). Other common diagnoses that affected at least half of respondents were postural orthostatic tachycardia syndrome (56%), hand/wrist/elbow pain (51%), and knee pain and back pain both at 50%. **See Figure 2** for all diagnoses in descending order.

Figure 1: Percentage of child's life that they have experienced pain

How Long	Percent	Responses
75%	30%	38
50%	28%	35
100%	24%	30
25%	18%	22

Figure 2: Commonly reported diagnosis

Ehlers-Danlos syndrome	**66%**
Headache/migraine	**66%**
Postural orthostatic tachycardia syndrome	**56%**
Hand/wrist/elbow pain	**51%**
Knee pain	**50%**
Back pain	**50%**
Foot pain	**46%**
Neck pain	**44%**
Hip pain	**42%**
Nerve pain or neuropathy	**34%**
Irritable bowel syndrome	**28%**
Complex regional pain syndrome	**25%**
Temporomandibular joint syndrome	**24%**
Other condition	**23%**
Fibromyalgia	**15%**

82% **indicated the child had lived with pain for at least 50% of their lives.**

Impact of Pain On a Child and Their Family

This survey offered a glimpse into the very hard, lonely, and ever-changing challenge of being a child growing up with chronic pain. It also underscored the severe lack of support for children with pain and their families.

Four core areas were investigated: Psychological impact, social opportunities and relationships, educational access and family impact.

"It can be really lonely."

— Noah, age 15

Psychological impact:

Children in chronic pain are not just suffering physically. They are also facing significant emotional stress due to the physical pain and its impact on their quality of life.

As seen in **Figure 3**, the survey revealed the large majority (84%) of kids with chronic pain experience anxiety while nearly half (48%) expressed guilt for being sick. Thoughts of self-harm and suicide were, tragically, not uncommon. Even more unsettling is the fact that 4% of kids have attempted suicide.

Figure 3: The Impact of pain on mental health

Experienced anxiety	**84%**
Felt isolated	**79%**
Expressed guilt for being sick	**48%**
Thoughts of self-harm	**42%**
Contemplated suicide	**22%**
Carried out self-harm	**16%**
Attempted suicide	**4%**

Clearly, these children are facing significant mental health trauma and need more support, relief, and care. They are navigating significant losses in quality of life as the result of being unable to fully enjoy hobbies and activities, social exclusion, and even bullying from their peers. They face anxiety over the future of their health, often have trouble keeping up at school, and so much more. Childhood is supposed to be a carefree time of growth, exploration, and discovering one's identity—instead, these children are grappling with immense suffering and stress.

Pain psychology has been listed as an area that caregivers desire better access to. Educational barriers and social isolation also must be addressed to allow these children to enhance their quality of life.

Social opportunities and relationships:

> “Sometimes people might call you weak or crippled, but don’t let that stop you, you can do anything.”
> — Kaiya, age 11

When asked about their child’s social opportunities and relationships, caregivers clearly communicated that access to both is lacking in their child’s life.

Children who experience chronic pain report feeling isolated at a rate of 80%, while 68% report being excluded from social activities due to their health condition. Nearly two-thirds (61%) have had to quit teams or clubs. More than half (54%) reported losing friends due to illness while 34% have been bullied due to their health conditions.

These staggering rates of exclusion and social isolation leave these children vulnerable to depression and can negatively impact self esteem. More understanding, empathy, and opportunity for social engagement among children with pain needs to be made available.

Stigma around disability:

More than two-thirds (69%) of families surveyed indicated that their child utilizes an assistive device. When asked what kind of device the child uses, responses included wheelchair (65%); limb brace (50%); crutches (23%); walker (22%); finger ring splints (20%); cane (15%); neck brace (12%); and catheter (7%). A total of 16% said their child uses other types of devices.

However, of the children who use assistive devices, caregivers reported that, on a monthly basis, many children avoided using them due to embarrassment. Approximately one-quarter (26%) of kids did not use their devices one to three times a month, 21% four to six times per month, 19% did not use 10 times or more per month, and 2% seven to 10 times per month. Almost one-third (32%) said the child did not avoid the device.

Nearly two-thirds (61%) have had to quit teams or clubs.

