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## Sculpting the Illness Experience

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# Sculpting the Illness Experience

## **Abstract**

Otto Kamensek provided the cover art for the Fall 2014 issue of the *Open Journal of Occupational Therapy*. “Glimmer of Hope” is part of Otto’s collection “Shard’s, Bone Deep,” which includes hand-built ceramic sculptures that portray his experiences with a lifelong chronic illness. Engaging in ceramic sculpture helps him process the experiences associated with Juvenile Rheumatoid Arthritis and provides a means to support others experiencing chronic illness.

## **Keywords**

Ceramic Art, Sculpture, Occupational Therapy, Juvenile Rheumatoid Arthritis

## **Credentials Display**

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Otto Kamensek provided the cover art for the Fall 2014 issue of the *Open Journal of Occupational Therapy*. Otto debuted “Glimmer of Hope,” a part of his “Shard’s, Bone Deep,” collection, at the Port Moody Arts Centre in April 2014. His body of work includes hand-built ceramic sculptures that portray his experiences with a lifelong chronic illness.

Otto describes “Glimmer of Hope” as a visual journal of the pain he has experienced throughout his life as a result of Juvenile Rheumatoid Arthritis (JRA). This very personal piece illustrates the changes and sensations that have occurred in his body. Different symbols of pain emerge from each of the joints to identify the types of pain he experiences and where it occurs. According to Otto, lightning bolts represent flashes of pain, needles represent sharp pain, melted down nails represent festering pain, and elongated pyramids represent monumental pain. The sculpture also depicts scars from hip and knee replacements, muscle wasting, and physical changes in the feet and hands. The title of this piece, “Glimmer of Hope,” reminds us that alongside the pain, scars, and changes resulting from chronic illness, hope remains. This piece represents some of the impetus for Otto’s new-found vocation as a ceramic artist. Engaging in ceramic sculpture helps him process the experiences associated with JRA and provides a means to support others experiencing chronic illness as well.

Otto uses his artwork to connect with people impacted by chronic illnesses, something he finds extremely satisfying. His sculptures visually express the physical, emotional, cognitive, social,

and psychological challenges that people living with chronic illnesses face. He believes that visual art can be a visceral experience and, rather than simply creating pretty pieces, he attempts to speak to people through his sculptures and connect with them on a deep level. His early sculptures focused on living with JRA while later pieces have evolved to reflect the universal experiences of life with a chronic illness. His sculptures range from detailed and symbolic depictions of a hand impacted by arthritis, to the bewildered face of someone who has just been given a medical diagnosis, to a small person staring up at a set of overwhelming stairs. These striking pieces each produce an emotional response in viewers, often related to their own experiences or an increased understanding of a loved one’s experience. Otto indicates that the important moments he creates by doing this type of artwork are in the connections and responses he elicits from individuals. For example, in a recent interview he described how a woman, while viewing one of his pieces, cried and expressed that his artwork helped her to understand what her father went through while suffering from a terminal illness. Otto’s hope is that his works can help people make these kinds of connections.

Along with using art as a means to connect with others and increase understanding of the illness experience, Otto hopes to bring attention to arthritis. In a recent interview, Otto discussed how arthritis is not an illness that receives a lot of attention, and that it is often misunderstood. The diagnosis of arthritis encompasses more than 100 inflammatory and non-inflammatory diseases that impact the joints and surrounding muscles (Frost & Harmeyer,

2011). Symptoms of arthritis include muscles pain, swelling, joint pain, edema, decreased range of motion, and decreased fine and gross motor control. According to the Centers for Disease Control (CDC, 2013), 52.5 million people in the United States had a diagnosis of arthritis in 2010-2012. Of those with a diagnosis of arthritis, 43% report arthritis-attributable activity limitations (CDC, 2013) and 11% report restricted participation in social activities due to the symptoms of arthritis (Theis, Murphy, Hootman, & Wilkie, 2013). Additionally, there is a strong association between arthritis and depression, likely due to the functional limitations that result from the disease (Dunlop et al., 2004). The prevalence of arthritis increases with age (CDC, 2014), which may lead many to believe this is an older person's disease. Otto attempts to illuminate some of the impact arthritis has on individuals of all ages, giving a voice to the pain and functional challenges that may not be easily detected or discussed openly. In addition to advocating for increased understanding and recognition of the impacts of arthritis, Otto also wants to focus future work on the positive aspects of the illness experience. He indicates that in future works he wants to highlight the sense of community and support he experiences from family, friends, physicians, researchers, and therapists.

