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“We Can Be the Hero of Our Own Stories”: A Narrative Analysis of the Journey
Through Topical Steroid Withdrawal

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Shelley Annette Ford

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Abstract

Chronic illness can profoundly disrupt biography and identity. Illness caused by iatrogenesis can present the additional experience of being harmed by treatment designed to heal. Topical Steroid Withdrawal (TSW) is an iatrogenic medical condition associated with the prolonged use of topical corticosteroids applied to the skin, typically to treat skin disorders such as eczema and psoriasis. Although existing research has primarily focused on biomedical explanations, little attention has been paid to how enduring TSW is experienced and made meaningful by those who live with it. This thesis explores the lived experience of TSW through a narrative analysis of an online blog written by an individual with the condition. The influential narrative model The Hero's Journey is used to interpret how suffering, identity, and disruption are storied within the blog. This research demonstrates how narrative structures can highlight meaning for the sufferer and demonstrate the challenges faced during the experience of TSW.

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Introduction



“If the responsibility of the ill is to tell, the responsibility of the healthy is to listen”

– Frank, 1997, p. 142



Illness

Those who create stories of ill health bear witness and transform illness from individual suffering into moral responsibility (Frank, 1995). The sharing of suffering is an occasion to convey meaning and to articulate the truth about suffering; a moral opening to demonstrate the harm, the hopelessness and the injustices of illness. Through the act of telling, individuals invite others to step through the moral opening with them and acknowledge the suffering, hear the challenges ill people face and recognise what illness means to them. It was through such a moral opening that I first encountered the story that would shape this research.

Departure

In 2019 my son developed Topical Steroid Withdrawal (TSW), otherwise known as Red Skin Syndrome (RSS). As an emerging, but clinically under-recognised chronic illness, it was challenging to find information to best support him in his suffering. During this search, I came across a documentary focused on the condition produced by a passionate advocate, and sufferer, of TSW (Banos, 2018). The film was deeply moving, and unsettling; but offered vast insight into the illness I was caring for my son through. The documentary was created by a woman named Briana, who had produced it during her own experience of going through TSW.

Through the film, I came to learn that Briana had also chosen to share her personal experience of TSW through a publicly available internet blog. The narrative of Briana's blog was compelling, and like the film, rich with insight. She described herself as a performer, an artist and a writer, and she appeared highly motivated to share her journey through TSW. While her film had captured the experience of many TSW sufferers and doctors who treat the condition, Briana's blog was a deeply personal tale of her own journey of life with illness.

Briana's story subsequently became the point of departure for this research journey. Thus, while I initially met Briana as a mother seeking guidance in supporting her son, I later came back to her story as a researcher, ushering a goal to use her words with purpose. Having borne witness to this condition firsthand and having immersed myself in Briana's storied experience, I had indeed stepped through a moral opening. Briana's testimony transformed me from a receiver of information into a witness, inviting recognition or response. With this knowledge came implications; how would I answer the call embedded in her story?

Initiation

Initially, the research plan was to study a variety of blogs by TSW sufferers and time was devoted to discovering a diversity of experiences of TSW, all captured in blog form. However, Briana's blog stood out for its richness in portraying life while suffering through illness - not just a showcase of the condition itself as many other blogs appeared. At nearly eight years in length, Briana's blog also offered a chance to witness and interpret a story spanning such a significant period, illuminating in intricate detail how TSW touched many areas of her life.

Briana's narrative invited analysis that befitted her experience and its representative blog. My role as researcher was to honour her story and acknowledge and interpret her suffering. Given that Briana was a filmmaker and writer, it followed that analysis should be appropriate and applicable to the storied nature of a blog recounting life through chronic illness. The call to respond to her narrative was answered by the Hero's Journey, selected as analytical framework to interpret Briana's narrative.

The Hero's Journey

Frank (1995) had produced fundamental groundwork of what illness means to the sufferer. The 'Quest Narrative' details the narrative form of viewing illness as a journey, where the sufferer discovers insight or transformation from the experience, and returns with an offering for others (Frank, 1995). While Frank (1995) sowed the idea that illness is a quest, Campbell (2008) and Vogler (2007) cultivated the narrative path to outline the journey of illness.

Campbell (2008) is regarded as the originator of the Hero's Journey framework, who describes the monomyth as a universal narrative which functions as a basis for heroic tales across time and culture. Campbell's (2008) narrative arc details three important stages for the hero: departure, initiation and return. Departure is marked by the hero stepping forth into the unknown world; initiation describes the challenges and trials that test the hero, leading to transformation. The return heralds the end of the transformation, where following personal suffering the hero brings something back for the collective good.

Vogler (2007) adapted Campbell's (2008) mythic structure into a framework to describe the Hero's journey specifically for writers and filmmakers. While Campbell (2008) describes the pattern of the Hero's Journey with emphasis on mythology and ritual, Vogler (2007) produced a concise, practical version of the quest for use by contemporary writers.

Psychological Relevance

A key aspect of the Hero's Journey is the meeting with archetypes along the path (Vogler, 2007). Drawing on Jung's concept, Fordham (1953) describes the archetypes as recurring personality traits reflected in characters and relationships. As part of our unconscious, Jung considered these to be innate, inherited structures of one's psyche (Fordham, 1953). Campbell (2008) took Jung's concept of archetypes and translated them into recurring characters and roles found within myths. Vogler (2007) furthered this concept for writers, describing how archetypes may become functions within the narrative.

Furthermore, the Hero's Journey has been applied as a theoretical tool in various psychological settings. Its use has been beneficial as a tool in therapy, allowing individuals to view their suffering as means for personal transformation and growth (Bray, 2023; Hartley, 2010; Williams, 2019). Research suggests viewing one's life as a hero's journey has been found to increase how meaningful life is felt (Rogers et al., 2023).

Purpose of this Research

In definitions and descriptions of illness the biomedical voice is dominant as medical experts categorise and diagnose illness. Additional input from patients regarding the lived experience of illness can be seen as anecdotal or irrelevant to western medicine practitioners (Carel & Kidd, 2014). However, while the biomedical view may reveal the diagnostic, scientific side of illness, it is limited in conveying what the experience of having such illness is like, and what illness means to the individual who experiences it.

The purpose of my research is to expose the lived experience of TSW and bring a marginalised and poorly understood condition into focus. Specifically, it is to give voice to the experience of living with this chronic illness, and to discover what being ill with TSW means to the individual.

Map of the Research Thesis Journey

While the research data depicts a journey through illness, so too does this thesis showcase the journey of the researcher producing an academic work. The moral opening for the researcher was to honour the voice of Briana and produce a thesis to convey what TSW means to her. The path through the thesis is as follows:

The Literature Review will lay the foundations for how TSW is regarded by western medicine. It will outline how TSW is recognised, diagnosed and treated. It will also highlight the contention between conflicting medical experts, and between patients and medical practitioners.

The Methodology section will outline narrative and narrative analysis, and the pertinent aspects of this kind of analysis. It will also justify the use of a case study and a blog, as less traditional forms of narrative in research. Finally, it will detail the rationality

behind the Hero's Journey theoretical foundation as constructively guiding the analysis of the blog.

Analysis of the blog will be detailed through seven chapters, each one describing an aspect or archetype of the Hero's Journey as interpreted from Briana's narrative. These chapters will move through the Hero's Journey from the beginning Call to Adventure (where the hero first steps into the unknown world), through to ending with The Return (where the hero returns, changed by the journey). Various archetypes are introduced as pivotal figures and functions within the Hero's Journey found reflected in Briana's blog.

Following Analysis will be the Discussion, where the interpretation of the narrative is examined and the theoretical framework of the Hero's Journey is scrutinised. Here is presented a discussion around the aspects of the journey that emerged from the data, and how the framework functioned to reveal them. Furthermore, implications of the research are considered, along with the deeper meaning of a life lived through personal struggle.

Literature Review

Topical Steroid Withdrawal (TSW) aka Red Skin Syndrome (RSS)


“Topical steroid withdrawal (TSW) is a newly described disease characterized by erythema and burning following withdrawal of prolonged topical corticosteroid application.”

– Brookes et al., 2023, p. 1007



Topical Steroid Withdrawal (TSW) is a condition that occurs after stopping the use of topical corticosteroids (TCSs). It presents as a myriad of symptoms that are physically, mentally and emotionally challenging. The process of withdrawal is variable but tends to follow a pattern of “flares” where the skin is exacerbated, visibly red, and moves through stages of burning, flaking and oozing, with pain, intense itch, and sensitivity; pain and burning being the most common symptoms (Brookes et al., 2023; Hajar et al., 2015) and red skin the most common sign (Hajar et al., 2015). In addition to the physical manifestations of withdrawal many sufferers experience anxiety, depression, insomnia and suicidal thoughts (Brookes et al., 2023; Rapaport & Rapaport, 2006). Kligman and Frosch (1979) were the first to describe the condition, pronouncing, “the despair of these patients cannot be conveyed in words.” (p. 25).

Fukaya et al. (2014) describe TSW as when the skin develops manifestations more severe and varied after ceasing TCSs than before application. The clinical signs and symptoms of RSS/TSW include burning skin, pain, erythema (red skin), prurigo (severe itch), oedema, desquamation (skin shedding), oozing, skin sensitivity, shivering, fatigue, anxiety, insomnia and depression (Brookes, et al., 2023; Fukaya et al., 2014; Hajar et al. 2015;). In addition there are physical signs specific only to RSS: ‘elephant skin’ (thickened, wrinkly skin), ‘red sleeves’ (red skin that ends abruptly at the wrist) and the ‘headlight sign’ (red face, but the nose spared) (Andrus, 2023; Brookes et al., 2023; Fukaya et al., 2014;

Hajar, 2015; Hwang & Lio, 2022; Juhasz et al., 2017; Kligman & Frosch, 1979; Rapaport & Lebwohl, 2003; Rapaport & Rapaport, 1999; Sheary, 2016, 2018, 2019; Tan et al., 2021). The list does not conclude here however, with speculation regarding further unclassified signs mentioned within the literature and on social media. Cotter et al. (2022) suggest symptoms of adrenal suppression could explain the profound weakness that some sufferers describe. Other authors identify the spreading of the rebound rash may extend across the entire body, sparing only the palms and soles, and that high fever can occur at the peak of the rebound (Fukaya et al., 2014).

Kligman and Frosch (1979) describe withdrawal as “agonizing” (p. 30) with a “maddening” itch (p. 26), the first few weeks of which are likely to be “a living hell” (p. 30). Rapaport & Rapaport (2006) accentuate that coping with the flares can be exceptionally difficult and insist that psychological support is paramount to reassure the patient during the worst phase. Psychological burden was featured in the review by Brookes et al. (2023) which emphasised how TSW patients were very distressed and suffered a “high burden of anxiety and depression” (p. 1007).

As an apparent demonstration of how little consensus there is regarding this condition, it can be found in the literature as Red Skin Syndrome (RSS), Red Burning Skin Syndrome (RBSS), Topical Corticosteroid Withdrawal Syndrome (TCSW), Topical Steroid Addiction (TSA) and Topical Steroid Withdrawal (TSW.). From here on I will refer to it by its most common acronyms: RSS or TSW. The terms addiction and withdrawal are used interchangeably in some papers, addiction referring to the state where the skin becomes dependent on the TCS, withdrawal is the difficult condition that occurs on ceasing to use TCSs. It is the later stage of withdrawal, with its array of symptoms, that is the focus of this Literature Review and thesis.



*“Corticosteroid addicted patients are exceptionally common
and are seen throughout the world”*

– Rapaport & Rapaport, 2006, p. 558



Kligman & Frosch (1979), the first to warn about TCS addiction, cautioned that the dependence on TCSs is a significant medical issue more common than realised, but “not high in medical consciousness” (p. 24). Fukaya et al. (2014) declare there is a significant number of sufferers, but note also that many cease to visit doctors, obscuring data on how prevalent the condition may be. After treating over 1500 people with the condition, Rapaport & Rapaport (2006) declare that TSW patients are exceptionally common, and prevalent across the globe. These dermatologists specify that each month they see between two and four patients presenting with the condition in their clinic, often referred by other practitioners who do not recognise TSW (Rapaport & Rapaport, 2006). A study by Furue et al. (2003) presented the results of six months of TCS use on over 1200 patients across 77 dermatologist clinics in Japan. They found 7% of infants, 10% of children and 19% of adolescents and adults had severe, very severe, or exacerbated dermatitis post application, consistent with RSS. In reference to Furue et al. (2003), Fukaya (2014) points out that while on average only 12% were considered addicted, it remains that the other 88% are still “potentially addicted patients” (p. 136). Findings indicate that its use has increased dramatically in the five years between 2016-2021, indeed by over five times on some platforms (Bowe et al., 2022). These studies point to a concern that TSW is spreading and more pervasive than others may attest to.

Further to these doctors suggesting TSW is gaining in prevalence, there is evidence to suggest that the lack of recognition of the condition by other practitioners creates an inadequate true representation in the data. Fukaya et al. (2014) speak to the problem of differentiating between tachyphylaxis and Topical Steroid Addiction (TSA). Tachyphylaxis

is the medical term for the decrease in effectiveness of a treatment; with TCSs this presents as the ointments no longer addressing the symptoms successfully. They point out that tachyphylaxis is not an appropriate term to represent TSW and suggest it is ironic that dermatologists have not experienced seeing patients with TSA, only tachyphylaxis, when tachyphylaxis occurs prior to withdrawal (Fukaya et al., 2014). Furthermore, Fukaya et al. (2014) acknowledge that many patients do not visit doctors anymore, a point endorsed by Takahashi-Ando et al. (2015) who conducted a survey to analyse previous TCS use by people who had since stopped applying. Their results show that patients believed ceasing TCSs was necessary for recovery yet felt continuing pressure from doctors to resume application (Takahashi-Ando et al., 2015). These researchers suggest this pressure creates an avoidance of doctors, which in turn leads to these patients being underrepresented in studies (Takahashi-Ando et al., 2015). Eichenfield et al. (2014) argue that while reported side effects of TCS are low, following up patients is rarely done so any long-term potential complications are not well documented.

However, despite these many indications, the quantitative evidence as determined by a review commissioned by the US National Eczema Association shows: “There are no data regarding the prevalence of this condition” (Hajar et al., 2015 p. 547).

Topical Corticosteroids (TCSs)



“Topical corticosteroids (TCS) are the first-line therapy for the treatment of atopic dermatitis”

– Hajar et al., 2015, p. 541



In 1951 the global dermatology community was revolutionised by the arrival of the miracle topical treatment corticosteroid (TCS). Sulzberger & Witten (1952) confirmed the following year that TCS applied to the skin elicited improvement by their first observation. Dermatologists have maintained a preference for this modern medicine for decades to

follow, which today continues to be the mainstay of treatment for skin conditions throughout the world. TCSs are ointments, creams and gels applied to the skin to treat a variety of skin complaints, most often prescribed for atopic dermatitis such as eczema and psoriasis. TCSs work by reducing inflammation (anti-inflammatory), suppressing the immune response (immunosuppressant), restricting blood vessels (vasoconstrictive) and reducing cell growth (anti-proliferative) (Sheary, 2019; Lovric et al., 2021). Eczema sufferers are said to have an incurable, chronic inflammatory skin condition. The Eczema Association of NZ (2025) states: “For over 50 years, topical steroids have been known to be highly effective in controlling this inflammation. There is no other medication that works as well or as efficiently” (para. 3). A work group of doctors experienced in treating atopic dermatitis who formed the “Guidelines of care for the management of atopic dermatitis” declared the efficacy of TCSs has been well documented in over 110 randomised controlled trials (Eichenfield et al., 2014).

Low to mid potency TCSs are considered safe and effective when used short term (Hajar et al., 2015; Hwang & Lio, 2020) and for intermittent long-term use (Bowe et al., 2022; Hajar et al., 2015; Rathi & D’Souza, 2012). The position of TCSs as the first-line treatment for skin complaints is well entrenched and second to none. In addition, some TCSs are available over the counter without a prescription. Cotter et al. (2022) declare more than 105 million TCS tubes were prescribed across England alone between 2020-2021. TCSs are classified into seven groups in America (and four in Britain), differentiated by their steroid strength. Seven is the lowest potency and includes the commonly prescribed hydrocortisone. Level one is the “super potent” TCSs, which are up to 600 times stronger than hydrocortisone (International Topical Steroid Addiction network, 2025). Some doctors treat using the lowest potency first, increasing the strength until the skin is under control, others preferring to begin with a high potency burst to quickly clear the skin, followed by tapering down to a lower potency TCS (Eichenfield et al., 2014). Guidelines for treating atopic dermatitis refer to twice daily application, although once a day has shown to be as effective (Eichenfield et al., 2014). These same guidelines also suggest TCSs should be used preventatively with twice daily application, when previously TCS were recommended only to treat already symptomatic areas. Fukaya et al. (2014) point out that this “proactive approach” means patients can never stop TCS use, which disregards the tendency for conditions such as eczema to heal naturally.


*“Over the years it has become increasingly apparent that TC
are being abused by doctors and patients alike”*

– Rathí & D’Souza, 2012, p. 252



The International Topical Steroid Addiction Network (2025) describes Red Skin Syndrome as “a debilitating condition that can arise from the use of topical steroids to treat a skin problem, such as eczema” (Para. 2). Kligman and Frosch (1979) were the first physicians to highlight the compelling appeal of steroid treatment felt by physicians. They likened the prescribing of them as to a reflex, where the benefits of TCSs were so impressive that prescribing and dishing out of such need not be delayed by diagnosis first (Kligman & Frosch, 1979). Rathí & D’Souza (2012) also imply that the fast amelioration of symptoms by TCSs can encourage prescription by doctors for any skin rash, prior to diagnosis. Kligman & Frosch’s (1979) paper from 45 years ago, one of the first to describe TSW, describes how many of their patients had seen multiple dermatologists who had increased the potency of their prescription or had encouraged more frequent application, not recognising the situation of withdrawal. One of the leading researchers on this condition dermatologist Dr Marvin Rapaport has produced multiple papers on the signs, symptoms, etiology and treatment of this debilitating iatrogenic condition in hopes of securing international diagnostic criteria and confirming its place within the dermatology profession (Rapaport & Rapaport, 1999; Rapaport & Rapaport, 2006). Rapaport & Rapaport (1999) draw a similar picture to Kligman & Frosch (1979), describing a consistent pattern of patients finding their creams losing effectiveness (‘tachyphylaxis’) leading to a stronger prescription. The new TCS treats the skin complaint for a short time, before again it stops being effective and even stronger steroids are prescribed (Rapaport, 2006). Eventually relief is unattainable, the skin no longer benefits from the TCS, and the patient is forced into withdrawal, often unrecognised by the physician who will continue to prescribe TCSs (Kligman & Frosch, 1979; Fukaya et al., 2014). Fukaya et al. (2014) note

that doctors may try to change medications for these patients, but that this approach will only benefit patients if addiction is recognised and TCSs are withdrawn.

Many papers within the literature consider the cause of withdrawal to be “misuse” (Ghosh et al., 2014; Hwang & Lio, 2022), “inappropriate use” (Bowe et al., 2022; Hajar et al., 2015; Hwang & Lio, 2022), “irrational use” (Lovric et al., 2021), or “prolonged use” (Hajar et al., 2015; Hwang & Lio, 2022) of TCSs. What counts as misuse or inappropriate use remains undefined but tends to mean excessive quantity, frequency and/or duration. Furthermore, other authors refer to the “abuse” (Ghosh et al., 2014) of TCSs, and concerns of TCSs acquiring a bad reputation. Rathi & D’Souza (2012) propose that TCSs are “being abused by doctors and patients alike” (p. 251). Hwang and Lio (2022) suggest physicians should educate their patients on the possible risks of extended use beyond “approved indications” (p. 1297), however these indications are similarly undefined. In contrast, Rapaport & Rapaport (2006) invoke different terms regarding TCS use, the opening line of one paper states: “Our goal is to help misdiagnosed, mismanaged, mistreated and distraught dermatitis patients” (p. 547). Lio (as cited in Andrus, 2023) denies that some of his patients have overused TCSs, although present with TSW regardless, further demonstrating the unknown application amount responsible for addiction and subsequent withdrawal.

There was also mention in the literature of problems with the prescribing of TCSs. Lovric et al. (2021) write of the possibility of TCSs being prescribed incorrectly for conditions that do not indicate their need. They suggest: “The practice of inadequate prescription writing may mislead the patient” (Lovric, 2021 p. 74). Hajar et al. (2015), after reviewing 34 studies on TCS addiction and withdrawal, advise that “physicians must avoid inappropriate overprescribing” (p. 548). Rathi & D’Souza (2012) advocate for accurate prescribing and argue that the onus of responsibility “rests primarily with the dermatologist” (p. 251), insisting that physicians must ensure information regarding frequency and quantity of TCS use is disseminated properly to patients. Rapaport & Rapaport (1999) also point out TCSs are frequently over-prescribed by doctors.

Various researchers state the cause relates to the TCSs being of mid to high potency (Brookes et al., 2023; Hajar et al., 2015; Juhasz et al., 2017). A review of patient records in one study found only 8% of TSW patients had used mild TCSs (Brookes et al., 2023). Similarly, the TSW review by Hajar et al. (2015) found 98.6% of patients had applied mid-

high potency TCSs. Kligman & Frosch (1979) believe withdrawal is unlikely from low potency TCSs like hydrocortisone. These dermatologists warn that stronger steroids, while having potentially larger benefits, come with the cost of greater risk (Kligman & Frosch, 1979). They posit many physicians follow modern trends and prescribe newer steroids that may be more dangerous, but not necessarily more effective (Kligman & Frosch, 1979).

The length of time applying TCSs responsible for TSW is unclear. Fukaya et al. (2014) believe the use of TCSs should not be applied continuously for more than two weeks. Rapaport & Rapaport (1999) suggest two months, Rathi & D'Souza (2012) suggest application should be limited to 2-4 weeks for any one stretch of use and only two weeks for potent/super potent TCSs. Kligman & Frosch (1979) experimented on four college students, applying a potent (class II) TCS to one side of the face only. By two weeks, three of them had significant skin eruption; at three weeks all four were in TSW (Kligman & Frosch, 1979).

Ultimately, while TCSs are the known cause, the amount, potency and length of usage required for addiction and subsequent withdrawal is undetermined due to a lack of accurate data.

Side Effects


“Frequent use of TC leads to several local and systemic side effects. A change to once daily application was suggested several years ago. Perhaps the biggest barrier to this has been our habit”

– Rathi & D'Souza, 2012, p. 255



There are many side effects of TCSs and they are well documented. While there are too many side effects to list here, most referenced are skin thinning, stretch marks, excessive hair growth, delayed wound healing, atrophy, acne, hypopigmentation,

increased bruising, hyperglycemia and rosacea (Aronson, 2009; Coondoo et al., 2014; Eichenfield et al., 2014; Juhasz et al., 2017). More serious and less common reactions include suppression of the Hypothalamus-Pituitary-Adrenal (HPA) axis, (Coondoo et al., 2014; Eichenfield et al., 2014; Walsh et al., 1993), Cushings Syndrome (Matejek et al., 2022), and glaucoma (Feroze et al., 2023). While these side effects are well documented, they are considered low risk, short term or rare. They are also said to be due to prolonged treatment and dependent on the strength of corticosteroid applied, more commonly caused by stronger TCSs (Coondoo et al., 2014; Eichenfield et al., 2014). The addition of addiction and withdrawal as an adverse effect of TCSs is spreading within the literature and gaining greater recognition.