Education:

When asked if their child attended school in-person prior to school shutdowns as the result of Covid-19, nearly half of respondents indicated their child was not able to attend school full-time due to chronic pain, stating the child did not attend in person at all (30%) or attended with a modified schedule (19%).

Children who were able to attend school in-person still encountered frequent absences such as sick days, going home early, starting late, or missing school due to doctors' appointments. In fact, 52% of respondents indicated they missed school at a frequency of up to two times per month, while 25% stated their child missed three to five days of school per month and 23% stated their child missed an average of five or more absences per month.

Frequent absences are concerning for a number of reasons. First and foremost, they indicate inadequate management of illness. Absences also put children with pain at risk of falling behind in their education —and likely result in added stress from needing to make up missed work. In addition, these absences likely correlate with days that parents or caregivers need to take time off from work, representing lost income and the difficulty of maintaining employment while caring for a loved one. Caregivers of children who did not attend in-person school, even prior to the pandemic, listed the following the reason(s) for not attending: their health condition prevented them from attending enough to have consistent education (58%), the school was not able to adequately meet the child's health-related accommodation needs (34%), child prefers to attend home school or online (16%), or the social climate was not healthy for child (11%). A total of 16% indicated other reasons.

Clearly, children with chronic pain have immense difficulty attending school as consistently as their able-bodied peers. It is especially concerning that more than one-third were unable to attend school because of a lack of accommodations. We have a moral and legal obligation to ensure children have access to quality education—regardless of health status or disability.

Family impact:

"It means you have to craft a life where you can drop all your other responsibilities at a moment's notice to go help your child if she is sick or has an injury. It is always advocating and explaining her needs, over, and over, and over again to teachers and family members who don't get it." — Maya, mom of a child with chronic pain

When a child is facing the challenges of chronic pain, they are often not alone. The entire family is impacted. The "normal life" that most families take for granted is not one typically experienced by the families of these children.

Figure 4 shows the results of when parents and caregivers were asked to indicate how often their child's pain has restricted their ability to to engage in basic activities.

THE ENTIRE FAMILY IS IMPACTED.

Caring for someone experiencing pediatric chronic pain negatively affects the caregiver's ability to care for themselves, physically and emotionally, and affects their quality of life in significant ways. We see a daily experience of both child and family being prevented from carrying out normal activities. The financial burden of work interruption and cost of care will be discussed in greater detail later in this report.

Figure 4: Impact of pediatric pain on caregivers' basic activities

Socialization	**67%**
Work	**65%**
Self-care	**64%**
Family vacation	**61%**
Hobbies	**58%**
Sleeping	**56%**
Exercise	**50%**
Household chores	**47%**
Romantic relationships	**33%**

Treatment Access

Finding consistent and helpful care for a child experiencing chronic pain is often difficult and involves many medical providers and visits to healthcare providers. When asked to indicate how many medical appointments their children average a month, 39% indicated between one and two visits, 35% marked three to five, 14% at six to nine, and 9% marked 10 and over. 4% of respondents average zero visits per month.

Out of these visits, primary care providers were reported as the most commonly seen medical provider (69%), followed by physical or occupational therapist (56%), mental health provider (53%), gastroenterologist (42%), neurologist (42%) and pain specialist (41%).

This shows that less than half of children in chronic pain have a pain specialist caring for them, which is concerning given the severity of pain reported. In fact, 38% of those surveyed indicated that they would like to see a pain specialist but have been unable to do so. **Figure 5** also indicates which provider is responsible for managing the child's pain condition, with highs of primary care physician (36%) and pain specialist (30%). These relatively low figures in comparison to the most commonly seen medical providers shows that pain management is oftentimes being left up to the caregiving family, who are forced to juggle multiple appointments and serve as the hub for their child's treatment.

Figure 5: Provider responsible for managing pain

Primary care physician	**36%**
Pain specialist	**30%**
Neurologist	**13%**
Physical or occupational therapist	**4%**
All other	**12%**

Treatment options:

When asked what type of treatment respondents felt their providers emphasized most, roughly one-third (32%) answered prescribed medications, followed by self-management like pacing, sleep hygiene, and nutrition (16%); restorative therapies such physical therapy, occupational therapy, hot/cold therapy, massage, and chiropractic care (14%); then mind-body and behavioral health care (12%) and over-the-counter medications (10%). Other categories that were lightly emphasized included complementary medicine (6%), injections or blocks (2%), and surgical interventions (2%). A total of 6% said their providers "emphasize all categories equally." **Figures 7 and 8** go into further detail on how many prescription and over-the-counter medications children take daily.

