VISUAL & PERFORMING ARTS | CRITICAL ESSAY

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Abstract: This paper offers a personal discussion of the use of art, sculpture specifically, to bridge personal experiences with chronic illness: juvenile arthritis. Drawing on the experiences of making work and sharing this work in different contexts, it focuses on what it is like to live with arthritis and how creative practice can be used to benefit both artist and viewers. The works discussed in the piece have been created to explore and develop understanding around issues that are not easily talked about in either the doctor’s office, or in public settings. The figures generated through this body of work provide a device or platform that allows the artist to look at the disease through the course of his life and in so doing, to adopt a third perspective on this sometimes difficult process. Reflecting on that young boy, that teenager, that young man struggling with arthritis, sometimes effectively, at other times not so, the art-making process and shared products allow the artist a certain freeing, revelatory view capable of reconciling trials and struggles with self-knowledge and empowerment. This work allows the artist “to dig into those dirty emotional corners”

ABOUT THE AUTHORS

Otto Kamensek is an accomplished ceramic artist, community volunteer, emeritus member of the Arthritis Research Center of Canada Arthritis Patient Advisory Board, and a community member of the Emily Carr University of Art + Design’s Research Ethics Board. Otto has spoken nationally and internationally on Art and Health to students, artists, health professionals, and the general public. Otto was artist-in-residence at Port Moody Arts Center 2013–2015, where he explored and created work related to his health and how it has affected his own body, and the world around him. His goal is to create a conversation about what art and healthcare can offer one another. Articles on Otto’s work are in the Journal of The Canadian Rheumatology Association (“Bone Deep: Where Art and Illness Intersect”) and The Open Journal of Occupational Therapy (“Sculpting the Illness Experience”). YouTube talks by Otto include: “Art & Arthritis with Ceramic Artist Otto Kamensek” (https://www.youtube.com/watch?v=IEefyS677As); “Art & Arthritis” (https://www.youtube.com/watch?v=f-mp7bqofOg); and “Otto Kamensek: Dave an Unexpected Tale” (https://www.youtube.com/watch?v=53oU2M0wF9E).

PUBLIC INTEREST STATEMENT

This article is based on material from an interview with Canadian ceramic artist Otto Kamensek, who describes how his art practice enables him to process his personal history. A series of works related to his health and how Juvenile Idiopathic Arthritis has affected his body and the world around him, are explored in the text. Kamensek further discusses the ways in which his work can be of benefit to people living with chronic disease, as well as their family members, and details how his work has generated empathy and understanding of what it might be like to live with chronic disease, for healthcare providers. Kamensek seeks to create a conversation about what art and healthcare can offer one another.

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and to work through uncomfortable thoughts. These works and the experience of discussing them has been useful in educational contexts, particularly germane to further understanding of creative practices, artworks, and their potential contributions to healthcare-related services and service providers.

**Subjects:** Graphic Arts; Chronic Diseases; Health Communication

**Keywords:** ceramics; sculpture; juvenile idiopathic arthritis; chronic disease; art and arthritis; arts and health education

**JD:** Your practice of sculpture, and using this medium to bridge your personal experience with chronic illness, can you explain how that came about?

**Otto:** It’s kind of interesting, because I remember when I was a kid, working with ceramics was not my favorite thing to do. Maybe because I had high expectations of myself, and if I couldn’t do something right away, I’d be frustrated. I actually stopped doing art altogether when I was in my 20s to focus on a career—the old adage of “starving artist” didn’t appeal. It’s interesting that this medium came to me, in some respects. I’d had arthritis-related surgeries and was actually going through rehabilitation. There was an art department there and I went down to fiddle around, and started creating masks out of paper mache. After I left rehab, I looked in the community for something similar, but couldn’t find anything. So I ended up going to an art studio that was doing masks out of clay, and stayed for several reasons: because of the camaraderie between the people at the studio; and it was tactile—something I could work with and play with, and that I enjoyed. So, in that way I think it picked me because I was enjoying it at that time.

