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## **VIA FEDERAL eRULEMAKING PORTAL**

June 16, 2020

Shannon Lee  
Centers for Disease Control and Prevention  
1600 Clifton Road NE, Mailstop S106-9  
Atlanta, Georgia 30329

**RE: Management of Acute and Chronic Pain - Request for Comment, Docket No. CDC-2020-0029**

Dear Shannon:

I am writing on behalf of the National Alliance for Caregiving (NAC) in response to the request for comments on the perspectives on and experiences with pain and pain management. We are providing data and comments on the experiences of family members and/or caregivers managing pain, choosing pain management options, and making pain management decisions. We appreciate the opportunity to provide a response to the CDC's **Management of Acute and Chronic Pain - Request for Comment (CDC-2020-0029)** and stand at the ready to provide information on the caregiver's journey in managing pain.

### **ABOUT NAC**

The National Alliance for Caregiving (NAC)<sup>1</sup> is a 501(c)(3) charitable non-profit organization dedicated to improving quality of life for unpaid, friend, or family caregivers through research, innovation, and advocacy. For more than twenty years, we have conducted public policy research on the caregiving experience of unpaid friends and family members, including the long-running research series *Caregiving in the U.S.* conducted in 1997, 2004, 2009, 2015, and most recently in 2020, in partnership with AARP.<sup>2</sup>

As an alliance of organizations, we conduct national research on caregiving in various areas including aging, Alzheimer's disease and dementia, cancer, mental illness such as depression and bipolar disorder, rare and orphan diseases, and autoimmune disorders such as inflammatory bowel disease. Our advocacy work engages grassroots networks of state and local caregiving advocates who represent communities across the United States and often provide services, information, or support to caregivers.

On the international stage, NAC is the founder and Secretariat for the International Alliance of Carer Organizations (IACO). In this role, we support a global coalition that includes 16 non-governmental organizations including Australia, Canada, Denmark, Finland, France, Hong Kong, India and Nepal, Ireland, Israel, Japan, New Zealand, Sweden, Taiwan, and the United Kingdom. Many of these nations have formal recognition of the role that caregivers (or "carers") play in the delivery of health and social care. This global coalition meets annually to share best practices and identify emerging trends in supporting caregivers as they support someone with an ongoing health care need or disability.

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<sup>1</sup> Learn more about us at [www.caregiving.org](http://www.caregiving.org).

<sup>2</sup> See National Alliance for Caregiving and AARP, *Caregiving in the U.S. 2020*, available at <https://www.caregiving.org/caregiving-in-the-us-2020>; <https://www.aarp.org/caregiving>; and <https://www.aarp.org/ppi/info-2020/caregiving-in-the-united-states.html>.

## FAMILY CAREGIVING AND MANAGING PAIN

***Challenge: Friend and family caregivers often lack support to help others with pain management, resulting in additional strain and potentially creating poorer health outcomes for families.***

In a 2019 study on family caregivers providing complex care in the home, AARP's Public Policy Institute noted the unique challenges of families who are asked to help manage pain.<sup>3</sup> More than 7 in 10 family caregivers across the United States who assist another individual with medical/nursing tasks reported that they help that same individual manage pain and/or discomfort. Yet despite the fact that most intense and complex family care providers are taking on pain management, these caregivers experience strain and difficulty due to concerns about *how* to manage pain.

More than eight out of ten caregivers rated pain management as stressful. Nearly half (40%) found it difficult to understand how to control pain, and more than one in four were concerned that they are not giving the appropriate dose of medicine to the person in their care. Men in particular worried about giving too much medication (31%) and many reported difficulty in getting prescriptions to help with managing pain (21% of men and 14% of women). These challenges disparately impacted communities of color – where nearly half of Asian American caregivers and Black or African Americans caregivers found pain management to be stressful.

