Seeing and Being Seen: The Impact of Art Making on the Experience of Isolation and Fear in Patient Care

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Abstract
A positive diagnosis for COVID-19 is a threat not only to the health of an individual but also to the community where the disease manifests. Rather than being the discreet experience of a few or some, many people now appreciate our shared vulnerability with the threat of uncontained and incurable illness in our midst. “In this era of unspecified isolation, contagious disease, and with no sign of returning to normal life soon, coronavirus is putting an adverse effect on people’s mental health” (1). While managing the spread of COVID-19 has necessitated the use of social distancing and isolation a means of expressing care, equating care with the experience of fear and isolation can place unseen mental health burdens on inner resources for supporting the well-being of patients and those who care for them. Art can offer a remedy for this experience, lending the quality of durability to our fragile human experience and inviting us to extend the ways in which we see, think, and make sense of the world.

Keywords
art making, fear and isolation, connection and care, health and human flourishing

In February 2010, I was diagnosed with the incurable and degenerative disease known as multiple sclerosis (MS). The fear and uncertainty provoked by the diagnosis was amplified several months later when I was prescribed Tysabri as second line of defense for an acute onset of the disease. Since then I have received more than 130 infusions of Tysabri, a disease modifying drug that also comes with the risk of an incurable brain infection known as progressive multifocal leukoencephalopathy. This means that every 4 weeks I need to be admitted as a day patient and submit to the procedure designed to mitigate the progression of MS by undermining my immune system. The people who I see in the hospital remain unseen in my life beyond the hospital and I always attend my appointments unaccompanied by family or friends. It is as though my experience of being a patient happens in a bubble of isolation which contains a range of responses to my treatment. Having begun taking the medication out of fear, it is increasingly clear that a remedy for the challenges of living well with MS and Tysabri, there is still a 100% mortality rate associated with my human condition. Human bodies are fragile and if we live long enough, we will all have the experience of living with a body that breaks down (2,3). Being willing to attune to the rhythm of disease when it arrives is challenging in a culture that borders on worshipping the healthy body.

While illness is a normal experience within the course of any life, incurable, chronic, and degenerative illness can provoke fear that leads to social isolation which in turn can provoke an Allostatic overload (1). Tova-Bailey sees the impact of her chronic illness on friends who visit saying, “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

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of those with good health” (4). MacKee reported that in May 2020 Australian clinicians were concerned that fear associated with COVID-19 may trigger a wave of severe noncoronavirus disease as “…patients with early symptoms of cardiovascular or other serious conditions have avoided presenting to emergency departments” (5). Gadamer posits that the art of healing is “an attempt to restore an equilibrium that has been disturbed” (6) and in doing so points to the need for a remedy in the human condition rather than a cure. If living in isolation amplifies our fear of illness and damages our trust in the social, psychological, and spiritual benefits being in interconnected human relationship, then art may be a remedy that restores the equilibrium.

Australian poet Leunig (7) calls us to consider that beneath everything we think and do, there are only 2 frameworks, motive, procedures, and results; love and fear (Figure 1). If we follow his lead in thinking this way responding to illness with love rather than fear supports an interconnected and holistic response to the public health challenge of caring for patients with many different experiences of illness during the current pandemic crisis. The following vignette describes impact a recent hospital experience where, even as COVID-19 protocols are updated daily, nursing care is still offered within a framework of love rather than fear.

Today when I went in for my treatment, the nurse found it difficult to find a vein that would work. The vein that she pierced collapsed and refused to release the flow of blood that would allow Tysabri access to my internal world. Undeterred she focussed on her task and I looked away until the cannula was successful inserted into another vein. When we eventually breathed easily and looked at one another face to face, the first thing she said was, “How is your rug going?” Her question revealed a memory of a conversation we had shared 8 weeks earlier. I have been making a latch-hook rug throughout the experience of lockdown and although it was now June, this question referred to the work I was doing when I drew a plan for the colors while I received my treatment back in April. I was thrilled that she had remembered and eagerly showed her a photograph of the progress I have made (Figure 2). As she commented that the work was evolving with colours that were different from my original plan, I realised the commitment to listening and attending she offers me with my treatment. Being heard and remembered, left me feeling safe. Ironically, the way she could hear and see me today meant that I felt safer than ever, as a patient in a global pandemic.

Ten years of Tysabri is an experience characterized by the art of repetition. The rug I am making is also a work of repetition, growing slowly as I knot individual threads. The process of knotting is always the same, but the color, texture, and thickness of different wools ensure that the design emerging in the rug is also a form of movement, a trail uniquely expressive of my iso-experience in 2020. Ingold has suggested that “Wherever there is life there is movement (and) the movement of life is specifically of becoming rather than being, of the incipience of renewal along a path” (8).

As the nurse worked to find a vein that was willing to submit to the process of infusion and tangle with the line she had put out to connect with me, our relationship was formed with the conditions that Ingold describes as characteristic of a knot. The relationship has a “…supple necessity that admits to movement, as both its condition and its consequence… a necessity born out of commitment and attention” (9). As we worked together in this way, we experimented with behaviors,
thoughts, and conversation that led toward reconciling and balancing the equilibrium of illness and health with love rather than fear.

The practice of art making supports my well-being as a patient when I am in isolation and creates opportunities for those who care, to hear, and see what is important for me in the work of becoming well. When a nurse listens to and remembers my story, we are both awakened to the experience of shared vulnerability and trust in the hospital setting. Health workers who demonstrate the commitment and attention that allows for this kind of movement within patient encounters effectively extend a line of trust, which when taken up by patients, will enable frameworks of connection rather than isolation and love rather than fear to flourish in our health care systems. When I am a patient, engaging with art making in a framework of love rather than fear enables me to see and be seen, which is a remedy for the isolation of the current COVID crisis.

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Author Biography
Libby Byrne works as an artist, art therapist and theologian following the invitation and discovery of art into new ways of being with people in liminal spaces. Within her studio practice her current research addresses the nature and significance of art, both made and received, in the process of healing that is required for human beings to flourish and live well with illness and in health. Libby teaches at the Master of Art Therapy Program, La Trobe University, while developing a growing body of research in the emerging field of Practice-led Theological Research as an honorary research associate with the University Divinity.