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June 15, 2020

Sandra Cashman
Executive Secretary
Centers for Disease Control and Prevention
1600 Clifton Road NE
Atlanta, Georgia 30329

Transmitted electronically

Re: CDC–2020–0029; Management of Acute and Chronic Pain: Request for Comment
85 Fed. Reg. 21441 (April 17, 2020)

Dear Ms. Cashman:

The American Cancer Society Cancer Action Network (ACS CAN) appreciates the opportunity to respond to the request for information regarding the management of acute and chronic pain. ACS CAN is making cancer a top priority for public officials and candidates at the federal, state and local levels. ACS CAN empowers advocates across the country to make their voices heard and influence evidence-based public policy change as well as legislative and regulatory solutions that will reduce the cancer burden. As the American Cancer Society's nonprofit, nonpartisan advocacy affiliate, ACS CAN is critical to the fight for a world without cancer.

Pain is one of the most feared symptoms for cancer patients and survivors - nearly 60 percent of patients in active treatment and 30 percent of patients who have completed treatment experience pain.¹ Pain can be caused by the cancer itself, for instance when tumors interfere with normal body function. Pain can also be caused by cancer treatments. Research has concluded that about one-quarter of women who have had breast cancer surgery have significant and persistent breast pain six months after the procedure.²

Given proper attention most pain can be treated and relieved. Integrative pain care that includes non-drug therapies along with medications can be effective in keeping patient pain under control. While not the only tool, opioid medications are recognized as a mainstay of treatment for moderate to severe cancer pain and can be a beneficial treatment for managing serious, persistent pain for patients in active cancer treatment as well as cancer survivors. If not treated, chronic pain can have long-term negative effects, including prolonged recovery and a weakened immune system. It can also affect a patient's quality of life; their ability to eat, sleep, work and carry on every aspect of their daily life.³

Many cancer patients, as well as other patients with serious illness, receive pain treatment as part of palliative care services.⁴ Palliative care – which is essential throughout the course of cancer treatment – helps prevent and relieve pain by systematically screening and assessing for pain and other symptoms, tailoring pharmacological and other interventions to patients' individual circumstances (including

medical history and stated goals of care), and carefully monitoring and adjusting treatment regimens as needed over the course of the illness.⁵

ACS CAN represents millions of cancer patients and survivors who have had to manage acute and chronic pain, as well as the healthcare providers who treat them. We appreciate the CDC requesting input from stakeholders on this topic, and encourage CDC to use this information and all the available evidence to update its 2016 Guideline for Prescribing Opioids for Chronic Pain, emphasizing that 1) the Guideline should not be used as a reason to limit or not provide pain treatment, 2) the Guideline was not written for certain patient populations including cancer patients, patients receiving palliative care, or patients in hospice; and 3) clinical practice guidelines specific to these populations should be used to guide treatment and reimbursement decisions regarding use of opioids as part of pain treatment in these cases.⁶ An updated CDC Guideline should be developed transparently, be based on strong evidence, directly acknowledge and incorporate these other guidelines for the appropriate patient populations, and integrate their promotion and use with the CDC Guideline.

Cancer Patient & Survivor Experiences with Managing Pain

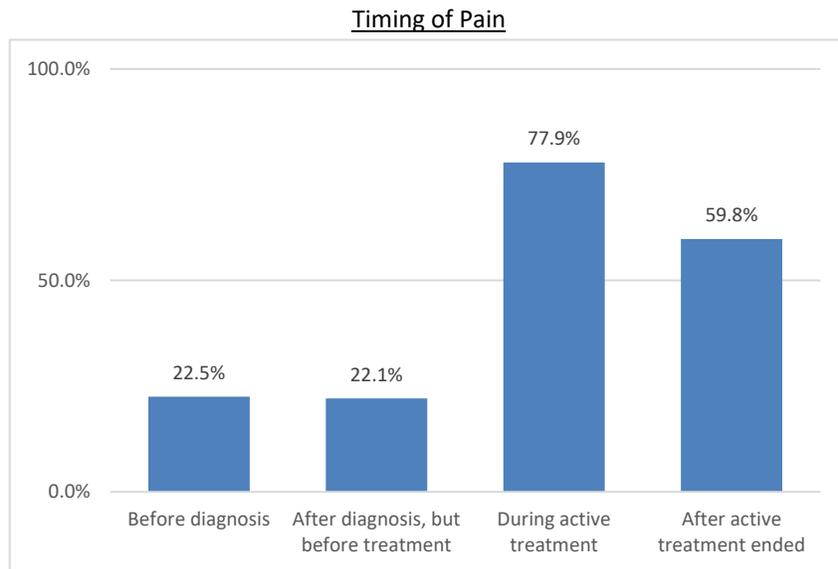
In this RFI, CDC asks for comments “specifically on topics focused on using or prescribing opioid pain medications, non-opioid medications, or nonpharmacological treatments (e.g., exercise therapy or cognitive behavioral therapy).”⁷