Diagnosis



“These patients would be cured if it was recognized that the rash and redness is corticosteroid dependant and not eczema”

– Rapaport & Rapaport, 2006, p. 559



While medical professionals usually elicit medical diagnoses, there were multiple cases within the research of patients compelled to seek an explanation for their suffering elsewhere. Dermatologist Lio (as cited in Andrus, 2023) advocates for TSW sufferers and aims for verification of this condition within the medical profession. Lio declared that in stark comparison to other dermatological conditions where patients arrive seeking a diagnosis, his TSW patients arrive at his clinic announcing they have TSW, having found answers to their concerns outside of a physician’s office (Andrus, 2023). A qualitative review study was conducted seeking to uncover evidence of whether TSW occurred in children (Juhasz et al., 2017). Finding no peer reviewed papers on such, these researchers instead engaged online blogs and found only 22% of the children in their data set of TSW sufferers had been diagnosed by a medical practitioner. A review by Brookes et al. (2023)

expressed that “many had researched their disease and the diagnosis of TSW through the internet” (p. 1011).

Fukaya et al. (2014) point out that addiction (TSA) is often not recognised by dermatologists. Kligman & Frosh (1979) also state TSW is frequently unrecognised and suggest that sufferers are unlikely to escape from the cycle (of addiction and prescription), “unless fortune furnishes a physician who recognises the situation” (p. 25). Research in Japan aimed at understanding patients’ preferences to avoid TCSs, listed “medical experts unwilling to listen to patients’ experiences” and, “unwanted treatments being recommended” as leading difficulties for patients who had chosen to cease TCS use (Takahashi-Ando et al., p. 59).

Dismissal by medical practitioners was a strong message across papers. Cotter, et al. (2022) warn that doctors risk being labelled dismissive if they ignore the concerns of this community of sufferers, suggesting that alienating these patients would only further entrench the aversion to TCSs, discouraging adherence to this ubiquitous treatment. Some doctors were aware of dismissal leading patients to find answers from online or alternative, unregulated sources (Andrus, 2023; Brookes et al., 2023; Cotter et al., 2022; Tan et al., 2021). There was acknowledgement that this caused them additional distress (Andrus, 2023; Brookes et al. 2023). Dismissal by physicians could lead to patients being “sensitized” (Cotter et al., 2022) and could result in the doctor-patient relationship being weakened (Tan et al., 2021). Sheary (2016) advocated for informed discussion between doctors and patients regarding TCS addiction and withdrawal, suggesting this could help those seeking answers from a trust-worthy source.

Working towards a consensus for diagnostic criteria was the aim of various research articles. Diagnosis was deemed difficult by some due to the lack of a clear diagnostic standard and because of the apparent similarity between TSW and the initial complaint. Initial skin complaints were often a form of dermatitis such as eczema that the TCSs were first adopted for (Tan et al., 2021). Simultaneously, other papers emphasised that TSW is “distinct” from other conditions (Brookes et al., 2023; Cotter et al., 2022; Hajar et al., 2015; Hwang & Lio, 2021). Rapaport & Rapaport (2006) state that TSW patients “were different from other eczema patients” (p. 547). Fukaya et al. (2014) point out TSW patients have “something different or extraordinary regarding them” (p. 134), pointing out that TSW is often distributed much more across the body, with only the palms or soles, spared.

Hajar et al. (2015) suggest physicians should advocate TSW over dermatitis flareup if symptoms include burning and erythema (red skin) alongside a prolonged TCS history, particularly when used on the face and genitals. Many authors reiterate the signs exclusive to TSW including 'elephant skin', 'headlight sign', and the 'red sleeves' emphasising that these are unique to TSW (Fukaya et al., 2014; Hajar, 2015; Hwang & Lio, 2021; Juhasz, 2017; Kligman & Frosch, 1979; Rapaport & Lebwohl, 2003; Rapaport & Rapaport 1999; Sheary, 2016, 2018, 2019; Tan et al., 2021).

Various researchers experienced in distinguishing and treating TSW have composed papers with the express aim of elucidating the clinical features of this condition to move towards a standard clinical diagnosis (Cotter et al., 2022; Fukaya et al., 2014; Hajar et al., 2015; Hwang & Lio, 2022; Rapaport & Rapaport, 2016; Sheary, 2016). Sheary (2016) produced one research paper expressly as an overview of the condition written for other GPs that includes detailed accounts of presentation and clinical signs, succinctly put together for other doctors to reference. Fukaya et al. (2014) also seek to create clear guidelines to recognising and treating TSW, describing the clinical features they have observed from treating many cases of TSW, detailing how to recognise and treat the condition. Rapaport & Rapaport (2006) elucidate the common histories of TSW patients, the presentation and evaluation of each one, through to the management of withdrawal in precise detail, with the objective of evidencing this condition for greater recognition. After treating hundreds of patients with RSS and publishing multiple papers on the condition the first line of one article seems to demonstrate the frustration at still seeking substantiation for something these doctors have treated countless times: "The intent of this article is to be provocative" (Rapaport & Rapaport, 2006, p. 547).


“Finally, what can be done for addicted patients? This is no enterprise for the short-tempered impatient physician. Withdrawal is agonizing and the doctor must be enrolled in the battle emotionally, providing strenuous support and unremitting encouragement.”

– Kligman & Frosh (1979, p. 30)



First and foremost, the principal approach to treating RSS/TSW was always the same: absolute cessation of TCSs. Rapaport & Rapaport (2006) declare, after treating over 1500 patients: “Cure occurred in all patients following total cessation of these medications.” (p. 547). Through a case series of ten children, Sheary (2019) also found all improved with the complete cessation of TCSs. Fukaya et al. (2014) state: “It goes without saying that TCS must be withdrawn in addicted patients” (p. 136), asserting that the patient will experience various phases and concerns, but that the skin will become normal with time.

There was various supplementary treatment options often used to mitigate the symptoms that withdrawal brought forth. Psychological support was recognised as paramount by many doctors (Brookes et al., 2023; Fukaya et al., 2014; Hajar, 2014; Kligman & Frosch, 1979; Rapaport & Rapaport, 2006; Sheary, 2019). Rapaport & Rapaport (2006) suggest further support can come in the form of pain relief, sleeping pills and medication for anxiety. Other authors mentioned antihistamines (Rapaport & Lebwohl, 2003; Sheary, 2019), ice packs or cool compresses (Hajar et al., 2015; Rapaport & Rapaport, 2006; Sheary, 2019), preventing infection (Fukaya et al., 2014) and immunosuppressants, antibiotics and phototherapy (Brookes et al., 2023). Ultimately, these additions were aimed at making the withdrawal more tolerable as no treatment had

been found to significantly decrease time until complete cure (Hwang & Lio, 2021). As Fukaya et al. (2014) make clear, the “medication” of most benefit is likely to be time.

Treatment did not go without challenges, a primary one being the lack of recognition of the condition and therefore a denial of its existence. Instead of treating TSW therefore, many patients were offered further TCS prescription, with no alternative. Fukaya et al. (2014) point out that patients often encounter physicians who are unsure how to treat them without TCSs and declare: “Patients cannot expect too much assistance from them” (p. 136).

Prevention & Education



“Addiction to topical steroids... will be prevented only when physicians become as impressed with the capacity of the steroids to do harm as they are with their remarkable power to suppress but not cure virtually any inflammatory disorder.”

– Kligman & Frosch (1979, pp.29)



Various papers concluded that patients should be counselled or warned of the possibility of TSW (Bowe et al., 2022; Juhasz, 2017; Sheary, 2016). Others simply concluded that clinicians should be aware or wary of it (Hajar et al., 2015; Hwang & Lio, 2022). Including patients in the process of understanding TSW was a feature of various conclusions and plans for moving forward. Brookes et al. (2023) suggested that the offer of support for patients should come with joint decision making. Another advocated for physicians to, “listen to patient voices, understand their concerns and learn from them” (Cotter et al., 2022, p. 780). Lio (as cited in Andrus, 2023) advises fellow practitioners that when confronted with a patient presenting with this condition, it is important to listen carefully rather than, “roll your eyes and dismiss people.” Another author suggested doctors acknowledge the influence social media can have and use this awareness to

“foster trust, counter misinformation and promote education” (Bowe et al., 2022, p. 1556). Fukaya et al. (2014) refer to patients’ earnest quest to treat their skin condition with sufficient medical knowledge, suggesting steroid avoidance has validity when knowledge of TCS use lacks sufficient rigorous data. Furthermore, they acknowledge patients’ rights to choose their own treatment when furnished with this knowledge (Fukaya et al. 2014). A review by Hwang & Lio (2022) point out the importance of clinicians appreciating their patients may have fears, and that doctors should realise where these stem from.

Concurrently, disseminating information about TSW raised concerns from some doctors as they felt it may have negative consequences. Fukaya et al. (2014) point out that sharing information about Topical Steroid Addiction (TSA) could mislead non-addicted patients who may then lose an effective treatment for eczema control. Similarly, Eichenfield et al., (2014), in their guidelines for treatment with TCSs point out that the risks are low and are outweighed by the benefits.

An important feature of education was addressing a commonly referenced term, “steroid phobia” (Cotter et al., 2022; Furue et al., 2003; Ghosh et al., 2014; Tan, 2021). While there was generally agreement that TSW was caused by excessive and prolonged use of TCS, there was also concern that patients were sometimes at risk of “undertreatment” and not applying enough TCS due to fear. Some researchers were concerned that “steroid phobia” would lead to non-adherence to TCSs (Hajar et al., 2015; Hwang & Lio, 2022) which they insisted were safe. Cotter et al. (2022) point out that dismissal by physicians would lead to non-adherence and increase steroid phobia. Despite studies such as that by Takahashi-Ando et al. (2015) showing 63.9% of people who had stopped using TCS insisted they experienced their worst symptoms ever after stopping steroids, steroid phobia was considered an “irrational fear” (Lovric et al., 2021), or considered a fear of the TCS, “rational or not” (Ghosh, et al., 2014, p. 468). Another described steroid phobia as, “vague negative feelings and/or erroneous beliefs” (Finnegan et al., 2023, p. 112). A study by Tan et al. (2021) involved reviewing TSA, TSW and TCS safety, producing a paper entitled: “Is there a basis for steroid phobia?” After extensive research into previous literature on TSW these authors summarise the contention that exists around TSW, reiterate the lack of consensus on diagnostic criteria, and tentatively conclude: “It is still rational to entertain the possibility of TSA/TSW” (Tan, et al., 2021, p. 839).

In contrast to those who saw steroid phobia as irrational, Fukaya et al. (2014) suggest that while many doctors presume avoidance of TCSs is because of basic fear stemming from patient ignorance, perhaps some concerns may be from patients who have already suffered TSW. Similarly, the questionnaire aimed at understanding the reasons why patients had ceased using TCSs found two-thirds of respondents declared that avoidance of TCSs was the reason for improvement (Takahashi-Ando et al., 2015). These same patients experienced redness, burning, intense itch and oedema extreme enough to elicit suicidal thoughts once TCSs were discontinued, consistent with TSW (Takahashi-Ando et al., 2015). A bold study by Finnegan et al. (2023) declared TSW did not exist. A letter written in response to this paper by opposing dermatologists points out that: “To worry about TSW, skin atrophy and hypothalamic-pituitary-adrenal axis suppression is not an exaggerated fear” (Moss et al., 2023, p. 697).

This seems to highlight the challenge in education around TCSs when there are conflicting arguments as to whether aversion of treatment is rational or not, and whether suggestions of the existence of TSA/TSW has potential to increase such fear.

Contention


“Doubts still exist whether this condition is legitimate.”

– Hwang & Lio (2021, p. 1293)



Conflict around TSW is multi-faceted, as demonstrated above. There is disagreement around whether fear of TSW is justified, whether information about TSW should be disseminated, regarding the distinct signs and symptoms needed to diagnose it and disagreement on the quantity, frequency and length of application required for addiction to occur.

Despite the early warnings and the many that have followed, recognition of the distressing withdrawal of TCS has struggled to penetrate the medical profession. This

polyonymous condition, decades after some physicians first attempted to legitimise it with a title is still lacking an accepted label. The idiom Red Skin Syndrome, used by dermatologists most familiar with the condition, was scarcely seen in the literature from other authors, many preferring Topical Steroid Addiction or TSA (Fukaya et al., 2014; Hajar et al., 2015; Hwang & Lio, 2022; Juhasz et al., 2017; Sheary, 2016). Bowe et al. (2022) conducted a study of how prolific the term TSW was across social media platforms, referring to it only as, “adverse effects”. Others also did not use the term TSW or RSS, preferencing more vague terms such as “steroid-induced dermatoses” (Lovric et al., 2021) or the lengthy “TCS-induced withdrawal exacerbation” (Takahashi-Ando et al., 2015).

Two authors reference the need to bridge the gap between doctor and patient (Bowe et al., 2022; Cotter et al., 2022). This gap in consensus evidently presides as much between doctor and patient as it does between individual doctors. Research by Finnegan et al. (2023) focused on misinformation found online about topical steroids; these authors referred to RSS and TSW as a “prevalent myth.” They suggest patients are attempting to “psychologically protect their sense of self by blaming external factors (e.g. TCS) for their skin disease” (Finnegan et al., 2023, p. 113). Ignoring all research that describes TSW they instead restricted their search criteria to “misinformation”, “disinformation”, “conspiracy theory” and “topical corticosteroids” (Finnegan et al., 2023). They were cognizant enough to mention their data was limited and “may have missed some content” (p. 113). Other dermatologists felt compelled to write in response to their conclusions and suggest their data appears to include papers by those with similar preconceptions to themselves, and advise their statements are out of touch and insulting to patients (Moss et al., 2023).

Positivism & Biomedicine

There is indisputable evidence that the literature covering TSW is controversial, and arguments for the causation, presentation and prevention of TSW are varied and sometimes opposing. Paradoxically, one thing that appears consistent is the origin of the data. Biomedical research dominates this literature review and nearly all the authors referenced above are medical physicians, predominantly dermatologists. Doctors and

the biomedical framework that they serve both draw on positivist thinking. Positivism is a philosophical position which holds that valid knowledge is derived from empirical observation, scientific verification, and objective measurement, typically through quantitative methods (Crotty, 1998; Park et al., 2020). If something is not objectively measurable, it is not scientifically valid. Many papers drew attention to the fact that there was not a confirmed diagnostic criterion for TSW or known quantities of TCSs applied by those who were treated for TSW.

Summary

Although topical corticosteroids (TCSs) have been a mainstay of treatment since the 1950s and are generally considered safe when used appropriately, TSW remains highly contested. Some dermatologists argue it is under-recognised and more common than acknowledged (Rapaport, 2006) while others refer to the lack of data highlighting prevalence (Hajar et al., 2015) or diagnostic criteria. Causes are typically attributed to prolonged or high-potency steroid use (Juhasz et al, 2017; Hajar, 2015; Brookes, 2023), though no consensus exists on the amount or duration required.

Diagnosis is complicated and many patients report dismissal by medical professionals. Treatment centres on complete cessation of steroids, with psychological support considered essential during withdrawal. Debate continues over prevention, education, and whether concerns about TSW reflect legitimate risk or contribute to “steroid phobia.”

Overall, TSW highlights ongoing tension within dermatology between patient-reported experience and biomedical standards of evidence.

Methodology



“The truth about stories is that that’s all we are”

– Clandinin, 2006, p.51



Stories

Stories are fundamental to human meaning making. As long as we have existed, we have existed through stories. Our narrative tales guide us, build our identities, and form ways of being (Smith & Sparkes, 2006). Through narratives we are able to form our identities and make sense of our position in the story. Humans fundamentally live storied lives, and are continually drawn to stories (Stephens, 2011).

Polkinghorne (2005) points out that individuals “do not have complete access to their experiences” (p. 139), and therefore stories do not act to fully mirror experience. However, people’s words act as evidence to support the events they are experiencing (Polkinghorne, 2005). Listening to stories is an act of witnessing, offering recognition for life accounts that might otherwise go unnoticed (Frank, 2019). Because qualitative psychologists study experience, it follows that stories are a useful tool to understanding human experience. Stories demand our attention, and much can be learned about lived events, if we give it.

Narrative

Our experiences, and our memories of events are organised into narratives (Bruner, 1991). Murray (2007) defines narrative as “an organized interpretation of a sequence of events” (p. 113). This organisation acts to bring order to a changing world that can appear disordered (Murray, 2007) and acts as an instrument in constructing reality (Bruner, 1991). This signifies that people choose narrative structures to detail important events and memories.

In understanding narrative, it helps that one also understands what it is not. Frank (2002) suggests narratives do not demonstrate an inner self trying to get out, nor does a narrative anticipate that others will “endow them with sense” (p. 13) as the narrative is unlikely to be intended for study. Narratives are not stand-alone, distinct objects waiting to be mirrored through text, as they exist only through the text (Bruner, 1991). Barthes (1975) argues that the role of narrative is not to transmit a fixed truth, but rather to bring to the surface, and make salient the particular truth that the story is attempting to convey. Furthermore, the temporal nature of narrative where stories weave between the present, the past and the future, resists simply placing events and actions in order (Beal, 2013). Narratives do not present the story of a character formed prior to the telling, but rather the self is formed through the telling (Frank, 2002).

There is also a critical social element, where the narrative is revealed through the relationship between the narrator and their audience (Bell, 2002). Barthes (1975) asserts that narrative cannot occur without both the teller and the listener, as narrative receives its meaning “from the world which makes use of it” (p. 264). As narratives are told, the characters themselves will depend upon the social context, and who they are told to (Murray, 2007). This reminds the researcher of what they bring to the listening, what assumptions they may already hold and what colours the lens they see the narrative through.

Like the self that is formed in stories told, events gain meaning through narrative. Events become functions when constructing a narrative as narrative choice may highlight what is meaningful; events described may be selected to accentuate significance (Bruner, 1991). As stories do not simply detail meaningful events but “events become meaningful because of the placement in a narrative” (Riessman, 1993, p. 18). Narrative acts to order our worlds and in doing so becomes a way of knowing (Smith & Sparkes, 2006). As people construct their worlds and make sense of events through narrative, studying narrative allows the researcher to investigate how people make sense of their experiences and what matters to them in the telling.

Narrative Identity

Individuals produce identities through stories (Bruner, 2004; Frank, 2002). We define ourselves through narrative, and these narratives provide structure to our basic sense of “selfhood” (Murray, 2007, p. 115). A narrative identity can be viewed as an individual’s “internalised and evolving life-story” (McAdams & Mclean, 2013, p. 233). Narrative is used to order and create continuity in our lives and in our identities, by bringing together parts of our lives and sequencing (Murray, 2007). Our episodic memories of the past alongside envisioned goals of the future integrate to create a life story that provides unity and purpose (McAdams & McLean, 2013). Consequently, people use narrative identities to “convey to themselves and to others who they are now, how they came to be, and where they think their lives may be going in the future” (McAdams & Mclean, 2013, p. 233). This narrative identity is what the researcher uncovers in studying an individual’s story, revealing how their experiences help to create the narrator’s life view and “selfhood”.

Narrative Analysis

Narrative analysis in psychology is grounded in the understanding that knowledge is socially constructed, shaped by the interactions, meanings, and contexts through which individuals interpret their life experiences. This epistemological stance aligns with a constructivist ontology, which argues that reality is not fixed but co-created and negotiated through social interaction. Narrative analysis positions the story told as the object of investigation (Riessman, 1993). Frank (2002) asks, “can we hear others’ stories as discoveries of what things matter to them?” (p. 12).

Through analysing narrative, we can observe the narrative structures which distinguish people’s lives (Clandinin, 2006) and to connect these structures to a broader context (Murray, 2007). Narrative analysis studies experience as it is storied (Clandinin, 2006). The narratives that people construct and draw upon give valuable rich insight into what matters to them, and how they ascribe meaning to events, such as illness.

Stephens (2011) describes narrative analysis as more a theoretical approach than a method. There is no set path or checklist for how one does narrative analysis, and each researcher brings something individual to the process. Just as the reader has a role in

understanding the narrative, the researcher brings their own assumptions to their research. (Murray, 2007). This requires reflexivity from the researcher to understand their own subjectivity while engaged in analysis.

Frank (2002) suggests that narrative analysis “begins with an attitude towards stories” (p. 11). This attitude requires that the researcher brings humility in their research approach. Charmaz (2002b) points out, “what a story means and whose story it becomes may change, when stories are research data” (p. 303). This points to the occurrence of researcher subjectivity, where individuals focus on the narrative through their viewpoint. Narrative analysis is not accomplished by an objective observer relaying what the narrative states as fact, but an analytical interpretation of how the researcher sees the meaning conveyed in the narrative.

Narrative analysis is interested in how people make sense of life events in a dynamic, fluid world (Murray, 2007). Exploring the language people use to construct their stories about their lives, gives researchers a powerful insight into what matters to them, and what life events such as illness, truly mean to the sufferer.

Narrative in Illness

Murray (2007) states that narrative “brings order to disorder” (p. 114), and a major cause of disorder to a life story is illness, particularly chronic illness. Bury (1982) introduced the concept of biographical disruption, which views illness as an event “where the structures of everyday life and the forms of knowledge which underpin them are disrupted” (p. 149). Illness creates a disruption to assumptions and current forms of understanding, requiring the individual to reassess their plans, and indeed their own biography (Bury, 1982). The concept of biographical disruption highlights how an individual adjusts and copes with illness (Williams, 2000). While our identities may be shaped through stories, illness arrives as a threat to such identities (Stephens, 2011).

Because illness disrupts one’s sense of self and requires new resources and structures to make meaning from suffering, it lends itself well to narrative and the study of this meaning making through narrative inquiry. Narrative analysis of illness stories allows researchers to view suffering as experienced from the perspective of the sufferer (Stephens, 2011). Narrative allows for the inclusion of existential qualities that arrive

alongside illness, such as grief, despair and moral hurt (Greenhalgh & Hurwitz, 1999). It also locates the illness experience socially, including the social relationship with healthcare professionals (Stephens, 2011).

Charon (2005) argued that illness is lived as a temporal experience and the details emerge through the stories individuals tell about their illness experience. Narrative conveys illness by highlighting the complexity of the patient experience (Woods, 2012), providing perspective and context (Greenhalgh & Hurwitz, 1999) and narrative is a ubiquitous means of making sense of illness and its subsequent disruption (Murray, 2007). Narrative is an appropriate means of sharing information about the experience of illness as individuals can articulate their embodied knowledge of their experience. Furthermore, it is a way to legitimise the perspective of the individual as a valid expression of knowledge of this illness (Woods, 2012).

Charon (2001) founded Narrative Medicine as a model for medical practice proposing that practitioners develop narrative competence, being “the competence that human beings use to absorb, interpret, and respond to stories” (p. 1898). Narrative Medicine focuses on the attention doctors should give to patient stories, to listen intently, interpret their meanings and honour what they are conveying (Charon, 2005).

Case study

A case study is an in-depth study of one voice (Sools, Murray & Westerhof, 2015). A pertinent aspect of case study lies in choosing “fertile exemplars” with rich data to analyse (Polkinghorne, 2005). Briana’s blog was selected to study specifically as it was rich in depth and length, with nearly eight years and many entries, divulging how TSW touched all areas of her life. Flyvbjerg (2006) argues the importance of case studies, highlighting that all research may benefit from exemplars. Furthermore, he asserts that a discipline lacking in exemplars risks being ineffective (Flyvbjerg, 2006).

Although case studies have been criticised for failing to produce evidence that can be generalised to broader populations, the study of a case does not intend to generalise. Thomas (2011) points out that by not trying to generalise, a case study is free to elicit something more nuanced and unique. Furthermore, generalisation is only possible with

predictable and mundane data, whereas “exemplary knowledge” is distinct, interesting and unpredictable; its complexity making it difficult to generalise from (Thomas, 2011).

In health research, a case exemplifies what it is to experience illness. Radley and Chamberlain (2001) argue that the inclusion of cases is key to understanding illness. While western medicine invokes case studies in quantitative research of illness, it does so with exclusion of the doctor’s role in the creation of such cases and fails to demonstrate what it means to be ill for the individual (Radley and Chamberlain, 2001). Case study is appropriate to studying the meaning in becoming sick and recovering, as the case is reflected in the story the individual tells (Radley & Chamberlain, 2001).

