Chronic Pain and Care Coordination: A Team Effort

By Penney Cowan, Founder and Executive Director of the American Chronic Pain Association, and Paul Gileno, Founder and President of U.S. Pain Foundation

Key Takeaways

• Chronic pain is a real and complex disease that may exist by itself, though it is often linked with other medical conditions like diabetes, high blood pressure, and heart disease.

• Chronic pain affects more than 100 million American adults – more than the total affected by heart disease, cancer, and diabetes, combined.

• Effective chronic pain care requires access to a wide range of treatment options, including medical interventions, behavioral health and complementary treatments.

• Care coordination is essential for the management of chronic pain. A provider – working with an empowered patient – can coordinate the needed care, but both need resources and cooperation to be effective.

Learn more about the Coalition for Medicare Choices by visiting www.MedicareChoices.org or following CMC on Twitter @ProtectmyMA or www.Facebook.com/ProtectMyMA
Background

Imagine being constantly in pain and not being able to identify the cause of the pain or to manage its symptoms. How would this affect your ability to earn a living? To maintain social relationships? To stay fit?

More than 100 million American adults suffer from some form of chronic pain.¹ That’s more than the number of adults with heart disease, cancer, and diabetes combined. Chronic pain is a pain that continues for at least three months, extends beyond the usual recovery period for an injury or illness, or that goes on for months or years due to a chronic condition. The pain is usually not constant but can interfere with daily life at all levels. For some, a cause may not be found, but their pain is still very real.

Chronic pain is the most common cause of disability in the United States and pain costs an estimated $560 to $635 billion annually in lost workdays, medical expenses, and other benefit costs.² Chronic pain is a real and complex disease that may exist by itself, though it is often linked with other medical conditions like diabetes, high blood pressure, and heart disease. Treatment is often challenging and there is not a one-size-fits-all solution for people with pain. It usually takes a combination of tests and treatments to determine the best course of treatment. It also requires that the patient with pain be an active participant, rather than a passive patient in his or her care. Effective chronic pain care often requires access to a wide range of treatment options, including biomedical, behavioral health and complementary treatment. This multi-pronged approach, coupled with the fact that providers sometimes may not acknowledge a patient’s pain or feel comfortable prescribing pain medications that may be habit forming, can cause patients to feel isolated and depressed, only increasing their stress which can lead to increased pain.

Mari Velar, one of 1.8 million Medicare Advantage beneficiaries with the Coalition for Medicare Choices working to protect coordinated care for Medicare beneficiaries, knows this all too well. Mari has had chronic pain for the last ten years and also suffers from lupus, fibromyalgia, migraines, and degenerative disease of the spine. “My life every day is so different because I never really know what I'm going to be faced with. When you have chronic pain, your whole life revolves around trying to get out of pain. It affects every ounce of your brain,” explains Mari.

Pain Awareness Month: September

The month of September has been declared Pain Awareness Month. The first Pain Awareness Month was in 2001, when the American Chronic Pain Association led a coalition of groups to establish September as Pain Awareness Month. Since then, more than 80 partners have joined ACPA and U.S. Pain Foundation to recognize September as a time to draw attention and awareness to those patients suffering from chronic pain.
The Issue: The Chronic Pain Journey

Given the nature of chronic pain, a patient’s journey through the health care system can be complicated. There are generally four stages of this journey:

1. **Identifying the cause of the pain.** This generally starts with a visit to a primary care physician, followed by visits to one or more specialists. The problem is that many patients may never find out what is causing their pain.

2. **Managing the pain.** Once they know what is causing the pain, providers work with patients to develop a treatment plan for managing the pain. This often includes the prescribing of medication, but can include other treatments, like physical therapy, counseling, stress management, and a host of other interventions.

3. **Adjusting the patient’s expectations.** Even with the most effective treatment available today, there still may be some level of pain that the person will have to live with. Often the treatment will help with one aspect of the patient’s pain, but not address other issues. Even still, sometimes, the treatment can create new issues, especially if the patient is being treated by more than one provider and his/her care isn’t being coordinated.