In 2019, ACS CAN launched its Survivor Views panel project, which has recruited survey panelists nationwide who have been diagnosed with and/or treated for cancer in the last five years.⁸ In August and September 2019, ACS CAN surveyed this panel on topics related to pain and palliative care.⁹ Several of the key findings from this survey address the topics on which CDC requests comments:

- 1. Experiences managing pain, which might include the benefits, risks, and/or harms of the pain management options listed above.***

Cancer patients must manage pain during active treatment, but pain also often lasts into survivorship.

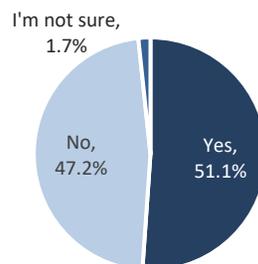
One quarter (25%) of survey respondents reported experiencing pain that “limits work, time with family, or social activities.” While pain was most common during active treatment, 60% of respondents who reported pain told us that their pain continued after the end of active treatment – into survivorship.



A majority of cancer patients currently take opioids or have taken them in the past to manage their pain.

Just over half of respondents have been prescribed an opioid for their cancer, and 13% are currently taking an opioid.

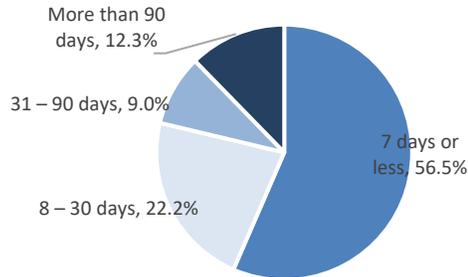
Have you ever been prescribed an opioid for your cancer?



Most cancer patients who have managed their pain with opioids used this medication for a limited amount of time. Longer-term use was associated with more advanced stages of cancer.

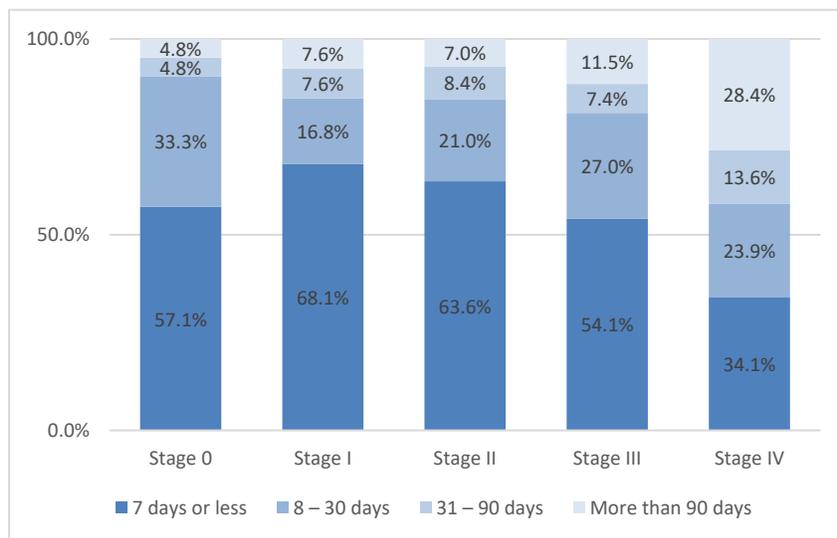
Among those who have taken an opioid, 57% did so for seven days or less, while 12% have taken an opioid for more than 90 days.