Flyvbjerg (2006) argues that quantitative research, with facts and rules, may only bring a student to an entry level of research whereas case study, requiring depth of analysis can be more thoroughly studied to achieve competence. The qualitative case study of illness, in contrast to the quantitative, medical version, offers a different mode of understanding (Radley & Chamberlain, 2001). While in medicine, the case may demonstrate a particular disease, in qualitative research we seek, in no less reasoned analysis, to understand what the experience of illness means to the individual (Radley & Chamberlain, 2001). Furthermore, reflecting on ethics of care, Radley & Chamberlain (2001) point out that understanding a case in health, “is central to all research that claims therapeutics as one of its aims” (p. 324).

Blogs

The use of blogs as narrative sites brings valuable benefits to understanding human experience. Blogs contain content created and published online from a personal perspective, often on a particular subject. Heilferty (2010) described blogs as “online personal journals” (p. 946). Blogs are valuable sites of information about illness experience as the narrative is not constrained by a specific format unlike other online resources for health information, that may appear limited to symptoms, causes, treatment and so on (Gualtieri & Akhtar, 2013). Furthermore, the outlet of a blog allows for communication of intense, personal and uncomfortable experiences, that may be more constrained in face-to-face interactions (McCosker & Darcy, 2013). Often focussed on a single topic, blogs frequently demonstrate the narrator’s strong opinion (Melhuish, 2010),

which is conducive to revealing the distinct, individualistic data that exemplary knowledge highlights over the generalisable (Thomas, 2011).

A further reason blogs can be useful sites for research is that the narratives produced by blogs are “unsolicited” (Heilferty, 2010). The author is not at risk of being steered or encouraged by the researcher to favour certain aspects of the narrative, retaining the narrator’s agency in articulating a story of their own choosing. Temporality is important in blogging also, as blogs are produced in real time (Heilferty, 2010; Melhuish, 2010). This timely response can allow for readers to witness genuine reactions and emotions to life events; were the story relayed later when the author felt more distant from events, these responses have potential to be lost.

Blogs reflect the social nature of illness and the “relationship of the author with the world” (Heilferty, 2010, p. 947). Ressler et al. (2012) found blogs allowed people to articulate and share illness experiences more freely. Many of Ressler et al.’s (2012) participants felt their blog allowed for free flow emotions, and sharing of their illness experience they felt uncomfortable sharing with their doctors (Ressler et al., 2012). Therefore, blogs may offer insight to the illness experience that is unlikely to be articulated to a healthcare professional otherwise.

The blog used in this research was chosen because it was a significant narrative of almost eight years in length. Briana’s blog began as fortnightly posts updating her health journey, but as life became increasingly tumultuous, they became less orderly, but with heightened detail and sentimental depth. After reading this blog multiple times, blog posts/statements were compiled into possible areas of the Hero’s Journey where they were most fitting.

Photographs

Narrative through photographs has the power to enrich the researcher’s understanding (Bell, 2002) and emphasise details that cannot be expressed in writing (Keats, 2009). Narrators choose images as interpretative forms, to assist the viewer in understanding aspects of the story being told (Keats, 2009). The use of images can support and add power to the literary narrative. Briana includes photographs, particularly

selfies, throughout her blog to visually convey her experience, and a selected few of this are included in the data analysis chapters.

Photographs are a snapshot of time, that coincide agreeably with the real time nature of blogs. In illness narratives, photos can be utilised to showcase changes in physical illness and can reinforce a timeline of healing with visual aids. Bell (2002) asserts, “photographic narratives imply temporally ordered events” (p. 10). In a blog, where posts are ordered and shared in real time, the use of photo narrative has a distinctive voice in relaying the changing body and appearance through illness over time. This is particularly true of Briana’s blog, where she uses photographs to showcase the progression of her skin condition over time.

The use of photographs in narrative can be particularly powerful in representations of illness. While words can articulate suffering and healing, photos add a deeper element that can speak to the bodily experience as viewed through an image. Photos of physical depictions of illness can record a “corporeal transformation” where variations from body norms can be accepted and highlighted (Tiidenberg & Cruz, 2015, p. 87). Bell (2002) argued that photography has traditionally acted coercively upon women, but that female photographers may “usurp and wield its power for themselves” (Bell, 2002, p. 11). Photographic evidence within Briana’s blog acts as testimony to her bodily suffering, that she willingly portrays for her audience.

The use of selfies has been said to be a political act and is “one of the most effective outlets for self-definition” (Murray, 2015, p. 490). Selfies have also been described as a practice of freedom, a form of resistance from being constrained. Including photos in narrative allows the teller to choose how to reflect the story in a visually striking way. Murray (2015) suggested: “Maybe the selfie is an instinct of self-preservation: a survivorship reflex” (p. 512); a means of showcasing an acceptance or overcoming of illness.

Just as our worlds are reflected in narrative, and narrative simultaneously creates our worlds, photos act to build stories about ourselves and our bodies within those stories. As Helle (2011) puts it: “Words give something to images...reciprocally, images re-contextualize and give something back to words” (Helle, 2011, p. 297). The use of photo images alongside literary narrative gives a deeper element to the narrative of illness and how it speaks to being ill. The embodied experience of the fellow reader allows for more

sensitivity and identification with the sufferer when visual body displays showcase the corporeal suffering so directly. While words can dictate a suffering body, an image strikes the reader, a witnessing embodied individual, as an immediate reflection of what it means to be suffering in that body. In short, photographs can communicate when words cannot (Keats, 2009).

Hero's Journey

Vogler (2007) wrote *The Writer's Journey: Mythic Structure for Writers* describing a common blueprint for storytelling, specifically reflective of a western linear structure of storytelling. His work details the narrative structure of the hero's journey through trials and tribulations, meeting people along the way who support or challenge them, and how the hero returns, changed, from the adventure. Vogler (2007) believes: "Heroes are symbols of the soul in transformation, and of the journey each person takes through life" (Vogler, 2007, p. 37).

The description of *The Hero's Journey* by Vogler (2007) examines the monomyth of the Hero's Journey, adapting Campbell's (2008) original work on myths into a practical guide for storytellers. Vogler's (2007) book was focused on the structure of writers, with examples from film, which felt especially fitting for a narrative analysis of personal writing, by someone who considers herself a writer and filmmaker.

The narrative stages and recurrent archetypal figures outlined by Vogler (2007) produce a pragmatic heuristic tool for writing and analysing an individual narrative. Various elements of Briana's narrative fitted well into the archetypal roles of the Hero's Journey, which became apparent when reading through her blog, and later became central to organising the data analysis. Given Briana is also a filmmaker, this framework seemed especially fitting given its filmic nature. Furthermore, Briana also refers often to heroes during her blog, even likening herself to a hero. Therefore, her own words supported the use of this framework as a fitting guide to interpret what her journey through illness meant to her.

In considering Briana's blog I was drawn to how her journey navigating life with TSW was one rendition of the Hero's Journey. She was thrust into this new world of illness, and her quest for wellness and quality of life during illness, are exemplars of a hero forced to

overcome challenges, all whilst seeking reward for her sacrifice. The use of this framework in a health and illness setting is relevant as the Hero's Journey has been previously utilised to interpret experiences of childbirth (Thomson et al., 2013), seeking of healthcare (Ramsden, 2010), self-transformation (Hartman & Zimberoff, 2009), psychotic experiences (Hartley, 2010), and therapy (Williams, 2019).

Briana's words, her path to wellness, her expression of what illness meant to her, all felt reflective of a hero's journey. As Frank (1995) puts it succinctly, "illness is the occasion of a journey that becomes a quest" (p. 115). The narrative told by Briana fitted the path of a journey of a hero, through illness, with relationships she experienced aligning with archetypes on the journey.

Reflexivity

An important component of narrative analysis is researcher reflexivity, where the researcher must engage in self-reflection to understand their own assumptions and biases that they bring to the research. As researcher, I am implicated in the production of this narrative, and the narrative produced is interpreted through my assumptions. Being reflexive means that as a researcher I am continually aware and reflecting upon my reactions and thoughts throughout the analysis and seek to understand and demonstrate how my personal lens plays a role in my interpretation of the data. Integrity and rigor in research are pertinent to qualitative research, and I have included reflexivity in each chapter of my data analysis to detail my self-reflections that arose during each stage of the interpretation.

Through engaging with the data and interpreting it through the lens of the hero's journey I have endeavoured to be mindful of the balance required "between deconstruction and reconstruction" (Finlay & Gough, 2003, p. 41). I have been careful to not pull apart Briana's narrative, appropriate it, or reinvent it, keeping her sentences together and in context of each part of the journey or archetype that they reflect. Burkitt (2012) argues that being reflexive requires putting emotion "at the centre of reflexivity" (Burkitt, 2012, p. 461). In interpreting Briana's blog, careful attention was given to recognising her suffering and acknowledging the aspects of her story that appeared central to me. As someone who firsthand has cared for someone through the same

illness, her words landed with impact, at times eliciting emotions that I acknowledged and reflected on. These were kept together in a research diary of evolving reflections.

Emotion is not something we look at in a disengaged way from a distance, but what we practice reflexivity *through*. In this way being reflexive is not just acknowledging emotion, but drawing on emotion to understand our values, how emotion shapes our thoughts, and how our perceptions are shaped by emotion (Burkitt, 2012). Briana experiences an array of grief, loss, anger and more during her blog and these required thoughtful interpretation, continually reflecting on my responses. Her emotions elicited responses in myself, such as frustration with her doctor and disbelief at how she is treated at times. There is no doubt that my interpretation of her narrative was influenced by my own values around TSW, medical treatment and medical professional narratives.

Through reflexivity I can recognise my choices in interpretation, and the parts of Briana's narrative that spoke to me loudest, such as the shock of realising TSW has been caused by treatment, and that medical professionals disagree regarding it. No doubt another researcher may not have identified the hero's journey but detailed another interpretation all together. Findlay & Gough (2003) assert that reflexivity requires that researchers disclose their individuality and how the research process is affected by it. I have strived to be continually reflective on my choices, my feelings and my perspectives that manifest as I consider Briana's narrative, detailing that I supported my son through TSW and therefore have feelings already embedded regarding how this condition is discussed and (in)validated.

Studying another individual's experience of the same illness inevitably drew me back to that challenging time of supporting my son through TSW. On reflection, I am sure my view of that period is influenced by hindsight, by reading about Briana, by writing a literature review of TSW papers, and all that I have witnessed since. As Polkinghorne (2005) points out, "reflection on an experience serves to change the experience" (p. 139). Just as our experience is shaped by the narrative used to convey it, I reflect upon my experience of TSW and how it is affected by Briana's narrative, just as how I interpret Briana's narrative is affected by my own experience, emotions and memories of TSW with my son.

Ethical Standpoint

Briana's words and photos have been used within this research as they are publicly available on the website (Banos, n.d.). Briana is an activist and advocate for TSW, and chooses to publicly showcase herself for the cause, through her blog, documentary and Youtube channel. Heilferty (2010) studied ethical approaches to using internet communication and states, "decisions about when and if informed consent might be the ethically sound approach depends on the perceived level of privacy" (p. 948). Briana actively resists privacy, deliberately producing images of herself to raise awareness of TSW, therefore the sharing of this information is grounded in ethical principles that support her cause, and potentially further it.

Furthermore, all quotes italicised throughout this thesis are Briana's words.

Data Analysis

Chapter One: Call to Adventure – Genesis of TSW

—
“How is it that severe eczema while using steroids is faulted for just the eczema getting worse, and no one ever points a finger at the treatment?”

— Briana

Most Hero’s Journeys begin with the Call to Adventure, which comes as the hero is still within the comfort of the Ordinary World (Vogler, 2007). Like Frodo at home in the Shire (Tolkien, 2005), we bear witness to their normal life before they are called to embark on the Hero’s Journey. Like many TSW sufferers however, Briana does not have the option to refuse the Call from the comfort of her Ordinary World. She finds herself receiving the Call to Adventure, Crossing the Threshold and discovering this Special World all at once; readers are witness to her ordinary world in retrospect only.



Figure 1. The Beginning

Vogler (2007) states the Call to Adventure presents a problem and “establishes the stakes of the game” (p. 11). Briana embarks on her journey of withdrawal, a journey of suffering and healing. Or is it? This new world she now inhabits, whether she is ready or not, means having a debilitating condition caused by the medication prescribed by her dermatologist to relieve dermatitis. Sontag (1978) refers to the “kingdom of the sick,” reflecting the sudden shift that occurs when illness strikes, and we shift from inhabiting the “kingdom of the well”. No one is exempt from having citizenship of both, and anyone may suddenly find themselves debilitated and even socially excommunicated by illness. The second chapter will detail Briana’s physical experience within this Special World; this chapter lays the foundations of what arriving here with TSW means for Briana.

The Call to Adventure is, “often a wrong which must be set right, an offence against the natural order of things” (Vogler, 2007, p. 11). The realisation of what has gone wrong for Briana, that medication prescribed to heal has on the contrary harmed - in fact produced *worse* health - is both vivid and categorical: “*This condition shouldn’t even exist.*” To not exist is to not be real; to be unbelievable. That is, for Briana, TSW defies belief, and she must come to terms with the number of things that have gone wrong and brought her here. Briana is plunged into this condition via the care of her dermatologist, and it seems to demonstrate multifaceted flaws in her care. The treatment has gone wrong, the doctor’s care has gone wrong, her condition has gone wrong, her trust was wrongly placed, the doctor’s knowledge is wrong, the order of sickness to cure is all wrong. The natural order is indeed offended.

The “natural order of things” in the case of Briana, would be visiting a dermatologist for a skin rash, treatment is given, the skin rash dissipates. This is akin to Frank’s (1995) restitution narrative where sickness is alleviated, doctors and medicine bring effective cure, and the patient resumes everyday activity. This is society’s preferred version of the story which is the comfortable and predictable happy ending. Briana recalls that first visit to the dermatologist when she was assured the doctor knew how to treat her: “*My heart wept. I was in so much discomfort. I nodded in thankfulness.*” The dermatologist, in Briana’s eyes, could take what had gone wrong and make things right. She too, was invested in the restitution narrative.

However, recalling her experience of consulting the same dermatologist to help heal her skin later, Briana explains: “*I trusted my doctor since she was the expert. My life*

drastically changed for the worse because of a trusted expert. Instead of healing me and helping my situation, she ended up giving me the worst gift.” This reference to a gift materialises TSW as something her doctor bestowed, as gifting is not achieved accidentally but rather requires intent. This implies Briana regarded her dermatologist as having agency and being obtuse. For Briana, this Call to Adventure establishes that the wrong done includes her doctor’s negligence.

The experience of going through withdrawal from topical steroids potentially overprescribed to her, leads to new revelations for Briana that form the basis of her hero’s journey. These revelations of things that have gone wrong include practical, existential and moral errors, corruption, and the realisation that TSW could have, and can be, prevented.

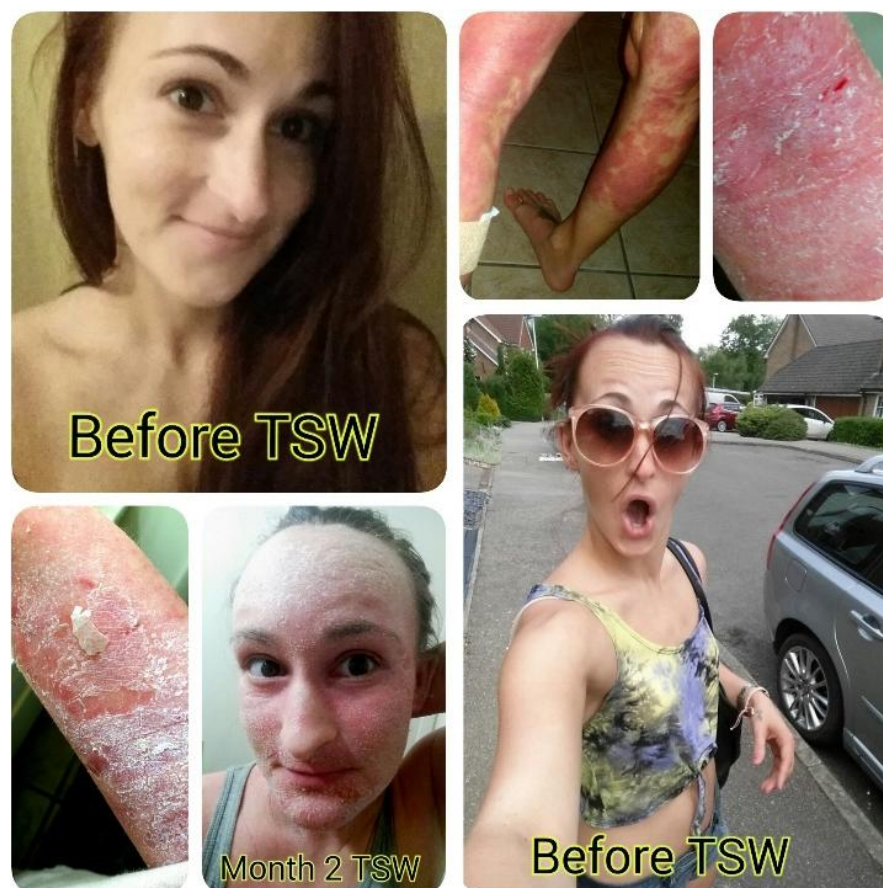


Figure 2. Before and During.



“Abusing these drugs can cause serious harm”

– Briana



How can a topical agent designed to heal skin, instead further harm the skin? The harm to individuals by medicine and medical practitioners is not a new phenomenon. While many pharmaceuticals are prescribed with little or no negative effects, such discoveries as thalidomide for morning sickness (Inakanti & Kumar, 2014) or amphetamines to combat fatigue in soldiers (Bird & Bird, 2005), can highlight how the routine handing out of pharmaceuticals, despite beneficial intentions, can have negative consequences. Reflecting on the three years prior to entering TSW Briana sees with hindsight how her doctor potentially overprescribed her medicine: *“Looking back, I should have freaked out. How can a doctor say she knows what is wrong with me if she gives me the entire medicine cabinet to take?”* Briana continued taking, at her dermatologist’s advice, seven different medicines to treat her eczema, including a topical steroid, topical immunosuppressant, antibacterial and antifungal. Briana continued to take these medicines, on and off for three years, her prescriptions continually refilled by the same dermatologist. Briana trusted her dermatologist to alleviate her skin complaints. Doctors are generally considered helpful allies (Jessop, 2014). In hindsight, once in TSW, she seems to doubt that trust.

Illich (1976) solidified the term ‘iatrogenesis’, the harm done by modern medicine, to be all-encompassing: on clinical, social and cultural levels, and both direct by way of harm and death, or indirect through health policies that promote, and ultimately also produce harm. He saw medical advancement grew at the detriment to health, as the medicalisation of society led to counterproductive steps in treating people (Illich, 1976). Befitting of TSW, Illich (1976) states, “in the most narrow sense, iatrogenic disease includes only illnesses that would not have come about if sound and professionally

recommended treatment had *not* been applied” (p. 35). Indeed, medical harm has been making its way up the ranks amongst the leading causes of death across the world, currently sitting firmly in fifth place (Peer & Shabir, 2018). TSW is not a fatal condition, and this statistic may seem obtuse, however it highlights the extent and gravity of medical harm in society today, which is relevant to Briana’s experience. In New Zealand a study of healthcare harm across General Practices found 2972 harms done across just over 9000 patient records (Leitch et al., 2021). They found approximately 20% of harm were avoidable, but most were a product of what is considered standard care. Of patient admissions to a rural hospital medical ward, also in New Zealand, 15% were found to be caused by prescribed medicine (Mackay, 1987).

The medical profession acknowledges iatrogenesis and errors within the system, however harm in medicine is limited to what may be calculated statistically (Varley & Varma, 2021). Knowledge of day-to-day harm, particularly privately experienced is patently difficult to calculate. Just as the biomedical means to understand illness within the body is reductionist and empirical, so too is the measure of harm done by treatment. Peer & Shabir (2018) point out the difficulty in classifying iatrogenesis, otherwise referred to as Adverse Drug Reactions (ADRs), the very name reducing harm to that produced by the medicine and absolving practitioners of any wrongdoing; although these authors suggest there are “errors of omission, errors of execution, and errors of planning.”(p. 311) A report on Pharmacovigilance by the WHO (World Health Organisation, 2006) stated 50% of medicines worldwide “are prescribed, dispensed or sold inappropriately”. This suggests inappropriate prescribing and dispensing of modern medicine is a significant issue internationally.

Briana’s earlier statement, “*I should have freaked out*” highlights how she later comes to realise how overmedicalised her situation was. Illich (1976) wrote extensively of how overmedicalisation ironically undermines health, or as he puts it: “The medical establishment has become a major threat to health.” (p. 11). Illich (1975) also refers to healthcare as “health-denying”; Varley & Varma (2021) call this “medicine’s shadowside”; Greenhalgh (2001) refers to it as “medicine’s failings,” and Ashe (2021) beseeches us to consider medicine’s “spiral of maleficence.” However you say it, it is harm done to people by medicine, by doctors and by treatment, and Briana is an exemplar.



“Doctors *bring it on to their patients*”

– Briana



The practical reality of treatment that harms instead of treatment that heals is but one layer of the wrong Briana faces. The wrong that must be set right by the hero seems also to be an existential wrong; its essence shakes the ground of what is real, “this condition shouldn’t even exist.” The word iatrogenesis comes from the Greek word “iatros” being the word for physician, and “genesis”, being the beginning. It begins with doctors, you could say. Or as Briana feels regarding TSW, “*doctors bring it on to their patients.*” Medicine is created by chemists, prescribed by doctors and distributed by pharmacists so the fault may not lie entirely with doctors, but Briana’s experience seems to be of putting all her faith in what her dermatologist prescribed for her skin. At five months into withdrawal – early days, although she does not yet know it - Briana declares: “*I am still in this hell, all from using topical steroids that a doctor prescribed me.*” Her realisation that the medicine prescribed by a trusted professional has made her drastically worse means a great deal more than just the topical steroids are at fault. Things combined to ameliorate: prescription, medicine, and the doctor, have sooner exacerbated.

Patients seek care from medical practitioners, trusting and relying on their guidance when in compromised, vulnerable states of wellbeing. Doctors can be seen as the gatekeepers of knowledge about health and wellbeing, who support us to make sense of our own health. The perception of doctors can vary drastically based on experience. While Ramsden (2010), a healthcare worker himself, studied how patients’ journeys through healthcare were akin to the heroic journey, he described doctors as “highly qualified and

respected authoritarian figures” (p. 329) and considered them as allies to the patients. On the contrary, Johansson et al. (1996) studied patients’ experiences with painful musculoskeletal disorders and found many patients felt disregarded or ignored and ultimately considered physicians ignorant. Jessop (2014) also found that those turned to for help became opponents, as consultants were found to be “unhelpful through ignorance” (p. 112). Werner & Malterud (2003) also found patients with chronic pain experienced scepticism, and felt rejected, ignored and belittled by doctors.

Similarly, Briana feels her concerns are ignored by her dermatologist and she is surprised to find herself unsupported in her withdrawal. This seems to come as a shock to her, *“TSW is overlooked by so many doctors that it is horrifying.”* Ashe (cited in Greenhalgh, 2021) says, attempting to conceptualise the feelings that lingered following her own experience of nosocomial iatrogenic harm, “it’s a state of perpetual astonishment” (p. 277). While diagnosis can sometimes bring relief, it may also leave individuals in shock. One study found that many individuals considered diagnosis akin to the ‘final ordeal’; the pivotal crisis point that challenges the hero most (Jessop, 2014). This is befitting for Briana as her Call to Adventure, realising she has TSW, encompasses this harsh realisation that her condition is largely unrecognised. She does not experience a formal diagnosis, and this is a pivotal part of her journey. For TSW sufferers like Briana, diagnosis is uncommon and many experience denial of their condition, meaning they do not experience relief from a recognised label, or support of a physician, and may instead experience shock at this lack of diagnosis. Therefore, most continue to rely on “their own stock of knowledge and biographical experience” (Bury, 1982, p. 153).