Health care providers and policymakers are often unaware of this impact or how these stressors translate into challenges in managing a care plan. Research has demonstrated that when facing psychological distress, caregivers may overstate a patient's level of pain and that caregivers may experience additional psychological distress from seeing the person in their care struggling with pain.<sup>4</sup> Caregivers may also experience fear about pain medication which can be a barrier to effective pain management.<sup>5</sup>

Despite the fact that these psychological stressors can make it more challenging for caregivers to assess patient needs, care delivery models may delegate a responsibility to a caregiver to report the effectiveness of a particular treatment course without taking into account how the caregiver's stress and strain from the disease may impact their ability to subjectively assess pain. Notable, palliative care centers have identified that training is a critical way to combat this issue. For example, the Memorial Sloan Kettering Cancer Center guide for older adults and ambulatory nurses identified older adults as "at risk" if they are living in a setting in which "the caregivers are not trained in the assessment and management of pain."<sup>6</sup> Best practice may require improved clinical outcome assessment tools to best pair caregiver insight with the plan of care in an objective way, and to include training and education for caregivers on how best to report progress in managing acute and/or chronic pain to a patient's care team.

<sup>3</sup> See Reinhard, Susan, Heather M. Young, Carol Levine, Kathleen Kelly, Rita Choula, and Jean Accius. Home Alone Revisited. Washington, DC: AARP Public Policy Institute, April 2019 <https://doi.org/10.26419/ppi.00086.001>, at <https://www.aarp.org/ppi/info-2018/home-alone-family-caregivers-providing-complex-chronic-care.html>.

<sup>4</sup> See, e.g., Yeager KA, Miaskowski C, Dibble SL, Wallhagen M. Differences in pain knowledge and perception of the pain experience between outpatients with cancer and their family caregivers. *Oncology Nursing Forum*. 1995 Sep;22(8):1235-1241 at <https://europepmc.org/article/MED/8532548>.

<sup>5</sup> Valeberg, Berit Taraldsen PhD, RN; Miaskowski, Christine PhD, RN, FAAN; Paul, Steven M. PhD; Rustøen, Tone PhD, RN Comparison of Oncology Patients' and Their Family Caregivers' Attitudes and Concerns Toward Pain and Pain Management, *Cancer Nursing*: July/August 2016 - Volume 39 - Issue 4 - p 328-334 doi: 10.1097/NCC.0000000000000319, at [https://cdn.journals.lww.com/cancernursingonline/Abstract/2016/07000/Comparison\\_of\\_Oncology\\_Patients\\_and\\_Their\\_Family.10.aspx](https://cdn.journals.lww.com/cancernursingonline/Abstract/2016/07000/Comparison_of_Oncology_Patients_and_Their_Family.10.aspx).

<sup>6</sup> See <https://libguides.mskcc.org/GeriatricPlan/pain> (last accessed 4/29/20).

## UNDERSTANDING PAIN MANAGEMENT OPTIONS AND SUBSTANCE USE DISORDERS

***Need: Educate and train family caregivers on the benefits and risks of treatment options for pain management, including how to protect against the risk of substance use disorder, to support informed decision-making by people living with pain.***

In addition to the general considerations described above on caregiving and pain management, one challenge for many families is understanding the benefits and risks of opioids versus non-opioid therapies in the management of chronic or acute pain. Families may struggle to choose among pain management options because of the fear of a substance use disorder resulting from the use of opioid medication. Many families need more information on various treatment paths in order to make informed decisions and to help the patient provide informed consent.

### *Managing Acute Pain*

The National Academies of Sciences, Engineering, and Medicines (NASEM) recently identified patient-specific factors that influence pain management, and the prescription of opioids in particular.<sup>7</sup> Many of these factors suggest that a friend, neighbor, or relative could be used as an essential partner in managing acute pain as described below (emphasis added):

Given the patient-specific factors that can influence pain management, it follows that special considerations may influence the approach clinicians take when prescribing opioids. These factors include

- patients who have not had appropriate pain treatment;
- **patients who are unable to communicate their pain**, such as infants or those with cognitive impairments;
- patients with chronic pain who are already using opioids and might be opioid-tolerant;
- patients in whom the pharmacology of opioids may differ from the typical, such as **children or the elderly**;
- patients for whom the **understanding of or adherence to a treatment plan of care may be challenging**;
- **patients who may be at risk for substance use disorder**; and
- **patients who have genomic or other medical factors that may affect their response** to opioid treatment.