Longest days in a row you've taken an opioid for cancer



The duration of opioid use increases steadily as cancer stage progresses, with 28% of respondents diagnosed at Stage IV reporting that they have continuously used opioids for more than 90 days.

Longest continuous use of opioid by stage



2. Experiences choosing among the pain management options listed above, including considering factors such as each option's accessibility, cost, benefits, and/or risks.

Cancer patients taking opioids have experienced barriers to accessing this pain treatment option.

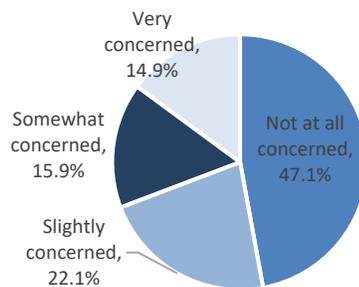
Among respondents who have been prescribed an opioid in the last year, 41% experienced one or more barriers to filling their prescription. The most commonly reported barriers were:

- Doctor indicated their treatment options for your pain were limited by laws, guidelines, or your insurance
- Doctor told you they had to get approval from your insurance before prescribing pain medication
- Pharmacist had to contact doctor before filling and sent you home without your prescription

Those respondents who experienced barriers to accessing opioids report a range of negative effects, including inability to participate in work, family, or social events, requiring additional visits to the doctor or pharmacy, and even trips to the ER for uncontrolled pain. A small number of those who experienced a barrier were never able to obtain their medication.

Based on media coverage and their own experiences, over 50% of respondents who have been prescribed opioids in the last year indicate some degree of concern about their future access to opioids.

Concern over access to opioids in future



Many cancer patients report being offered and using non-opioid pain treatment options. Smaller percentages of patients report having wanted to use a non-opioid treatment and not being able to.

The survey asked respondents to consider a range of non-opioid treatment options¹⁰ and indicate which, if any, they had: 1) been offered by a provider; 2) used; or 3) wanted to use but weren't able to. Below are the top five most selected response options for each category:

Offered by Provider		Treatments Used		Wanted to Use but Couldn't	
Physical, occupational, or speech therapy	31%	Over-the-counter NSAIDs or other non-opioids	28%	Medical marijuana	9%
Prescription-strength NSAIDs	27%	Physical, occupational, or speech therapy	26%	Massage or myofascial release	7%
Over-the-counter NSAIDs or other non-opioids	24%	Prescription-strength NSAIDs	25%	CBD-derived products	7%
Nerve stabilizing medications	17%	Massage or myofascial release	17%	Acupuncture	6%
Massage or myofascial release	15%	Nerve stabilizing medications	14%	Therapies for cancer-related cognitive impairment	4%

*Note: colors indicate same selection in multiple columns

The use, recommended use, or desire to use non-opioid treatments was analyzed by other respondent characteristics to identify trends in the data based on the different courses of their disease and/or

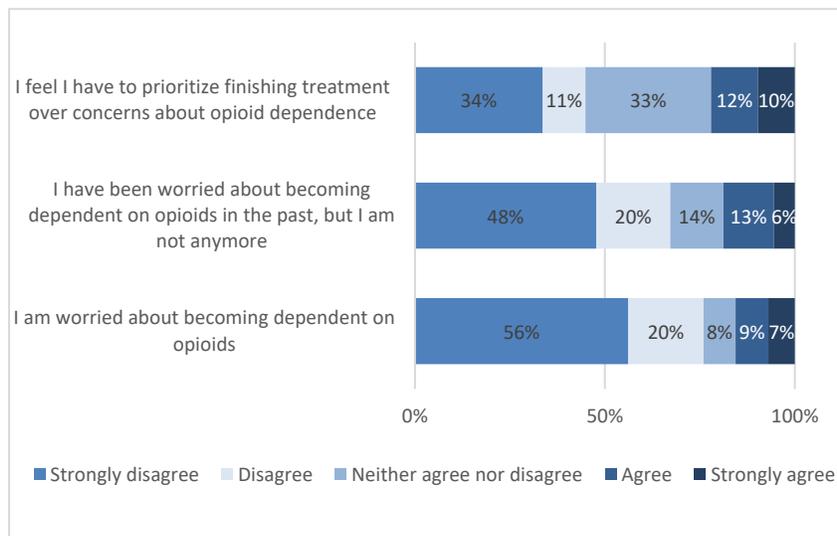
treatment. Specific analysis was conducted by stage at diagnosis, symptoms reported, time since last treatment, and treatments received. Key findings from these analyses include:

- Survivors with stage IV disease are more likely to need interventions, but they are not necessarily being offered non-opioid treatments at higher rates than others. 32% of participants diagnosed at Stage IV report being offered none of the interventions listed, while those diagnosed at Stages 0, I, II, or III were more likely to have been offered these treatments.
- Among those patients with pain, only 49% were referred to physical therapy, occupational therapy, or speech therapy.
- Patients who received treatment for their cancer more recently (within the last year) were more likely to have used NSAIDs and other non-opioid treatments. This could be an indicator of increased difficulty accessing opioids or changing prescribing patterns (but also may be related to difficulty remembering specific treatments after more time has passed).
- Patients who indicated that they had received palliative care were more likely to have been offered and to have used the non-opioid treatments.

Most cancer patients do not report concerns about the risk of addiction when choosing to take opioids.

For respondents who have been prescribed opioids, concern over becoming addicted was relatively low, with only 16% agreeing or strongly agreeing that they are worried about becoming dependent, and 19% saying they have been worried in the past but are no longer.

Sentiments about opioid addiction



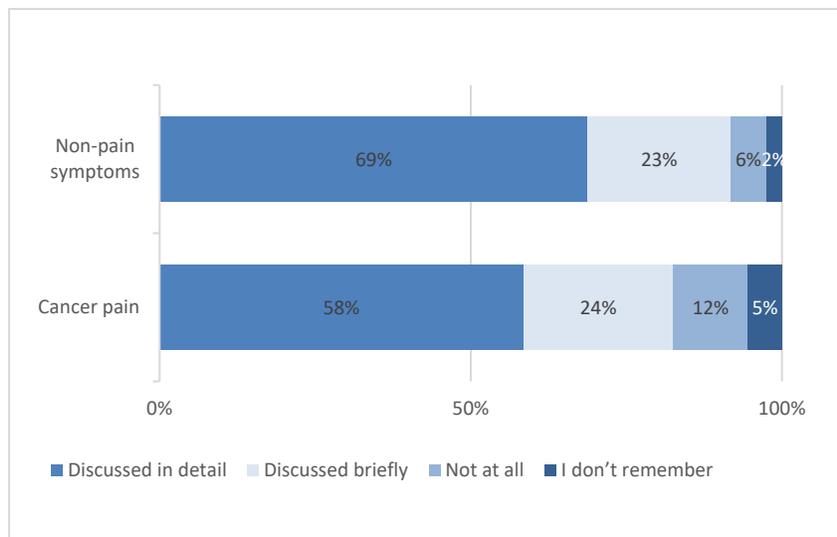
Among those who did have some past or present concern about addiction, the most common actions taken were to limit dosing of opioids (50%), substitute OTC pain relief (49%), or try non-opioid interventions (44%).

3. Experiences getting information needed to make pain management decisions.

Most cancer patients report discussing symptoms with their providers. They report discussing pain slightly less than discussing other symptoms.

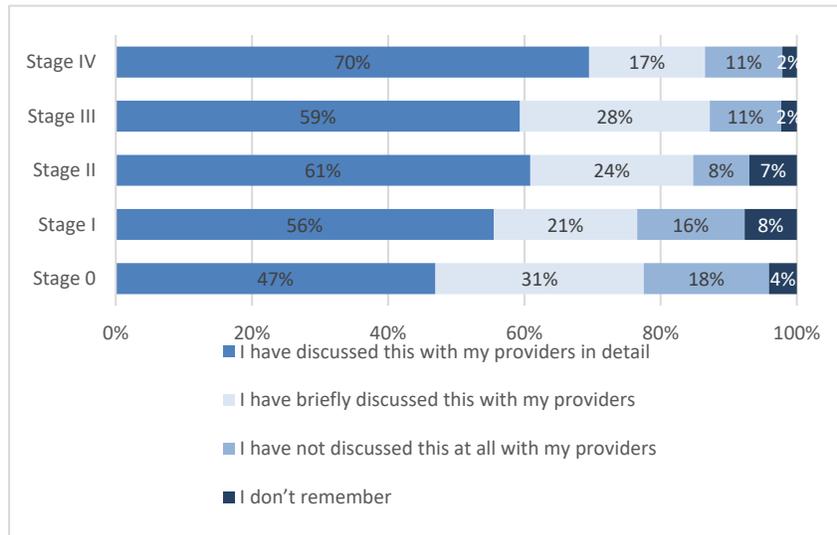
The survey asked all respondents (regardless of whether they had reported pain or other symptoms) to describe their experiences discussing pain and other symptoms with their providers. 92% of respondents had at least briefly discussed their non-pain symptoms and a slightly smaller percentage (82%) had discussed their cancer pain.

