The Art of Exclusion and Embrace

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To link to this article: http://dx.doi.org/10.1080/23312521.2016.1239154

Published online: 15 Dec 2016.
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ABSTRACT
This article considers the themes of exclusion and embrace, noting how they are embedded within the author’s own art-making practice, a recent doctoral inquiry into the theological question of the art of healing, and within her life with multiple sclerosis. The article addresses how art can be a remedy for the experience of social exclusion that can accompany illness and disability. It also addresses the need for art as a remedy for the experience of separation that follows when we attempt to exclude the possibility of illness and disability from a normal, healthy life. This article was delivered to open an Art Exhibition at the “Exclusion and Embrace: Disability, Justice & Spirituality Conference” in Melbourne, Australia on August 21, 2016.

I am honored to be with you today and to have the privilege of saying a few words to open this exhibition. The theme to which the artists have responded is extremely important for us all to see and hear. Artists: The work you have made and now show us helps us to see and then learn about what it is like to be excluded but also what it is like to be embraced. These are themes that are embedded within my own art-making practice, my recent doctoral inquiry into the theological question of art of healing and indeed within my life with multiple sclerosis. I suspect that it is for these reasons that I have been asked to speak here today.

I think that the first thing I need to say is that for human beings to flourish, we need to really know who we are and how our presence in the world makes a difference. Being aware of ourselves in relationship to others creates opportunities for connection that enable human flourishing. Art is a way of saying, “I was here,” and that makes a difference. Art is an experience of connectedness, an assurance that we are not alone in our human journey. Mikel Dufrenne says that we discover who we are within a work of art because the work awakens us to ourselves (1973, p. 60). In doing so, art speaks into and from the depth of our spirituality.

But who we are in the world is something that changes throughout the course of life. In my own experience, my sense of who I am was radically changed when I
received a diagnosis of multiple sclerosis (MS) in February 2010. In the months that followed, art helped me to say both to myself and to the world, “I am still here,” and this was a lifeline for me. It was no small challenge to do this as I lived with the symptoms that were both unstable and relentless, but finding ways to be with art materials and also with my symptoms offered me a powerful way of including my old self and embracing my new self. Many of the symptoms that come with MS are not particularly visible. I was deeply aware of a significant gap between the way other people saw me and the way that I was now experiencing the world. Making art about what it was like to be like this was a way of maintaining a connection with the world around me, from behind the veil that is MS.

In the years since my diagnosis, it has been increasingly apparent to me that there is nothing particularly unusual about the challenges that this change in my health has provoked. Certainly MS is a very particular illness that has, in some senses, a life of its own within my body, but my body is in so many ways still just like every other body. Human bodies are fragile and challenged by the effects of aging and decay. If we live long enough, we will all have the experience of living with a body that will break down over time.

The difficulty is that we so often take a healthy body for granted. It is only when something goes wrong with the body that we begin to notice it. Rather than accept the ordinary experience of mortality and the effects of illness, our culture encourages us to resist and even to fight these natural processes in the hope that we can remain in a perpetual state of health. The fear of what may happen to my body in the future can lead me to deny experiences that are inherent in the conditions of being human, such as the presence of illness, disability, ageing, and even death. In my own case, this denial led to a delay in making an appointment to go to the doctor with my symptoms. I had a sense of dread—knowing that the things that were happening could probably not be good, and that led me to ignore my lived experience for a time. Even as I did everything I could to enhance my experience of health, the illness progressed. Denial of our own experience is a particularly difficult form of exclusion—and this is why we need art. To help us see what is really there in our own experience.

Susan Sontag notes that the experience of illness and wellness is common to all human life. She says, “Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick” (1978, p. 3). As the illness invaded, my memory of being well seemed to retreat into the distance. In thinking about how to live as a person with MS I began to wonder about the question of health. I wondered whether it was possible to live in both of the kingdom of the well and the kingdom of the sick at the same time, rather than have the diagnosis prescribe where I belonged or where I could stay.