People who require a patient advocate to give voice to their care needs – such as people who are caring for children or older adults with pain, caregivers of people at risk of substance use disorder, and those with medical complexity. These caregivers, however, need information and education on pain management to support treatment goals and avoid potential harms to the family unit and community at large.

Opioids can be an effective tool in the management of pain; at the same time, opioid treatments can pose risks to both patients and to family members and the community when prescribed without necessary

<sup>7</sup> See National Academies of Sciences, Engineering, and Medicine. 2020. Framing Opioid Prescribing Guidelines for Acute Pain: Developing the Evidence. Washington, DC: The National Academies Press. <https://doi.org/10.17226/25555>; available at <https://www.nap.edu/catalog/25555/framing-opioid-prescribing-guidelines-for-acute-pain-developing-the-evidence>.

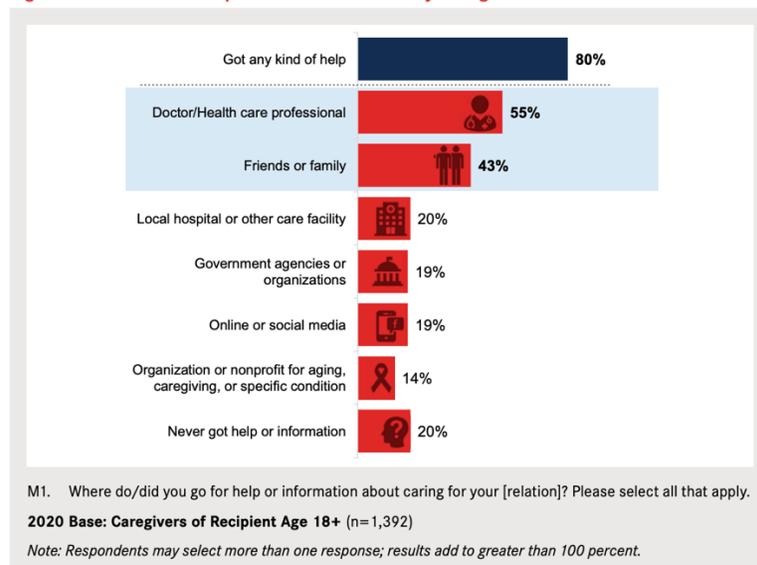
information on how to manage them. This is due, in large part, to the prescription of opioids in a post-acute or post-operative setting, when the patient has been discharged to the home or community. Patients and their families become responsible for managing their treatment plan with less oversight from a professional clinical provider, and they can only do this effectively when empowered with training on appropriate use. It may be for some families that non-opioid medications or even non-pharmacological solutions are most appropriate. Families need information in order to make these kinds of choices.

The NASEM report describes how roughly 41% - 72% of patients do not use opioid medications as prescribed. This creates a risk of diversion or misuse because many are unsure of how to safely dispose of opioids or want to guard against future pain by reserving medications for later use. The report reviews the association between opioid prescriptions and overdose among family members, particularly children and adolescents, indicating that the presence of opioids in the community may pose risks to families without appropriate safeguards and training for family members. Particularly for individuals who may be at risk for substance use disorder – whether the patient or the friends and family who care for them – the need for safeguards and education can be a life or death matter.

People and their families need choices about their plan of care and appropriate education on the benefits and risks of a particular course of treatment. The NASEM report recommends that one avenue to provide this information is through evidence-based clinical practice guidelines address both the need and proper usage of opioids and the role of non-opioid alternatives.

We believe that improving clinical practice guidelines may improve how families caregivers receive information. In our most recent national study, we found that most caregivers wanted more information about caregiving (62%), and in particular, they wanted information on keeping someone safe at home (26%) and managing their own stress (26%).<sup>8</sup> For most, the primary source of information is health care professionals (55%) – indicating that empowering professionals with tools to train caregivers could be an effective means of supporting a care plan after a patient leaves the office or facility.

**Figure 75. Sources of Help or Information used by Caregivers**



<sup>8</sup> See n. 2 – Final Report, page 73 on “Caregiving Training and Information Needs” and page 75, “Sources of Help or Information.”