And, you know, at certain points in your life, you’re not ready to do things: emotionally or physically in some respects, or financially. Ceramics is a medium that I’m now using to story tell with anyway, which is good. For some reason, now that I am working in a 3D manner, I’d find it hard to go back to two dimensions. In some ways that’s a good thing; in some ways, it’s not a good thing.

**JD:** You talked at the symposium about the narrative of your Juvenile Idiopathic Arthritis, would you like to expand on that?

**Otto:** I think sometimes it can be important to know the background story of an artist, just to understand where the work’s coming from. I was diagnosed at the age of nine with what back then was called Rheumatoid Arthritis; Juvenile. It’s now called Juvenile Idiopathic Arthritis, because they still don’t really understand the disease, to a certain degree. Looking back, I probably had it when I was 8 years old, because I had symptoms for a year prior to getting diagnosed with the disease. In some respects, I was lucky because there were only two specialists in Canada at that time for Rheumatoid Arthritis; Juvenile, one in Ontario and the other in B.C., so I was actually diagnosed a lot earlier than some people in other provinces might have been. Not to say that treatment was great at that time, because it was 14 aspirin a day, which wasn’t good, but the disease was quite active. Of the five subgroups within Juvenile Idiopathic Arthritis, I was diagnosed with the one called Systemic, which, out of the five, is typically the more aggressive. Within the first five years or so of being diagnosed, the disease created a lot of damage on my body which has caused me to have numerous hip and knee replacements, and most recently a couple of neck surgeries.

So that background, it definitely affected my life. As somebody who grew up in this country with Juvenile Idiopathic Arthritis, my path was sort of set in concrete for me. I knew I wasn’t going to be doing a job that had a lot of physical activity or so called blue collar work and I think a lot of people just expected me not to do paid work at all; to be on disability, but that wasn’t acceptable to me, so I ended up going into the workforce. I had a few different weird and wonderful jobs in the beginning, but settled into a job as a buyer, or purchasing agent, for many years, with different electronic companies. I also did one stint as a sales rep as well. But the disease hampered that kind of work,
because it tired me out over a period of years. When I worked full-time, I would end up in the hospital every three or four years and in the long run, I didn’t see that as viable. I couldn’t sustain that. So then I had to go on to disability, which now, looking back, was the right choice.

JD: So were you making art, were you sculpting in that time period, when you were also working as a purchasing agent?

Otto: No, I totally dropped it. Looking back, I think that was a mistake for me. When I did get back to the art, after not doing it for 13 or 15 years, it was like running into an old friend and starting up the dialog again, and enjoying the company of that friend. It was like a part of me was lost for those 15 years. I wish I would have dabbled in it, and continued to work at it, because I think it would have helped me. But, being a young guy, I was stubborn and hell bent on conquering the “working world”, kind of thing. And I believe that there was also a denial aspect for me—that I was not even ill—I was going to work no matter what.

JD: So how did your ceramic work develop over the years?

Otto: I went to the Port Moody Arts Center and began working there. I started playing with a blob of clay; it’s kind of hard when someone throws that in front of you. A blob of clay—it could be anything. Therefore, it can be tough to start something. But actually, once I started working with it, cascades of ideas started coming to me. I started out by making boxes, and I had a show at the Port Moody Arts Center called, “Is it the box or what’s inside”, with those pieces.

I started working on other subject matter; figurative work, or just playing. Every year I’d get into a show with one or two pieces, and it just went from there—from an emerging hobby to becoming an artist. Going to an arts center is a good thing, because one can learn some skills and you also have an opportunity to show your work and grow as an artist, which can be a huge step. So a bit like the process that I now go through to create a piece of work: there is a process to becoming an artist.

JD: So making the art related to your health came later, did it?

