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Destigmatizing Complex Regional Pain Syndrome through Art and Research

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Destigmatizing Complex Regional Pain Syndrome through Art and Research

Abstract

Bill Dambrova, an artist based in Phoenix, AZ, provided the cover art for the Fall 2023 issue of the *Open Journal of Occupational Therapy* (OJOT). Bill's paintings explore the intrinsic and extrinsic relationships between living things. Through the Artists + Researchers (ARx) program, Bill was teamed with Dr. Gretchen Bachman, OTD, OTR/L, MBA, CEAS, CHT, and Dr. Cindy Ivy, OTD, OTR/L, MEd, CHT, occupational therapy professors and researchers from Northern Arizona University. Their goal was to create a work of art that could disseminate research on complex regional pain syndrome (CRPS). The partnership led to the creation of "Invisible War," a 74" x 74" mixed media painting on canvas. The piece illustrates the visible and invisible challenges of people experiencing this debilitating condition. Through art and research, the team hopes to inform future studies and destigmatize CRPS.

Keywords

occupational therapy, research, art, complex regional pain syndrome, artists + researchers program, Bill Dambrova

Cover Page Footnote

The editors would like acknowledge Jennifer Fortuna for her substantial contributions to OJOT. After serving seven years as the Art Editor, this is Jennifer's twenty-ninth and final Occupation and the Artist publication. Thank you, Jennifer, for sharing these stories in such meaningful ways and always being so enjoyable to collaborate with.

Credentials Display

Jennifer Fortuna, PhD, OTR/L

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In the early 20th century, surrealism originated as an avant-garde cultural movement. Artists often portrayed dream-like scenes that combined images and objects in unusual ways. Influenced by the work of psychologist Sigmund Freud, surrealism is often referred to as an expression of the unconscious mind (The Museum of Modern Art, 2023). Artist Bill Dambrova's style has been described as surrealist and visceral (see Figure 1). Bill, an artist based in Phoenix, AZ, is known for creating colorful paintings that highlight the intricate structures and functions of the human body. "It's the life force I'm trying to capture with imagery," he said. Bill's curiosity surrounding anatomy and physiology began early in life.

As a child with asthma, he felt disconnected from his physical body. "Exploring the anatomical forms of the human body grounded me," said Bill. "There is something about the beauty of the shapes and visceral qualities that bring me back into my body." Bill continues to find the human body fascinating. "Hidden worlds. Things unseen. Forces that act on their own," he said. "The only thing we have control over in our bodies is breathing. Everything else does what it wants." In 2021, Bill had an opportunity to explore the underlying forces associated with complex regional pain syndrome (CRPS).

Figure 1

Photo of artist Bill Dambrova.



Bill provided the cover art for the Fall 2023 issue of the *Open Journal of Occupational Therapy* (OJOT) (see Figure 2). Bill's paintings explore the intrinsic and extrinsic relationships between living things. Through the Artists + Researchers (ARx) program, Bill was teamed with Dr. Gretchen Bachman, OTD, OTR/L, MBA, CEAS, CHT, and Dr. Cindy Ivy, OTD, OTR/L, MEd, CHT, occupational therapy professors and researchers from Northern Arizona University (NAU). Their goal was to create a work of art that could disseminate research on CRPS. The partnership led to the creation of "Invisible War," a 74" x 74" mixed media painting on canvas. The piece illustrates the visible and invisible challenges of people experiencing this debilitating condition. The team hopes to inform future studies and destigmatize CRPS through art and research.

Pain is a significant public health problem in the United States (U.S. Department of Health and Human Services, 2019). CRPS is a condition that causes excess and prolonged pain and inflammation following injury to an arm or leg (National Institute of Neurological Disorders and Stroke, 2023). In addition, the pain may be acute or chronic, with shifts in intensity throughout the day. The exact cause of CRPS is unknown, and there is no cure (Mayo Clinic, 2023). In some cases, the symptoms persist for years. Chronic pain can cause significant changes in one's psychological state, relationships, and occupational performance (Fisher et al., 2007; World Health Organization, 2004). "Lack of sleep can make the pain worse and often leads to depression and self-doubt," said Cindy. "It's a vicious cycle." Occupational therapists' understanding of how the mind, body, and spirit impact engagement in meaningful occupations makes the profession uniquely qualified to treat chronic pain (American Occupational Therapy Association [AOTA], 2020). Research has shown active engagement in meaningful

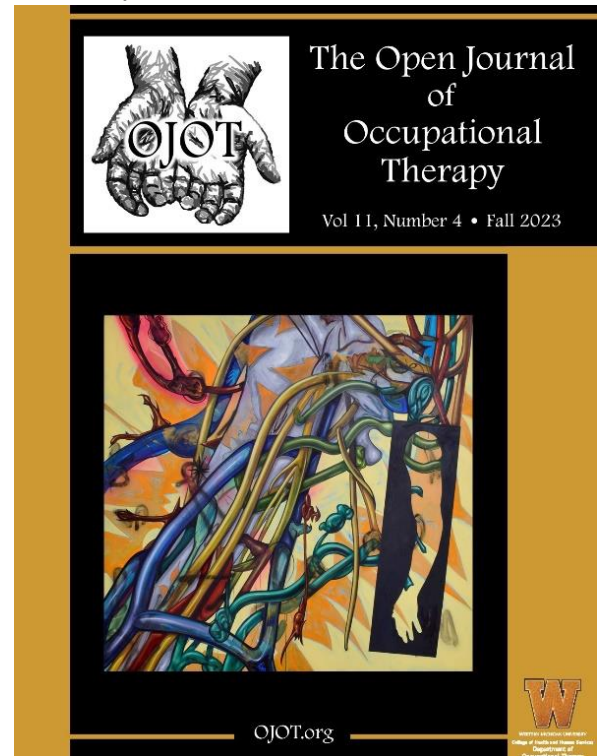
occupations can reduce pain levels and promote, support, and maintain health and participation (AOTA 2020; AOTA, 2021; Fisher et al., 2007).