In the course of my treatment, I have encountered many people living with MS. They are all so different … but there was an encounter in the first year that challenged me to rethink the possibility of being well, with MS. It was the moment in a hospital setting when someone who shared my diagnosis was meeting me for the
first time and referred to me as a “fellow sufferer.” I knew that I was unwell, but until that moment I had not considered that I was suffering. My fear of being pulled into what seemed to be a potential pit of suffering meant I excluded the possibility of having any empathy for this person even as we shared the same ward and treatment. I created a mental distance between us and tried to find ways to focus my attention on my own healing rather than on her suffering. While her suffering was very real for her, my own experience in that moment was different. Her assumption that I was a “fellow sufferer” didn’t allow me the opportunity to be the same, but different. My response was to shrink away emotionally and psychologically and thus probably affirm her own experience of exclusion and isolation as a person with MS.

The reality is that physical disability often also leads to social isolation. The uncomfortable experience of watching someone experience disability can awaken a depth of fear that results in the marginalization of those who are already separated from the mainstream of life. Elisabeth Tova-Bailey says of her experience of being with people who visited her while she was living with chronic illness, “I could see that I was a reminder of all that they feared: chance, uncertainty, loss[,] and the sharp edge of mortality. Those of us with illnesses are the holders of the silent fears of those with good health” (2011, pp. 39–40).

It was possibly my fear of exclusion and social isolation that led me to consider the theology of healing in my doctoral work. I wondered whether the language and experience of faith would provide a place of belonging for me as I became increasingly ill. I also wondered about praying for healing and wanted to understand whether I should expect that such a prayer could result in a cure?

Over several years, I explored what it means to desire healing while living with incurable illness within my studio practice and then in the gallery. Having made a body of work about illness, I invited the public not only to see but also to offer their own words to title the images. As I read the responses, I was aware of a shared experience of vulnerability and connection. People saw what they needed to see in the work and then they shared that experience with me as an artist/researcher. In this, there was an opportunity for us to be the same but different. People were free to see the same work, in the same place, in very different ways, and in this there was an experience of inclusion and embrace. As a result, I discovered that as I live with illness, it is important not to not limit my understanding of healing to an outcome labeled being healed and particularly not to think that healing will mean being cured. I learned that to speak of healing is to describe a process that requires recognition and participation.

This means that to be healed, we must be willing to participate in the whole contingent experience of living, rather than resisting painful experiences in favor of those that are perceived to be good. Indeed, we must find ways not just to accept that these things are part of life but to embrace them as we seek to live life in all its fullness. This is not to say that we need to be happy about being unwell, but we
need to be compassionate and inclusive toward our own selves when we are ill. This compassion is both the focus of and the answer to my prayer for healing.

I remember being asked soon after my diagnosis whether I felt my body had betrayed me. I was surprised by the question and a little offended on my body’s behalf. Betrayal is a powerful word that suggests that my body had been unfaithful in guarding me from illness or unsuccessful in maintaining health. Betrayal suggests that my body has not fulfilled a commitment to carry me through life in a particular way. But such a commitment was never part of the deal. Illness and disability are, however, very much part of the deal of living this human life: They are important and powerful experiences that need our care and attention if we are to embrace what it means to be fully alive and wholly human. They remind us not to trust in the hope of certainty but to live into the possibility that is faith.

So what then of healing?

When we consider the possibility of embracing the whole of life in this way, healing can be understood as seeing and being seen, knowing and being known—just as we are in all our many states of illness and health. This is the essence of a life of faith. For me that means taking up art materials and doing whatever it takes to resist the seduction of isolation and exclusion that can be part of the package of living with chronic illness and reach into the world in the hope of connection. Being here today to see this work and share in this experience with all of you is in this sense an experience that is healing. Art is a remedy for the experience of social exclusion that can accompany illness and disability. It is a remedy for the experience of separation that follows when we attempt to exclude the possibility of illness and disability from a normal healthy life. I am thankful for the courage and compassion that is evident in the work that our artists are sharing with us in this exhibition.

I want to finish with a special word for the artists. Artists, I trust in the journey that you have shared with us in these images. Your work is a gift that helps us to renegotiate the binary and exclusive notion of the difference between “sickness and health,” “us and them,” and especially the difference between “faith and certainty.” In your work we can learn to see what is shared in our human experience while recognizing what is unique and different within our own stories. Your work encourages me to continue living in the faith that all will be well. My hope is that as we see your work today, we will do our part to fulfill the creative calling that you have so generously offered.

References