Another realisation for Briana is that doctors are fallible; she explains to her readers: *“You desperately wish to sit in a room where a knowledgeable human donning a white coat will be able to give you all the answers, and there is just no such thing.”* Briana seems to have become aware that there are limits to doctor’s knowledge, particularly regarding TSW. Bury (1982) posits one of the realisations that ill people have is “that medical knowledge is incomplete and that treatment is based on practical trial and error” (p. 153). Society expects that medical professionals treat illness and prevent harm. Ultimately, Briana feels she has discovered that treating illness is less black and white.



“They failed you”

– Briana



Alongside practically and existentially wrong, Briana also seems to feel the wrong to be set right is a moral breach. The doctor’s overprescribing presents an error in the dermatologist’s execution of care, which Briana explains away as: “*Doctors use steroids as the ‘quick answer.’*” She reasons further that: “*Most of these doctors are taught to praise this drug – topical steroids.*” Her words indicate she feels medical training produces doctors who trust and rely on this medication. It feels at first like Briana is avoiding faulting doctors, as prescribing these topical steroids is simply following their teachings. But other statements suggest otherwise as Briana’s words indicate she saw her prescriptions as negligent and careless, not precisely inscribed by a physician steeped in knowledge and attention. She says: “*There are an inappropriate amount of doctors who do not understand the very treatment they are giving... I know this because my former dermatologist is one of them.*” While experience with one doctor seems insufficient to generalise to an “inappropriate amount of doctors” misinterpreting topical steroids, I believe Briana’s generalisation here comes from bearing witness to a community of other TSW sufferers who have experienced similar regard from their own doctors. Varley and Varma (2021) define this simply as “‘too much’ medicine and ‘too little’ care” (p. 146).” Society expects that doctors are inherently benevolent, their actions always beneficial to health and their intentions always good. Ashe (2021) writes about how decisions by doctors are to be made “not only with authority but also with benevolence, rendering it apparently disinterested, impartial, and – most impressively – *good*” (p. 257).



“They exploited you”

– Briana



The notion of corruption in medicine as introduced by Illich (1976) posits that the industrialisation of anything ultimately corrupts it. Illich (1975, 1976, 1999) argued that the growth and standardisation of activities such as healthcare, undermined health by eroding human relations and community, and individual autonomy. Ashe (2021) birthed the phrase “spiral of maleficence” to explain medicine’s immanent decay into violence and corruption, urging that the technical nature of medicine grows only in correlation with its capacity to harm. These may seem bold claims in relation to TSW, but Briana feels that this world of TSW does include unscrupulous action. Briana’s words: *“Doctors are going to continue to ruin lives because of a dollar”* indicates her thoughts that the doctor entrusted to care for her had priorities above her treatment and care. It is important to note that the healthcare model in America, where Briana lives, is of course quite different to the public health system that New Zealanders receive where financial gains for doctors is less relevant.



“This condition is preventable”

– Briana



Perhaps the greatest revelation Briana has in the Special World is that this condition, and her suffering, were preventable. This is an important aspect of the Call to Adventure as Briana realises that her suffering was not inevitable and the problem presented to the Hero, was avoidable. This word is crucial in Briana’s narrative, and she references it often. The weight of what could have been avoided is evident in her words: *“This preventable condition takes away jobs, love, family, opportunity, trust in the medical community, self-worth, and most of all, time.”* All the things that went wrong that culminated in TSW were not inescapable consequences, but rather a cascade of treatment and execution error.

Briana says, *“I think back constantly to our first consult”*, where the dermatologist prescribed a plethora of medications without any swabs or tests. Charmaz (1991) observes that ill people often look back to before sickness to make sense of how they arrived there. They may wonder if things could have been different, or whether they contributed in some way. In hindsight, Briana feels she *“should have freaked out”*. This suggests she has regret in being complacent in reception of her treatment. Charmaz (1991) believes there is a resolution required to move past reflecting on the genesis of illness, particularly to prevent such a thing happening again. Briana cannot undo her preventable condition, but she discovers meaning by advocating to prevent others going through the same, which seems to act as an effective way to move on from her own experience of a preventable, problematic condition.

Briana has stepped forth into the world of TSW, steeped in the new knowledge that she came here through a series of preventable wrongs. But what is her Call to Adventure? What are the “stakes of the game”? It is the call to prevent others acquiring this condition through advocacy. Frank (1995) acknowledges advocacy as a common version of the quest story that gives the hero a purpose. The stakes of the game for Briana are the chance

to make TSW known and prevent future suffering; to make doctors acknowledge this condition and prescribe topical steroids more carefully. Briana's personal wrong cannot be made right, but she can highlight the need for change publicly. By doing so, she can take steps towards fixing the natural order of things: *"My documentary could be a stepping stone in the right direction."* Much has been written about the importance of making meaning from illness, and how it affects individuals' abilities to cope with their ill health. Bury (1982) considers how the search for a cause of illness simultaneously seeks to uncover its meaning. Creating meaning and making sense of illness helps people adjust to adversity (Purc-Stephenson & Edwards, 2024). For Briana, creating a documentary to highlight TSW for the public, alongside educating doctors, gives her a powerful purpose and reason to keep pushing through withdrawal and resolve "the natural order of things".

Reflection

Briana's words, to me, were a distinct mixture of shock, betrayal and disbelief, demonstrating the unique experience of realising that medicine trusted to heal, and the professional who offered them to do so, have together led to the predicament of worse suffering. As a researcher I know my exposure to healthcare professionals during my son's eczema and his withdrawal colours how I am drawn to parts of Briana's narrative. Perhaps as I have had those same feelings of shock, betrayal and disbelief, they were more easily recognisable within her narrative.

This chapter was an important one for me to write but was difficult to achieve. My bias was apparent and I was continually worried that I was going to appear prejudiced rather than analytical. Yet it was important to reflect the clinical denial of this condition and the dismissal of individual experience by medical practitioners that Briana experienced because this lack of support is a significant issue that compounds what is already a vulnerable condition.

Discovering that Briana's dermatologist had no interest in reading the TSW paper she presented was upsetting, and I imagined how isolating that would feel. Diagnosis can bring relief for many people, with any illness, yet this was something Briana did not get to experience. This reminded me how grateful I was that our GP was happy to receive

information about TSW from me – in fact I gave him the very same paper that Briana offered, and he read it.

Chapter Two: The Special World – The TSW Body

—
“A chronic pain that you can’t hide because it’s advertised
for the world to see”

— Briana

Once the Hero has accepted the Call to Adventure, they must then step forth into the Special World. Vogler (2007) describes this crossing of the first threshold as an act of will requiring courage, that is simultaneously a leap of faith. The path of the Special World “may be exhausting, frustrating or disorienting” (Vogler, 2007, p. 130). Briana enters the Special World of TSW, trusting this is the right decision for healing. This is a world where she suffers through TSW and experiences her body-self divergently. As she notes, *“I’ve never felt more like a stranger to myself. It’s debilitating. It’s embarrassing... I’m tortured with the reflection in my mirror.”*

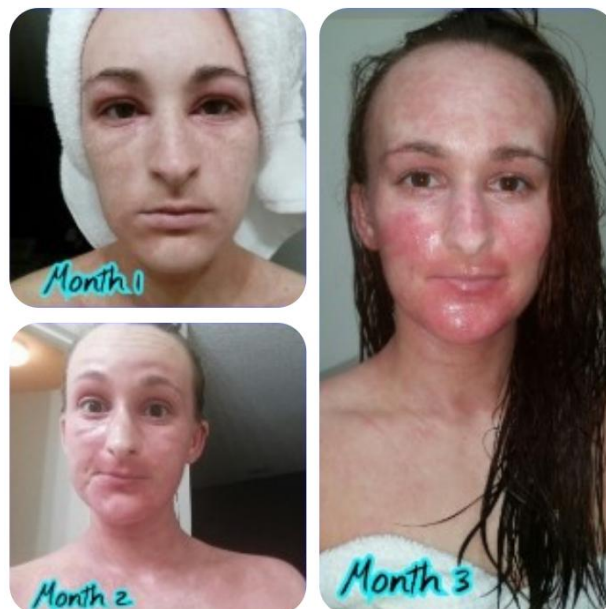


Figure 3. A New Reflection.

Furthermore, Briana explains: *“I was a performer before this happened”* and often mentions hopefully how she anticipates returning to dancing and performing. But stepping forth into the Special World of TSW means giving up such bodily pursuits, as this world is one brimming with bodily pain and physical restrictions. Briana states: *“At first, it’s usually the pain that overwhelms us. It’s a struggle just to get out of bed.”* A loss of bodily autonomy and physical ability is challenging for anyone, and this is especially true for Briana who has grown accustomed to an active, fit body. Experiencing TSW means relinquishing this bodily control and succumbing to a body that instead rules her ‘self’. She states: *“Everything about me has turned fragile. I used to be so strong”*. Her embodied experience as a dancer and performer is that of being deeply associated with her body, regulated and acutely aware. But as TSW commandeers her body-self, her bodily association manifests anew, in photos detailing her journey into a divergent embodiment of having a severe, painful skin disorder, thereby showcasing this novel version of her physical self.



Figure 4. Divergent Embodiment.

We experience the world through our bodies. Our bodies are not just mediums that we use to act, but *are* us acting (Carel, 2008; Gadown, 1980; Radley, 2000). For Briana, this new world is an abrupt disruption to her usual bodily experience. In this Special World of TSW her suffering is understood *with* her body (Radley, 2000) and Briana comes to know how her life materialises in an ill, constrained body. Briana’s lived experience is one of being a body that cannot do what she previously did. She describes: *“It’s mentally*

crippling to try and be as I was, purely out of desperation to live that nostalgic normal life, yet always being yanked into the reality that I, unfortunately, am not able to be that person.” To be a person who can move freely and dance for a career, has ceased to be reality for Briana.

As Frank (1995) states: “The disciplined body experiences its gravest crisis in loss of control” (p. 41). This loss of agency in the Special World is so stark in contrast to her role as a dancer and leads to fresh attempts to reassert control over a rogue body. *“The mornings are the hardest and most painful. I try to shower twice a week. The shower is nice, but its pure hatred after. My skin dries back to being cracky and painful.”* Early in her withdrawal, predictability is regained through a morning routine: *“You fight through the pain, the exhaustion of your mundane existence of bathing, flaking, itching, wrapping, moisturising...same thing over and over.”* This gives a semblance of control and agency through caring for the body. A few months later when she begins losing her hair, she once again asserts her agency by shaving her head: *“I did the unthinkable. I chopped off all of my hair... I had VERY LONG hair.”*

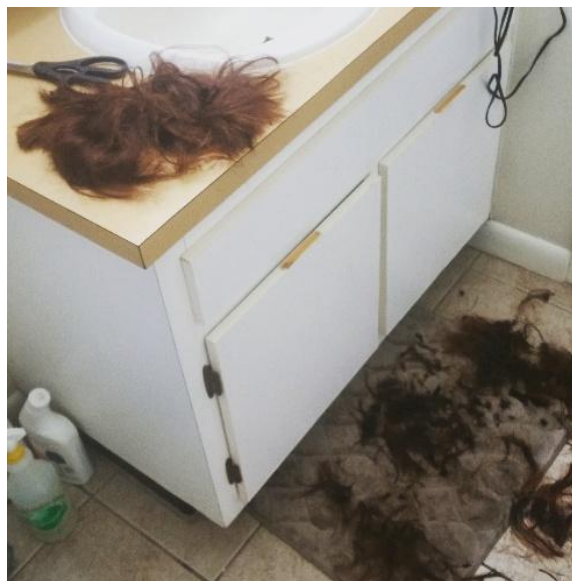


Figure 5. Loss of Hair.

The accentuation of the length of her hair suggests what an extreme shift this act is for Briana. This fresh persona embodies that of decisiveness, not that of an ill person whose hair is slowly eroding. Over time, there are further examples of attempts to exhibit control over the body, such as through diets, detox, and getting gene testing in the hope of finding answers as to why her withdrawal persists so long.

While associated with her body through measures such as purging her hair and ritualistic actions of skincare and diet, Briana is growing further dissociated from her body simultaneously, commenting that, *"I look in the mirror and see someone I don't recognize."* She declares, *"Now, with performing off the table, I feel dismembered"*. This aligns with Wagner (2024) who describes the body in pain as "dislocated" (p. 326). Briana's use of the word "dismembered" is a poignant expression of how she is experiencing her ill body now, as dysfunctional, or even comparatively disfigured. The 'now' she is referring to is at the two-year mark of her withdrawal, where control has slipped further from her grasp, and her body continues to remain unfamiliar to her past self. Unable to regain control of her diminished form, Briana admits to a new embodiment. She concedes her well body is defeated, accepting her temporary reality as embodying an ill person, with a visibly sick exterior. *"The only solution is to love myself just as I am and accept myself in this new body."* This physical form, previously known to her as bringing esteem and gratification – indeed, making a living and sustaining her - has now become her source of suffering.

Furthermore, she experiences herself in a loop, where her anxiety and mental state require action. She knows 'working out' and exercise is a cure, but her body reacts by sweating, which in turn causes significant skin reactions and further mental anguish. *"I have been stretching again... trying to do pushups and crunches... Perhaps that too has been contributing to my skin issues since sweat makes me itch... I don't want to stop doing something that is positive for my body."* Radley (2000) describes how bodies enable us to signify and express ourselves, and to act as a subject in a social world. Part of Briana's self-expression comes through exercise and dancing, but the world of TSW limits her ability to express herself through this medium, or to provide something that she considers a benefit for her body.

Briana writes a blog post for other TSW sufferers where she emphasises her understanding of what others are experiencing. She writes: *"I know your pain... we search for ways to explain the hurt, this unyielding, overpowering suffocation that is TSW. It's usually to no avail. The dictionary just doesn't hold the answer. It's only something other sufferers understand."* Scarry (1985) describes pain as an experience that reduces individuals to feeling silenced and isolated. Because pain cannot be expressed in language or meaningfully shared, it defies meaningful expression, reducing the structures

of our reality of the world, leading to an “unmaking of the world” (Scarry, 1985, p. 23). Ashe (2021) affirms the notion, after her experience of torturous nosocomial harm in the name of medicine, she says, “Today I encounter *my* unmade/remade world everywhere.” (p. 267). This Special World of TSW for Briana, is a deconstructing /reconstructing of her lived experience, an inhibited and oppressive world. At four and a half years in she admits: “*This is not living. It is pain management. It is surviving. I wish this on no one.*”

For many people, becoming ill means attention is suddenly drawn to parts of the body that may have previously gone unnoticed. The body-self is disrupted, making the body distinct, and the individual experiences constraint from the body (Gadow, 1980). Carel (2008) emphasizes how a healthy body can be transparent; when functioning normally we do not notice ourselves writing or walking, or at least we do these things without special attention as they are well practiced and habitual. Wagner (2024) states: “Pain disrupts the habitual rhythm of life” (p. 326). Disruption of such a bodily function brings it to our attention, or as Kirmayer (1992) puts it, “places the body in the foreground” (p. 324). Gadow (1980) describes the immediacy of the lived body, where there is no distance or distinction between the body and the self. This immediacy is shattered by illness, where phenomena such as pain coming from the body ruptures immediacy through incapacitation or constraint (Gadow, 1980). The individual’s attention is so entirely drawn to the body and its physical affliction. When Briana finds herself unable to straighten her arms, it is the beginning of what she later describes as being “trapped” in her own body. The relationship between body and self in illness can lead to the body feeling like an object, that oppresses the self (Gadow, 1980). Wagner (2024) describes how the body, previously an intentional subject, begins to feel more like a material object. What is accepted as a temporary, short-term state at the beginning, an ill body brimming with pain and limited movement, becomes harder to sustain as time passes. At five years she declares: “*I hate being trapped in this body*”, which seems to illustrate that her past embodiment and identity as a dancer is consistently viewed as imprisoned by the present, sick body.

Whilst Briana has offered her body to her followers via her blog in a controlled, online medium, outside this she then experiences entering a familiar world but with an unfamiliar body. Because we experience the world through our bodies, a disruption to the biological body alters our experiences and actions within the world. As Carel (2008) puts

it, “it strikes at the heart of subjectivity” (p. 37). Briana finds herself challenged by society, where strangers respond to her highly visible illness. On her one-year wedding anniversary she is determined to celebrate with a trip to an aquarium. While in a wheelchair at children’s height she must tolerate staring by multiple children intrigued by her appearance. On another occasion, while in an elevator she is rattled by a stranger asking, “what’s wrong with your hands?” She discovers her body is now somehow available to the public for critique. Briana says of this toll, *“the socially unacceptable body I carried around where, for some reason, was socially ACCEPTABLE to comment on in public”*. Carel (2008) refers to this as “a body that cannot keep a secret” (p. 72) Carel (2008) writes about illness from the experience of personally carrying a visible illness, where she says encounters with strangers are done “in the shadow of my illness” (p. 62) Similarly, Briana also encounters others in the shadow of her illness. One evening while trying to close a car door, with limited mobility (and a shaved head), the driver attempts to get her attention to offer advice: “Sir, sir”, to which she hears herself respond, *“I’m not a Sir!”* before an emotional breakdown takes hold and her husband takes her aside and consoles her. Not only is her appearance unfamiliar to herself, but she is unrecognised by others too.

The aberrant, deviant body not only poses a challenge to the self but also confronts those that come across it. There is unspoken societal pressure to regain control of an aberrant body as it disrupts social harmony. Illich (1979) explains the challenge to the public, as “people who look strange or who behave oddly are subversive” (p. 124). Overtly sick people tend to be kept isolated and Briana, in her weeping, red skin causes discomfort to others. This deviance from the social order is seen as a threat to the health of others, as a throwback to fear of contagion as in earlier times. Although more than just a personal existential discomfort, it feels bigger than this, as if the deviant body is an affront to the greater medicalisation that keeps society healthy. Illich (1976) goes on to posit that we, as a society, isolate sick people rather than actively create a society able to accept and provide a social tolerance for the unwell. It begs the question of whether Briana’s appearance is most troubling because it signals to others one of two possibilities: either her skin is incurable (medical failure), or she is deviant in refusing to treat it (medical dissent). Visibly sick individuals can therefore be viewed as rational but morally suspect by choosing illness, or irrational but then mentally incompetent and

morally blameless (Lock & Gordon, 1988). Both options lead to dissonance in a public that is steadfast in its trust of modern healthcare.

As Briana loses control of one experience of embodiment, she finds herself becoming in another body. This is the physical body she will write about, and from. Her narrative is told through her ill body, and her new embodiment is formed through her experience in the Special World of TSW. While she may feel imprisoned within a body she did not choose, she has the power to use this body to tell a purposeful story and the secret her body cannot keep is willingly shared for the benefit of others through her blog, in words and photographs.

Reflection

It made sense to me that the Special World for Briana meant a sudden shift toward experiencing life with a restricted, deficient embodiment. As previously a dancer and performer, I felt this shift in embodiment was a dramatic modification for Briana and reflected the distinct transformation from using her body with precision and competence to a then weak and restrained embodiment.

I was unsure of using photos at the beginning, but over time progressed in wanting to convey what TSW is really like. The inclusion of photos was to convey Briana's discomfort in a way words cannot, but it was also important that the photos chosen were ones that exemplified Briana's story, not just TSW. I considered that when we witness a physical injury, part of the impact comes from the ability to imagine that trauma to our own body. While Briana's words tell the reader that she is aching, her skin is peeling off, burning, painful and weeping, these words do not seem as powerful as when coinciding with pictures of what that description *looks* like. I'll admit that I hoped they were a little confronting, which likely projects my own feelings of desiring recognition and understanding of this condition.

Chapter Three: The Mentor - In Sickness and in Health

—
“I COULD NOT *do this without my husband*”

— Briana

There are various archetypes that the hero encounters along the path of their quest. These characters act as functions, each playing an important role in shaping and guiding the hero (Vogler, 2007). One such character is the Mentor, whose function is “to prepare the hero to face the unknown” (Vogler, 2007, p. 12). Vogler (2007) explains that the Mentor archetype is apparent in characters who protect the hero and offer them gifts, which may come in the form of motivation and reassurance.

Briana’s husband fits the role of Mentor as he supports her to take on TSW; his support sets the journey in motion. Briana adamantly states early on, referring to coping with TSW that she, “*COULD NOT do this without my husband.*” Over the first two years she reiterates how grateful she is for him and how much she relies on his support. He takes care of her, wrapping her skin, pushing her wheelchair and bolstering her spirit. Vogler (2007) explains that the Mentor acts to motivate the hero and supports her to overcome her fears.



Figure 6. The Supportive Mentor.

Shortly before the two-year mark of her withdrawal Briana discloses her marriage is ending, following the discovery of deception and infidelity by her husband. The details are only alluded to, but what is apparent is that there is another woman, and he has abandoned Briana. She thinks back to her wedding vows that finished with *“no matter what”* and berates, *“no matter what stood for when times got hard with sickness or financial instability, not infidelity.”* This appears to demonstrate her belief that their marriage was meant to withstand the turmoil of her illness, and she struggles to comprehend how he has left her during it. She voices, *“I felt like we were in it together... that this was going to just be a phase in our lives that was abhorrent...and something we could celebrate triumphantly over once we made it through to the other side.”* The “we” here suggests Briana viewed her illness as something they were undertaking together. *“That not only my bravery was something to be proud of but his courage to stand by my side as well.”* Briana seemed to view the challenge of TSW as a joint pursuit, requiring the courage and tenacity of them both. Bury’s (1982) concept of biographical disruption posits that assumed structures of a person’s life are disrupted during illness. Briana may have assumed her husband would be without her throughout her illness, instead she must come to terms with his abandonment.

Briana appears psychologically devastated at the prospect of enduring TSW without her support person: *“It’s like having a cast on your foot and two crutches, but then suddenly someone takes the two crutches away and says, now figure it out. You never thought you’d have to figure it out.”* Briana feels suddenly thrown into a role she had steadfastly declared she could not fill. With part of the Mentor’s role being to prepare the hero for the unknown, her husband’s departure feels befitting of the Mentor as she remains in the uncharted space of caring for herself.

Another aspect of the Mentor is to protect the hero. Briana speaks of how her husband acted to defend her: *“I feel like a shield that I cherished has now been stolen and I am left vulnerable to the world”*, illustrating how he made her feel safe. Carel (2008) writes about illness, philosophy and phenomenology; during her own experience of illness, she speaks of the need for her husband’s support: *“I cannot face my own decline, my body’s failure, and its terrible implications alone”* (p. 49). The idea of facing illness alone is a daunting task for Briana.

Jayawickreme & Di Stefano (2012) studied the psychology of heroic qualities and found “heroic behaviour... is frequently solitary in nature” (p. 174). Jessop (2014) conducted a narrative analysis of individual accounts of illness and concluded that such journeys were ‘lone quests’, where there were no companions on the journey. Jessop (2014) added that while patients may not structure their narrative into the quest deliberately, the quest narrative can still demonstrate insight by what is and is not included on the journey. These studies support the idea that Briana must take on TSW alone and accept the path ahead of her. Vogler (2007) says: “The mentor can only go so far with the hero. Eventually the hero must face the unknown alone” (p. 12). Briana must face the journey through TSW alone, befitting of the hero.

