Healing in the Absence of a Cure

Libby Byrne, DipVA, BEd, MAT, GradDipTheol, PhD1,2

Abstract
This article offers a series of 3 vignettes exploring how art making has enabled me to understand my experience of the psychological and spiritual questions that have arisen throughout my diagnosis and subsequent treatment of multiple sclerosis (MS) in the private hospital system in Australia. The findings of the article indicate that the challenge to maintain a sense of identity that is separate to the experience of illness is critical for people who are living with MS and the language employed by health-care workers has a profound capacity to help or hinder this. Opportunities to make art in hospital supports the efficacy of prescribed medical treatments by enabling patients to exercise power in the midst of a process over which they have little or no control.

Keywords
patient perspectives/narratives, patient arts and photography, patient-/relationship-centered skills, spiritual and integrative care

There is a substantial emotional burden that people experience when making the status transition from being a person without multiple sclerosis (MS) to being a person with MS (1). There are also some distinct challenges in living with MS relating to the persistent struggle to find the power to live life with dignity in the face of this degenerative and incurable disease (2). In the absence of a cure, there is a need for healing, the formulation of care that is focused on what can be done and power that can be exercised by the patient, unifying and consolidating a sense of personal capacity and identity other than the experience of illness (2). This article offers a series of 3 vignettes exploring how art making has enabled me to understand the psychological and spiritual questions that have arisen throughout my diagnosis and subsequent treatment of MS in the private hospital system in Australia (3).

Diagnosis (2010)
When I was first diagnosed I lay in hospital receiving daily infusions of steroids, somehow expecting that this treatment would return my health to normal. Despite the medication on day 3, I was significantly worse. I explained this to a nurse and earnestly asked why the medicine was not making me better. She stood and listened, then said in a very measured way, “You have MS and we can’t do anything to stop it.” This short sentence cut me adrift from my life before MS, leaving me with no choice but to find a place in the “the kingdom of the sick” (4). Hospitals are a cacophony of life and loss, chaos and order, beginnings, and endings. I used to work in a hospital. . . . when I was well. I was once an art therapist who helped people who were sick. In the days after my diagnosis, I realized that I was now a patient who was sick and I needed help. Hearing that there was nothing they could do to stop, this led me all too quickly into a desperate struggle to understand who am I know that I am ill and then what if this gets worse? The nurse’s words had created a liminal space, a threshold of perception between what had passed and what was still to come. In the solitude of this space, I remembered I was an artist and so I drew. I drew my fear, which could not be spoken, but needed to be seen (Figure 1).

1 Department of Public Health, School of Psychology and Public Health, College of Science, Health and Engineering, La Trobe University, Melbourne, Australia
2 Whitley College, University of Divinity, Melbourne, Australia

Corresponding Author:
Libby Byrne, Department of Public Health, School of Psychology and Public Health, College of Science, Health and Engineering, La Trobe University, Melbourne, Australia; Whitley College, University of Divinity, Melbourne, Australia.
Email: e.byrne@latrobe.edu.au
What Happens Now That This Is Worse? (2010)

New symptoms continued to surface, and within 2 months of receiving the diagnosis, my neurologist told me that I had an aggressive form of the illness. I needed to make a decision: to allow the MS to progress unchecked or to begin taking Tysabri, a drug that came with the risk of an incurable brain infection known as Progressive multifocal leukoencephalopathy (PML). I didn’t want to do either. I was however assured that the risk of PML was nothing compared to the devastation that what MS would cause if we didn’t act now. My neurologist was using the pronoun we, assuring me that there was in fact something that could be done. I was scared and fragile as his measured words convinced me that, “We need to knock this on the head now.” It was clear to him that I had no choice. In less than 5 minutes, my neurologist had recognized and mobilized my fear in such a way that I was willing to agree to the plan he believed was in the best interests of my physical needs. His work was done for now. My work was just beginning. I was left with the psychological and spiritual work of making room for his faith in the midst of my fear. Once again I drew, firstly in hospital as a patient (Figure 2) and then in my studio as an artist (Figure 3).

When I am making art I am absorbed by the marks that I make and I am learning to breathe through fear (5).

For several years I lived with a persistent gnawing fear that PML might infect and kill me, while trying to have faith that Tysabri was making me well. This was a spiritual challenge,
the magnitude of which led me to develop a research procedure and begin a practice-led PhD exploring the question of healing in the absence of a cure. In the studio, I discovered that fear and faith coexist in my art making practice, and together they encourage me to risk. From Simone Weil I learned that, “Risk is an essential need of the soul . . . a form of danger which provokes a deliberate reaction . . . and represents the finest possible stimulant” (6). The risk associated with Tysabri had stimulated a creative response and my work in the studio was now informing and shaped by my experience as a patient. The work of integrating and articulating different layers of knowing required the integration of my identity as patient and artist and so the work of making art was healing the disabling fear of incurable disease.