Otto: Eight or nine years later. It almost paralleled my volunteer work at the research center, and other volunteer work related to arthritis. I thought “what if I melded the two together?” At that point, I’d started reading a lot about art history, and understanding what other artists did—typically they take a genre and put it together with something that isn’t already there. So I’m hoping that what I do is original. Chances are that it’s not—somebody may have done it, but I haven’t bumped into that yet.

JD: In the course of showing your works, have there been any surprises for you?

Otto: Yes. When I started focusing on doing art that had a purpose or a story behind it—the art that was related to my health—it actually was hard to do because I questioned myself about doing that kind of work. “Will I do it justice? What were other people going to think if I was doing this?” So I was apprehensive about doing the work at first—I was worried that I wouldn’t be able to convey what other people were going through. Because it would be like telling somebody “well, this is your experience”. That was hard, until I came to realize that I can never express what other people are going through. I can only speak about my personal experiences of living with this disease, and express my own observations and feelings about things. And if I’m lucky, it may be true for other people. Which would be great.

But what shocked me was that, although I was doing this work in relation to arthritis, people with other diseases would come up to me and say, “Yes. You know what? You have hit the nail on the head with this (piece)”. These were people living with issues around cancer, or chronic pain, or chronic fatigue. An example of this, is a piece called Chronic Disease (Figure 1). It depicts a little figure...
standing on the bottom of a staircase, and the stairs get bigger and bigger and bigger. Sort of a nightmarish dream—where you know you can never accomplish something. Initially, I wanted to call it “Rheumatoid Arthritis”, but I thought, OK, well there are other inflammatory arthritis groups out there, and there’s also osteoarthritis; I’ll expand the scope and call it “Chronic Disease”. And as I said before, people with cancer came up to me and said, “Oh I get that. You spoke a language to me that I’ve never seen before and I appreciate it”. That’s when I started understanding that, in a disease there’s a commonality or a thread of commonality of experience that goes through it. So even though my art reflects arthritis, the work can also hit notes that people with other diseases understand.

When I do connect with people on that level it’s a special feeling to me; when somebody says, “I understand this”. It’s difficult to put a word to that feeling, or a specific word. Because it’s not pride, or anything like that. I’m still grappling with what the emotional term is around it. I think I need to sit down and really think about it one day, to figure out what it is.

JD: The pieces that you brought to the Arts and Health Symposium, were created as a result of you going back to, as you say, some “dirty emotional corners”? Can you say a little more about that process?

Otto: I talked at the Symposium about digging into the “emotional dirty corners”. I use the hockey analogy to explain this, because going into the corner in a hockey game is a brutal place. You know you’re going to get hit, smashed; put into the wall. As an artist, you’re going to a place you went through in the past and emotionally, you don’t want to go back there. But when I did go back there,
I went back—maybe as a way of protecting myself—as a third person; you’re re-experiencing those emotions or situations, but you’re looking at the situation from a different perspective.

So, looking back to when I was 9 years old from the perspective of an adult—you’re looking at a young child grappling or struggling, and dealing with, a disease that turned his life and his family’s life, upside down. Revisiting the emotional aspects of being away overnight from home for the first time at the hospital; my parents weren’t allowed to stay, they had to leave. So there you are as a nine-year-old boy sitting in a cold, stark room by yourself. It seems like punishment. It’s bad enough that you’re sick, but now your parents are taken away from you. And the treatment was kind of rough and tumble—I call it the stone age of arthritis care. There are all these brutal insults with the disease, to who you are. And as a child, you don’t always have the emotional toolbox to deal with that.

As a child, I was thinking that somehow it was my fault that I was ill. Everybody was saying “you do your exercises and you’ll be better”. Well, it doesn’t always work that way. The disease did what it did. And no matter how much exercise I did, it wouldn’t have changed anything. So I look back at that child, you know, he went to regular schools and didn’t quit. From the perspective of somebody older, I look back and I think, “that kid was pretty brave”. And when I did that, it lifted a sort of heaviness that I guess I’d been carrying with me for a long time. That kind of freed me. I think there was a certain amount of extra weight that I’d carried around from being ill as a child and an adolescent. Maybe with adult onset illness you don’t have to carry that extra weight, but I’m not sure if that’s true or not, because I’ve never really discussed that with people.