4. **Taking a multi-disciplinary approach.** Next, providers and patients might need to work together as a team to restore a reasonable quality of life and level of functioning while reducing one’s suffering. The key is to continue to work together, allowing the person with pain to maintain his or her wellness.

Expecting a person with chronic pain to navigate the health care system on his or her own without any resources or support is setting up the patient for failure. They must manage multiple providers and appointments, and keep track of all the tests, labs, and treatments those providers prescribe or recommend. They have to do this while in pain – which often consumes every bit of energy they may have, and does not allow them to focus on anything else. The risk of medical errors, complications, reduced quality of life, prolonged pain, and higher costs is great.
“Navigating the healthcare system is difficult because you have to know what you're doing. When you have chronic pain you have to have a clear head and mind. The most intelligent people can have a hard time navigating the healthcare system. So when you're in chronic pain, you are at a disadvantage because your ability to concentrate is greatly reduced. Your mind is cloudy,” explains Mari.

This is why care coordination is so important for people with chronic pain.

The goal of coordinated care is to make sure that patients get the right care at the right time, while avoiding unnecessary duplication of services and medical errors. Often times, a patient's primary care physician will serve as the “care coordinator,” but others – such as nurses, social workers, health plans or other providers – can also serve in this role. The key is that the coordination is deliberate and that all people involved in the care of the patient – the primary care physician, specialists (like neurologists, orthopedists, endocrinologists, etc.), physical and occupational specialists, complementary and alternative medicine providers, pharmacists, social workers, patient, family caregivers, and others – be an active part of the team.

Medicare Advantage is one program that emphasizes the importance of care coordination, allowing patients to focus on preventative care and managing their pain, rather than navigating the often-confusing healthcare system. A 2013 study published in Health Affairs found that MA plans' performance on measures for breast cancer screening, diabetes care, and cholesterol testing for individuals with diabetes and cardiovascular disease were consistently better compared to FFS Medicare.¹

Luckily, Mari, who is a Medicare Advantage beneficiary, has found a partner in her primary care physician. “I always can go to my primary doctor. I know I can talk and he'll listen. I trust his judgment. It's a good team effort,” Mari shares. “So many people don't know the difference between Medicare Advantage and traditional Medicare… but it has so many great programs. And, in the long run, it has helped me save money and given me the flexibility to see providers I might not have otherwise been able to afford to see.”

Unfortunately, many people with chronic pain do not have a designated care coordinator. Most primary care physicians don't have the resources, time or training to provide this additional service for their patients and 77 percent of people with chronic pain are seen in this setting. Therefore, it really becomes the patient’s obligation to take responsibility for coordinating their own care, but they can't do this without support and resources.

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Resources for Addressing Chronic Pain

Fortunately, there is a lot we can do to address this problem.

First, it is important to educate providers on chronic pain and care coordination. Advocates are working tirelessly to get more information about pain management and care coordination into the curriculum for medical, nursing, pharmacy and physical therapy schools and to educate current practitioners.

Second, it is imperative that people with chronic pain have access to resources to become empowered to self-manage and coordinate their own care, especially in the absence of a formal care coordinator. This includes access to support groups and resources – many of which are available from the American Chronic Pain Association (ACPA) and U.S. Pain Foundation, including:

1. **Pain Maps**: These online tools are available for back pain, head pain, fibromyalgia pain, and diabetic peripheral neuropathy pain. The user indicates on the tool where they are experiencing pain, the intensity, what makes it worse and symptoms at onset so they can print out the resulting diagram and share it with their provider. They can also use these print outs to monitor how their pain has changed over time. Available at: [http://www.theacpa.org/Communication-Tools](http://www.theacpa.org/Communication-Tools).

2. **Pain Log**: This online tool allows patients to track their pain and possible triggers (like medications, alcohol, stress, exercise, etc.). Patients are encouraged to make entries on a daily basis and to print out the log to share with providers during their appointments. Available at: [http://www.theacpa.org/painLog/default.aspx](http://www.theacpa.org/painLog/default.aspx).


