


Unless Something Goes Wrong: Making Art to Understand and Mitigate the Risk of Therapeutic Inertia in the Treatment of Multiple Sclerosis

Journal of Patient Experience
Volume 10: 1-3
© The Author(s) 2023
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/23743735231151550
journals.sagepub.com/home/jpx


Libby Byrne, PhD, MAT, GDipTheol, BEd, DipVA^{1,2} 

Abstract

In the long-term management of a degenerative illness there is a risk that the approach we take to treatment can be characterized by therapeutic inertia (TI). With no evidence of disease progression clinicians can be reluctant to make a change to treatment regimes. This can lead to less choice and suboptimal outcomes for people with multiple sclerosis. The risk of TI is however greater when clinicians have an aversion to ambiguity and a low tolerance for uncertainty. (1) This article is an art-based inquiry into the possibility of TI in decision making when the advice from my neurologist was to stick with the treatment unless something goes wrong. (2) Through a unique process of rusting an existing canvas, the article reveals that the phrase, unless something goes wrong, is an expression of openness to uncertainty and ambiguity. (3) Art making offers the artist an opportunity to lean into and grow and capacity for tolerating uncertainty and ambiguity, thereby minimizing the risk of TI.

Introduction to the Issue

In the long-term management of a degenerative illness there is a risk that the approach we take to treatment can be characterized by *Therapeutic Inertia (TI)*. Saposnik and Montalban (1) suggest that with no evidence of disease progression clinicians can be reluctant to make a change to treatment regimes (2,3). This can lead to less choice and suboptimal outcomes for people with multiple sclerosis (MS). The risk of TI is however greater when clinicians have an aversion to ambiguity and a low tolerance for uncertainty (4). Over time, a clinician who is experiencing TI in the management of incurable and degenerative illness may negatively impact a patient's capacity to access an optimal treatment plan. It is therefore important for patients to find ways of engaging with clinicians to consider and contribute their own thoughts, ideas, and experiences about the treatment of chronic illness.

When in 2010 I was forced to consider the risk–benefit analysis of taking Tysabri as a treatment for newly diagnosed and rapidly progressing MS (5,6). At the time I was told that Tysabri came with a 1:1000 risk of contracting a fatal brain infection known as *progressive multifocal leukoencephalopathy (PML)*. The failure of Betaferon in my case led me to believe, along with my neurologist, that I really didn't have a choice. I needed to take the risk with Tysabri, at least for 2 years, by

which time something better should be available. It is now 2022 and I am still taking Tysabri.

In 2020, after 10 years of Tysabri infusions every 4 weeks, I had developed a high standard of interpersonal communication with my neurologist as together we established mutually acceptable goals and risks in my treatment (7). And yet I was thoroughly sick of attending the hospital so regularly and we were both concerned about the state of my veins and possible exposure to COVID-19 in the hospital environment. My neurologist told me that there was reliable research to support extending the time between treatments and I changed to 6 weekly infusions. The extra 2 weeks between treatments gave a sense of space and freedom that was deeply welcome. For the past 2 years I have enjoyed the extra time to move around in the world, before returning to the hospital.

In August 2022, my neurologist noted during a regular check-up that there is a new research revealing 4x weekly

¹ School of Psychology and Public Health, La Trobe University, Bundoora, Australia

² Whitley College, University of Divinity, Melbourne, Australia

Corresponding Author:

Libby Byrne, School of Psychology and Public Health, La Trobe University, Bundoora, VIC 3083, Australia; Whitley College, University of Divinity, Box Hill, Melbourne, VIC 3128, Australia.
Email: E.Byrne@latrobe.edu.au



Tysabri doses do have preferable outcomes. I asked what he thought that meant for me and his response was that I seemed to be coping well with the longer gap. He asked me if I would like to stick to the 6 weekly regime and think about changing if something goes wrong. This seemed reasonable and I felt empowered to make the choice for myself. It was later, when I had time to reflect, that I repeatedly heard the phrase, *if something goes wrong*. I wondered about what that might mean for me. A rising level of dis-ease with the phrase led me to consult with my general physician and MS nurse. Both people asserted strongly that I had the right to insist on receiving Tysabri every 4 weeks to achieve the best outcome. They encouraged me to contact the neurologist and ask for a change in the prescription.