Figure 6: Treatments emphasized by providers

Prescribed medication	32%
Self-management	16%
Restorative therapy	14%
Behavioral health	12%
Over-the-counter medication	10%
All categories equally emphasized	6%
Complementary and integrative therapy	6%

Figure 7: Prescription medications taken daily

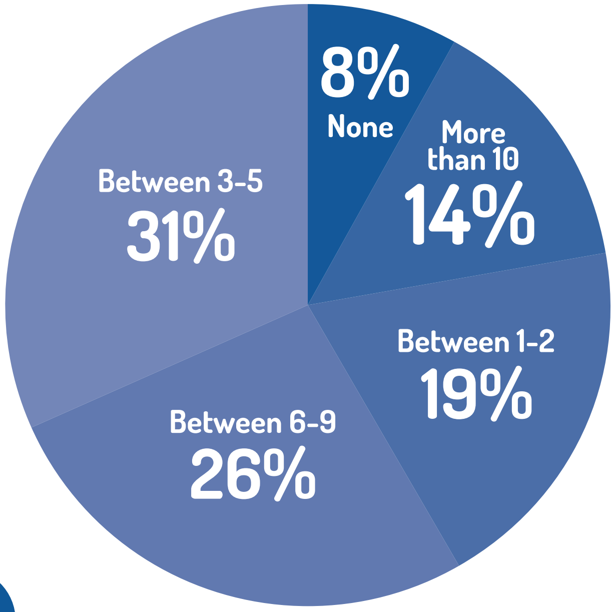
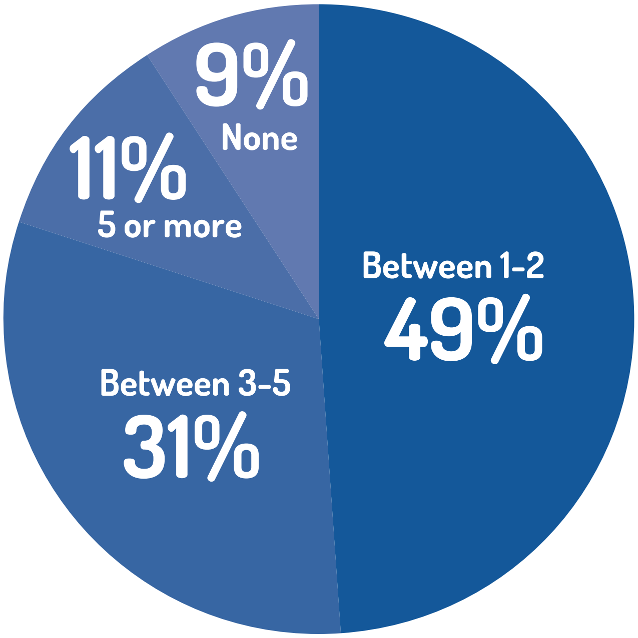


Figure 8: Over-the-counter medications taken daily



Desired providers and treatment:

When asked what kind of providers caregivers would like their child to see but have not been able to due to limited resources such as cost, insurance barriers, travel, and similar issues, the following specialties and rank were revealed:

Figure 9: Desired caregivers

Pain specialist	**38%**
Massage therapist	**38%**
Physical or occupational therapist	**32%**
Naturopath, homeopath, or functional medicine specialist	**29%**
Psychologist, psychiatrist, or other mental health professional	**21%**
Geneticist	**20%**
Nutritionist	**16%**
Neurologist	**15%**
Headache/migraine specialist	**14%**
Sleep specialist	**14%**
Gastroenterologist	**14%**
Acupuncturist	**13%**
Chiropractor	**12%**
Rheumatologist	**12%**

ONLY 22% of respondents said, “There is no category I wish was emphasized more.”

Also noted at less than 10% were endocrinologist, neurosurgeon, orthopedic surgeon, urologist, primary care physician, dermatologist, and oncologist. 14% of respondents answered none.

