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Chronic pain, vulnerability and human spirit while living under the umbrella of COVID-19

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Abstract

The purpose of writing this article is to describe what added challenges people like us who are living with chronic pain are experiencing during the COVID-19 pandemic. We explore what this challenging time means to us and how it affects our lives, along with providing insight into our experiences. This is not a research study, but instead an article that shares perspectives from people with lived experience of chronic pain. Our narratives are presented to create an awareness of the plight for people already living with challenging health conditions and how the COVID-19 pandemic has added additional layers of vulnerability. While these stories offer brief accounts of some of the challenges we face, they also provide glimmers of hope that others with similar challenges can look to for inspiration. We also hope that our stories and reflections provide discussion points and perhaps even case studies for clinicians and policymakers who are working to strengthen clinical care and health systems for people with chronic conditions during pandemics such as COVID-19. Sharing our lived experiences with chronic pain during this global crisis may also spark critical conversations among all chronic pain stakeholders to ensure that we could continue to provide excellent care, strong self-management support and optimal health policy-making as this pandemic continues to unfold and for consideration for future health emergencies.

Keywords

COVID-19, chronic pain, lived experience, resilience, and vulnerability

Introduction

Living with chronic pain during the global COVID-19 pandemic is extremely challenging. Since this is undoubtedly a strenuous time for everyone living with chronic pain, we feel that it is important to share with each other our experiences of what it means to live with chronic pain during the COVID-19 pandemic, so we can know that we are not in this alone. Working collaboratively, as people who are living with chronic pain, we hope that sharing our personal narratives can inform healthcare providers and researchers about what it is like to live with chronic pain during this pandemic. We hope to increase awareness and inform those not living with chronic pain to gain insight and an understanding of what it is like to live with chronic pain during a pandemic. Lastly, and crucially, we hope to validate others who are living with chronic pain through our shared experiences, so we can know that we are all in this together, learning from each other and offering a supportive context through our writing.

Pain, further adaption and resiliency

Delane Linkiewich:

“Living with chronic pain during the COVID-19 pandemic has been very challenging for me. I have not been able to access regular treatments (e.g., massage), my routine has been disrupted, and I have experienced higher levels of stress. Combined, these things result in higher pain levels, and I experience more flare-ups, which makes it increasingly difficult to get through the day.

Since I am isolating as much as possible and experiencing increased pain, I have had to find a new way to adapt to this new situation. For example, I am pacing myself more than usual and being mindful of my daily tasks so that I do not risk a flare-up from occurring. I sit for shorter periods of time and do low impact exercises. It terrifies me that if I get a flare-up, I may have to risk my health to fix it. I have also had to change the way that I see my healthcare providers. Using telemedicine has been an overall positive experience; however, there have been some difficulties. My care team cannot use hands-on approaches to help manage my pain, and I have had to incur the costs of the visits, as my insurance does not cover telemedicine. I have been adapting for the past 12 years whilst living with chronic pain, so I would like to think I am fairly good at it. However, due to the increased isolation and lack of resources, it is extra challenging to adapt during these times.

Even though there are many negative aspects living with chronic pain during COVID-19, there is one positive element that comes to mind. Through speaking to others with chronic pain and reflecting on my own practices, I am proud to see how resilient we are during this time. While living with chronic pain is not easy, especially now when resources are not available and we are self-isolating, we are all doing things to help us get through the day. We are finding new ways to exercise, to speak to healthcare professionals, and to manage our pain. It is inspiring to be a part of a community that can take an extremely negative situation and find new ways to make it work. I hope that we can use learnings from this experience to help the chronic pain community in the years to come.”

Many people worry about vulnerability, social isolation, and lack of community resources when living with or caring for people with chronic pain. Prior to COVID-19 our chronic pain created the possibility of social isolation and a sense of vulnerability due to physical and emotional obstacles like reduced mobility, exhaustion, anxiety and depression. We need to be able to access health services (which are often hands-on modalities) that are essential for one’s personal pain management strategies.

Layers of vulnerability

Richard Hovey:

“We as human beings are magnets for pain: physical, emotional, and existential. It is not chronic pain or ageing itself that causes a sense of vulnerability for me, but the social conditions, medical access, rehabilitative services, social engagement, and loss of life affirming activities that I previously experienced before pain. Before my pain experience 8 years ago, the idea of what was available and what was accessible held a completely different meaning than today. I view and experience my own sense of vulnerability on a sliding scale influenced by internal and external factors. The internal factors are based on my perspective of what I am able to do from day-to-day. These are both actual and perceived, which result in times when I feel confident and willing to take a risk, to others when my confidence is so low that I feel I can barely hold my life together. The interesting part to this dichotomy is that my pain levels are still about the same and my intentions are to engage; however, the exhaustion and anticipation of further fatigue opens up my sense of vulnerability. COVID-19 adds another layer of vulnerability as my world has become smaller and more isolated around me. Going to the hospital for blood tests, appointments and an MRI becomes overwhelming with the actual or perceived risk of coming into contact with COVID-19. COVID-19 restricts everyone’s life to a certain degree, to go carelessly shopping, participate in recreational activities, experience anxiety about their employment with perhaps the fear of losing or the actual loss of one’s livelihood, social engagements and so on; it is a long list. COVID-19 adds an additional layer of restrictions to an already limited life living with chronic pain. Feeling vulnerable can be frightening, but our resilience can help to reduce our sense of vulnerability and anticipated vulnerability as we confront the future or new life events such as COVID-19.”