This third person perspective that I talk about gives me the ability to look at that situation from an adult standpoint and say, “that kid did the best that he could, and survived it”. At the time, you deal with it and push it to the back of your brain so you don’t have to think about it, do you know what I mean? That’s what the emotional dark corners are all about—you push crap like that into those areas so you don’t have to deal with it.

A therapist used the analogy of someone having a garbage can full of emotional angst. You open up the garbage can and let one out to look at again and re-evaluate it, then close the top of the garbage can. Some people kick the top of the garbage can off and there’s so much negativity in there, that it’s overwhelming. So they put the lid back on and they don’t go in there again.

My art allows me to pull out one negative thing at a time, assess it and go, “OK, I don’t need to be afraid of that anymore”. That’s what art gave me—the sense of freeing, or getting rid of those dark corners.

One piece that as yet is unfinished—it’s done as maquette, or a little study—I would call it Little Deaths. That sounds dramatic, but it represents the grieving process for little parts of your personality that get sliced off when you become ill. It might be the aspect that you loved to play soccer, and that was taken away from you, so there’s a grieving around that. Or riding your bike, you grieve that; certain friends don’t come around anymore because you used to ride bikes with them. If you don’t ride bikes, they don’t know what to do with you, there’s grieving around that. The same thing as a young adult, having expectations of things that you want to do and that are taken away from you because of the constraints of the disease.

I know other artists that have disease aspects, and they don’t want to go to those emotional places, because the art is the freeing part. Going into, or taking the art into that dirty corner is something they don’t want to do. I think it’s freeing if you can do it, but I get why people don’t want to: because the art is the escape from the disease, so why would you want to go there?

Some people with arthritis have found it emotionally affecting to look at certain pieces that I’ve made. I gave a talk to a hundred or so people that had some form of arthritis, and a lot of them got
emotionally involved with the work, which to me, was somewhat surprising. People told me that there were a lot of watery eyes in the room. It wasn’t my intent to do that, but obviously the work spoke to them at what I hope was a deep and emotional level. I asked one woman attending, an interior designer, “do you ever get that kind of response from your clients?” She says, “never”. As an artist, it’s a special relationship, or a special moment for me, and like I said I still can’t put my finger on exactly what emotion or word encapsulates the whole thing. It’s a profound feeling when people understand something at a deeper level.

JD: Maybe there’s something visceral in your work, that people understand at that level?

Otto: Which words don’t always capture. It’s the old adage of ‘a picture says a thousand words’. That’s why I think it’s important, or can be important, that art play a role in the education of healthcare providers. I’m hoping that the work that I’m doing will provide healthcare providers with a better insight and understanding of what it might be like to have a disease. On two different occasions, I’ve had somebody come up to me and say “You know, my father’s been dealing with arthritis for a long time”. One of them actually got weepy, and I felt bad that I put her into that emotional space. But she said “Oh, don’t feel bad”, “I now understand better what he’s going through”. Creating that kind of understanding or empathy for a family member, to me was deeply satisfying. Same thing with a student at a pharmacy-related talk that I gave, they said “You know I never really understood, but those images that you created, gave me a better understanding”. I don’t know what that means exactly, because I’m not sitting there measuring their level of understanding. It’s just something that people say to me. So, I’m hoping that it’s on a deeper level and when they see their parent, they will have a better understanding of the sort of life that they’re living.

JD: Where do you do these educational talks?

Otto: I’ve given talks at the University of British Columbia, I’ve been doing talks for some years with the pharmacy students there. I’ve also given a talk at conferences, some international conferences. I’ve given talks to other artist groups.