The following question, “Which categories of pain management do you wish were emphasized more by your providers?” revealed a preference for a much broader range of therapies than are typically offered or covered by payers. The most common answers were restorative therapies (46%); complementary and integrative therapies (43%); mind-body and behavioral health approaches (31%); self-management strategies (28%); neuromodulation or electrical stimulation devices (26%); prescribed medications (25%); injections and blocks (18%); surgical interventions (6%); and over-the-counter medications (4%).

Only 22% of respondents said, “There is no category I wish was emphasized more.”

Figure 10: Wished for pain management

Restorative therapy	**46%**
Complementary and integrative therapy	**43%**
Behavioral/mind-body	**31%**
Self-management strategies	**28%**
Neuromodulation or electrical stimulation	**26%**
Prescribed medication	**25%**
No category I wish was emphasized more	**22%**
Injections and blocks	**18%**
Surgical interventions	**6%**
Over-the-counter medication	**4%**

Barriers to care:

Beyond not being able to access the kinds of providers they desire, when asked, "Have you faced any of the following barriers to your child's care?" 65% said they can't find a provider who is knowledgeable about their child's condition; 58% felt their provider didn't believe their child or take them seriously; 55% have been told there is nothing else they can do for their child; 42% stated they lack coverage for multidisciplinary treatment options (PT, massage, acupuncture, etc.); 40% cited high out of pocket expenses; 36% reported problems with prior authorization; 30% said there was lack of pain specialists in their area, 28% noted hitting maximum annual visits; and 27% named step therapy or fail first insurance requirements.

Additionally listed at lower rates were medical marijuana laws, surprise medical bills, dropped by doctor (for any reason), transportation difficulties, forced tapered off medication or dosage drastically reduced, and nonmedical switching (insurance coverage changed mid-year). 6% did not face any barriers.

What is particularly troubling is that the top three barriers all highlighted a lack of care available to children with chronic pain. These responses paint a picture of a health care environment with providers who are not knowledgeable about pediatric chronic pain, don't take pediatric pain seriously, or feel they have little to offer to meet the needs of these children.

More abundant and varied treatment and services are needed to provide a more comprehensive approach for pediatric pain management. There is no standard approach or best practice when it comes to the treatment of children's chronic pain. This has left caregivers in the position of fighting for children's needs as well as feeling they, themselves, need to become the experts to lead their children's care teams.

The Cost of Care

Unaffordable treatment:

The vast majority of children were reported to have some kind of health insurance. However, even with health insurance, a combination of out-of-pocket expenses coupled with high rates of employment disruptions have left chronic pain families vulnerable to economic depression.

Respondents were asked how many times they have had to decline desired treatments or therapies due to not being able to afford it. This question was asked irrespective of insurance, given that many therapies are not commonly covered (such as massage, acupuncture, etc.).

More than 60% of respondents reported having to decline services due to cost. The most common response was declining 1-3 services (36%), followed by 4-6 services (18%), then 10 or more services declined (5%) and 7-9 services declined at a rate of 3%. Only 39% said they had not declined services due to cost.

Out-of-pocket expenses:

While most children were covered by insurance (98%), coverage limitations and out-of-pocket costs prove to be a significant barrier. When asked how much they pay in out-of-pocket expenses for their child—including insurance deductibles, copays, medication, self pay medical treatments, devices, etc.—nearly half of respondents reported paying between $2,500 -$10,000 annually. The specific amounts can be seen in **Figure 11**.

Impact of pain conditions on caregiver employment:

In addition to the medical expenses inherent to health care, pediatric pain families often face employment challenges for the caregivers, with 65% of respondents indicating that caring for their children's chronic pain needs has impacted their ability to work. Of those respondents, 49% have had to reduce the amount they are able to work, 31% have had to stop working to provide care for their child, 9% have been unable to pursue employment due to their child's care needs, 7% have had to take a different position or job, and 4% have lost their job due to their child's care needs.

In short, families of children with chronic pain find themselves facing higher expenses while earning less money. Coupled with other income challenges, out-of-pocket medical expenses are having a drastic and negative impact on families, forcing them to struggle to make ends meet and introducing another compounding stressor.