In Briana’s mind her husband’s departure means an assortment of difficult truths. One major realisation in Briana’s eyes is that she is a burden to others because of TSW. She seems to feel her state of health is too much for others to bear, and that this is manifest in his leaving: *“I could see the suffering he was going through because of my condition, the toll it was taking on our ability as a couple to be like we had once been. I get why partner’s stray.”* She believes TSW was supposed to be a challenge that they got through together, that lead to a subsequent stronger relationship. *“I wish he and I could have grown through our sorrow together, to push past the woes and perhaps be reminded of what happiness felt like after two years of medical anxiety and impatience.”* Charmaz (1983) explains how becoming a burden for ill people leads to feeling immobilised and stands in contrast to their self-image. This becomes symbolic of how they may no longer claim identity based on previous actions, and that their identity is demeaned by being a burden (Charmaz, 1983). Being a burden for Briana, appears to mean she may no longer sustain the role of a wife with a loving partner, and this part of her identity has fallen away. She also draws on the notion of being a burden to others as the fundamental reason for new relationships not being an option for her: *“I just don’t find it fair to plop all of this baggage onto someone else.”* She goes on to say, *“I very much view myself as tarnished, unlovable, and not worth the time.”* The loss of her husband appears to leave her questioning her worth, as his departure signifies to her that she was not worth riding out the storm for.

Part of Briana’s identity is attached to her relationship with her husband. The loss of a partner leads to a loss of the sense of self constructed within that relationship (Jakoby,

2015). Taylor (2012) explains that scaffolding of the psychological self-image involves the tangible attachments individuals rely on for wellbeing, such as partners, careers and future plans, and that these things act as building blocks to construct one's sense of identity. Suffering loss erodes such scaffolding and produces an undermined, diminished self (Charmaz, 1983). Therefore, Briana's identity and image of 'self' seems altered by this loss of partner. It means TSW, in her eyes, has left her single and she must construct a new identity that involves going through TSW single.

Repeatedly she returns to the past, reminiscing on how supportive and caring he had been in the first year: *"My ex truly was such an unimaginably terrific carer the first year of this."* The misalignment of these memories alongside her new reality proves exhausting to reconcile. Charmaz (1991) says: "An irretrievable past, an unsettling present, and an irrevocably changed future alter an individual's view of self" (p. 229). Charmaz (1991) writes about the challenge of interpreting the stark contrast between present and past functioning, "for the past remains so close" (p. 22). These memories of the past loom large for Briana and at times she appears stuck rethinking this past, so close and so unexpectedly lost. Jakoby (2015) explains that nostalgia can act as a mode of continuity of identity, as it relates the past, present, and future together. Charmaz (1983) describes how supportive partners can bolster the sense of self of the ill person, which helps to maintain a continuity with the past self, before illness. For Briana, this loss of supportive partner acts to sever that continuity of self, and her identity based on the past becomes eroded.

Beyond coping with her illness and the thought of new relationships, the end of her marriage to Briana also means the shattering of the future. A strong means of getting through TSW was the promise of the future with her husband and losing him also means losing that future: *"I fear letting go of the life that I thought I was going to have."* Briana appeared to see the future as a beacon that kept her afloat amidst the chaos of TSW, a promise of a new life. With that future obliterated, this means to her that her time with TSW is more than an interruption; TSW has affectively severed her future, and she is stuck here in the present with her illness. She tries desperately to move on from him and forge a new path but finds herself held back by her health. This in turn means that she cannot move on from her husband: *"Until my skin is healed, I'm not sure my heart will be healed."* Charmaz (1991) posits that people can transcend negative events and feelings if they are

able to create new lives. For Briana, were she able to head out and begin taking strides towards a new life she feels she could move on from him, but TSW keeps her stuck at home, surrounded by his things, which entwines the two into a present she feels unable to evolve from.

Frank (1995) describes how illness causes the sufferer to become a “narrative wreck” where they must assess what is left after the storm and form a new map. The temporal nature of the current situation lies in relation to the past, and what is anticipated in the future. Frank (1995) declares: “The illness story is wrecked because its present is not what the past was supposed to lead up to, and the future is scarcely thinkable” (p. 55). Briana’s past, present and future were securely entwined with her husband and his departure leaves everything in their wake destroyed. *“I will always wish I could have had more time with my husband when life wasn’t hailing down so hard on us. Perhaps we could have made it through the storm.”* This new wreckage: TSW solo - is assessed by Briana and she is forced to take stock: *“I am nowhere near where I want to be. I am going through a disgusting health condition; I don’t really have a job...I’m struggling to raise funds for my documentary; I’m about to get divorced at 28”*. None of this fits with the life she had envisioned, and TSW alongside the departure of her husband, means Briana is a narrative wreck and she must begin a new chapter in her life story.

Vogler (2007) details a stage of the hero’s quest called the Ordeal, which marks a critical moment where the hero experiences a symbolic death or near-death moment that they must be reborn from. The loss of her husband fits this description as Briana finds herself completely devastated by her new situation. This is the stage where the hero hits rock bottom, confronting their greatest fear (Vogler, 2007). Frank (1995) reflects on the wreckage left by illness and posits, “only the bottom is solid” (p. 126). Therefore, when the hero reaches this state of crisis the only certainty is contingency, and the hero is forced into acceptance (Frank, 1995). Being in crisis may cause a breakdown of the psychological constructs relied on to bolster oneself, and this dissolving of attachments leads to surrendering to the predicament (Taylor, 2012). However, acceptance is not a place one can suddenly leap to. As Kübler-Ross & Kessler (2005) point out, one experiences acceptance as a process they move through. Lefebvre & Levert (2006) describe losses such as divorce, while they also require grieving, usher in “the potential

for learning and growth” (p. 342). While Briana may have found herself experiencing the bottom as solid, she can only ascend from there, while building a new sense of self.

In a more overt way, the blog shifts at this point, further proving how tumultuous this shift is for Briana. Prior to this pivotal point in her narrative Briana had used the blog to showcase her TSW timeline, with regular fortnightly posts including detailed photographs of her condition. The blog becomes more disorganised at this point, her posts further apart but with much richer detail of her lived experience and all the emotions she must process. At two years and three months into her withdrawal, shortly after her marriage ends, she declares: *“It’s shocking to think I am on a larger emotional rollercoaster now than when I first started this hell. And I know it was because I had a partner.”* The shift in narrative seems to reflect the lack of order in Briana’s life, and her story shifts significantly.

The abandonment by her husband whilst going through TSW means a great deal more to Briana than just the end of her marriage. She had seen TSW as a temporarily disturbed present, where her future would follow on from her past after she was healed. Therefore, for Briana, the ending of her marriage carries immense meaning and bears stark witness to the disruption of TSW. Her condition has made her a burden; it has forced her to become single, and she must either remain single or relearn her worth to step back into the dating world. It also means her future is severed, making her present more than a brief interruption. Fortunately for Briana, she does manage to see life differently after some time. At four years into withdrawal, she says: *“I lost my husband, but... maybe he is the one who lost out.”* There is no doubt that her husband leaving causes a monumental shift in her narrative, and Briana continues the journey through TSW with a new map.

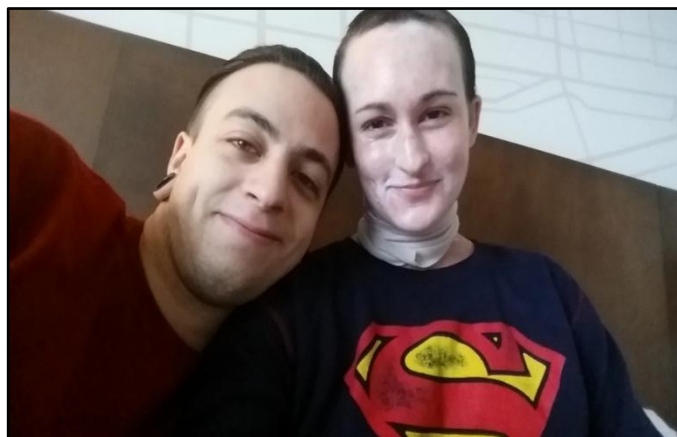


Figure 7. The Mentor Leaves the Hero.

Reflection

The narrative of abandonment was a crucial turning point for Briana which is why this chapter was included. The departure of her husband ruptured her support and increased her sense of vulnerability. The aim of this chapter was to highlight how damaging relational collapse was for Briana at a time of such extreme vulnerability. I initially created this chapter focused on the divorce itself as a significant event, but through analysis came to realise that the importance of the divorce was most reflected in having a supportive partner, and then suddenly being unsupported.

There was care taken to remain analytical and not choose the narrative parts that focused on judgment of her husband or the drama that ensued around him leaving, but rather the parts that highlighted what he meant to Briana. From the initial study of her narrative, it was apparent that her divorce was a pivotal point in her story and its inclusion in the analysis was quickly determined. After deciding upon the Hero's Journey as a framework however, it really illuminated how her husband fitted the role of the Mentor departing. It was not just the end of her marriage but the profound termination of her husband's assistance and care for her, leading to a significant shift in Briana's sense of safety and support. In a narrative sense, the journey shifts significantly for Briana here as she becomes a lone hero, battling TSW without a partner. I felt much heartache for her during this chapter as having witnessed this condition, the thought of doing it alone is quite distressing.

Chapter Four: The Hero – Advocacy and Sacrifice

“We can be the hero of our own stories”

– Briana

Briana becomes an advocate for TSW and dedicates her time to publicising the condition while supporting others going through it. Social psychologists Goethal & Allison (2012) argue that heroes do something moral and challenge conventional ways of thinking. Briana is morally motivated to highlight TSW. Referring to the documentary she creates about TSW, she says: *“I look forward to (hopefully) creating an immortal picture of our suffering that deserves justice.”* She is aware that conventional thinking in the medical world downplays or even denies TSW. Briana’s role therefore becomes one of advocacy: *“My documentary could be a stepping stone in the right direction. I don’t want to be idle. I want to fight. I want to embody that cliché of being the change in the world.”* The drive for justice aligns with the Superhero Spiderman who Briana refers to often in her blog: *“If you are a follower, you are very aware that I have a deep attachment to Spiderman and all things Peter Parker.”* Spiderman seems to encourage Briana to be the hero of her own story, where she is driven by a moral code and acts to challenge convention.



Figure 8. Attachment to Spiderman.

Briana takes inspiration from this modern-day Superhero, the split persona of Peter Parker/Spiderman. Allison & Goethals (2016) posit that humans tend to develop heroes who they worship and feel inspired by. Furthermore, these authors suggest that hero narratives offer a blueprint of how we ourselves may live and inspire us to greatness (Allison & Goethals, 2016). Briana declares herself a fan of Spiderman, but through her writing we can see it as much more than fandom but rather resonating with his character, even comparing herself to him: *"Watching Spiderman on that screen was like watching myself."* This fits with Vogler (2007) who describes heroes as having qualities that individuals may identify with, and recognise within ourselves. Referencing a Spiderman film she says of the hero: *"He keeps trying so hard to fix things, fix situations that are caused due to their proximity to his life... for some reason, I felt right there with him."* This seems to highlight Briana's view of herself as someone trying hard to fix things too, like Spiderman.

Briana appears drawn to the fact that Spiderman demonstrates greatness but simultaneously has human failings. This view of Spiderman's imperfections seems to allow her to practice grace towards her own weaknesses. In describing superheroes Briana declares, *"they, too, are not immune to awful feelings of doubt, uncertainty, and despair."* This statement, including herself with the "too" appears to be a way of allowing validity to her own uncertainties and despair. If Spiderman can experience these very human emotions while still successfully portraying the hero, in her eyes, it gives space for her to accept her own shortcomings while continuing to fight and be a hero for her community. She says: *"Watching Spiderman on that screen was like watching myself"* and, *"not even Spiderman can hold it all together after awhile. I found myself this past year having a hard time holding it together."* This fits with Allison & Goethal's (2016) argument that heroes benefit us and our communities "by providing scripts for prosocial action" (p. 187). Briana seems to aspire for greatness and positive action but is bolstered by the thought that she can fail and have doubts yet remain a hero in her community as Spiderman does.

Challenging the medical status quo is an example of challenging conventional thinking and requires features befitting of a hero. Such heroic features include persistence and self-sacrifice (Goethals & Allison, 2012), courage and determination (Thomson & Downe, 2013) and overcoming challenges (Goethals & Allison, 2012; Vogler,

2007). Like David versus Goliath, or perhaps more like Erin Brockovich, Briana considers herself an underdog: *“I’ll push through that bubbling terror in my throat in order to keep typing those emails and fighting for the underdog instead of taking a break.”* Kim et al. (2008) argue that individuals tend to root for the striving underdog as we can all resonate with the universal experience of struggle and disadvantage. The authors suggest that supporting the underdog may satisfy a desire that the world can be fair and make us hopeful of our own abilities to succeed against adversity (Kim et al., 2008). Briana’s words seem to support this hopefulness when she says, *“I want to share stories of overcoming, about faith in oneself, about the underdog, and the phoenix that rises again.”* Research suggests that successful underdogs are often later seen as heroes (Goethals & Allison, 2012).

In Vogler’s (2007) description of a hero he reveals that while strength and bravery are pertinent features of a hero, they are secondary to another feature that heroes must willingly accept the possibility of: self-sacrifice. Researchers agree that sacrifice is an important characteristic of a hero (Allison & Goethals, 2016; Allison et al, 2019; Campbell, 2008; Goethals & Allison, 2012; Smith, 2002). Briana reflects on her own journey and how much she has sacrificed for the cause to elucidate and eradicate TSW: *“I’ve been an advocate, shedding blood, sweat, and tears for this condition and yet I never seem to get better.”* The injustice of toiling so hard for something but still being at its mercy seems to sit heavily with Briana. She resonates with how Peter Parker *“had sacrificed more than he could possibly bare losing and that the fight he was facing didn’t feel worth the loss.”* Sacrifice is a powerful moral trait that Briana values in Peter Parker but also writes consistently about from her own experience of living with illness. She declares succinctly: *“TSW is sacrifice after sacrifice.”*

People thought of as heroes, are often the same people who are thought of as leaders (Goethals & Allison, 2012). Briana appears to take on the role of a leader in the TSW community, as she feels she has the capacity and resilience to do so. Whilst her blog is written to bolster her community, within it she details how she partakes in interviews, Youtube videos, conferences and the creation of a documentary. She seems to know that leaders give much of themselves: *“Leaders in any community, especially the chronically ill, are constantly treading water, our legs kicking ... and kicking to stay afloat while our arms are reaching out and trying to be of help in any way that they can.”* Goethals & Allison

(2012) believe there is often overlap between leadership and heroism, and Briana appears to strive for both.

This drive for advocacy fits with Frank's (1995) example of the quest narrative as "involvement in patient advocacy is one enactment of a quest story" (p. 116). This drive to advocate for a largely unacknowledged condition keeps Briana from losing hope: *"If I didn't have a reason to get out of bed, then I'd be in real trouble. That is when the hopelessness wins."* Advocacy seems to empower her to be a leader and hero for the TSW community. Briana has lofty goals of protecting future sufferers from enduring TSW and leaving a legacy of positive change. Nearly six years into her withdrawal, while deep in self-reflection she says, *"who do I want to be — memorable."* Indeed, heroes remain in our memories long after their heroic acts, and Briana seems hopeful her advocacy will leave a mark.

Another important characteristic of the hero is reflected in the moral code that they are compelled to adhere to. DeScioli & Kurzban (2008) believe that superheroes are fundamentally moral. They point out that being morally impartial with their judgements is necessary for heroes to laud justice over personal benefit (DeScioli & Kurzban, 2008). However, they could use their powers for personal gain instead of meddling in situations that ultimately have nothing to do with them but which they bring their third-party moral judgements to (DeScioli & Kurzban, 2008). These authors ask: "Why do we admire superheroes for this lapse in rationality?" (DeScioli & Kurzban, 2008, p. 254). While editing the documentary she is creating about TSW Briana is often confined in her home alone. This fits with Franco, Blau & Zimbardo (2011) who describe heroism as "often a solitary, existential choice" (p. 99). Briana realises, *"I've completely ignored my need for companionship in order to finish this plague of a project."* This quote seems to reflect both her personal sacrifice and her drive to complete a project that aims to vindicate the suffering of people with TSW. Furthermore, while toiling for the greater good in her role as TSW advocate and documentary creator, Briana describes the time working on the documentary as, *"...torment. Honest to god, torture."* Immersed in editing the footage she finds herself reminded of the suffering and loss over and over, however she seems deeply compelled to highlight this condition for fairness and justice.

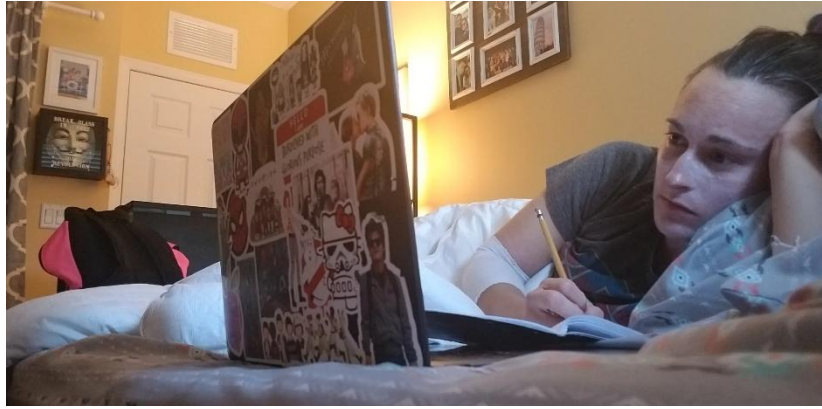


Figure 9. Online Advocacy Work.

In Briana's eyes, her personal sacrifice for the moral good of showcasing this condition to the world is a necessary offering for justice. Allison & Goethal (2016) posit that two important functions of heroes are that they inspire us to elevate our own morals and encourage personal growth. Briana reflects on all her advocacy work and gives commentary on its correlation to her beloved Peter Parker: *"No good deed goes unpunished" sometimes rings true in this community as much as it does with Spiderman's kind heart and will to do what is right, not what is easy.*" Briana appears to acknowledge that she has, like Spiderman, chosen to fight for what is right, despite the personal toll. Her actions align with Allison & Goethals (2016) statement that, "heroes use their wounds to transform themselves and to redeem the world" (p. 198).

Another important feature of the hero is that they must overcome obstacles (Goethals & Allison, 2012; Vogler, 2007). Briana faces numerous challenges during her withdrawal: divorce, loss of career, surgeries, travel, physical pain and discomfort – and these are only the tangible. She also faces anxiety, lack of confidence, loss of self-worth, financial strain and loss of identity. Says Briana: *"It feels like all the things I've loved have viciously been ripped from me, but this is my narrative, my journey to process through."* Like Smith (2002) states of the hero's journey, the hero must accept the trials and surrender to the process. Briana states:

"It doesn't mean I don't shed tears, that I don't live with demanding anxiety perched inside my ribcage singing a requiem of fears. It just means I use these reminders and goals to conquer each day knowing I can either let my anxiety lull me into a crippling comatose state, never leaving a cocoon that

would ultimately suffocate me, or I can quiet her as much as possible and find something in each day that makes me smile, laugh, and be thankful for another precious day of life.”

This quotation seems to reflect that Briana acknowledges her anxiety but views it as her responsibility to overcome it and grow despite the challenges she faces. Kim et al. (2008) explain that it is human nature to root for someone challenged with a difficult task, and Briana fits the role of hero as she experiences difficulties brought about by TSW yet is consistently motivated to prevail. Resilience is a powerful feature of Superheroes who according to Briana are *“incredible beings that can withstand the toughest of battles.”* Later, looking back on five years of journeying through TSW, Briana declares her own resilience, *“fortitude lives in these veins.”*

Frank (1995) argues that sufferers on the hero's quest may use their illness for a purpose. Briana uses her illness not only as a means of advocacy and educating the medical profession, but her personal suffering drives her to remain grateful for life and appreciate all that she has. Two years into her withdrawal, Briana declares: *“I was given all of this for a reason and I intend on living out an incredible life despite it all.”* The idea of being “given” TSW and its subsequent challenges implies there is a meaning to Briana having this condition. Briana reflects on someone who once wrote to her and speculated that, *“perhaps this happened to me because I was someone who would use their voice, and that she was grateful it happened to me... I guess I volunteered as tribute, existentially speaking.”* This seems to reflect that Briana believes there is significance to her having this condition, suggestive of something greater than personal healing.

Furthermore, enduring TSW “for a reason” suggests Briana has an expectation of herself to find motivation from her experience and to create something from it. At her five-year TSW anniversary she states: *“I don’t know if I believe in ... “Everything has a purpose,” because I think we give it purpose ... It’s our responsibility to ... find the gravity of it; to figure out a way for it to be useful.”* In Briana’s eyes, she has made her suffering of use by making a documentary and advocating for TSW education. Allison & Goethals (2016) suggest that the purpose of the hero is to share knowledge and wisdom, inspire others and support psychological growth. Briana’s advocacy work fits with this definition as she aims to increase knowledge about TSW and support the followers of her blog.

Finding meaning through suffering seems to be pertinent to Briana. After her illness flares and her health deteriorates further, she states: *“it took a lot of emotional digging to see that I needed to find some meaning in my journey again. I need to channel my energy into something that may be helpful or productive.”* Hero narratives may act to give individuals “meaning, hope, inspiration and growth” (Allison & Goethals, 2016, p. 187). Briana’s narrative demonstrates her desire to make TSW be of worth; that she is unwilling to suffer meaninglessly. This fits with Campbell (2008) who declares: “A hero is someone who has given his or her life to something bigger than oneself” (p. 151). Briana’s motivation seems clear: *“I want to leave something behind in this world that made it better, that gave someone hope and comfort.”* Two years later she reiterates the sentiment with: *“I did not spend two years of my life creating a documentary to allow us to continue to suffer in vain.”* Throughout the years of the blog, it appears evident that Briana is determined to make meaning from her illness for the betterment of others and that her suffering is viewed as a catalyst to progress.

Jayawickreme & Di Stefano (2012) ask, does a hero “need to be *objectively* moral and noble, or is it sufficient for one to *believe*” (p. 166) they are moral and noble? Befitting of an answer, Goethals & Allison (2012) believe “heroism exists in the eye of the beholder” (p. 230). Briana appears to view herself as a hero, exhibiting sacrifice, advocacy, leadership, and being driven by a moral code. She also finds purpose by acting for the underdog and overcoming obstacles. Briana views herself as a hero by comparing herself to Spiderman and believes, *“we can be the hero of our own stories.”* In the eye of the researcher (at least this one) Briana fits the role of the hero on a journey through TSW.

Reflection

I felt Briana most wanted to be a healed hero, one who could show that it really was TSW and that she came out the other side better, without steroids. Despite a strong belief in knowing TSW to be true, without support there may have been flashes of self-doubt for her. For myself, when we saw a new GP who was very supportive and admitted that he agreed my son was in TSW, I did not even realise how isolated I had felt until I suddenly had the adverse feeling of support, which brought immense relief. As Vogler (2007) says “Eventually the hero must face the unknown alone” (p. 12); I think Briana truly fitted the

role of a lone hero, who despite moral support from friends and family, really did take on TSW and advocacy alone.

The sacrifices Briana made to make that entire documentary herself was impressive, and incredibly admirable. Her actions really were heroic at times, at least that's how I felt, yet I had concerns that it could be construed as cliché or saccharine to represent her this way. But she genuinely has made gains within the TSW community with her advocacy and reach, and I felt her work in this area was commendable and humbling.

I began a chapter juxtaposed with this Hero chapter but later removed it. The removed chapter was about The Villain, positioning TSW in opposition to Briana. I came to discover this was too blatant however, just as Briana was positioned as a hero in a more nuanced way, her adversary was more complicated than simply illness to be overcome.

Chapter Five: Threshold Guardians – Doctors and Epistemic Injustice



*“It’s unjust and abominable to have
a 4 decade history of this without any reform”*

– Briana



Vogler (2007) describes the Threshold Guardian archetype as guarding the way of the hero. They may represent oppression and hostility, but their primary function is to test the hero, as they are “part of the training of any hero” (Vogler, 2007, p. 129). Threshold Guardians can represent obstacles faced by the hero, and Briana encounters medical professionals as Threshold Guardians on her quest. As she aims to have TSW medically recognised, and acknowledgement brought to those who suffer, Briana must learn how to engage medical professionals in order to progress through her journey and gain validation for TSW.