The last time I was in the hospital, I mentioned my ceramic work to the coordinator of the massage therapist program, and she said “You’re Otto?”, “You’re the Otto?”, and I started laughing to myself because it’s so weird. But she says “I’ve seen your work. I went back twice to see your work, in that first show”. That kind of response was humbling. Especially when she worked in healthcare, that’s what she does for a living. Another woman I know from the arts center told me that her daughter wrote two pieces at school that related to the work that I did. If I can communicate in that sort of a way, it’s very humbling to me.

I’d like to see educational institutions add that kind of understanding and make it part of their curriculum. Those are goals I have for broader change in the healthcare system.

JD: What kind of art speaks to you?

Otto: I can appreciate art that’s pretty—and there’s a place for that. But the type of art work that I’m really drawn to, typically has a story behind it. I look around, at least in sculpture, and I don’t always see work that has language of this kind, that I’m speaking of. I think as one artist said, or there was a shirt that said it, “my art shouldn’t match your couch”, or “art shouldn’t match the colour of your couch”.

I never know when I’m going to get enthusiastic, or spoken to. Sometimes there’s art that isn’t always as expressive in that manner, and I fall in love with it. But usually I am attracted to work that has a bit of a deeper meaning behind it, that sticks with me. And it doesn’t necessarily have to be art that I bring home, it might be work that I see in museums. A piece that I saw at the Art Institute of Chicago, that has stuck with me over the years, was The Freedman, a bronze sculpture by John
Quincy Adams Ward. The piece just spoke to me so deeply—just the way the body language was speaking, it stuck with me. I told other people about it, and they felt the same when they went to see it. There was a reason why it was in the Institute—obviously it’s a great piece of work.

JD: You mentioned earlier that some pieces had been hard for you to do, or hard for you to work on. Would you like to expand on that?

Otto: I think the piece that was the biggest bottleneck or logjam for me, was the piece called the Glimmer of Hope (Figure 2). Basically, I see it as a visual journal of all the pain, and the types of pain, that I’ve been dealing with for a lifetime. This is where I was asking the questions “is this going to be correct for other people?” “Am I speaking for other people with arthritis?” I think it took me a year and a half to finish that piece, not because it was so technically difficult, but mentally it was tough and difficult to go there: did I want to finish it? I also had to go back to those places where I felt pain, and the types of pain, and think about it. I think that’s why it slowed me down. And in some ways, a lot of people are drawn to that piece, more so than some other pieces that I’ve made.

JD: Who would you like your work to be seen by?

Otto: That’s a good question. The more people that are able to see it—that’s great. I think those that may benefit from it, are people living with chronic illness or pain—just to let them know that there are others out there that understand. I’m also hoping that those who work in the medical profession and healthcare are able to see it, and that they get something from it. I’ve heard that if you create an emotional moment, which doesn’t have to be someone crying or being angry or whatever, but just an emotional moment with an educational moment, it’s supposed to go into your long-term memory. And if you can create something that sticks with people throughout their lives, create empathy or understanding, I think that’s a good thing.

Figure 2. Glimmer of Hope.
Image courtesy of the artist.
I’ve also done two pieces related to female aspects of living with the disease; 66% of Rheumatoid Arthritis sufferers are women. One woman I know was saying that, because of the damage to her toes, she had been affected by not being able to wear certain kinds of shoes, and corresponding outfits, anymore. Although I know I can’t fully do justice to the feelings involved, I felt it was important to reflect that. The piece is called “Healed” (Figure 3).

Another piece, called ‘Dorothy and Goliath’, is a maquette, still unfinished as yet. The work represents the relative amounts given for funding different kinds of diseases in Canada. For example, some disease groups get in excess of $1000 per person—in the early 2000s, arthritis got about 93 cents per person, even though the disease affects over four million people in Canada. I wanted to let people know, especially women, that they are not getting the resources needed to fight this disease.