## Managing Chronic Pain

When it comes to the management of chronic pain, many caregivers fear drug addiction and side effects from the use of opioids. A systematic literature review published in 2020 in the *Journal of Cancer Education* examined a number of attitudinal barriers to effective chronic pain management in adult cancer patients.<sup>9</sup> The review found that the patient’s attitudes towards chronic pain management was influenced by the perspectives of their caregiver and that family caregivers reported “hesitation to administer opioids.” Many caregivers reported concerns about the potential for addiction as well as opioid-related side effects, including constipation and harm to kidneys.

Some caregivers viewed opioid medications “as a path to death” – driven by fear of addiction, religious reasons, or cultural prohibitions. These concerns were related to lack of knowledge about how to manage chronic pain, and how to assess pain and help the person in their care take appropriate doses of opioids. The fears were lower in the United States compared to other nations, indicating better infrastructure to educate and prepare caregivers to care—yet there is still much to be done to empower families to care.

The solution to tackling a “fear-based” approach to pain management is to identify the role that family caregivers can play and to equip them with the education and support they need. This may mean incorporating the caregiver into patient assessment tools, as recommended by the Substance Abuse and Mental Health Services Administration (SAMHSA). SAMHSA’s Treatment Improvement Protocol for adults with chronic pain in recovery from substance use disorder identifies key roles for family members, summarized as follows:<sup>10</sup>

Patient Assessment Element	Caregiver Role
Collateral Information	Providing information on concerns, beliefs, and observations about the patient’s level of pain, function, substance use, and other factors
Contingencies	Family support of “wellness vs. illness” behavior
Substance Use History and Risk for Addiction	Family history of substance use disorder

Notably, friend and family caregivers can be partners in identifying behaviors of a patient who may be at risk of substance use disorder by observing and reporting concerns to the care team. Caregivers can play a role in the exit strategy when opioids no longer are needed or are no longer appropriate. Clinical providers also may want to document the family’s response to pain management — particularly, whether the family member is “supportive,” “enabling” or “rejecting” — as part of understanding the role of family

<sup>9</sup> Makhoulf, S. M., Pini, S., Ahmed, S., & Bennett, M. I. (2020). Managing Pain in People with Cancer—a Systematic Review of the Attitudes and Knowledge of Professionals, Patients, Caregivers and Public. *Journal of cancer education : the official journal of the American Association for Cancer Education*, 35(2), 214–240. <https://doi.org/10.1007/s13187-019-01548-9>, at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7076060/>.

<sup>10</sup> Substance Abuse and Mental Health Services Administration. Managing Chronic Pain in Adults With or in Recovery From Substance Use Disorders. Treatment Improvement Protocol (TIP) Series 54. HHS Publication No. (SMA) 12-4671. Rockville, MD: Substance Abuse and Mental Health Services Administration, 2011, at <https://store.samhsa.gov/sites/default/files/d7/priv/sma13-4671.pdf> (last accessed 6/16/20).

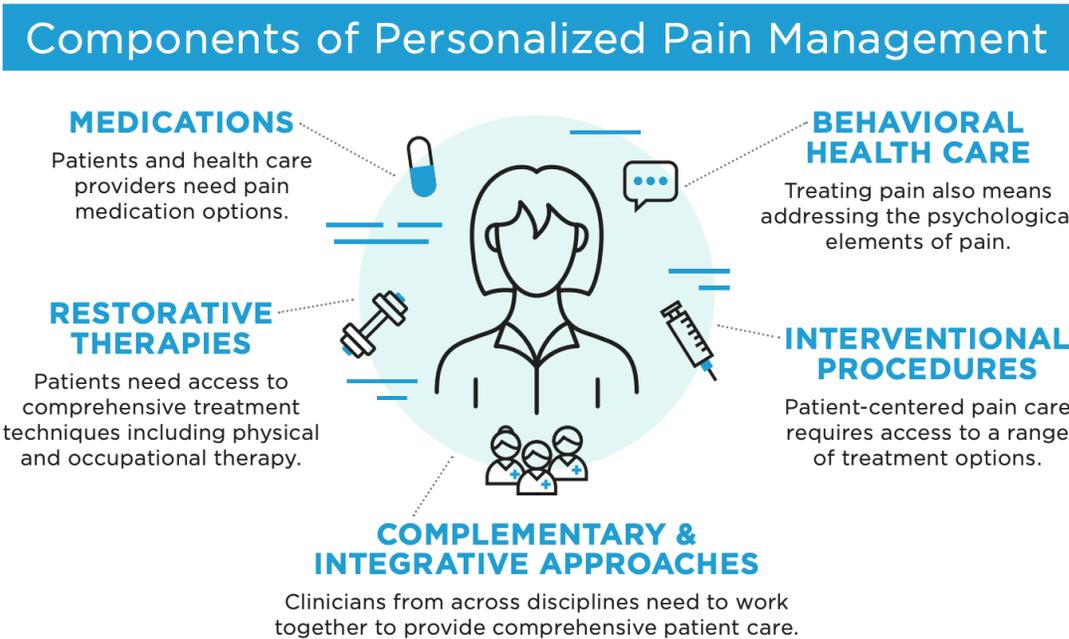
in managing pain. In each of these domains, family caregivers have insight to offer about the safety and efficacy of a particular course of treatment.

