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Daring to care! An autoethnographic journey of recovery from bipolar affective disorder and complex trauma

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Introduction: the power of one

My lifelong journey of recovery from bipolar affective disorder and complex trauma is the subject of my autoethnographic research. I am undertaking this research as a doctoral candidate in the Department of Social Inquiry of La Trobe University. Conceptualised as *'Mental Health Literacy, Woundedness and Spiritual Wellbeing—Human-Centered Narratives Informing Personal Recovery and Leadership in the Mental Health and Substance Use Sectors'* (Camilleri 2019¹), I argue that critical systematic analysis of my personal experience can act as a catalyst for transformation of the mental health and substance use sectors through cultural and legislative reform.

Given this context, the observations and musings shared in this paper aim to demonstrate how I, as an individual who is prepared to be vulnerable by being empathic and compassionate, can not only make an emotional investment in my personal recovery but also make a significant contribution to the establishment and maintenance of a caring, soulful community that unconditionally embraces diversity with awe and wonder. This journey is best described as a human-centred longitudinal project which can be achieved through constancy of purpose and consistency of approach. It is a strengths-based pilgrimage that requires acceptance, stamina, conviction and resilience. The road is not always well signposted, but a mindful life has a habit of pointing the way in an unexpected but emphatic way.



Photo by Cecil Camilleri

“... a mindful life has a habit of pointing the way in an unexpected but emphatic way.”

Reading this document may evoke feelings that are both challenging and disturbing. If you, the reader, need a listening ear then I encourage you, in the first instance, to **contact Lifeline on 131114**.

There’s method in the madness!

This *living*, evocative paper is a harbinger of performative autoethnographic research that will be undertaken as my ongoing commitment to continuous professional development and trauma-informed, personal recovery from mental illness (Camilleri 2019²). Autoethnography, which essentially integrates biography and ethnography, gives voice to lived-experience within a socio-economic, cultural and spiritual context (Ellis *et al.* 2011³; Forber-Pratt 2015⁴). In my case, it also provides me with the opportunity to practice therapeutic expressive writing (Pennebaker and Smyth 2016⁵), which not only diminishes stress and heals old wounds but also improves relationships and personal wellbeing. Moreover, as a person who has lived and worked in rural and remote areas in Europe, Papua New Guinea and Australia, I believe I am well placed to make a significant contribution to the mental health and wellbeing of communities residing outside metropolitan areas.

The ‘I’ in the Autoethnography: An Introduction to the Writer

In this section I provide an overview of those aspects of the *true* or *authentic self* that principally define who I am. The true self and the soul are sometimes used synonymously as both refer to the deeply held values and beliefs that motivate authentic attitudes and behaviour. The following provides an insight into what makes me tick.

I was born and raised in Malta, a country steeped in Roman Catholic heritage dating back to 60 AD when Paul of Tarsus was shipwrecked on the Island whilst on his way to Rome to face his detractors (Acts 28: 1-3). I was exposed to Catholic social justice teaching at the age of four or five. Unsurprisingly, I became besotted with the idea of altruism and social justice at a very early age. I

left the Island at the age of 19 to pursue what I understood to be my spiritual calling, namely to develop competencies to work in underdeveloped countries and to minister to the rural poor.

At the age of 61, my profession is that of a social ecologist, and I have consistently practiced sustainability as individual, social, economic and environmental wellbeing (Camilleri 2003⁶; 2008⁷; 2015⁸). As a social entrepreneur with a primary interest in human development I have encouraged the management of the countryside and urban areas as a multifunctional landscape using principles of industrial ecology, agroecology and landscape ecology. In other words, I understand *people* to be intrinsic components of the cultural (rural and urban) landscape and the focus of sustainability. I believe this approach makes it possible for me to effectively and efficiently implement a culturally sensitive, human-centred agenda to promote biopsychosocial and spiritual development with due diligence and without compromising the life options of current and future generations (Camilleri 2018⁹). Spirituality, to my way of thinking, is about how we seek and express meaning and purpose; the way we emotionally (subjectively) experience our connection to the moment, self, others, our world, and the sacred or *Wholly Other*. Significantly, it is an aesthetics, sensory approach to the complexities and mysteries of life. Swinton and Pattison (2001¹⁰) are more reflective and identify spirituality as

‘... that aspect of human existence that gives it its ‘humanness’. It concerns the structures of significance that give meaning and direction to a person’s life and helps them deal with the vicissitudes of existence. As such it includes such vital dimensions as the quest for meaning, purpose, self-transcending knowledge, meaningful relationships, love and commitment, as well as [for some] a sense of the Holy amongst us.’