Have you discussed symptoms with providers?



Participants who were diagnosed with their cancer at a later stage are more likely to have discussed their pain with their providers.

Discussion of cancer pain by stage



Patient Stories

Respondents to the survey were also given the opportunity to tell their story about cancer, pain and palliative care in their own words. Many of the respondents addressed their experiences managing pain, choosing between pain management treatment options, and/or choosing to go without pain treatment. Below is a selection of these stories.¹¹

I have found that since surgery to remove my primary tumor, eating is always painful. You go through life taking for granted the ease of digesting food until you are unable to. My pain is every single meal. I worry greatly about addiction to pain meds with the news and opioid crisis. So I generally skip meals to avoid pain and need for medication. It is debilitating both physically and mentally. Chronic pain associated to cancer is horrible and I realize how [judgmental] doctors and pharmacists and even insurance companies can be. So I limit my use greatly, but also limit food intake.

Pancreatic Cancer Survivor, California

I have Multiple Myeloma - cancer of the plasma cells... I live with pain daily, the only change is in degree. I take the bare minimum I can, in order to be able to function somewhat during the day, drive, and remain independent. I've not worked since the third month I was in treatment. I worry when I hear about restrictions in medications because of the "opioid crisis." I experimented at one point without pain meds other than OTC meds for several days. The pain is real; I needed quite a lot of OTC meds, which I know the doctors don't want me doing over the long haul because of damage to the liver and kidneys. Bone pain is unlike muscle pain, and unlike any other pain I've experienced. You can't "stretch it out" or "warm up" to alleviate it. I'm grateful not to have had difficulties with getting what I need, and

seriously hope I'm never put in the position of enduring unnecessary pain as a result of policies meant to curb a different type of pain medication use.

Multiple Myeloma Cancer Survivor, Oregon

My cancer pain was a shock and then lasted much longer than I could have imagined. Being in physical pain also leads to emotional issues, like depression. When medication is your only option for pain it affects your daily life as well. I was on medications that prevented me from driving, and since I have kids and live in the suburbs that presented a major life challenge. And often those around you are worried about the types of medications you are receiving. I didn't worry about addiction; I just wanted to get out of pain. I was Stage 4 so everyone was more liberal with the prescriptions. But even in the hospital it took hours to get nurses to believe the pain and call a doctor and then finally I had to get a pain specialist. If you have cancer and you're in pain, you need relief. End of story.

Breast Cancer Survivor, California

Pain affects every part of your life. It not only affects your physical ability to do things, but your emotional state and your motivation to try and do things. For the most part, the treatments I have received have been effective. However, I do not think that access to opioids should be limited for people who truly need them and have found other treatments ineffective. There have been times when I have not used opioids that have been prescribed to [me] because I knew that there might be worse pain coming and that it would be difficult to get more.

Breast Cancer Survivor, Pennsylvania

As someone who is dealing with long term on and off chronic pain from my previous cancer [diagnoses], I struggle at times with being able to adequately get prescription medication at times to help manage. I continue to seek and utilize non medication treatment and relief, but sometimes that alone is not enough and some of it is not covered by my insurance making it unaffordable and unattainable. I am limited to the number of visits I have each year with both my Chiropractor and Osteopathic Manipulation Doctor and massage therapy is not a covered benefit for me. Currently, I am pregnant and the non-opioid medications I typically use for pain management are not allowed during pregnancy. I can however use [an opioid] (though I prefer not to by choice unless absolutely needed). However it took 2 months and being bedridden several times to get a prescription because 2 of my 3 doctors will no longer even write prescriptions for [opioids]. While I understand there is a problem with abuse, this problem has created major issues for those of us with real long term pain, like cancer patients. Much of my depression, anxiety and limitations on daily living are directly related to the continued pain that I have on a regular basis.