Doctors can play the role of threshold guardians in the medical community as they guard access to diagnosis and treatments. Doctors can present medical certificates, referrals, benefits, time off work, exemptions and so forth. Therefore, society has granted scientific medicine the exclusive right to treat illness (Illich, 1976; Greenhalgh, 2001). Vogler (2007) explains that learning how to navigate Threshold Guardians is “one of the major tests of the Hero’s Journey” (p. 52). Briana appears tested by doctors in their role of gatekeepers of diagnosis as she is denied an official diagnosis of TSW. McNiven & Ryan (2022) studied the experience of diagnosis of skin conditions and declared, “diagnosis is not necessarily a neutral event or action” (p. 2). These authors believe diagnosis affected people’s orientation in life, how they looked to a future and viewed past events (McNiven & Ryan, 2022). A diagnostic label also had a useful social function that could explain

symptoms and reassure support people (McNiven & Ryan, 2022). For Briana, a lack of diagnosis denies her that functional and potentially reassuring label.

Briana's devastation that her doctor has not cared for her well enough to prevent TSW appears to grow only stronger and feel more unjust, when the same doctor denies she has TSW. This imbalance is best described by Fricker's (2007) term 'epistemic injustice' which is "a wrong done to someone specifically in their capacity as a knower" (p. 28). Epistemic injustice is the credibility of one's knowledge being doubted or viewed as inferior to another, which Briana experiences when her dermatologist refutes her belief that she has TSW caused by the topical steroids prescribed to her. Fricker (2007) divided epistemic injustice into two kinds: testimonial injustice and hermeneutical injustice. Testimonial injustice relates to the undermining of the speaker, where prejudice can lead to doubting of the speaker's credibility (Fricker, 2007). Briana uses the following analogy as an example:

If your tire went flat, and you took it to a mechanic, and they said "Put more air in it" you'd probably not question their expertise. However, your tire goes flat again, and again. They say the same thing, "you need more air" and continue to charge you for it. You finally get down on your hands and knees and see there is a leak. So you ask them, "I found a leak. I think that is what is causing the problem." They say, "No it can't be a leak. You just need more air." You desperately try to show them, even point directly at it and they defensively say, "You don't have a leak."... THAT is what it feels like at the moment in a dermatologist's office when trying to discuss Topical Steroid Withdrawal.

This links to Fricker's (2007) idea by illustrating how Briana feels she has a valuable contribution to share with the doctor, but finds her experience and credibility deemed ineffectual. This is significant for Briana as it reflects the unfairness of not being heard and validated and seems to solidify the distress.

Many researchers have studied the concept of epistemic injustice in the healthcare space. Kidd & Carel (2017) argue that ill people are particularly vulnerable to testimonial injustice due to western medicine being task-based, not patient-focused, and measured by efficiency. Greenhalgh (2001) points to the objectification of the body, quantifying of

the results, and focus on pathology that the biomedical endeavour requires of doctors which in turn undermines patient experience. Carel & Kidd (2014) further argue that a credibility deficit of patients is entrenched by the sense that sick people are compromised, therefore unreliable cognitively and emotionally, rendering their accounts suspect. These studies highlight how patient experiences with doctors can feel like being tested, as doctors fit the role of Threshold Guardian. Threshold Guardian archetypes have been described by Vogler (2007) as “beings who try to block your way” (p. 129). Doctors, at the threshold of healthcare can appear to patients as a means of being tested, where their credibility may be scrutinised rather than valued.

While epistemic injustice degrades some personal accounts, epistemic privilege simultaneously esteems others. Carel & Kidd (2014) describe epistemic privilege as “accorded by virtue of their training, expertise or third-person psychology” (p. 534-535). In the situated doctor-patient interaction, medical training and patient experience may compete for equal footing. The individual experience can often involve detailing a complaint to a physician, who in turn translates such experience into medical jargon. Illich (1976) calls this biomedical language, “linguistic mystification” (p. 175). As Foucault (1973) states, the two are “homogenous, but alien to each other” (p. 30). Doctors’ epistemic complaints reveal that patient testimonies contain superfluous remarks or are simply medically irrelevant (Kidd & Carel 2017). Epistemic privilege means that a doctor’s evaluation, in the situated doctor-patient interaction, trumps the patient’s narrative.

Researchers suggest reasons why patient input may be dismissed by physicians. Carel & Kidd (2014) offer several reasons to account for epistemic privilege within medicine: physiological mechanisms are the goal of treatment (therefore first-person accounts inconsequential), medicine is a performance-based culture (therefore patients’ views irrelevant), and this performance is measured quantitatively (therefore qualitative input unhelpful). The views of patients may also be viewed as merely anecdotal, and there are so many – which ones should be acted upon? Foucault (1973) references the “medical gaze” that focuses on observing the pathology of the patient and using analysis to determine disease – again, belonging to the individual is tangential or at best, “in parentheses” (Foucault, 1973, p. xviii.)

Briana describes her initial visit to the dermatologist, years before TSW, as a time of relief. She recalls: *“This dermatologist saw me and said she knew exactly what I needed and that she would fix me right up. My heart wept. I was in so much discomfort I nodded in thankfulness.”* This illustrates how Briana was initially trusting of the medical expert, believing that she knew what was needed to help her, and trusting that what the expert

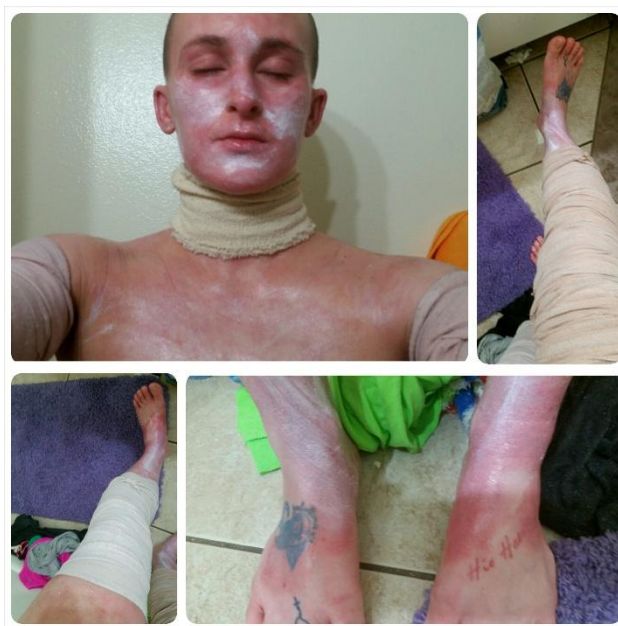


Figure 10. Patient Experience.

knew was accurate. Briana later refers to this initial consultation as a time, *“when hopes were high and knowledge was scarce.”* Thereafter, when Briana confronts the same dermatologist with TSW and finds her beliefs and experience denied, she ceases to trust that the dermatologist *knows*. Therefore, because the doctor knew (in this case, that Briana did not have TSW), no further evidence or patient testimony was required as “the security of knowledge downgraded that of truth” (Illich & Cerella, 2017, p. 288).

Briana details her thoughts on why doctors may not listen to patients:

“Especially with doctors, it never seems to gain stride as to how UNBEARABLE this whole process of speaking to them about RSS can be. Some of them don’t want to believe it; some don’t even care to hear us out since they are the professional, and know all.”

Again, there is the suggestion that doctors already know everything. Briana's words "know all" indicate sarcasm, and perhaps a deeper frustration at her doctors' prejudice, or portrayal of a role that mere patients cannot assimilate or effectively compete with. The experience of being wrongly diagnosed is shared by Ashe (2021) who was unjustly labelled anorexic. Ashe (2021) states: "They did not need to verify their suspicion with an observation. They knew." (p. 260). Ultimately, as Briana feels she has learned, it is not for patients to know what is wrong with them as that is the work of western doctors, for "The facts" of medicine are not discovered but humanly created" (Greenhalgh, 2001, p. 317). It is doctors who produce the diagnosis and compose patient notes, solidifying the evidence of the diagnosis. As Ashe (2021) describes, the patient is constituted by the doctor's interpretation as he "fixes in truth a particular narrative of fact" (p. 257).

Because doctors are epistemically privileged and have the knowledge and power to diagnose, patient experience may be refused if it conflicts with medical decisions. Briana refers to other TSW sufferers who come to the threshold seeking care who find *"they are literally turned away from doctors since they won't take the steroids"* and are similarly denied a diagnosis of TSW. Their testimony and experience, like Briana's, is rejected. Charmaz (2002b) writes of how illness can silence people, or silence may surface from the sense that others know more than them, or they do not understand the illness. Illich (1976) states: "The sick person is deprived of meaningful words for his anguish" (p. 175), such as when doctors deny the patient experience or reinterpret their words. Consequently, patients may feel meaning is removed from their suffering as the search for a cause of illness is subsequently a search for meaning (Bury, 1982). But Briana does not appear willing to accept silence. If she is denied a diagnosis, then she will proclaim ever louder through strong statements in her blog such as: *"Doctors NEED TO LISTEN!"* She warns her readers: *"If your doctor tells you it's fine to keep using them for years on end, THEY ARE LYING TO YOUR FACE!"* Asserting herself gives power to her suffering; her insistence of this self-diagnosed condition solidifies it. "By giving voice to suffering, people make it theirs" (Charmaz, 2002b, p. 310).

The work to appear credible to doctors, and not to feel silenced by them, can require patients to balance their approach and be assertive and smart, but not so much as to be appear overbearing (Werner & Malterud, 2003). Some patients, acutely aware of the doctor's power in the clinical setting fear not only rejection but being given a mental

health diagnosis (Johannson et al., 1996; Werner & Malterud, 2003). Ashe (2021) presents the actualisation of this fear in terrifying proportions when she describes entering a hospital with severe gastrointestinal complaints and is incorrectly diagnosed with anorexia. In her words, “my testimonial integrity vanished, and the entire diagnostic – and interventive – trajectory changed radically and inalterably.” (Ashe, 2021, p. 260). This fear of being labelled mentally unstable is true for Briana also, as she remarks: “*We have to be careful. We need to be smart. We are already perceived as crazy by many in the medical community.*” This trepidation seems to add to Briana’s duty to have her concerns honoured while simultaneously risking judgement and potentially negative diagnostic labels.

For Briana, the grievance of the conflict with threshold guarding doctors is greater than not being heard and having her condition inadequately treated, but simultaneously the injustice of being consigned to elucidate the condition to a largely disbelieving medical profession. She asks her readers: “*Is it fair that we are the ones who have to advocate for ourselves? ...Absolutely not.*” Werner & Malterud (2003) studied the nature of “work” patients did to be believed by doctors and found many considered it strenuous having to repeat themselves, but still not be met with acceptance or respect. For Briana, this extra work involved in her role of advocacy appears to function as both a driver and as a cause of great frustration, which only seems to entrench the injustice. Frustration is evident here when she says, “*We shouldn’t be the ones educating them, arguing with them, being bullied by them.*” Not only are there despair and unfairness here as Briana confronts the epistemically privileged medical profession, but she suggests feeling bullied by them. This fits with Werner & Malterud (2003) whose research of people in chronic pain showed they felt rejected, belittled, and blamed for their condition.

Vogler (2007) advises a variety of approaches for engaging with Threshold Guardians along the hero’s journey. This author suggests one of the best ways is to take on the spirit of the guardian, even taking on their role and ultimately converting them from perceived enemy into an ally (Vogler, 2007). Briana instinctively appears to know this as she plans for how to make doctors an ally: “*Diplomacy, research and accurate-stimulating questions are what we need in order to reach doctors.*” She tells her readers: “*We are all angry (I totally get it, we feel our doctors should be held accountable), but anger will get us nowhere. Instead, use that passion to gather as much research ... and spread it around*

to local doctors.” Regardless of where this quest is taking her, Briana recognises that doctors guard the threshold of medical diagnosis and care, and she must utilise them and their capabilities during her quest. This aligns with Vogler’s (2007) words about Threshold Guardians: “They occupy a difficult niche and it wouldn’t be polite to pass through their territory without recognising their power and their important role of keeping the gate” (p. 129).

Briana appears to attempt differing approaches for how best to work with the threshold guardian doctors: *“I want to work alongside doctors for answers instead of constantly battling them.”* Befitting of Vogler’s (2007) suggestion to assimilate the role of the Threshold Guardian, Briana attempts to appease the dermatologist by an offering in the same language, delivering her dermatologist a peer-reviewed dermatological paper on TSW. Later, the dermatologist admits not reading it and tells her she would continue to prescribe steroids to any patient presenting analogous to Briana. To this, Briana responds: *“THIS is what is wrong with the dermatology world.”* For Briana, there were initial feelings of being silenced when TSW is denied, but to make such effort to enlighten her dermatologist and be met with resistance, is a distinct renunciation of her knowledge and experience. This aligns with Scheper-Hughes & Lock (1986) who describe how patients are “twice victimized, further into the cage of his or her illness: shunned, silenced and shamed *in addition to* being very sick” (p. 137-138). This rejection points to a reductionist view of health and treatment, and again, the patient’s input is relegated to a partial tool for diagnosis, rather than a partner in the doctor’s diagnosis and treatment. This has been referred to as ‘epistemic vice’ which “demands that the doctor suppress evidence whose existence contradicts his narrative, produce evidence whose existence justifies it, and silence the patient – the voice of the aberrant body – whose testimony refutes his” (Ashe, 2021, p. 257).

Briana’s narrative gives insight into her interpretation of the language doctors use. She declares, *“doctors are not the enemy”*, reasoning that a physician who presents as uncaring is likely because, *“most of these doctors are taught to praise this drug — topical steroids.”* This suggests she views doctors as oblivious or simply unfamiliar with TSW. This fits with Jessop (2014) who studied the patient journey through healthcare systems and found “consultants may be unhelpful through ignorance” (p. 112). However, over time her words suggest she is less forgiving of doctors’ unawareness, likening it more to a wilful

ignorance. *"I believe in the dermatology world less and less"*, she states after the dermatologist refuses to read the peer-reviewed paper on TSW. And later she says: *"we are all waving a huge middle finger to a medical system that has forsaken us."* In other instances, her words indicate a perception that doctors do not always speak the truth, such as her reference to *"the intricacies of fact vs. what most doctors say to our face."* This indicates she believes doctors may be deliberate in malpractice and her mistrust appears evident.

Briana innocently views doctors as allies at first but seemingly learns otherwise: *"They failed you. They were supposed to be your friend, the answer to your qualms. Instead, they are the origin of your suffering."* She appears disillusioned by many medical professionals in relation to TSW, particularly the dermatologist who denies that she is experiencing TSW. Fricker's (2007) epistemic injustice highlights the inherent asymmetry between doctor and patient knowledge, and the power imbalance between medical professionals and those seeking their care. Briana is tested by doctors, the threshold guardians on her quest, but knows they guard the way to acknowledgement of her condition and to diagnosis and care for those who succeed her. Therefore, despite her disillusionment and those blocking her way, Briana appears determined to have TSW validated, and she works to make allies out of those guarding the threshold of diagnosis.



Figure 11. Diagnosis Denied

Reflection

Briana writes extensively about medical professionals as she has many encounters throughout the years of her blog. The choice of which ones to include in the data was difficult, but measured, by including narrative that spoke most directly to her sentiments and troubled experiences. Sometimes she appeared passionately infuriated, at other times drawing heavily on optimism, ever hopeful that doctors will reform and TSW will cease to occur. I attempted to use the quotes that revealed a deeper understanding of her feelings, beyond anger and hope, to illustrate how she felt about her treatment, being denied a TSW diagnosis and the struggle of disclosing new information in a relationship with an inherent power imbalance. Briana knew anger would not help future TSW sufferers, so she attempted to stay measured in her approach to medical professionals, yet that anger and grief were undoubtedly still there.

Having been carer and advocate for my son while he went through TSW, this chapter seemed crucial to highlight the additional difficulty that patients with TSW must attend, including a lack of knowledge of the condition, often within the medical professionals

who we turn to for help. To suffer from a debilitating, chronic illness, which is caused by medication, *and* to be denied validation for your illness, is patently traumatic. I reflected on my own experiences with doctors here and my own feelings around treatment and the narrative my son and I were privy to during his time in TSW. I had to remind myself that there are benevolent doctors who can be entrusted to listen and care for us, despite some experiences that suggest otherwise.

Chapter Six: The Shadow – A Boulder of Grief


Admitting you fight daily, doleful demons within yourself,
especially when you've been fighting for so long, is gut-wrenching.
Not when you are supposed to be the optimistic one – the one who is
reliable, and productive, and strong; the person whom you list out
many admirable attributes on your fingers, setting them higher and
higher on a pedestal

- Briana



Vogler (2007) describes The Shadow archetype as representative of fears the hero carries and the hero's undesirable qualities, they are reluctant to let surface. While these hidden shadow elements may be “all the dark secrets we can't admit, even to ourselves” (Vogler, 2007, p. 65), the Shadow can also be “healthy, natural feelings we believe we're not supposed to show” (Vogler, 2007, p. 68). It may also reflect rejected possibilities, life choices denied, “unexplored potential... that goes unexpressed” (Vogler, 2007, p. 68). Jung first introduced the concept of the Shadow as the primitive, uncontrolled part of ourselves (Fordham, 1953). It is the Shadow where we harbour “our ideal personality, all that we are ashamed of, all that we do not want to know about ourselves” (Fordham, 1953, p. 50). However, like all the archetypes, the Shadow reflects internal, personal challenges. While the Shadow harbours repressed aspects of oneself, personal growth comes from balancing and reconciling the opposing aspects of the conscious (self-identified) and unconscious (repressed) (Halfond, 2023). Briana's journey includes coming to terms with her own shadow.

Briana's Shadow, the grief, fear and anger that she tries to conceal with positivity and purpose, is fed by all the losses generated by TSW. She declares loss an inevitability with TSW: “*Loss of self, of control, of love, of your career, of your friends or family... you name it, it's on the table.*” Jakoby (2015) explains that while loss is an elementary

experience for humans, the emotions of nostalgia and grief that come with loss are “modes of continuity” (p. 122) that support one’s sense of identity, relating the past, present and future together. For Briana all the loss she experiences seems to mean a loss of self as she loses elements that constructed her identity, such as performing: *“I lost my career as a performer, as well as the opportunity to be a personal trainer. I had just passed my certification.”* Alongside her career, another aspect of Briana’s identity was her marriage: *“My marriage turned to shambles just when I started to venture into a new job, as well as kickstart my fundraising for my documentary... I felt mentally abused, let down, and sadly, a loss of all confidence.”* This fits with Charmaz (1983) who writes extensively about the loss of self that comes from suffering losses in chronic illness.



Figure 12. Grief.

Briana declares: *“The loss is the most impacting. Loss after loss.”* Ongoing loss has been found to lead to chronic sorrow (Ahlström, 2005; Roos, 2018; Weingarten, 2012). Roos (2018) describes chronic sorrow as “pervasive, profound, continuing, and recurring grief responses resulting from a loss or absence of crucial aspects of oneself” (p. 25). Ahlström (2005) interviewed people with chronic illness and found more than half were in a state of chronic sorrow. Says Briana: *“There are some days I am pitted in sadness and my heart is heavy and my mind is devouring any sort of positivity.”* Briana actively tries to

avoid feeling sorrow, she looks to the positive instead and encourages her readers to do similarly: *“Use it as fuel. Let the anger or loss inspire you.”* But despite her best efforts, at times it appears she cannot escape it.

Boss (2006) describes ambiguous loss as “an unclear loss that defies closure” (p.xvii). While her description is based on more overtly ambiguous losses such as losing a loved one psychologically to dementia, or someone who is physically missing but their existence unknown, I feel this relates to Briana’s experience also as her withdrawal and its subsequent losses, are of an unknown severity and length. Briana thought recovering from TSW would take one year, but her blog runs for nearly eight years and ceases with Briana still not physically healed. Boss (2006) details how ambiguity, coupled with the pain of loss, is immobilising and traumatising, and may lead to loss becoming chronic. Boss & Couden (2002) note that in relation to physical illness, “ambiguity often becomes as debilitating as the illness itself” (p. 1352). Briana seems to affirm this when she declares: *“You become anxious and weary that anything you may do could cause you to regress. It’s tremendous fear. You start to associate your life with “surviving” not “thriving”.”*

The shadow seems to incapacitate Briana and keeps her living in a suppressed state, the ambiguity of her condition omnipresent. As Charmaz (1983) states: “The unpredictable course of many chronic illnesses fosters uncertainty and fear” (p. 174). As Briana describes it: *“There is no set time frame for healing, leaving no light at the end of the tunnel.”* She refers often to being in limbo or living a *“half life.”* For Briana, her condition brings so many unknown factors that she becomes stifled and unable to make real plans or start living her life with real intention. *“A constant building of a life that never gets lived,”* Briana describes it, demonstrating the constant uncertainty that comes with her withdrawal, and her fear that a fulfilling life is so far off.

Briana seems to anticipate having moved on from her grief and can appear disappointed at herself. Her grief, from losses caused by TSW, includes the loss of her husband. Only ten months after her marriage ends, she feels, *“defeated, and even foolish”* when she admits to her followers *“I am not over my marriage.”* Her expectations of herself are further highlighted when she states: *“I should be over this by now. I should be done with hurting, with the past.”* Lefebvre & Levert (2006) argue that the grieving process in chronic illness is never complete. Boss (2006) observes that without closure,

trauma may become chronic. But Briana's words allude to her own belief, reflected in her blog repeatedly, that thinking positively is paramount rather than dwelling on pain and loss. Halfond (2023) explains how the shadow contains repressed feelings that are in opposition to how one chooses to identify. Briana consciously chooses optimism, *"I will incessantly reach for the positive instead of the negative."* Therefore, when negative emotions wash over her, it is as if she feels that all her attempts to stay positive and focus on advocacy for purpose, have failed to lead to a positive reward, such as recovery from her divorce. But what Briana calls dwelling may otherwise be labelled avoidance. Parkes (1998) states that "most people oscillate between confronting and avoiding grief" (p. 1521), and that avoidance may be due to fear of consequences.

At six and a half years in, Briana divulges another aspect of her Shadow is anger. *"Anger is a constant piece that has settled in me, and I keep trying to knock it away, break it into smaller pieces, yet it is this boulder, heavy. So, so heavy. It refuses to budge."* This in turn leads to another realisation that it is not anger at all, but in fact grief. Frank (1992) argues that anger is not only a positive emotion rebuffed by society, but indeed a necessary vulnerability that he likens to prayer or love: "Anger is one privileged moment of opening." (p. 18) This opening of anger for Briana allows her to witness her hidden grief; to admit she still carries love and sorrow for all that she has lost. She becomes aware that anger masks her grief: *"I've wondered sometimes if it really is anger at all but a disguise for something even harder to bear. Grief. It is so much easier to say you're angry."* Kübler-Ross & Kessler (2005) describe grief as like "being lost at sea", whereas anger, aimed at something or someone, may be anchoring and bring structure. Hence, while anger is a natural response to the injustice of loss, it may also be chosen by those suffering, to avoid the more difficult, underlying feelings until they are ready to face them (Kübler-Ross & Kessler, 2005).

While Briana reveals grief and anger are hidden in her shadow, the most powerful aspect of her Shadow may be fear. Briana appears scared to admit the future she hoped and planned for ceases to be a possibility: *"I fear letting go of the life that I thought I was going to have."* Because part of her identity is performing and being physically adept, Briana fears admitting this no longer befits her. Becoming single leads to thoughts of a new relationship, but again fear takes hold when she says: *"Knowing that someone else could potentially leave based on the fact that my condition gets in the way... I fear I would*

not recover a second time.” This fits with the notion that the shadow harbours things the hero does not want to admit, and highlights the gap between her current self, and her hoped-for self. Chronic sorrow is said to form from a “painful gap” between who someone was, who they currently are, who they dreamt of being, and who they may still long to become (Weingarten, 2012). Briana refers to getting back to her former life often throughout her blog, it is only at six and a half years in that she realises she is being held back by her illness and anticipating a future that may never eventuate.