This definition supports the view that humans are social, biological, emotional, physical and spiritual beings and any understanding of the relationship between spirituality and mental health exists within this integrative context. I choose to understand health as more than the absence of disease, disorder or infirmity. As a social ecologist, I take a wider, dynamic and more inclusive approach. Health, from this point of view, is a changing emergent property in the complex, dynamic human web that leads individuals and communities towards or away from biopsychosocial and spiritual wellbeing. Spiritual wellness recognises the individual’s search for deeper meaning in a complex socio-ecological environment that is greater than the sum of its individual components, temporally unpredictable, its components labile, their relationships nonlinear, and their behaviour emergent and sensitive to the ‘*butterfly effect*’ (Plsek and Greenhalgh 2001¹¹; Wiklund and Wagner 2013¹²). When we are spiritually well our actions become increasingly consistent with our deeply held beliefs and values—the *true self*. Significantly, spiritual wellness should not be conflated with emotional wellness. Being happy in one’s skin implies satisfaction with ‘*self*’, one’s life, and the ability to effectively cope with stress whilst pursuing pleasure, enjoyment, comfort, and reduced pain. In turn, ‘*happiness*’, or ‘*hedonia*’, is not synonymous with ‘*eudaimonia*’, the state of wellbeing or the pursuit and/or the experience of meaning, excellence, a virtuous life, personal growth, self-actualisation, and flourishing (Huta and Waterman 2014¹³; Synard and Gazzola 2016¹⁴; Vittersø 2016¹⁵).

An Autoethnographic Reflection on Mental Health

I don’t know where to start.

Or how to bare this heart.

But I fear I’ve become what’s been done to me.

Alana Levandoski (2016^{music-16})

The diagnosis of Bipolar Affective Disorder (BPAD) on the 22nd of January, 2015 (Fielke, K. 2015, pers. comm.¹⁷) had a profound impact on my understanding of what it means to be *human* and, in particular, my appreciation of the *neverending* biopsychosocial and spiritual recovery. The recovery road has not been without its potholes and speed-bumps. Along the way I embraced vulnerability wholeheartedly. I dropped the body-armour and cultivated courage, empathy, compassion and connectivity. Or so I thought! I also convinced myself that I had successfully scaled the mental illness iceberg. I was on top of things. In control. Moreover, I believed it was sufficient to accept that I was the victim of the '*imposter syndrome*' (Rääbus 2018¹⁸; Sherman 2013¹⁹), that persistent gnawing feeling of unworthiness, bereft of self-compassion, self-empathy and self-kindness, and the shame associated with the belief that sooner or later I will be exposed as a '*fraud*'. There are instances, too many, when I believe that I am not sufficiently broken to belong to the mental health cohort. Paradoxically, I frequently and openly mock myself in a jocular fashion in the belief that this lightheartedness will liberate me from the internalised fear of imperfection. After all, I do have a diagnosis of a mental illness. I am flawed. A *mad* person. A person with a chronic disability. I was, and still am, not '*normal*'.

To my way of thinking, my genetic disorder (Craddock and Sklar 2013²⁰) became the epitome of original sin, that Christian theological belief that the human person is flawed from conception. Surely, there is no better metaphor for this ancestral flaw, this disability that I had managed to hide for almost a lifetime. After all, I was sworn to keep this '*social embarrassment*' a secret by my parents. Since childhood, I was told that my mother's mental illness, and my father's '*coping shenanigans*', were both an illusion: what I was witnessing was, at best, a misinterpretation of reality and, at worst, a figment of my overactive imagination. Persisting with such notions was surely a sin; a sin of the worst kind, one that could not even be divulged as a penitent to a father confessor in the hope of receiving absolution. To the young, developing brain coping with this '*illusion* of my making' was traumatic. Was I responsible for my mother's electroconvulsive treatment (ECT)? Was I responsible for my mother's madness and father's sinfulness? Was I responsible for the unhappiness in the family? Why did I persist with the sinful belief that all was *not* well in the family? To make matters worse, my older sibling and only brother, denied his self-harming and berated me when I innocently, as a seven or eight year old, expressed my concern for his wellbeing and welfare. Desperate supplication for divine intervention fell on deaf ears, except on those occasions when, apparently for no reason at all, my mother got a reprieve from her erratic mental illness. These instances were to me evidence of some form of divine mercy which seemed to be just as unpredictable as my mother's behaviour.