Notably, SAMSHA indicates that for opioid therapy, step one is to “educate patient and family” about the treatment options, with a focus on the goal and expected outcome of therapy. The next step is to discuss the treatment agreement with the patient and family.<sup>11</sup> From the outset, the family caregiver is a central component of a successful pain management strategy. When prepared to care, family caregivers can be effective partners in managing pain and improve health outcomes overall.<sup>12</sup>

**EDUCATION ON BENEFIT/RISK AND THE NEED FOR BALANCED PAIN MANAGEMENT**

***Opportunity: Incorporate innovative, multifactorial approaches to patient education that reflect person- and family-centered care models; provide education on existing and new interventions for pain management, including pharmacological and non-pharmacological solutions.***

The Alliance for Balanced Pain Management’s work on pain management offers an innovative approach to the issue. AfBPM is a national coalition of health care organizations, patient advocacy organizations, and innovators who are working to ensure “appropriate access to integrated, effective, and safe care.”<sup>13</sup> In April 2020, AfBPM released new task force recommendations on pain management. These included five components to a personalized pain management approach, such as evaluating whether opioids and non-opioids may be appropriate and identifying non-pharmacological supports to improve long-term outcomes.



<sup>11</sup> See n. 9 – specifically Chapter 3 – Chronic Pain Management (Exhibit 3 – 5) and Section 4 – Managing Addiction Risk in Patients Treated with Opioids (page 54 on “Inclusion of Family, Friends, and Others.”

<sup>12</sup> See n. 7, citing Glajchen, M. (2001). Chronic pain: Treatment barriers and strategies for clinical practice. *Journal of the American Board of Family Practice*, 14(3), 211–218.

<sup>13</sup> See About AfBPM, <https://alliancebpm.org/about-us/>.

Person- and family-centered care includes education about the various components of an effective pain management system. We agree that a personalized approach, where people are fully informed about the benefits and risks of various treatment options, allows patients and their families to identify what treatment course best fits them. Getting buy-in at the beginning of treatment and equipping people for self- and family-management of pain could significantly improve health, financial, and emotional outcomes people in pain and the caregivers who are by their side. Better education on the benefits and risks of opioids, non-opioids, and non-pharmacological interventions can help ensure that pain is managed safely and effectively at home and in the community, improving population health outcomes as well.

## CONTACT INFORMATION

Thank you for your time in reviewing this comment. Should you have any questions about this comment or seek additional information on the needs of family caregivers, please contact me at [grace@caregiving.org](mailto:grace@caregiving.org) or (202) 918-1016 with any questions or concerns; you may also contact my colleague Karen Lindsey Marshall, J.D., Director of Advocacy and Engagement, at [karen@caregiving.org](mailto:karen@caregiving.org).

Kind regards,

A handwritten signature in black ink that reads "Grace". The signature is stylized with a large, looping initial "G" and a long, sweeping underline that extends to the right.

C. Grace Whiting, J.D.  
President and Chief Executive Officer  
National Alliance for Caregiving

### **Attachments:**

*Caregiving and Pain Management Infographic – Home Alone Revisited (AARP 2019)*

# Family caregivers providing complex medical/nursing care

## PAIN MANAGEMENT

Today's family caregivers provide *intense and complex care*, including medical/nursing (M/N) tasks and managing multiple health conditions that are often accompanied by pain.