Vogler (2007) describes the Shadow as a function; its actions “create conflict and bring out the best in a hero” (p. 66). Singer (2009) explains that the Hero and Shadow archetypes “are often pitted against one another.” (p. 35). For Briana, the Shadow’s force appears to keep her in her hometown, in an unfulfilling job, in a state of limbo, scared to act and live a life with intention. Referring to her hometown, Briana says: *“Time seems to stand still here. I scribble in my journal about my hopes and goals to get out of here, to run away to a different city and start anew.”* However, she remains here for more than three more years, perhaps secure in a routine. A shrunken, unfulfilling life – but a predictable one. At a psychological level of course, the Shadow is only a part of oneself, therefore, to outrun it is impossible. As Halfond (2023) points out the conscious and unconscious need to communicate to become whole – therefore Briana needs to acknowledge her fears and shoulder them. Jung believed that all individuals have shadows (Halfond, 2023). There can be no shadow without the sun, Jung argued, the mutually exclusive relationship requires we accept both parts of ourselves. Regarding the Shadow, Jung argued, “man is incomplete without it” (Fordham, 1953, p. 50).

Briana acknowledges the Shadow at various points throughout her years in TSW, often reluctant to sit with the emotions for long. When these emotions surface, she has tended to hasten to find the positive, highlighting direction and purpose to help maintain her optimism. This fits with Jung’s analytical psychology where the Shadow is “the opposite of what is consciously valued as good or noble” (Singer, 2009, p. 36). Briana values rising above her suffering and focusing on positivity, not wallowing in the negative emotions of her shadow. At two years in she admits, *“you can only distract yourself so much before it becomes just that, a distraction.”* At four years she speaks of still trying to quieten the intrusive thoughts and *“deafen the dialogue”* with keeping busy. At six years, after having multiple surgeries on her hip and finding herself back to an earlier phase of

TSW, her skin deteriorating, wheelchair bound and reliant on others, she hits another emotional low and discloses: *"I'm not okay. That feels liberating to write."* She details feeling trapped, exhausted and, *"a mess"*.



Figure 13. Surgery.

However, at six and a half years into TSW Briana says: *"I've felt this shift. An alignment, perhaps."* She describes the *"loud silence"* she finds herself in, home alone with her mind wandering, *"churning up the sediment in me, in the things I've been suppressing."* There seems a turning point here where she appears ready to confront the shadow. She says (of the intrusive thoughts she had been burying): *"I finally embraced it one day, and suddenly, I didn't want to run from it. Instead, I've been running towards it."* Ultimately, she lets the shadow out into the light, and it's great unveiling allows her to succumb to a powerful realisation: *"If I wasn't sick, I would be living a completely different life. Just typing that makes me angry. It brings watery eyes and tremors"* and an outpouring of emotions she had kept under wraps until now, is relinquished. She expresses the grief and the anger she has been avoiding, but she declares she feels ready to move on: *"I know I will be making some hard decisions these next few months, but this boulder of grief must go. She has grown like a tumor into the fabric of my life ... I don't want to feel her anymore."*

The multitude of losses can be viewed as a dwindling of the “scaffolding” of one’s sense of identity: the beliefs, hopes, career and partner that help construct the individual’s ‘I’ (Taylor, 2012). However, avoidance diminishes any potential transformation (Taylor, 2012) and Briana learns she must face her shadow head on to overcome its power. The grieving process, while painful, affords the sufferer the power to learn and grow (Lefebvre & Levert, 2006). As Vogler (2007) says of the internal aspects of the shadow, they may be disempowered by “bringing them out of the shadows and into the light of consciousness” (p. 68). Briana’s Shadow appears to lose its power when she takes life into her hands and stops avoiding her deeper traumas. As psychiatrist Parkes (1998) puts it, “once the secret has been shared we no longer need to be on our guard against it.” Briana becomes ready to confront her fears, “*instead of living in fear’s shadow, I decided to take him on.*” Briana appears to realise that her fear has only the control that she affords it. More than three years after she shares her dream to move away from her hometown, simultaneously declaring that she knows she is not meant to be a substitute teacher, a job that she feels “*has sucked my spirit dry*”, Briana finally takes the leap. “*To everything I clutched — my job, my apartment, my unhappy comforts — I let them go.*” After so many years stuck, she uproots herself and chooses travel, diving into the unknown, defying her fears, no longer letting the Shadow take charge.

Jung argued that accepting the Shadow required moral effort, and often letting go of treasured ideals, because such ideals were an illusion or too lofty (Fordham, 1953). Charmaz (1995) studied adaptation in impairment and reveals the tensions between opposing metaphors, such as the ideal body vs the real body, must be resolved to move forward. Frank (1997) writes about illness as a moral occasion, where the sufferer can make choices to become “successfully ill” (p. 144) accepting that challenges are not going away. Briana, at the end of her blog, appears to have accepted her Shadow. The grief, the loss, the fear. In one of her final blog posts, evidently no longer fighting against the emotions she announces: “*So, cheers to the unknown. It’s been a gift to drift along in this nomadic sea.*” If grief is akin to being adrift at sea, Briana has finally learnt to swim.

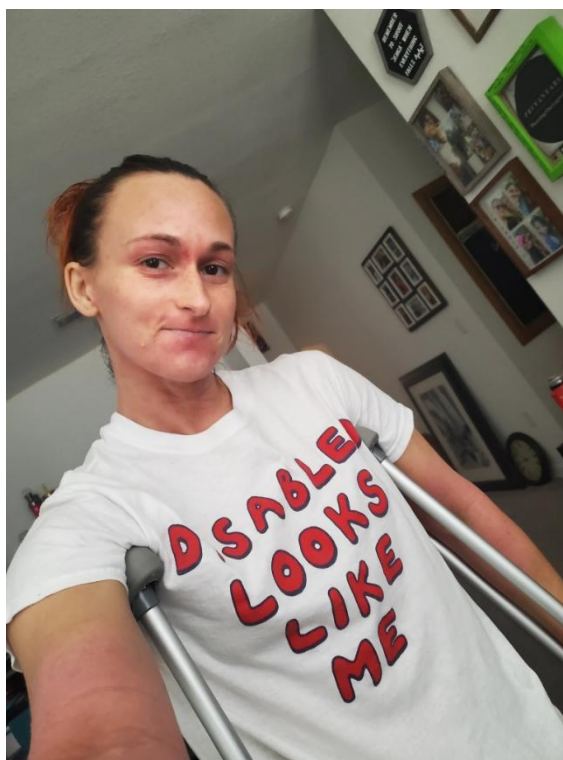


Figure 14. Disabled Looks Like Me.

Reflection

Briana's grief and anger were often masked by optimism, particularly near the beginning of her journey into TSW. She appeared absolutely determined to stay positive and to not let her suffering get her down. At first, I was impressed by her positivity – her physical appearance was very similar to my son when he went through TSW, he was in almost constant pain, and it was so difficult to make him comfortable. Therefore, her attitude to suffering was admirable at times. But I also questioned it having borne witness myself to how relentless TSW was. I think I almost felt a sense of relief when she finally faced her deeper, darker emotions and admitted her anger and grief. Because she had such rage towards medical professionals at times, I was dubious to whether her positive front truly reflected her outlook or was it something she thought she needed to be? Perhaps my relief let me off the hook too because I was certainly not that optimistic during my son's TSW.

Chapter Seven: The Hero Returns – Successfully Ill



“Every year I beg the universe for better health, yet it never comes. This year will be different. I will no longer be asking”

– Briana



The quest comes to an end when the hero returns, transformed by the journey. One may expect of a journey through illness that the end would mean healing, that the elixir is health. However, the journey delivers the hero something more profound and cathartic. As Bruner (2002) states regarding stories of plight, they are about the journey more than the destination it leads to. Vogler (2007) describes the hero, returned after surviving the ordeals of the journey, has “a sense that they are commencing a new life, one that will be forever different because of the road just travelled” (p. 219). The journey also brings the hero a boon or elixir, something they return with to show what they have learned. The hero must shed parts of oneself (Williams, 2019) and embrace others (Smith, 2002). Hartley (2010) argues that understanding the Hero’s Journey outline helps to reframe internal experiences with a mythic perspective. Briana’s story illustrates the hero’s return, as I will detail in this chapter.

Illness, particularly chronic illness, requires renegotiating a new sense of self. In the first few years of the blog Briana seems to cling to the past and her identity as a dancer and performer, hoping to claw back pieces of her former life, seemingly unwilling to accept that she is altered by TSW. This appears evident when she says: *“When we are healed, we will be able to get back to the life we were meant to live.”* Carel (2008) writes from her experience of illness and what she refers to as the taking over of the life of the person, meaning that the healthy person before ceases to exist: “There is only one narrative, one life. And that life now becomes the post-illness...transformed life.” (p. 163). This transformation into a new identity post illness is endorsed by Ashe (2021) following her experience of nosocomial harm with longstanding effects. When Greenhalgh (2021)

asks her about repercussions following the experience Ashe replies, “there are *only* long-term consequences... they constitute and limit my total...experience-in-the-world” (p. 277). These examples illustrate how illness can sever oneself from the former, pre-illness identity, which Briana appears to come to experience.

Later in her blog Briana seems to admit she will not be returning to her previous life. She states: “*I am not the same person I was before I became ill and I need to reestablish that connection with myself.*” Briana seems to feel that her sense of self has been eroded, and she needs to rebuild her identity. This is befitting of Bury’s (1982) concept of biographical disruption where illness interrupts the individual’s assumptions about their identity, body and future. The return from the quest for Briana I believe, heralds a true acceptance of this new, post-illness identity; a willing reconstruction of her sense of self instigated by biographical disruption.

When Briana ends her blog, two months shy of eight years into TSW, she strikes me, the researcher, as evolved from the person who innocently began withdrawal and the blog all those years prior. At the beginning she appears motivated, adamant that she will remain positive, and confident that positivity will buoy her to healing. She consistently writes statements to encourage herself and others, such as, “*turn all the negative into positive*” and “*always see the positive*”. Nearing the end of the blog it becomes apparent this sentiment has shifted: “*Thinking positive thoughts doesn’t outweigh reality. Sometimes, it’s even to my detriment.*” To consider positivity as detrimental is a long way from where she began and suggests a newfound understanding that embracing other, more unfavourable emotions is beneficial, simultaneously admitting clinging to positivity did not bring the salvation she initially hoped. Charmaz (1991) points out that: “Fighting to be positive can exhaust, but living in the reality of illness can free energy for new possibilities.” (p. 178).

The final blog post is short and sweet; there is nothing profound or vain about it, which solidifies, for this researcher, how it heralds a transformation: “*This blog site has been my home for so long. Since I started TSW, Topical Steroid Withdrawal, in 2015, I’ve lent hard on this platform. From sharing my skin to my thoughts, it has been a blessing of a community.*” She follows this with, “*I won’t be posting here at this site anymore.*” The choice of the word “home” illustrates perhaps the safety and comfort she found through blogging but also suggests this is not something she needs further. There is a sense of

peace; there are no words of frustration or fighting anymore. No grandiose adjectives about how “impossible” or “abominable” or “horrific” it all is. The shift appears to be towards acceptance. This fits with Frank (1997) who likens acceptance of illness to peace, where learning to be with illness is not resignation, but honouring the possibility that life can be divergent, as the individual has undergone a shift.

Part of the Hero’s Journey is to experience a transformation. The hero’s journey involves communication between the conscious and unconscious parts of one’s psyche, acceptance of the shadow, and finding wholeness as a more evolved individual (Halfond, 2023). As Alison et al. (2019) describe, “the hero’s outer journey is a representation of an inner, psychological journey” (p. 3). By traversing the quest, having met and incorporated various archetypes along the path to healing, the hero experiences a greater realisation. Briana’s journey, from the outside, involves losing her husband and mentor, her career, her physical abilities, and battling with medical professionals for recognition. Internally, she has taken on grief, anger, loss, lack of confidence, and rebuilt her sense of self. The archetypes of the monomyth live within us and urge the hero to confront the trials of the journey: “Humans cannot become whole; they are by their nature whole” (Smith, 2002, p. 7).

Alongside personal transformation and acceptance of all parts of oneself, the hero must evolve past egocentric ways that prior to the journey were normal, but restricting personal growth (Bray, 2023). The hero initially believes themselves separate from all the archetypes: the villain, the shadow, the mentor – but must surrender and accept them as part of oneself. Briana initially believes embracing positivity is paramount but later learns the value of embracing other emotions and the personal growth that ensues from accepting all parts of herself. According to Jung, the unconscious (shadow) and the conscious (ego) are both essential elements to forming a complete self (Fordham, 1953). Halfond (2023) states that the balancing of opposing parts of one’s personality is required for healthy psychological growth.

Transformation and acceptance take time as suffering may initially appear confronting. Charmaz (1983) asserts that “suffering undermines the self” (p. 169). Cassell (1991) argues that for suffering to take place a threat must exist that challenges the “intactness of person” (p. 26) and that threat, by its very nature, alludes to the future. Briana initially seems to fight hard against the suffering and loss to prevent the erosion of

self and deny the threat TSW poses to her future. But over the years of her blog, she gradually becomes accepting of how TSW has changed her. Near the beginning of her blog she says, *“all those happy memories I’ve been floating back towards will be in my future some day.”* This suggests she still has expectations that her future will flow from her past and that she feels meant to carry on the future she had planned. Again, this is befitting of biographical disruption, described as the interruption of an individual’s expected life trajectory due to chronic illness, challenging previously stable routines, roles, and self-identity (Bury, 1982). Later, at four years in she says, *“it is miraculous to see how far this journey has taken me. I am not the same person.”* This reflection demonstrates the beginning of her acceptance that TSW has deeply transformed her. And at the six-year mark she reaches a pivotal point where she admits defeat, apparently surrendering to all the grief and loss. This is when she confronts the Shadow as detailed in the previous chapter; this is when the resurrection begins.

The resurrection is an important stage of the Hero’s Journey. Vogler (2007) describes this as a climax, where “a new self must be created for a new world” (p. 198). As the ordeal, detailed in the previous chapter reflects the hero’s final inner test that plants a seed of transformation, the hero is pushed to the brink in a final test at the resurrection. Briana appears to reach this moment shortly after six years into TSW, after multiple surgeries on her hip, causing her TSW to flare horribly. She is in a wheelchair reliant on others to care for her; this is the point where she admits she is not okay. *“I want to be left alone. Healing starts with getting at your core and fixing from within. It usually involves crying and purging, but with constant babysitters... I feel like a constipated dam of tears.”* Vogler (2007) describes the climax as a “final purging and purification” (p. 197), where the hero may experience their final confrontation with the shadow, or villain, which brings catharsis. Williams (2019) uses the Hero’s Journey as a model for individuals in therapy coming to terms with personal challenges. He describes the resurrection as an event that is feared by the client, but highlights when dependence shifts to responsibility, and clients transition out of avoidance and act (Williams, 2019). The resurrection is a chance to show that the ordeal created a shift; that the hero has transformed. Briana seems to reach this point when she eventually gives up her job and travels overseas. Taking life by the reigns, she says, *“I took every signal and sign from the universe and went.”*

Transformation from suffering has been researched by many. Taylor (2012) studied individual experiences of transformation through suffering, where people maintained positive changes to their lives and attitudes following traumatic events. The author suggests that transformation may occur because trauma acts to dissolve psychological attachments, where individuals accept their predicament and surrender ideals, hopes and ambitions (Taylor, 2012). The individual's self-image, scaffolded by a partner, job, status, beliefs, falls away during suffering, creating space for transformation (Taylor, 2012). Briana learns to accept she is not a married dancer soon to become a personal trainer, which is how she seemed to identify when her TSW began. Instead, she says: *"I'm starting to realize that maybe TSW gave me more than my former life could ever have given me."* This suggests gratitude for the self-growth that came through suffering, where she learns to give space to grief and anger as well as positivity. She points out: *"We are meant to embrace all emotions. We must acknowledge them all because that is where compassion lives. Where growth lives."*

This growth that Briana mentions appears to be found through allowing space for a variety of feelings and experiences, individual to the hero. Frank (1997) reflects that one's life, and one's story "can only be one's own" (p. 137). While embracing an array of emotions, Briana seems to realise that this assortment of feelings is not only valuable, but necessary for growth. This fits with Jung's argument that we are not complete without a shadow (Fordham, 1953). In her second last blog post, seemingly renewed from acceptance and travel, she says: *"I know that I will be okay. It doesn't feel like it at the moment, but I know I will be... I am now 7.5 years into TSW and what I have endured over those years has been rough. Knowing when to show myself grace is key in all of my healing."* The words "all of my healing" suggest healing is bigger than her skin condition. Briana seems aware that she has deeper, more complex parts of herself that require healing also. While travelling, she refers to an expedition: *"Usually an expedition is more than one person, but I feel like various parts of me trekked along – the ones that feel lost and afraid, as well as the ones that are excited and ready."* This appears to highlight the complexity of healing and personal growth that she is experiencing, and her own awareness of her emotional intricacies.

Seven years into TSW, Briana chooses to uplift herself and travel overseas. After years of sedentary life in her hometown, she realises she must actively create change: *"I*

could not, and cannot, keep drowning in the deep end of my own life.” Ross (2019) studied women’s experiences of transformation and integration following travel. She found that the return from travel marked the transformation but was only the halfway point, as integration of what was discovered from the transformation was required to successfully transform into the complete embodied hero (Ross, 2019). Ross (2019) reveals how old patterns need to be broken, and old identities surrendered to make way for the new, “aligning with one’s integrity” (p. 507). Ross (2019) concluded that integration was complete when the individual fully embodied the transformation, and a difference no longer existed between the actual and ideal selves. This fits with the absorption of the Shadow which harbours our ideal selves – acceptance of the Shadow means giving up these ideals (Fordham, 1953). This also aligns with Briana’s move to give up substitute teaching and start afresh. She describes her teaching role as *“a job that is neither a calling nor vocation.”* Therefore, to relinquish it suggests she is aligning with her integrity and letting go of parts of herself that do not align.

Briana comes to terms with the longevity of her illness and stops waiting for healing. Frank (1997) suggests that to be successfully ill requires accepting that the challenges are not going away. The term “successfully ill” recalls Sontag (1978), who argues that metaphors put pressure on sufferers to perform, such as to fight against illness. But to be successfully ill, requires acceptance and grace. Says Briana, *“The grace I show others I must learn to show myself”*, illustrating her insight into the expectations she had placed on herself to fight illness and stay positive while doing so. Does it also mean to triumph over illness, or find happiness despite adversity? Frank (1997) continues that, “each must discover his or her own terms of success” (p. 137). Briana appears to learn to lower her expectations: *“Instead of focusing on all the things I’m juggling, I need to tackle only a few things per day and call it a success instead of beating myself up.”* This is supported by Hartley (2010) who argues that a successful return by the hero means “finding our own authority and our own personal myth” (p. 235).

Carel, Kidd & Pettigrew (2016) argue that you cannot know how an event will transform you, therefore Briana’s initial expectations of being healed and returning to the life she had planned are normal, innocent assumptions. These authors reason that transformation through illness is both epistemic and existential – epistemic because one can only understand the experience of TSW by going through it, and existential because

one cannot know prior how such an experience will change the individual (Carel, Kidd & Pettigrew, 2016). Briana appears to grow, to process these changes, and in time accept that she has been transformed by TSW in a way she could not have anticipated. Accordingly, her actions and future must adapt similarly. Williams (2019) points out that taking on challenges individuals were unaware they would be expected to, or were capable of, acts to “unknowingly disprove previously limiting beliefs about themselves” (p. 525).

Briana’s transformation begins when she starts to embrace her Shadow and allows suppressed emotions to surface at six and a half years in. Her blog posts are few from here on, the next one, just shy of seven years reveals further deep purging of emotion after watching “Spiderman: No Way Home.” The blog post is entitled “TSW: No Way Home.” While explaining that even Spiderman can struggle to hold it together, Briana likewise says: *“I found myself this past year having a hard time holding it together.”* She appears to still be processing her grief here: *“Crying has been second nature. Everything in my life keeps reminding me of what I don’t have...Healing toys with my spirit. The limbo of it all. A constant building of a life that never gets lived.”* As detailed in the previous Hero chapter Briana expresses a connection to Spiderman, and this is especially evident here as she resonates with a pivotal point that Spiderman faces. However, she ends with a sense of renewed hope, again resonating with her cherished Spiderman: *“Spiderman’s story is nowhere near over at the end of the movie. It is just beginning some could argue. I’m right there with you, Spiderman.”* This materialises as a vital moment – Briana seems like she is ready for a new beginning.

At seven years in, Briana emerges ready to “shed the personality of the journey” (Vogler, 2007, p. 198). Williams (2019) states that the hero sheds the aspects of their old self that no longer serve them. For Briana, her new identity steps forth as she gives up her job and apartment, throws caution to the wind and travels overseas: *“It was completely uncharacteristic of me to just unravel my life, especially with my health on such an uneven foundation. But I was suffocating. I didn’t recognize my life anymore.”* For years Briana has said she wanted to leave her hometown and finish substitute teaching, and here she achieves it. Regarding processing of grief, Kübler-Ross & Kessler (2005) state: “Little by little, we withdraw our energy from the loss and begin to invest it in life” (p. 28). Briana has spent so long waiting to get well, waiting to start life again. It seems the real

transformation comes when she accepts that her life is happening presently, and she must choose to stop waiting and begin to invest in it. Reflecting on things, Briana says:

"I took a teaching job, not because I loved it, but because I had to survive. I did it for 5 years and as each year passed it killed me more and more. I couldn't do it another year, not to my body and not to my soul."

The career she had taken "to survive" finally is relinquished to make room for something of her choosing.

The Hero's Journey ends with the hero returning with an elixir or boon, something to show for the toils. Briana's elixir may be simply acceptance that her life is occurring now, and she must stop fighting against the loss and ill health and choose to be present in it. Says Briana, while away travelling: *"I haven't been able to just be since my health took control."* Jessop (2014) suggests that the lasting boon may be learning to live with illness. The boon has been said to change the hero, leaving them more aware, more in touch with the world. Vogler (2007) asserts that the boon may be the "elixir of experience" where the hero is simply wiser for the adventure. Psychologists Alison et al. (2019) studied the metamorphosis of heroes and declared the boon to be "the gift that separates the hero's journey from simply being a test of personal survival" (p. 4). Briana did not just survive TSW, but she appears to have evolved because of it.

In one of her final blog posts Briana declares: *"Every year I beg the universe for better health, yet it never comes. This year will be different. I will no longer be asking."* There is ambiguity here regarding what it means to be no longer asking. Does it mean that she will not be seeking permission, or being passive in her healing because she intends to take control? Or does it mean she will not be attending to the attainment of health as priority anymore, or focusing on ill health at all? I believe it is the former as she also says: *"My health, still a hurdle, would not stop me. Now, she has tried...She can scream and wail and throw off my plans, but she will not hold the reigns."* While Briana may struggle to control her health, this suggests that she can control her life otherwise, her plans, and her future. As Frank (1991) suggests, "The victory was not over the disease but in the willingness to live otherwise." (p. 136).

Frank (1997) says: “If success is to be defined at all, it can only be defined as living a story that finally can be told.” Briana ends her blog, her story of nearly eight years enduring TSW, of a life weaved within and around illness. As the hero of her own quest, she returns from the journey renewed, ready to live life on her own terms. Charmaz (1995) asserts that “surrendering to the sick body means the end of the quest for control over illness” (p. 659). Briana’s quest ceases to be about controlling illness and more about living a life despite it. Whether Briana’s elixir is acceptance, moving forward and creating future plans, appreciation of suffering and difficult emotions or diving deeper into advocacy of TSW, is not entirely clear or necessary. Hartley (2010) used the hero’s monomyth as a framework to guide understanding of her own personal journey through mental illness, and found that for modern-day heroes, the prize brought back on their return, is their story. Briana’s journey, at least the part given to blogging, ends here. And Briana returns successfully ill perhaps, with her story now told.