And so I tried to enter into divine contracts: make my mother better and I will abstain from having confectionery for a couple of weeks, or even a month. Depending on how desperate the family situation was I even forsook any plan that I had to ask Father Christmas for a particular gift that I had coveted for months. That was hard! The length and content of the self-sacrifice was proportionate to my anxiety. Somehow, however, I still was to blame. Why would God answer my prayers if I was not responsible for the unhappy circumstances in the family? There were times when He seemed to be particularly accepting of my offered contract and there would be periods of relative emotional calm. Such periods did not last very long. I began to discern a monthly cycle and I became very anxious towards the end of each month. In addition, as I approached my teenage years and announced my career plans, my mother upped the ante and blamed her illness, in particular her ECT sessions, on me in an effort to extract compliance and reverse my plans of going overseas to develop my career. Unfortunately, at the same time, my father did not hesitate to use me to shield himself from my mother's jealousy, especially when he was caught out! There were times when I became complicit in his tales in order to keep the peace. I came to hate my adolescent years and joked that if there was such a thing as reincarnation then I would gladly skip the formative and teenage years.

All this increased my resolve to leave for England in 1975. I carried much emotional baggage including what I discovered later in life to be the mental health condition of *Bipolar Affective Disorder* (BPAD) (Fielke, K. 2015, pers. comm., 22nd January). I believe I started to 'detach' from the reality of my family during my formative years: indeed, I created my very own *magic doorway*, a 'Wardrobe' not too dissimilar, I venture to say, from that of C.S. Lewis's *The Lion, the Witch and the Wardrobe* (2011²¹). This heroic 'dreaming' provided, and continues to provide, detachment, sanctuary and respite from aspects of everyday experience in the form of *derealisation*, or separation from the external world, and *depersonalisation*, separation from the sense of self (Hunter et al. 2017²²; Mula et al. 2009²³; Sierra and David 2011²⁴).

In the contemporary present this impulsive habit troubles me. I see these thoughts, this parallel reality, as intrusive, alarming, another piece of evidence of my madness. This manner of 'leaving' the present reality to become absorbed in another type of experience is a considerable challenge to manage despite my significant competency in socio-cognitive and meditative mindfulness as techniques to intentionally achieve presence, to purposefully be in the here and now. The result is normally a protracted, exasperating period of time spent dragging myself from the intoxicating alternative here-and-now to the existing present. Whilst *embodied self-awareness* involves interoceptive self-awareness, that is, internal sensing of emotions and body sensations in the *subjective emotional present* (Fogel 2013²⁵), the pull of the subjective emotional *other-present* is equally real and significant. To my contemporary way of thinking, living in this 'other-present' verges on the delusional and, despite the strength of its emotional attraction, must be discouraged as it provides substantial evidence, additional proof, of my state of madness. And that 'imposter syndrome' is nothing more than an alternative palatable term for the painful feeling of shame, the belief that I am relationally flawed and therefore unworthy of love, belonging and connection (Brown 2018²⁶). 'Simply not good enough' and the reproach, 'who do I think I am?!', underwrite my self-doubt and self-criticism.

In addition to the term *Bipolar Affective Disorder* I eventually also had to become 'comfortable' with and 'accepting' of an additional medical descriptor: *complex post traumatic stress disorder (aka complex trauma)* (Fielke, K. 2018, pers. comm., 27th October 2018). Within a period of about eight years, my recovery journey had seemingly become more complicated. However, the medical model became more precise as I found additional courage to experience more vulnerability and share more missing pieces of the puzzle that is my life with my clinical psychologist (Minette Emery²⁷) and psychiatrist (Dr Ken Fielke). Consistently, my resolute aim was and still is to discover my *true self* and be who I was born to be (Boyle 2009 ^{music-28}).