Gretchen and Cindy have bonded over their shared interest in CRPS. “This condition is so complex, multifaceted, and ill-defined,” said Gretchen. “When Cindy came on faculty at Northern Arizona University, we had a brainstorming session.” Gretchen and Cindy quickly realized they both enjoyed working with patients with CRPS. “It’s challenging, and we both like challenges,” said Cindy. “There is no cure. What works for one patient may not work for another.” After 35 years of clinical practice, the patients Cindy remembers best are those with CRPS. “I remember them all by name,” she said. “You develop a different relationship with these patients.”

In 2021, the Artists + Researchers (ARx) program was launched through a collaborative partnership between the Phoenix Bioscience Core and Bentley Gallery (Phoenix Bioscience Core, n.d.). Local artists and researchers from Arizona State University, NAU, and the University of Arizona College of Medicine, Phoenix, were invited to attend a speed-dating style event. During the event, artist Bill Dambrova was matched with Gretchen and Cindy, who are both occupational therapists, researchers, and professors in the Department of Occupational Therapy at NAU (see Figure 3). Gretchen and Cindy wanted to create an abstract piece that evoked feeling and empathy for people who experience CRPS. Bill’s role was to create a powerful painting that exuded the energy, frustration, and pain experienced by people with this condition.

As Gretchen and Cindy described what it was like to live with CRPS, Bill allowed the imagery to unfold in his head. “I have always painted from a place of joy,” he said. “With this project, I wanted to come at it with anger.” Bill had never approached a painting like this before. For Bill, this project was about empathy and channeling the frustration felt by people with CRPS. “If I imagine what CRPS would be like, the marks should come on their own,” he said. Although the original marks are no longer visible on the canvas, the movements of Bill’s brush strokes began to resemble an ongoing battle. Over time, the pain and frustration caused by CRPS emerged on the canvas. Bill’s technique is an example of automatism, where the creation of art provides access to the unconscious mind (Museum of Modern Art, 2023). After researching imagery and testimonials from people with CRPS, Bill titled the painting “Invisible War.” He adopted an empathy approach to find out if the title was accurate. “I made the painting huge because I want people to know we are listening to you.”

Figure 2
Cover Art for OJOT, Vol 11, No 4, Fall 2023.



Gretchen and Cindy's desire to work with patients experiencing CRPS is not shared by all health care providers. "Because it is an upper limb condition, doctors, surgeons, and hand therapists are working from the medical model," said Cindy. "Since CRPS does not have a cure, providers may not want to treat these patients." In addition, many patients find it difficult to trust health care providers. According to Raja et al. (2021), treatment for CRPS is often characterized by the clinical frustration of physicians and the disappointment of patients (Raja et al., 2021). "There is so much going on regarding depression and trauma," said Cindy. "This can drive the therapeutic relationship to a deeper level."

Gretchen and Cindy believe there is a stigma surrounding any chronic pain or disorder. "The patients even experience internal self-stigmatization," said Cindy. "There is often bias from health care providers toward people with CRPS," she said. "Patients get passed around to providers and referred all around, but do not get the resources they need." Although there are guidelines for the diagnosis and treatment of CRPS, not every provider knows what to do. "The treatment is not universal," said Gretchen. "Living in a rural area, poor access to health care, and caregiver burden. These factors play into the stigma surrounding CRPS."

People with CRPS experience both visible and invisible consequences. The external symptoms can include swelling, hair growth, and changes in skin color (Mayo Clinic, 2023). "People refuse to go out because they don't like the way they look," said Cindy. CRPS is an invisible condition in terms of patients not feeling seen or heard. "We want to help change this," said Gretchen. "We like to stop and listen. Really be with the patient to help them feel heard and not dismissed." For Gretchen, listening to her patients creates a feedback loop that makes her want to do more. "We can learn so much from them."

Gretchen and Cindy do not assume they understand the lived experiences of people with CRPS. "We understand that no two people experience the condition identically," said Gretchen. "Health care providers often make assumptions, but do these patients really feel this way?" To investigate this concept further, Gretchen and Cindy are developing a qualitative study that aims to explore personal perceptions of the painting. "We want to know if the painting describes how people experiencing CRPS really feel," said Gretchen. "What does this painting do for them?" Gretchen and Cindy want to explore and develop this concept further.

Through art and research, a powerful work of art was created that increases awareness of chronic pain while disseminating knowledge in a unique way. The painting evokes feeling and empathy for the invisible war experienced by people with CRPS. Gretchen and Cindy hope innovative research collaborations like these will continue to help destigmatize conditions like CRPS.

Figure 3

Photo of Gretchen Bachman, Bill Dambrova, and Cindy Ivy.



View more of Bill Dambrova’s paintings in the OJOT gallery:
https://scholarworks.wmich.edu/ojot_occupationandartist/44/

Visit Bill’s website:
<https://billdambrova.com>

Follow Bill on Instagram:
<https://www.instagram.com/billdambrova/>

Recommended Resources

American Society of Hand Therapists: <https://asht.org/>
American Society for Surgery of the Hand: <https://www.assh.org/s/>
Bentley Gallery: <https://bentleygallery.com/>
Reflex Sympathetic Dystrophy Syndrome Association (RSDSA): <https://rdsd.org/>

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