Nearly **7 in 10** who perform M/N tasks help their family member manage pain and/or discomfort.

### WHEN PERFORMING PAIN MANAGEMENT



- **8 in 10** caregivers rate pain management as stressful

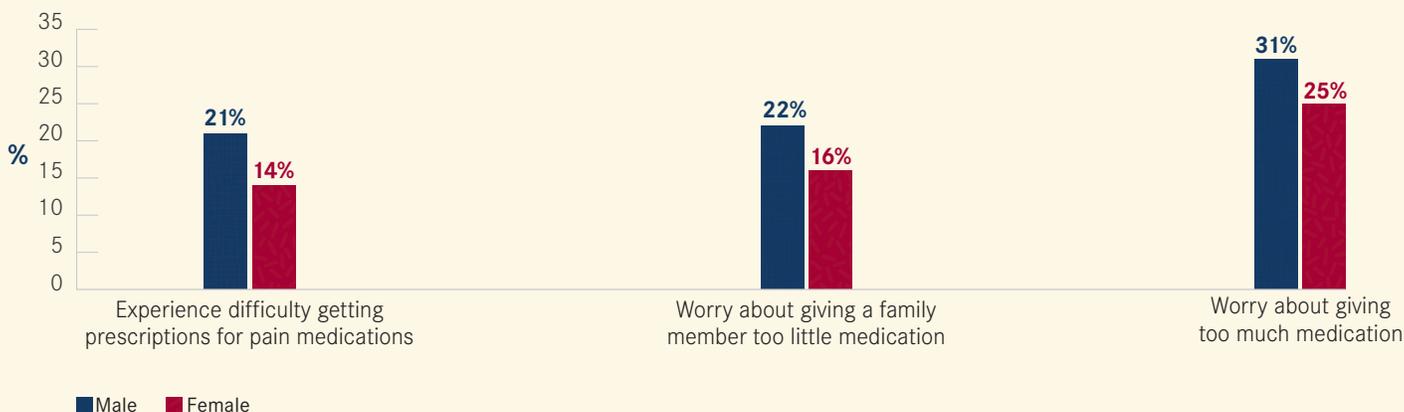


- About **4 in 10** face difficulties with controlling pain

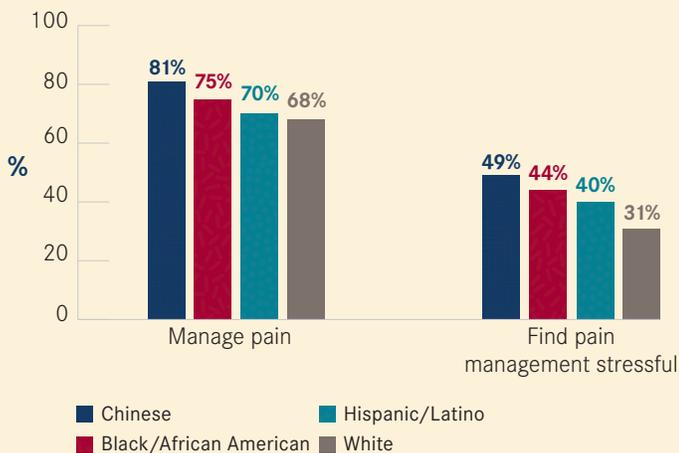


- More than **4 in 10** express concerns about giving the optimal dose

### DIFFERENCES BETWEEN MALE AND FEMALE FAMILY CAREGIVERS



### DIFFERENCES BETWEEN CAREGIVER RACIAL AND ETHNIC GROUPS



### DIFFERENCES BETWEEN GENERATIONS



Find managing their family member's pain very stressful:

- **Nearly 50%** of millennial, younger adult, and generation X caregivers (combined)
- **About 33%** of baby boomers
- **About 25%** of silent generation



Experience difficulty getting prescriptions for pain medications:

- **More than 20%** of millennials and younger adults
- **Almost 20%** of generation X
- **Less than 10%** of silent generation

EXTRACTED FROM THE 2019 HOME ALONE REVISITED STUDY

THROUGH FUNDING BY:



The John A. Hartford Foundation

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