In a colloquial interpretation of the word resilience, with its meaning rooted literally as the “act of rebounding” with the inclination to leap or spring back from, in this case, adversity. Life with chronic pain is a continual process of learning about what works to help deal with the pain. These are not constant as we age and acquire different types of pain and other conditions that influence how we adapt and learn to live well with pain. However, time and time again we need to find the strength to carry on through supportive networks, friends and family. Even writing an article like this one, which brought the three of us together to share our experiences, was both cathartic and healing for me.

Pain self-management & perseverance during uncertain times

Mary Brachaniec:

“I have had chronic pain relating to inflammatory arthritis and fibromyalgia for almost 3 decades and have managed my health challenges reasonably well with assistance from my health care team and my commitment to stay as active as possible, both physically and with family and community roles.

The last three or four years have been particularly difficult for me with a number of additional health issues that have set me back in terms of my ability to exercise and to continue with much loved volunteer roles.

I was laid up at home following minor surgeries for several months before the COVID-19 pandemic and was becoming rather despondent towards the end of this time, as I was missing out on my usual everyday activities. Once I could attend our local YMCA therapy pool every day, however, my spirits began to lift, and I was making progress with pain management and mobility.

In response to COVID-19 lockdowns and physical distancing measures, my sense of isolation returned after the closure of local gyms and pools. Long line-ups at local stores and service providers have also made it almost impossible for me to independently carry out daily activities as needed.

I had hoped that an urgent referral for possible early CRPS to a multidisciplinary pain clinic in a larger centre could help, but this was cancelled as all outpatient clinics in the region were closed at the onset of the pandemic. As this would have been my first appointment, there was no opportunity for a virtual visit.

As there is a scarcity of health services for people with persistent pain in my home province of New Brunswick during normal times, the COVID-19 pandemic only exacerbates extremely long wait lists and lack of access for patients.

I worry that the delay I have experienced in accessing pain services and exercise facilities will have a long-standing impact on my well-being and quality-of-life. This in turn affects my family members, which is difficult for us to bear.

Surely some chronic disease management clinics could have continued (at reduced capacity) during this COVID-19 pandemic, particularly when there were few active cases in the region?

Now that the province is easing its pandemic restrictions, I will be attending the multidisciplinary pain clinic next week. I am hopeful that this opportunity and follow-up care will help me stabilize my persistent pain condition and improve my mobility and quality of life.

Our local YMCA has also recently re-opened, and I hope to regain some lost ground there as well.

Despite the challenges I have described, I have seen several bright lights during this challenging time. There have been more opportunities to connect with family and friends online, and many pain networks and stakeholders have come together in mutual support. These opportunities certainly make it easier for those of us with chronic pain to 'weather this storm'."

Living well with chronic pain requires perseverance and an ability to take an active role in managing it. We cannot expect health professionals to “fix” our pain, but rather, come to accept our own critical role in managing our condition and optimizing our quality of life. It really is “up to us” to find our way with the support and guidance of our healthcare team.

We learn to anticipate pain flares from time to time and understand that we will sometimes struggle to cope when our pain levels are at their highest. At this point, perseverance and the self-management skills learned through the years are crucial. This is particularly important during the COVID-19 pandemic and yet another challenge is added in discovering our “new normal” and bringing joy back to our lives and roles within our families and communities.

Reflections and applications

Through these personal narratives, we explore both vulnerability and resiliency through our patient experiences. We describe resilience in managing our chronic pain and striving to remain as active as possible within our families and communities¹. We also feel particularly vulnerable as people living with chronic conditions during the COVID-19 pandemic. With these considerations in mind, however, we wonder whether this resiliency can serve us well as we seek to manage the challenges we face during and following the COVID-19 pandemic. These include increased difficulties with social isolation, anxiety, stress and mental health, along with barriers in accessing necessary therapies and treatments. Our hope is that sharing these brief accounts of living with chronic pain under the umbrella of COVID-19 may open conversations with others to express their reflections on these challenges and the positive ways we can respond to them.

From the perspective of patient consultants, we encourage ongoing conversations between all pain stakeholders as the pandemic waxes and wanes in order to understand our challenges and optimize health services for people living with chronic pain. For example, we must provide appropriate accommodations for people who cannot sit or stand for long periods of time within our communities and healthcare settings. People experience chronic pain differently, so it is important to invite everyone with the lived experience of pain as consultants to inform the delivery of healthcare and the accessibility and comfort within these settings.

References

1. Lord, J., and Hutchinson, P. (2007). *Pathways to inclusion: Building a New Story with People and Communities*. Concord, Ont.: Captus Press