Where to from here? From Self-Awareness to Advocacy and Self-Care

Do you have the courage to bring forth the treasures that are hidden within you? ... What you produce is not necessarily always sacred, I realized, just because you think it's sacred. What **is** sacred is the time that you spend working on the project, and what that time does to expand your imagination, and what that expanded imagination does to transform your life.

Elizabeth Gilbert, 2016²⁹ (original emphasis)

A lifetime of experience and conceptual thinking has taught me that I can come to know who I am, my *true self*, through *socio-cognitive mindfulness* (Yeganeh and Kolb 2009³⁰) or *embodied self-awareness*, that ability to be intentionally present, in the here and now (Fogel 2013³¹); namely, to be aware of my emotions and my senses (*interoception*), as well as my body in relation to space (*proprioception*), without judgemental thoughts. In turn, being in the *subjective emotional present* fine-tunes my *conceptual self-awareness*, what I think about myself and my environs; how I define

myself in relation to my physical and cultural environment. Being who I am in my own skin is how I come to *dwell* in myself through the tangible feeling and expression of my *embodied self-awareness*. When my *conceptual self-awareness* is not attuned to, or in sync with, my *embodied self-awareness* then a sense of 'unreality', of depersonalisation or derealisation, exists. This is the time when I am functioning outside my '*window of opportunity*', that state of mind when my embodied and conceptual forms of self-awareness are attuned with each other. A state of dysfunctionality exists when my *conceptual self-awareness* takes flight (*hyper-arousal*) or is morbidly subdued (*hypo-arousal*). These two states reflect my *false self*. On the other hand, the best occasion for making a decision that is beneficial to me and others is when my conceptual self-awareness is informed by my embodied self-awareness. In other words, when the heart and the mind are in agreement, then the decision is most likely the right one. This rule of thumb continues to assist me with the development of purpose and meaning in my emerging recovery journey.

Through embodied self-awareness I became increasingly accustomed to complex revelations and new-found understanding of '*self*'. With the passage of time, I even discerned that I was in a unique position to practice mental health advocacy in regional and rural areas. Over a period of four years my commitments included frontline advocacy as well as participation in the development of mental health policy and strategy. In addition, '**bracing**' for prospective emotional upheaval during my recovery journey meant that I needed to be constantly aware of certain '*existential elements*' that collectively ensured my capacity to function within my *window of opportunity* without triggering the states of hyper- and hypo-arousal. These existential elements, adapted from Brown (2018³²), include:

1. **Boundaries**, particularly those that ensure
 - a. a 'private life ~ work ~ family' balance;
 - b. personal health and safety; and
 - c. respect for other's personal needs and safety.
2. **Reliability**, or commitment to my recovery and advocacy work expressed as constancy of purpose and consistency of approach.
3. **Accountability**, or acceptance of responsibility for any decisions or choices that I make.
4. **Confidentiality** in terms of
 - a. how much of my personal life I should divulge;
 - b. who needs to know; and
 - c. how will others and I gain from an appropriate level of self-disclosure.
5. **Integrity**, or behaviour that is ethical and consistent with my beliefs and values.
6. **Non-judgemental** state of mind and demeanour demonstrated by
 - a. practicing empathic, positive unconditional regard, as well as
 - b. compassion for self and others.
7. **Generosity**, with respect to the amount of time, details of personal circumstances, and other resources that I should reasonably allocate to relational work and advocacy without
 - a. impacting the health and wellbeing of self or others, or
 - b. compromising the life-options of self and others, as well as those of current and future generations.

Being present within my *window of opportunity* whilst simultaneously *bracing* for any emotional turmoil has meant that I can trust myself to lead a functional life and be an effective advocate. My

advocacy across urban and rural South Australia has become a way of being in the world, a way of relating to life unselfishly with altruistic motivation and a disposition to care for others even if some form of risk to self is involved. This positive existential mind-set underpins my servant leadership and commitment to mental health (Neill and Saunders 2008³³; Trastek *et al.* 2014³⁴). It's all about the power of one³⁵ to do small things with great love³⁶ and empathy, the latter being that capacity to be affectively attuned to another's feelings and to be cognitively aware of their situation, in particular the nature and intensity of their suffering. *'Feel the fear and do it anyway'*.³⁷ This adage was and continues to be my *modus operandi*.