Key Factors for Consideration

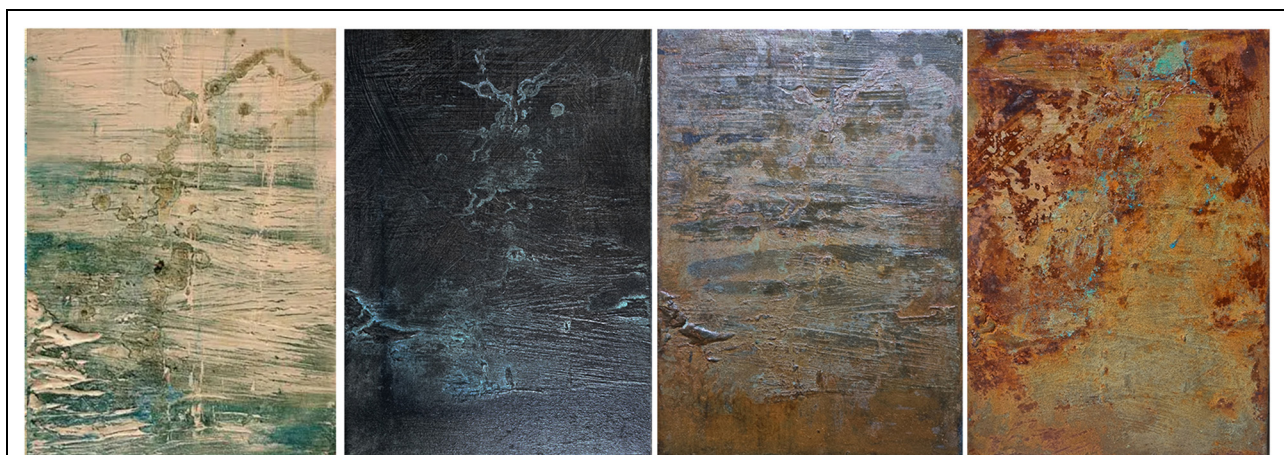
It was with a sense of shame that I began to wonder why I had not thought about the decision in this way at the time. Why had I not insisted on the best regime possible? Why had a less than optimal plan seemed empowering? Had I reached a point of inertia in my willingness to make different decisions about my treatment? Had I become complacent about the nature of the illness and the possibility that something might go wrong? Or had my capacity for decision making, "...a complex skill that requires preserved executive functioning and memory, (become) impaired with MS"? (8).

"Art-making is a complex neurological task involving sensory, cognitive, emotional and motor pathways characterised by the nonverbal expression of sensations, perceptions, feelings, thoughts, ideas and experiences." (9) To understand more about the nature of this experience I returned to an art-making process originally employed in my PhD inquiry in 2012 to 2014, when the metaphor of rust was a helpful symbol for the decay in my nervous system and my experience of agency in the choices I had about a treatment regime (6). Beginning with an existing painting titled *Freedom (2012)*, I spent several weeks in the

studio remembering the uncertainty and ambiguity that is part of my illness and treatment (Figure 1).

The 2012 expression of *Freedom* was initially created with layers of acrylic paint and splatters of dirty olive oil, the detritus from cleaning brushes laden with blue oil paint. Using materials in this way was an early experiment in my PhD inquiry, looking for a way of experiencing the instability of life with a degenerative illness, on the canvas. Making the choice to cover this work with a base coat of Dulux Design Rust Effect paint gave me the freedom to see the texture of the original painting, without the distraction of color. Having begun to work with the older canvas in this way meant I would never see the original in the same way again, which is an experience that reminds me of what it is like being diagnosed with an incurable illness, when nothing will ever be the same again. Applying the rusting solution to the canvas in a regular and slow process over several weeks was resonant with the process regular Tysabri infusions. I took photographs before and after each application of the solution, paying careful attention to the way the surface changed over the weeks.

Through a process of indwelling (10) the original image and the resulting photographs I could see the slow movement from opaque darkness into different shades and tones of nuanced color that was alive and responding to its environment. In the texture of the image, I found consistency, in the presence of several marks that are part of the life of the painting, just below the surface. The way these shapes are seen and experienced is routinely affected by corrosive work of rust, and each stage of the work offers difference and a new way of seeing and being seen. When I found colors and shapes that I enjoyed, I surrendered to the process, continuing to accelerate the process of rusting. I knew that there was a risk that too much solution would mean the loss of the surface I could recognize, but I was committed to the process. I kept rusting, wondering how long I could tolerate working with this image, wondering how long it would be before something went wrong, and noticing what that felt like.



Libby Byrne, (2012-22). *Exploring the freedom of ambiguity*, Oil, acrylic and rust on canvas, 350 x 250mm.