He also has a broader goal for his artwork—to help health care professionals develop a better understanding of the illness experience. Otto notes that people learn in many ways, and that a visual representation can be powerful. Ultimately, he hopes that his sculptures create a new dialogue about the illness experience. This aspect of his

work is similar to the concepts of photovoice, which is used by researchers in health care and public policy. Photovoice is a research process that involves participants documenting their everyday realities through photographic images and written narratives (Stoffel, 2011). Similar to Otto's work, photovoice uses visual media to articulate the lived experience to health care providers, policy makers, and advocates to effect changes in service delivery; and, it begins to explore questions about what health concerns of the patient have been overlooked, unconceptualized, or ignored (Baker & Wang, 2006). Using visual imagery to express the illness experience can be valuable to the individual, and also an important part of informing health care providers.

Otto has many connections to the health care community and views his sculptures as a culmination and an integration of his artistic abilities and his experiences with health care providers. After being diagnosed at the age of 9 with JRA, Otto participated in occupational therapy (OT) treatment. The American Occupational Therapy Association notes that OT practitioners provide interventions to people with arthritis, including pain management (physical agent modalities, stress management techniques), edema management (splinting, positioning, exercise), strategies to improve and maintain range of motion and strength (stretching, exercise), and enhancement of ADL and IADL function (functional splints, energy conservation, joint protection, adaptive equipment, modifications to daily routines) (Frost & Harmeyer, 2011). Otto received many of the interventions noted above,

including splints, exercises, and activities to maintain range of motion and strength, pain management strategies, and adaptations to increase function. He was also introduced to ceramic art through OT when, at the age of 16, he created a chess set using slip casting and molds as a part of his therapy. He expressed that being involved in OT gave him a sense that there was always someone there to help and support him. Also, engaging in art-based activities during treatment provided him with the important psychosocial benefits of increased self-concept, self-expression, and healthy habits and routines. As a young boy with an illness preventing him from participating in valued sports activities, he was able to develop new art-based leisure activities that helped him adjust to his chronic illness. As an adult, Otto received knee and hip joint replacement surgery and rehabilitation. While in rehabilitation, he visited the art department frequently between therapy sessions to engage in art making. This experience, along with transitioning from employment to disability, prompted him to engage in art activities more frequently. After a few years of regularly participating in ceramic arts, he found that “spending 5% of daily and weekly life (doing art) made everything sweeter.” Otto reinvented himself by changing how he used his time.

In 2011, he applied for and achieved a competitive ceramics artist residency at the Port Moody Arts Centre near Vancouver, BC. There, he completed several pieces for his show “Shard’s, Bone Deep.” This year, he achieved a second residency at Port Moody Art Centre that provides space, equipment, and a gallery show. In the next

year, he plans to highlight the experience of the onset of arthritis symptoms in a young man through ceramic animation.

In addition to increasing his participation in art making, about 10 years ago Otto began to volunteer with the Arthritis Research Centre of Canada (ARC) as part of the Consumer Advisory Board (now the Arthritis Patient Advisory Board). He was the first co-chair of the board and participated in many projects as a consumer collaborator. One of the main goals of the Consumer Advisory Board was to assist in transferring research findings from researchers to consumers. Otto participated in roundtable discussions with researchers to aid in creating outputs that consumers and the public could understand. During this experience he began to recognize an association between the goals of his work with the ARC and his own artwork that focused on arthritis. He began to meld together his passion for advocacy through volunteering with the ARC and portraying the experience of living with JRA through ceramic art. He also began acknowledging that all people with chronic illnesses have some shared experiences, and he broadened the focus of his art to include the common strings that run through the illness experience.

By creatively intertwining reflections on his personal health experiences, his passion for supporting others, an investment in improving the care of people with arthritis, and his talents as a ceramic artist, Otto provides new insights into the illness experience. Otto’s achievements also demonstrate the value that visual arts can bring to

health care practice, both for recipients of our services and for providers.

**To view a video and samples of Otto's art work, visit:**

**[http://scholarworks.wmich.edu/ojot\\_occupationandartist/](http://scholarworks.wmich.edu/ojot_occupationandartist/)**

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