Head and Neck and Non-Hodgkin Lymphoma Cancer Survivor, Michigan

I have tried all non opioid medicines, OT, and steroids to help with lymphedema pain caused by cancer treatments with no help. The meds are the ONLY thing that helps me be able to do semi normal daily things. I do not abuse my meds and I only use them when necessary.

Breast and Cervical Cancer Survivor, North Carolina

I am a stage III b rectal cancer survivor. The treatment was very aggressive and has left me with chronic pain and other permanent health conditions. I am 53 and single so I need to work. I switched to a part

time job to take care of my health and my new insurance doesn't cover some treatments for pain. I can no longer get massage therapy so my hips are constantly painful. My new insurance doesn't cover a generic drug to treat the vaginal scarring from radiation. I'm at increased risk of [gynecological] cancers, but I may not be able to undergo screening because of radiation damage. My new insurance doesn't cover acupuncture so that's no longer an option. I work at a hospital, but can't take care of my health conditions because of insurance.

Rectal Cancer Survivor, Washington

Conclusion

Thank you for allowing ACS CAN to provide input and share the stories of our Survivor Views panel on these important topics. Many cancer patients and survivors report having to manage pain during and after active cancer treatment, and these survey findings provide incite into patients' experience managing this pain with opioids, choosing and accessing (or not being able to access) alternatives to opioids, and discussing treatment with their healthcare providers. If you have any questions or want to discuss the survey data presented here, please contact Jennifer Hoque, Senior Policy Analyst, at 202-585-3233 or Jennifer.Hoque@cancer.org.

Sincerely,



Lisa A. Lacasse, MBA
President

¹ Institute of Medicine. (2011). *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education and Research*. National Academy of Sciences.

² Miaskowski C, Cooper B, Paul SM, et al. (2012). Identification of Patient Subgroups and Risk Factors for Persistent Breast Pain Following Breast Cancer Surgery. *J Pain*; 13(12) pp 1172-1187.

³ Institute of Medicine. "Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education and Research." June 2011. <http://www.nationalacademies.org/hmd/Reports/2011/Relieving-Pain-in-America-A-Blueprint-for-Transforming-Prevention-Care-Education-Research.aspx>

⁴ "Serious illness" is defined as a health condition that carries a high risk of mortality and either negatively impacts a person's daily function or quality of life, or excessively strains their caregivers. See Kelley AS, Bollen-Lunds E. Identifying the Population with Serious Illness: The "Denominator" Challenge. *J Palliat Med*. 2017 Nov 10. doi: 10.1089/jpm.2017.0548.

⁵ Morrison LJ, and Morrison RS. Palliative care and pain management. *Med Clin N Am*. 2006; 90(5):983-1004. doi: 10.1016/j.mcna.2006.05.016. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/16962853>

⁶ See https://www.nccn.org/professionals/meetings/oncology_policy_program/pdf/2019_CDC_letter_to_NCCN_ASCO_ASH.pdf

⁷ 85 Fed. Reg. 21441 (April 17, 2020)

⁸ For more information about Survivor Views, please visit <https://www.fightcancer.org/survivor-views>

⁹ For the overall key findings for this survey, please visit <https://www.fightcancer.org/policy-resources/survivor-views-pain-and-palliative-care-survey-findings-summary>

¹⁰ For the full list of response options for this question, please see appendix A.

¹¹ Patient stories are provided verbatim and have only been edited for spelling and grammar where indicated.

Appendix A – Response selections available for survey question regarding accessing non-opioid treatments:

Over the counter NSAIDs or other non-opioid medicines
Physical, occupational, or speech therapy
Prescription strength NSAIDs
None of the above
Massage or myofascial release
Nerve stabilizing medications
CBD derived products
Acupuncture
Psychological therapy/ or other treatment by a mental health provider
Medical marijuana
Other
Surgery
Therapies for cancer-related cognitive impairment
Anesthetic injections or nerve blocks
Transcutaneous electrical nerve stimulation
Dry needling
Hypnosis
Botox injections for pain or function
Radiofrequency ablation
Spinal cord stimulation (SCS)