Figure 11: Out-of-pocket medical care

$5,000–$10,000	**26%**
$2,500–$5,000	**22%**
$500–$2,500	**21%**
$0–$500	**20%**
$10,000–$25,000	**8%**
Greater than $25,000	**4%**

Education and Support

As illustrated by much of the previously presented data, caregivers often find themselves in the position of searching for care options in a medical arena that otherwise does not or cannot easily offer robust treatment for pediatric pain.

Respondents were asked the open-ended question, "What types of therapy or medications would you like more education/information about?" While answers varied, the most commonly desired education centered around alternative and integrative medicine and services, followed by pediatric pain management care, mental health care, and experimental or investigational treatments. Additionally, a significant portion of respondents simply stated "anything that will help."

When given a list of educational topics and asked which three would be most valuable to their family in a webinar format, respondents indicated advocating for best success at school or work (46%), art and music therapy (42%), and non-medication pain management information from a physical therapist and medication education about types and uses of medication from an expert tied at 38%.

Families of children with chronic pain are searching for as much education and help as possible as they navigate, often on their own, the difficult path of care options. Educational resources regarding childhood pain are limited and more and more caregivers are turning to nonprofits and similar organizations to supplement their care planning.

Figure 12: Therapy or medications respondents would like more info on

Alternative/integrative (Acupuncture, functional Medicine, nutritional supplements, massage therapy, natural medicines including CBD and medical marijuana, etc)	**52%**
Pain management services	**35%**
Anything	**59%**
Water therapy	**14%**
Experimental/investigational	**10%**
Mental health	**10%**
CBD and or medical marijuana	**7%**

> **"ANYTHING THAT WILL HELP."**

Conclusion

Pediatric chronic pain has proven to be devastating for both children and their families. As this report illustrates, pediatric pain is not adequately addressed and caregivers are left searching, on their own, for care options and more adequate resources for their children.

We recommend the following steps be taken to enhance the care provided to children and families affected by chronic pain:

Increase emotional and educational support

Children and families should be provided more opportunities to socialize and meet their emotional needs. We know that 68% of pediatric pain families stated they aren't able to socialize, while 79% of the children feel isolated, and 61% of families have been unable to take family vacations due to the impact that chronic pain has had on their lives.

Efforts should be made to connect families and children, along with pediatric pain experts in an accessible teaching arena.

Furthermore, pediatric chronic pain is not well recognized overall, but especially so in the school setting, where it proves to be a daunting task to establish and maintain accommodations for these children. We recommend the following steps be taken to enhance the quality of care provided for children in educational settings:

- School administrators and staff need to be educated on the topic of chronic pain and the challenges that it presents in an educational setting.
- 504 and IEP plans need to be more easily accessible, customized and consistently actionable in the interest of the child.
- Not only teachers, but all children should be provided with a curriculum that helps to better understand disability and foster empathy to avoid bullying and exclusion of children with any disability, including chronic pain.
- A myriad of educational options should be made available— including online options, which school districts have learned to provide over the past year.

Increase access to providers and treatments

The survey results highlight the need for more providers and treatments for children experiencing chronic pain to provide a more comprehensive approach for pediatric pain management.

Provide affordable and robust care options

No child, or adult, should have to go without care that could help them. Pediatric pain patients would benefit from insurance plans that allow coverage for comprehensive pain care including, but not limited to, unlimited physical and occupational therapy, psychological support, currently non-covered medication, and holistic care such as massage or acupuncture.

Educate physicians on pediatric pain

Health care systems also have the potential to reduce the severity of pediatric pain by educating their current providers about approaches to pediatric pain management and hiring more pediatric pain specialists including pain management doctors, pain psychologists, and pain aware physical therapists.

Stand together

As we have indicated, pediatric chronic pain is often inadequately treated and both children and their families do not receive the support they need. This does not have to be the case.

By providing greater emotional, educational, financial, and healthcare support, we can change the lives of millions for the better. We hope this report shines a light on these critical issues and points a path forward for meaningful change.

Because no one should fight pediatric chronic pain alone.

To learn more and to find support, please visit
uspainfoundation.org and **pediatricpainwarrior.org**.

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