Figure 1. Exploring states of change through the process of rusting of a painting on canvas.

Recommendations

There are some distinct challenges in living with MS that require the formulation of care focused on expressing power as a unifying action towards one's own body and metaphor can be a powerful tool in this work (11). In working with the metaphor of rust I learned that the phrase, *if something goes wrong*, is an expression of openness to uncertainty and ambiguity. At each stage in the making, the artwork offered me a unique quality of experience on the surface, drawing my attention to see that which is consistently present in the work, even as it perpetually changes state. When my neurologist suggests sticking with what we are doing *unless something goes wrong*, he is extending an invitation for me to live with ambiguity and uncertainty. Far from this being inertia in our decision making, it is an invitation to risk staying with the course we have charted, being aware of and responding to the impact of changes in my state along the way. In a world where I am encouraged to insist on the best treatment, the choice to stay with what seems right unless something goes wrong, is a subversive engagement with the ambiguity of risk designed to support me in the art of being well. With 6 weeks in between treatments there is plenty of time for art making which supports my capacity for engaging my body with the experience of living with illness and healing. Listening and thinking to my experience in this way engages different aspects of sensory and bodily perceptions which can in turn "...have positive results on (any) impaired functional and emotional status" (12).

Conclusion

Making and seeing art enhances my capacity for tolerating uncertainty and ambiguity and in doing so, supports me over time to process content discussed in a routine neurological consultation. Working with art and my clinician in this way helps to avoid both therapeutic inertia and reactive responses to research that reveals something new in the treatment of MS. Taking time after a neurological consultation to think in and with art materials can therefore promote trust in the uncertain process of living well with a degenerative and incurable disease as we see something ineffable about the experience of living with this disease and its treatment.


Author Contributions

The author confirms sole responsibility for the study design, data collection and analysis, drafting, review and correction of this paper.

Funding

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

ORCID iD

Libby Byrne  <https://orcid.org/0000-0002-3306-0929>

References

1. Saposnik G, Montalban X. Therapeutic inertia in the new landscape of multiple sclerosis care. *Front Neurol.* 2018;9(1):174. doi:10.3389/fneur.2018.00174
2. Saposnik G, Sempere AP, Prefasi D, et al. Decision-making in multiple sclerosis: the role of aversion to ambiguity for therapeutic inertia among neurologists. *Front Neurol.* 2017;8(1):65. doi:10.3389/fneur.2017.00065
3. Saposnik G, Sempere AP, Raptis R, Prefasi D, Selchen D, Maurino J. Decision making under uncertainty, therapeutic inertia, and physicians' risk preferences in the management of multiple sclerosis. *BMC Neurol.* 2016;16(1):58. doi:10.1186/s12883-016-0577-4
4. Almusalam N, Oh J, Terzaghi M, et al. Comparison of physician therapeutic inertia for management of patients with multiple sclerosis in Canada, Argentina, Chile, and Spain. *JAMA Netw Open.* 2019;2(7): e197093. 10.1001/jamanetworkopen.2019.7093
5. Byrne L. Healing in the absence of a cure. *J Patient Exp.* 2019;6(1):7-10. doi:10.1177/2374373518770828
6. Byrne L. Excavating evidence from experience. *JAAH.* 2014;5(2):219-26.
7. Kachuck NJ. When neurologist and patient disagree on reasonable risk: new challenges in prescribing for patients with multiple sclerosis. *Neuropsychiatr Dis Treat.* 2011;7(1):197-208. doi:10.2147/NDT.S17522
8. Ron MA. The neuropsychiatry of multiple sclerosis. *BJPsych Advances.* 2018;24(3):178-87. doi:10.1192/bja.2017.19
9. Michaels D. Neurology and art therapy. In: Liebmann M, Weston S, eds. *Art therapy with neurological conditions.* Jessica Kingsley Publishers; 2015:39-61.
10. Fenner P. Heuristic research study: self-therapy using the brief image-making experience. *Arts Psychother.* 1996;23(1):37-51.
11. Olsson M, Lexell J, Söderberg S. Meaning of women's experiences of living with multiple sclerosis. *Health Care Women Int.* 2008;29(4):416-30.
12. Efremova V, Vasileva D, Efremov J. Combined kinesiotherapy in multiple sclerosis with elements of art therapy. Paper presented at: XIX International Congress of Medical Sciences; May 13–16, 2021; Sofia, Bulgaria. Accessed November 17, 2022. <https://eprints.ugd.edu.mk/28097/2/Abstract%20book.pdf>.