JD: You’ve spoken about several different ways in which your art benefits yourself as artist and viewers. Are there any others you want to mention?

Otto: I talk about my process, and how I go about doing the work. I find that other artists or hobbyists may get something out of that. One researcher I know said “I can’t do that (make art)”. And I said, “well in some ways my art process and your research process are somewhat similar”, research doesn’t happen without many steps, and in my mind these steps create a better finished outcome. I usually start out with a basic idea, I do a thumbnail sketch so I don’t forget it. For example, something tweaks a thought, like one of the volunteer members that I used to work with, he always used to say, “I’ve got an angry joint today”, and that just gave me a flood of ideas, from which I created a piece called An Angry Joint (Figure 4, Title Image). It’s basically a life-sized leg, and in the joints, I put little heads coming out with different emotional aspects of pain, or dealing with pain. It might be the fact someone’s just simmering with pain, they’re not expressing anything but you can feel that somebody’s not happy because they’re biting their lip from the pain that they’re having; others are grimacing from, or growling about, pain. It was interesting how those three words, “an angry joint”, gave me such a mental image.

I drew a little thumbnail sketch and I did what I call a little maquette, or a little study of it, because you never know what it’s going to look like in 3D. When you do a painting, you don’t have to worry about the backside or the other third side. With ceramics, you have to make the piece look interesting from three different directions. Sometimes I have to do two or three drawings or maquettes to get what I want to say in an understandable way.

Figure 3. “Healed”.

Photo credit: Otto Kamensek.
As I'm working on the piece, the full size piece, I might change things as I go through, there's a constant change. With research, I see it as similar; that you have an idea, you take the idea, you work with it, you kind of ask a question about it, you put the question out there, you get responses for the question, and you get an answer. And I think some of the process is somewhat similar—the outcomes might be totally different, but I see similarities in path, or understanding of creating work.

Some artists want to work from a visceral place, and they'll create something that has no thumbnail sketch, no maquette or whatever. And that's viable too. That's art. I've also done that, but for me and the work that I do, the thumbnail sketch and the maquette has a stronger voice than something that I do just in a visceral way. That's my personal preference. I'm not saying it's better or worse.

JD: Are there any key messages from your experiences of expressing your health through your art that you'd like to end with?

Otto: I think this journey that I've taken over the last seven or eight years, needs to be shared with other people. Whether that's healthcare providers, or people that have illness in their lives. I know that not everybody wants to go to those places, but it can be beneficial. It can be a good thing. Our educational systems are typically heavy on the written word, which doesn't always express emotion well. Historically, science was about taking the emotion out—now they seem to be talking about putting some of it back in; because you can’t actually take emotion out.

It's important that healthcare providers who are treating people have a sense of empathy. In many cases, people have been inspired to become doctors because a family member has been sick at one time. But sometimes, even with that background experience, they don't get what it's like to have a disease. I'm hoping my work, as this extra layer or this postscript to the current system, could enhance education for healthcare workers. When I show my work and do talks at the university, the feedback is that students refer to that experience a year later in their evaluations of the course—without fail. So, in schools where students do not have access to someone who has an illness, that aspect is currently missing.

I think art can be extremely important in education, it just depends on how you use it.
Methodology
The interview with ceramic artist Otto Kamensek took place over the telephone, in two stages. The first stage in April 2017 (approximately 50 min long); the second in May 2017, (approximately 30 min long). The interview was written up by Jacqueline Davidson who worked with Otto Kamensek on several iterations, leading to the final piece.

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Author details
Otto Kamensek
E-mail: OttKam50@gmail.com
Jacqueline Davidson
E-mail: jacquelinemadavidson@ecuad.ca
ORCID ID: http://orcid.org/0000-0002-1408-3324
1 Port Moody Arts Centre, 2425 St. John’s Street, Port Moody, Canada, BC V3H 2B2.
2 Emily Carr University of Art + Design, 520 East First Avenue, Vancouver, BC, Canada.

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