4. **Heroes of Healing**: A program of U.S. Pain Foundation, an online, closed support group that offers an opportunity for those in pain to connect in a safe, secure space. Along with blogs and videos, patients can participate in discussion forums and live chats. Available at: [http://www.heroesofhealing.com/](http://www.heroesofhealing.com/)

5. **INvisible Project**: A national campaign of U.S. Pain Foundation focused on sharing incredible stories of perseverance and struggle, the INvisible Project will help others understand the toll pain takes on an individual. Available at: [http://www.invisibleproject.org/](http://www.invisibleproject.org/)
It is important that people with chronic pain are aware of these resources and that other resources continued to be developed so that patients are empowered to coordinate their own care and partner with their providers.

Third, we need to advocate for broader change. In 2011, the Institute of Medicine recommended that the Secretary of the Department of Health and Human Services (HHS) should develop a comprehensive, population health-level strategy for pain prevention, treatment, management, education, reimbursement, and research that includes specific goals, actions, time frames, and resources. In response, HHS created the National Pain Strategy Work Force and released a Draft National Pain Strategy earlier this year. The Strategy sets forth national objectives for greater collaboration between primary care clinicians and pain specialists in different clinical disciplines and settings, including multispecialty pain clinics, as well as professional education and self-management programs. This is the first time there has been a national, coordinated effort to improve awareness, education, and treatment of chronic pain.

Conclusions

- Care coordination makes a difference for those with chronic pain.
- Sometimes a provider will take on the role of care coordinator, but more often patients must take on this role themselves.
- Providers and patients need more resources to better coordinate care and manage pain.
- There is work underway to better coordinate care for people with chronic pain, but more can be done.

Sources

About The Authors

Penney Cowan is the founder and chief executive officer of the American Chronic Pain Association (ACPA). She herself is a person with chronic pain and established the ACPA in 1980 to help others living with the condition. The ACPA provides peer support and education in pain management skills to people with pain and their families. The ACPA also works to build awareness about chronic pain among professionals, decision makers and the general public.

Since 1980, Cowan has been an advocate and consumer representative for pain issues. She was awarded the Jefferson Medal for Outstanding Citizen by the Institute for Public Service, Washington, and is listed in Who's Who in America, 24th Edition. The American Pain Society awarded her the 2005 John and Emma Bonica Public Service Award, Presidential Commendation, American Academy of Pain Medicine, 2013 and the Elizabeth Narcessian Award for Outstanding Educational Achievements, from the American Pain Society, 2013.

She served as: Consumer Representative for the FDA/CDER Anesthetic and Analgesic Drug Products Advisory Committee (AADPAC) for 2012 and was appointed to Interagency Pain Research Coordinating Committee of the National Institute of Health from 2013 to 2015.

Cowan began the Partners for Understanding Pain campaign in 2002 in an attempt to raise awareness about the need to better understand, assess, and treat pain. There are more than 80 partner organizations. The campaign, under the direction of the ACPA, successfully established September as Pain Awareness Month.

Paul Gileno is the founder and president of the U.S. Pain Foundation, and a strong force in the chronic pain awareness movement. His mission and message in life is to empower and support those living with pain. Having pain himself as the result of an accident while working at his gourmet food and catering business makes the issue of pain care a personal and public matter for him. In 2006, Paul started the Connecticut Pain Foundation to help pain survivors get the resources and support they need. The organization grew quickly and became the U.S. Pain Foundation with chapters in dozens of states in just a few years. U.S. Pain now has over 45,000 members and continues to grow as a grassroots organization.

About the CMC MACC Task Force: Despite the fact that two-thirds of Medicare beneficiaries have two or more chronic conditions, care for many of these individuals is fragmented. Beneficiaries often may shuffle between numerous providers serving in multiple care settings, including doctors’ offices, the ER and in-patient hospital facilities. Without sufficient coordination across these various points of care, the health issues these beneficiaries are already facing may be compounded. To address this important problem and critical need, the Coalition for Medicare Choices (CMC), an AHIP-founded effort, is collaborating with leading aging, caregiver, patient, provider and minority health organizations on a unique venture called the Medicare Advantage Care Coordination (MACC) Task Force.