Figure 15. Successfully Ill.

Reflection

I wrote this chapter last. While positioning the earlier chapters, I had in my mind that this chapter would detail her becoming well. Of course, I came to discover that she was not returning to health but rather returning to life; she had finished waiting to get well. I suppose I was hoping for society's preferred restitution narrative also. Briana suffered so much and gave so much of herself for the greater cause, I was hopeful to see her healed.

From my own experience navigating TSW with my son, I can attest to feelings of anger and grief. I held anger towards the dermatologist who prescribed my son strong steroids without explanation or warning; and I had grief that my son spent much of his intermediate years bedbound. These are emotions I moved through, leaving me with acceptance. I am grateful for the research I discovered during this process which guided me in understanding iatrogenesis and epistemic injustice to uncover the meaning of Briana's narrative, but also to uncover some of my own journey.

Discussion

This discussion will re-introduce the Hero's Journey framework and consider how it functioned to highlight elemental aspects and archetypes of Briana's story, in particular the Call to Adventure, Threshold Guardians, Transformation and the Return. Discussion will then cover the methodology of Briana's narrative meaning-making, regarding Narrative, Blogging, Photographs and her positive mindset. Lastly, alternative narrative frameworks will be covered along with limitations of the Hero's Journey.

The Hero's Journey

Frank's (1995) Quest Narrative, along with Briana's own reference to heroism formed the initial connection to The Hero's Journey (Vogler, 2007). From Briana's blog it emerged that her relationships, sentiments and experiences while suffering aligned with the recognised path of the Hero's Journey outline for stories, as described by Campbell (2008) and Vogler (2007). Campbell's (2008) original heroic arc emerged through interpreting western myth. Vogler's (2007) adaptation recast the heroic narrative specifically for writers and filmmakers, with filmic examples throughout. Given the initial encounter with Briana was through film, Vogler's (2007) western Hero's Journey framework transpired as well-suited to interpret an American writer and filmmaker's narrative.

Various elements and archetypes of Briana's narrative surfaced, and the chapters produced in the Data Analysis were formed from those emerging details. The Hero's Journey does not require that all archetypes be represented or all events (Vogler, 2007). Therefore, the aspects and archetypes that emerged from the data became the focus. For example, there are other archetypes on the Hero's Journey, such as Trickster and Shapeshifter (Vogler, 2007) which did not emerge from the data and were therefore not included in the analysis.

Viewing illness as a quest has been found to be helpful in various settings (Bray, 2023; Lamprell & Braithwaite, 2016; Hartley, 2010; Jessop, 2014; Williams, 2019). Hutchinson (2000) suggests that the Hero's Journey may be the most appropriate model

to turn a story into something meaningful. Rogers et al. (2023) found that individuals viewing their lives as a Hero's Journey can give those lives deeper meaning. Subsequently, viewing Briana's life as a Hero's Journey, and illness narratives generally offers the chance to witness greater meaning in the narrative.

Call to Adventure

While the Call to Adventure summons the hero to begin the journey, the notion of iatrogenic harm felt fitting as the introduction for Briana, as the sudden awakening for her is the realisation that she has a new condition, brought on by her eczema treatment. Vogler (2007) describes the Call to Adventure as an offence, or wrong to be set right. For Briana that wrong materialised as the realisation of iatrogenic harm. Illich (1976) describes iatrogenesis as structural harm that forms from medical institutional expansion and the expropriation of health.

Positioning the beginning of Briana's journey as her initial knowledge of being hurt by medicine, gave space to highlight the shock and betrayal she experienced, *"I trusted my doctor since she was the expert. My life drastically changed for the worse because of a trusted expert."* This brings to light the notion that not only do we, as a society trust medical professionals to care for us, but they are also afforded autonomy and authority over our care. Illich (1976) posited that individuals may cease to understand or care, their dependence on intervention leads to impoverished social and environmental supports and decreases the individuals' coping mechanisms. Greenhalgh (2001) describes this loss of autonomy as "ripping the right to know that body out of the hands of the person inhabiting it" (p. 35). Becoming dependent on the technical side of medicine can diminish individuals' autonomy of their own health (Illich, 1975). Briana recalls how she entrusted her doctor to have autonomy over her care, with regret: *"I should have freaked out"*.

Mount (1993) describes how sick individuals, existentially vulnerable, seek medical assistance in hopes of healing, "in confidence that at least they will not be harmed because of the tradition of the healing profession" (p. 59). This highlights the trust society affords medical professionals, and the subsequent depth of betrayal at the realisation that they instead have been harmed, just as Briana experiences at the Call to Adventure.

In New Zealand, research reviewing healthcare harm concluded that increased healthcare visits coincided with an increased likelihood of harm (Leitch et al., 2021). This fits with Illich (1976) who argued that the industrial complex of western medicine becomes more harmful, the more it grows in capacity and reach. This is further supported by Russell (2019) who reasoned that the pattern of ‘scaling up’ in medical practice ultimately leads to an increased likelihood of being harmed, without increased benefit. Kligman & Frosh (1979) argued that doctors had a tendency to prescribe stronger potency topical corticosteroids (TCS) that came with increased risk, without increased benefit. Ashe (2021) refers to contemporary medicine as bound by the limits of the technical, insisting that iatrogenic harm may only spiral into iatrogenic violence; “that violence in medicine is only the inevitable derivation of a technic medicine whose corrupted seed could hardly sprout otherwise” (p. 256).

The American healthcare system that Briana experiences and references is a predominantly privatised model where she pays for medical insurance, medical appointments and prescriptions. Shaped by market incentives, decisions within the American medical system may be financially driven, as Briana suggests when she states: *“Doctors are going to continue to ruin lives because of a dollar”*.

In Aotearoa New Zealand we benefit from a predominantly public healthcare system where doctors are less financially motivated or incentivised. Research found patient harm in Aotearoa New Zealand was “common” and approximately 20% was preventable or potentially preventable (Leitch et al., 2021). Varley & Varma (2021) recall that iatrogenic harm disproportionately burdens minoritised populations subjected to racial and colonial systems. While harm minimisation is presented as a universal ethical safeguard within biomedical research, Māori communities have not experienced a corresponding reduction in medical harm (West-McGruer, 2020). Further understanding of iatrogenic harm, and the underlying colonial and neoliberal conditions that may perpetuate it, has particular potential benefit for Māori, Pasifika and minority groups.

Threshold Guardians

Framing Threshold Guardians as archetypal medical professionals was beneficial in highlighting epistemic injustice. Patient experiences of medical professionals include

feelings of ignorance (Jessop, 2014), rejection (Werner & Malterud, 2003) and feeling disregarded (Johannson et al., 1996). Briana experiences similar as her dermatologist refutes that she has TSW. Carel & Kidd (2014) argue that medical professionals privilege empirical, impersonal data over personal accounts. Furthermore, Greenhalgh (2001) suggests patients may be treated as objects, where their subjective knowledge is silenced.

Vogler (2007) points out that Threshold Guardians “occupy a difficult niche and it wouldn’t be polite to pass through their territory without recognising their power and their important role of keeping the gate” (p. 129). Briana appears to acknowledge this position as she offers a research paper on TSW to her dermatologist yet is met with disinterest. This supports the epistemic privilege of medical authority who have the “power of decision” to decide when sufficient evidence is presented and a matter is settled (Carel & Kidd, 2014). Ashe (2021) argued that this privileged testimony acts to silence the voice of the patient, replacing their self-knowledge with that of the doctor, whose knowledge credibility is favoured. Briana reiterates this injustice throughout her blog when she sarcastically refers to how some doctors consider that, “*they are the professional, and know all.*” The act of inscription by a doctor when diagnosing a particular condition, solidifies the condition by their privileged epistemic position, fixing it in truth within the medical records (Ashe, 2021). This is befitting of a Threshold Guardian who keeps the gate and decides who passes through the threshold.

This imbalance of power and credibility of knowledge is reiterated in the language of addiction and phobia as seen in TSW literature (Cotter et al., 2022; Furue et al., 2003; Ghosh et al., 2014; Hajar et al., 2015; Hwang & Lio, 2022; Tan, 2021). It further highlights the inequitable position of labelling illness that doctors are afforded, and patients denied. This befits the pathologisation discourse that doctors of biomedicine often employ, attributing disease labels to patients (Greenhalgh, 2001). The very label Topical Steroid Withdrawal (TSW) specifically names withdrawal, and withdrawal as a term implies addiction. Indeed, dermatologists advocating for further recognition of the condition introduced the less pathologised term Red Skin Syndrome (RSS) (Rapaport & Rapaport, 2006).

Furthermore, phobia, as used in the literature in “steroid phobia” (Cotter et al., 2022; Furue et al., 2003; Ghosh et al., 2014; Tan, 2021) regarding an aversion to topical steroids,

implies an “irrational fear”, a striking example of epistemic injustice where patient credibility is eroded, simultaneously heightening the testimonial credibility of the doctor. The label of addiction as in Topical Steroid Addiction (TSA) used frequently in the literature (Andrus, 2023; Fukaya, 2014; Juhasz, 2017; Kligman & Frosch, 1979) may delegitimise the patient experience by instead implying moral weakness, consistent with definitions of addiction. Not only may TSW sufferers experience a debilitating iatrogenic illness, in addition they may experience epistemic exclusion as their experience is rejected, and furthermore they may find themselves labelled as having an addiction or phobia. As Sontag (1978) reminds us: “Nothing is more punitive than to give a disease a meaning” (p. 58).

Greenhalgh (2001) reminds us that doctors may use labels as a function, and that truth is produced by “what is discursively possible” (p. 28). The inscribing of patient notes by a doctor means their interpretation is a production and restriction of truth about that patient (Ashe, 2021). This inscription is made operational by the privileged epistemic position of the doctor (Ashe, 2021). This action affords them the power to define what constitutes illness, who is ill, and what shall happen to those individuals (Illich, 1976).

Transformation

In the beginning, Briana appears to view her illness as an interruption, where life plans have been thrown by TSW, but she maintains an expectation to return to full health and continue life as before: “*When we are healed, we will be able to get back to the life we were meant to live.*” Initially, transformation appears to not be anticipated, only healing. However, as illness trajectory extends in length and life disruption, she begins to realise there is more to uncover than wellness. When she says: “*Everything that happens to us gives us choices and allows us to transform into the person we want to be*”, and “*healing is a journey*”; a new expectation of personal growth and transformation begins to emerge for Briana. While transformation has been a criticised assumption in illness narratives (Woods, 2011), after the loss of her husband, career and intended future, Briana consistently references her aspirations for transformation.

While loss of self is significant in chronic illness (Ahlström, 2005; Charmaz, 1983), the Hero’s Journey framework allowed for a deeper analysis of The Shadow archetype

which harboured not only loss for Briana, but grief and anger. To grow and transform, Briana seems to learn that she must attend to these emotions and accept them, to move past them. Avoidance of one's predicament has been found to reduce potential transformation, whereas surrender leads to acceptance (Taylor, 2012). Briana appeared stuck in purgatory, waiting to become well so she might carry on with life. She likens her experience to Tantalus, who is destined to a life of torment with food and water permanently just outside his reach. Says Briana: *"Much like going through TSW, everything seems just out of reach."*

Ross (2019) describes how transformation comes after one must "break out of a dysfunctional self-preservation pattern and enact a healthier behaviour" (p. 507). Briana breaks free of self-preservation, gives up her job and moves away from the city she declared for years she desired to leave. As Williams (2019) describes, the Hero's Journey requires that in addressing challenges, personal change is ultimately necessary. The Hero's Journey necessitates confronting the Shadow, accepting trauma, and making decisive action to move on. Williams (2019) references the road back as signifying that the avoidant individual who began the journey, ceases to be. Briana acknowledges the transformation of TSW sufferers: *"We are definitely changed by it, good and bad."*

The Return

Viewing Briana's narrative as transitioning through the Hero's Journey resisted the closure that typically comes with healing as the culmination of the journey. As Briana says at the end of her blog: *"Every year I beg the universe for better health, yet it never comes. This year will be different. I will no longer be asking."* The Return, for Briana heralds a rejection of the restitution narrative; she ceases waiting to be healed. Frank (1997) proposes, "being successfully ill – begins by resisting biomedical rhetoric" (p. 144). Individuals may learn to resist the restitution narrative that society expects and choose acceptance and transformation. As in the case of iatrogenesis, sufferers may counter the harm by refusing closure, linearity or biomedical rationality (Varley & Varma, 2021). Briana's narrative resisted the biomedical discourse that denied her illness, or any wrongdoing and shared her own truth.

Frank (1997) reminds us that learning to live with illness is not resignation. While the restitution narrative may encourage a focus on wellness, transformation comes perhaps from realising there is more to life. Hartley (2010) states: “A successful hero’s return requires finding our own authority” (p. 235). Briana continues to advocate for TSW and her Return, while not full health, is a return to a life of her choosing.

Narrative

The Hero’s Journey arc highlighted how Briana’s narrative brought meaning to her suffering, and advocacy gave her purpose. Individuals construct narratives to help them come to term with illness (Charmaz, 2006). Scarry (1987) argues that as pain and suffering act to unmake the world, storytelling becomes an act of remaking and rebuilding the world. Briana’s blog demonstrates how she used narrative to rebuild her world. As she encourages her readers: *“We will find our purpose and reason for this suffering. Use your story to inspire others and to spread awareness.”*

Narrative acts to order our worlds and produce ways of knowing (Smith & Sparkes, 2006). Briana was able to use her blog as a means of contesting the biomedical stance that denied her illness, where she instead constructed her own reality where her suffering was recognised and her experience validated. As Charmaz (2002) describes: “By giving voice to suffering, people make it theirs.” (p. 310). Briana takes back control by denying biomedicine’s epistemic exclusion of her experience and giving voice to TSW sufferers. When she states: *“Topical Steroid Withdrawal is overlooked by so many doctors that it’s horrifying”*, positioning her lived experience as denied by doctors.

Frank (1998) describes telling stories as a technology of the self, an approach to speaking one’s truth where the narrator can voice self-knowledge, reaffirming legitimacy. Frank (1998) continues to say that personal narratives act as care for the self, “reclaiming a voice that bodily trauma and institutional treatment have caused to be silenced” (p. 336). This fits with the idea of biographical disruption, where Bury (1982) argued that responding to disruption leads to a mobilisation, where the individual makes steps to begin adaptation.

How one lives their life and how they choose to tell it are not separate events (Bruner, 2004). Therefore, by writing about reclamation and rebuilding of a life during illness

solidifies the act. Charon (2001) identifies that for ill people narration is a therapeutic act. Furthermore, acceptance of an altered identity fosters hope that one can move forward confident in a new identity. As Pennebaker (2000) puts it, “translating distress into language ultimately allows us to... move beyond the experience” (p. 13).

Briana’s Blog

While Briana may have created her blog to support others and advocate for a poorly understand illness, blogging may also act as a means to be seen, to perform and continue to be relevant. Blogging about illness has been found to decrease feelings of isolation and increase one’s sense of purpose (Ressler et al., 2012). Briana’s blog seemed to grant her a purpose to advocate for her condition, but perhaps also to recreate her own identity and community through narrative. Blogs reflect the social nature of illness and the “relationship of the author with the world” (Heilferty, 2010, p. 947). The Hero’s Journey highlighted meaningful relationships Briana formed, such as with her husband and her dermatologist, that had powerful ramifications for her journey through TSW.

The linear nature of the Hero’s Journey framework highlighted transition across time for the hero, including how Briana identified as a performer. The blog seemed to allow her to continue to perform and bear witness. Frank’s (1995) notion of the communicative body, one that desires to be productive befits Briana as she was able to be a body for other bodies. Frank (1995) considers it an “ethical choice to place oneself in a different relationship to others.” (p. 37). While Briana is familiar with performing in a strong, confident physical form, through the blog she performs conversely in an ill, vulnerable form showcasing her body for a different kind of performance – of self-expression and vulnerable authenticity. Regarding vulnerability, Briana states: *“It’s a... ruthless truth and it’s actually one of the main reasons I write and have made videos. You have to take off the heaviness sometimes and just show up — with candor, with tears, with authenticity.”*

Photographs

This vulnerability is evident in the photographs she shares, detailing the physical suffering in vivid form. This fits with Murray’s (2015) “representational agency”, where

bloggers have the power to curate their narratives and define themselves by their choosing. The timeline of photographs showcasing Briana's shifting appearance befitted the Hero's Journey, demonstrating progression. Given her initial belief that she will be healed in a year, her photographs that show the chronic suffering for many years beyond this demonstrates the tenacity and dedication of the hero.

Spence photographed her journey through the clinical reductionist approach to breast cancer that she felt violated her and used her photography violently back at medicine (Bell, 2002). Photographs may defy the passive patient role; Briana becomes an active participant in her narrative of suffering; resisting being silenced by medical discourse. While western medicine often reduces people to sick bodies, photographs contest this by showing the human, lived experience (Bell, 2002). Photography has often been used coercively, to objectify women (Bell, 2002). By photographing herself, Briana has the power to wield the camera at her own choosing, defying being shrunk by illness, resisting shame, disgrace and blame. Tiidenburg & Cruz (2015) argue: "Selfies can be celebrations of corporeal bodies or knowledge devices through which variations of corporeality are spotlighted, accepted, internalized" (p. 94).

Positive Thinking

Briana appears to value having a positive mindset to support her in enduring suffering. She seemingly wore her positivity as armour to bolster her through hardship, often telling her readers: *"Try to stay positive. Even when you're tired and feel drained, happy thoughts help you through."* This recalls McAdams (1993) who writes about narrative tone, where an author can choose to write optimistically regardless of circumstances. Ehrenreich (2010) considers positive thinking an American ideology, despite comparatively low happiness rankings and America's consumption of two-thirds of the world's antidepressants. The practise of positive thinking has worked to convince people that maintaining a positive mindset can increase their chances of a positive result (Ehrenreich, 2010). Briana, reflecting on her positive outlook, says: *"Being positive has always been an ingrained trait."*

Charmaz (2002a) considers part of what constitutes the self are our habits, including "habitual modes of thinking" (p. 315). During illness, individuals may find

themselves changing habits (Charmaz, 2002a). For Briana, her positive attitude is significantly challenged and she later admits: *“Thinking positive thoughts doesn’t outweigh reality.”* Appreciation of the value in giving attention to other, less positive sentiments brings a realisation for Briana that focusing on positivity may not have always benefited her. McAdams & McLean (2013) refer to narrative identity as one’s “evolving life-story” (p. 233). This evolution for Briana involves extending herself grace, letting go of the positive façade and admitting to other emotions. The Hero’s Journey was a useful tool to highlight this evolution as the hero must face the Shadow, the less favourable parts of oneself, and witness what lies beneath the positive exterior.

Alternative Narrative Models

The Hero Quest narrative was chosen for analysing Briana’s blog over other narrative models. Frank (1995) offers three different types of narrative in illness, which he suggests are told “alternatively and repeatedly” (p. 76). These are the Restitution Narrative, Chaos Narrative and Quest Narrative (Frank, 1995). Briana’s experience did not speak to the Restitution Narrative which moves towards healing and highlights a return to the pre-ill identity. The Chaos Narrative also felt inappropriate as Briana maintained purpose and order through her journey by making a documentary and dedicating herself to advocacy. Her narrative revealed personal transformation and meaning from illness, unlike the distress and lack of order and hope present in the Chaos Narrative (Frank, 1995).

While Frank’s (1995) Quest Narrative is similar to the Hero’s Journey (Vogler, 2007) Frank produced his as a descriptive way to explain how people tell stories of their lived experiences; Vogler’s (2007) framework is symbolic and rich in archetypes and stages. Given Briana’s advocacy, Vogler’s (2007) outline which includes an ‘elixir’, or offering of newfound wisdom, to bring back for the community befitted Briana. Furthermore, her blog repeatedly references filmic Superheroes and heroic discourse as she likens herself to a hero and her story to being on a journey.

The Hero's Journey Framework Limitations

Despite its utility, there were limitations to the Hero's Journey framework. One such being an overly linear arc where the orderly cohesion of the stages of the journey may be viewed as compartmentalising and taking a continuous, messy experience of illness and translating it into something discrete and sequenced. Briana experiences emotional turmoil, but often resurfaces with determination, before suffering emotional lows again. With nearly eight years of blog there are an array of moments of solitude, sadness, gratitude, loss, and everything in between repeatedly throughout the timeline of the blog. but any chaos appeared masked by the heroic arc.

While case study has various benefits in methodology as detailed previously, it contains inherent limitations such as cultural restrictions and an individual viewpoint. In Briana's case, being a white American woman, limited the narrative culturally and restricted the data to a specific western voice. Given the Hero's Journey framework is culturally embedded it may reinscribe dominant norms of western culture, such as the lone hero, or fail to represent collectivist cultures where meaning-making (and consent) is communal (West-McGruer, 2020). Medical harm often affects minority communities foremost (Matthews, 2017; West-McGruer, 2020). Further research may involve communities to study how normative medical practices affect indigenous cultures, such as Māori. Alternative narrative frameworks may better reflect the illness narratives of other cultures and function to extend epistemic inclusion of the lived experiences across cultures.

Discussion Summary

Although there were limitations, the Hero's Journey framework was a beneficial tool for analysing the blog bringing significant insight to the journey Briana took through TSW. Studying the transformation that came as her narrative evolved over nearly eight years highlighted how her focus shifted from vigilant positivity waiting for cure, to a balanced redefining of what illness meant and where it took her. Briana's narrative, encounters with threshold guardians, her ill body laid bare and her positive outlook revealed themselves as testimony to a hero called to adventure, who returned transformed.



*“Looking back to Day 1, when hopes were high and knowledge was scarce, it is
miraculous to see how far this journey has taken me.
I am not the same person. Sometimes that makes me sad because it means I lost a life that I
vigorously worked towards. And sometimes I am unfathomably grateful for all the beauty I
gained from sitting at rock bottom.”*

— Briana



Conclusion

When I began this research journey, I had a drive for justice and a strong desire to make amends somehow, and to increase awareness of TSW. Vogler's (2007) description of the wrong to be made right seemed to fit my personal Call to Adventure. Embedded in my own experience and Briana's narrative, was the call for me to respond to what I had witnessed.

My response took me down a research path that led me to discover vital background research, that brought a greater understanding of structural inequality that feeds into our health outcomes. Research into epistemic injustice and iatrogenic harm laid the foundation of what Briana's narrative highlighted of the broader social context. This demonstrated, for me, how desperate the level of iatrogenic harm is, and how little we value the lived experience and patient voice. Considering that indigenous populations in colonised countries have significant concern regarding medical harm and their voices being unheard (Penney et al., 2011; West-McGruer, 2020), future research would do well to attend to such cultural marginalisation. Indeed, we have much work to do.

The invitation to step through the moral opening had brought me here, to acknowledge suffering, hear the challenges ill people face and recognise what illness means to them. I spent much time with Briana's suffering, poring over the pages; she taught me that illness can be tragic, yet transformative. Smith (2002) says: "We are continually on the journey of healing; however, there are times on the journey where we need the vision and heart of the hero" (p. 7). Briana certainly exemplified both.

O'Sullivan (2015) suggests that through analysing and representing the voices of others "researchers develop their own voices" (p. 212). This research was a means for me to articulate Briana's narrative, but also my own. It may be the culmination of my own Hero's Journey, where I have returned with my offering of this research. Nevertheless, Vogler (2007) points out: "The best elixirs are those that bring hero and audience greater awareness" (p. 221). I do hope that Briana and I have achieved that much.

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