The Question of Healing (2015)

Art Therapist Shaun McNiff says that, “Art heals by accepting the pain and doing something with it” (7). In 2015, I was hospitalized for 3 days of intravenous steroids which were administered over a 2-hour period each day. I knew that art making supported my physical healing and I took 3 small canvases with me into hospital. Each day as I received the infusions I employed a set of watercolor pencils, a brush, and a glass of water to explore my inner world and the question of healing. On the first day, I located a billabong beyond a mountain that grew steeper and steeper through the first hour of the infusion. Throughout the second hour I worked with the foreground of the painting, finding a way through the scrub while acknowledging the distance that lay between me and the billabong (Figure 4). It was helpful to see this image and to know that I still had the agency to speak and act toward my own healing. On the second day of my hospital stay, I hung the first painting on the wall to be still with the art as the steroids surged through my system (Figure 5). My skills as an art therapist were now being engaged as I worked at my own bedside negotiating the limited space. As I utilized these skills for my own benefit, I was aware of my capacity and my identity beyond that of a patient. By the time I had completed the second piece, I had accepted the sense of separation and isolation that is part of being in hospital. I could see the distance I had covered in these first 2 days and hanging this work on the wall extended the way I was able to think about what was happening. My
healing process was embodied in the artworks that hung over my bed and I could see what was happening for me as well as what was happening to me (Figure 6).

The next day the nurse unit manager (NUM) came into my room and noticed the artwork hanging on the wall was covering my name plate. She insisted that it was removed saying, “We can’t see who you are”. I felt these words with a deep sense of irony as I sat upright and awake in the bed, my credentials firmly strapped around my wrist, able to respond clearly and articulately when spoken to, and yet somehow not able to be seen. I heard the NUM’s request and took a moment to be aware of the presence of the painting behind me. The work that had enabled me to see who I really am was not a language that translated easily in this context. I understood the NUM’s concern was for my physical safety and so I removed the image, but not before I had photographed it in this place (Figure 6). The value of the image is in its capacity to transcend the ordinary sense of what it means to reside in this place, as it was there one moment and gone the next. The photograph of this brief residency remains a potent reminder that I am a person actively desiring and working toward healing, rather than a patient passively receiving treatment.

**Conclusion**

The challenge to maintain a sense of identity that is separate to the experience of illness is critical for people who are living with MS, and the language employed by health-care workers has a profound capacity to help or hinder this. Opportunities to make art in hospital supports the efficacy of prescribed medical treatments by enabling patients to exercise power in the midst of a process over which they have little or no control. Making and being with art in hospital have enabled me to integrate the layers of fear and faith that are part of my spiritual and psychological experience of being treated for MS. This in turn means that that when I am in hospital I am now a whole person, who is also a patient, trying to live well with an incurable illness.

**Acknowledgments**

The author would like to acknowledge and thank my neurologist, Dr Mark Marriott, who took over my care in 2012 and continues to work with me to manage my health in the midst of illness. The author would also like to also thank and acknowledge Rev A/Prof Frank Rees for supervision of author’s PhD work into the Art of Healing.

**Declaration of Conflicting Interests**

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

**Funding**

The author(s) received no financial support for the research, authorship, and/or publication of this article.

**References**

1. Vickers MH. Illness onset as status passage for people with multiple sclerosis (MS). J Health Hum Serv Adm. 2010;33:197-227.
2. Olsson M, Lexell J, Söderberg S. The meaning of women’s experiences of living with multiple sclerosis. Health Care Women Int. 2008;29:416-30.
3. Byrne L. Healing art and the art of healing. Melbourne: Whitley College, University of Divinity; 2016.
4. Sontag S. Illness as metaphor. New York: Farrar, Straus and Giroux; 1978.
5. Byrne L. Healing art and the art of healing. Melbourne: Whitley College, University of Divinity; 2016.
6. Weil S. The need for roots. New York: Routledge Classics. 2016:33.
7. McNiff S. Art heals: how creativity cures the soul. Boston: Shambala Publications; 2014. V.

**Author Biography**

Libby Byrne is an art therapist who is currently teaching and researching in the Master of Art Therapy Program at La Trobe University. She has worked as a practising and exhibiting artist for the past 20 years, extending our understanding of the interdiscipli- nary applications for material knowing and studio practice in research, with a particular focus on developing a systematic method of Practice-led Theological inquiry with the University of Divinity. Her work addresses the nature and significance of art, both made and received, within the process of healing that is required to flourish and live well with illness and in health.