'Coming out', that is, disclosing and being open about my mental health condition, is not just an existential challenge. It also points me to possibilities for my own becoming. The diagnosis was initially debilitating, but progressively, it became transformational. It was another instalment to many small, often unrecognised changes that led to an enduring expansion of consciousness, increasing awareness that expresses itself in terms of a more inclusive sense of self, a larger repository of meaning making, and a changed way of being in the world. My journey has been and continues to be that of the wounded researcher and wounded healer. I am privileged to have deeper insight, empathy and compassion as a result of my intimate, first-hand experience of what it means to have the lived experience of mental illness. But this privilege does not come without responsibility. Duty of care to self and others, as well as reverence for the sacred or the *Wholly Other*, is an ethical and moral imperative. Living with the mindset of *'open mind, open heart, open soul'* requires me to purposefully and intentionally live my vocation and calling with the knowledge that walking a mile in someone else's shoes to appreciate their suffering will increase my vulnerability and expose me to daily biopsychosocial and spiritual uncertainties. I must be prepared to be *touched with fire* when I respectfully and gratefully accept the invitation from others and the *Wholly Other* to enter their space and experience their reality and level of consciousness with awe and wonder.

Conclusion

I would like to think that my existential approach to mental health and wellbeing is having a profound impact on those *'touched'* by the presence of an individual who is prepared to be vulnerable, to *'feel the fear and do it anyway'*. Acceptance and commitment, as well as servant leadership, *'silently'* and unpretentiously encourage others to travel the journey of recovery with courage and conviction. By staying the course, and through constancy of purpose and consistency of approach, this mind-set has a catalytic effect on the recovery journey of others. Aesthetic leadership inspires and motivates by using dialogue and broader communications that go beyond rational and objective perceptions. In essence, it is leadership by example. It is about the power of one to do *small great things*.

Significantly, I am cognisant that some individuals may find my work disturbing, unusual and complex; perhaps even professionally perplexing and confronting, if not offensive. The fact that it is an *'unusual'* and *'complex'* paper highlights the *'unusual'* and *'complex'* lives that confront individuals with mental health issues. As an autoethnographic piece the fact that it is *'unusual'* and *'complex'* is a good indication that the paper has captured the essence of the unusual and complex lives led by individuals with mental health conditions. The paper is intended to evoke complexity and positive deviance. Positive deviance and complexity, not conformity, are the hallmarks of innovation and creativity. These are defining characteristics in the arts and the humanities. Aesthetic knowing, as captured by life-writing, the medical humanities and narrative medicine (Camilleri 2019³⁸), brings a multi-dimensional framework that is inclusive of sensory, emotional and somatic awareness—that is, felt meaning or embodied self-awareness.

As a mental health advocate I have a duty of care to my readers. I encourage those who have found aspects of this paper confronting to, in the first instance, **contact Lifeline on 131114** and to **seek safety in the company of authentic friends**.

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Presenter

Cecil Camilleri (BSc (Hons), MSc, B Litt (Hons), Pg Cert Coaching, Dip Couns, PhD (Charles Sturt University), DTech. (Deakin University), PhD (UniSA)) was born and raised in Malta and is a social ecologist specialising in sustainable wellbeing and resilience. Cecil, who has the lifetime experience of living with and recovering from bipolar affective disorder, identifies mental health and disability advocacy as his vocation and calling. He has an ongoing active association with Lifeline, the South Australian Health and Medical Research Institute, the Centre for Wellbeing and Resilience, the Health Consumers Alliance of South Australia, the Community Visitor Scheme and the South Australian Office of the Chief Psychiatrist. He has recently developed linkages with the International Initiative for Mental Health Leadership, UniSA’s Centre for Business Ethics and Responsible Leadership, and Country Health SA Local Health Network Inc. Cecil is a statutory officer with the CVS, a crisis support worker, a community educator, coach and mentor. As an adjunct research fellow with the School of Management, which is part of the UniSA’s Business School, his main research theme is ‘Mental Health Literacy, Woundedness and Spiritual Wellbeing—Human-Centered Narratives Informing Personal Recovery and Leadership in the Mental Health and Substance Use Sectors’.