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The Inward Journey: Writing, Thinking, and Being Through the Illness Story

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Abstract

This paper explores the cohesive and insightful narrative that emerges where research, thinking, writing, and being converge, emphasising the dynamic essence of academic inquiry in the journey of knowledge creation. It examines the interplay between my doctoral research journey titled *Women Living with Autoimmune Invisible Illnesses: An Autoethnographic Study and Narratives in Malta* and the writing process of this paper. Inspired by J. Campbell's insight that 'where you stumble, there lies your treasure,' my writing unfolded as a transformative exploration, revealing layers of self in tandem with the project's evolving layers. Kierkegaard's notion that life must be lived forward but can only be understood backward resonates throughout, guiding my oscillation between the past and present in the realms of writing and thinking. Navigating memories, events, and reflections enriched the narrative, highlighting that this process was not a straightforward one. While writing, I came to realise that although my focus evolved from my doctoral thesis, the narrative in this paper continued to expand—the story is never fully or exhaustively told. Beyond the material and patterns identified in my thesis, I reflect on the transformative process, acknowledging its ongoing impact on my unfolding life story.

Keywords: writing, thinking, autoethnography, illness narratives, transformation, knowledge creation

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Introduction

When embarking on preparing a presentation for the Creative Bridges Conference 2023, my initial intention was to share with the audience some of the reflections I experienced when crafting my doctoral thesis titled *Women Living with Autoimmune Invisible Illnesses: An Autoethnographic Study and Narratives in Malta*. As I immersed myself once more in the words that shaped my thesis, I found myself revisiting different moments, revealing a spectrum of emotions, and once more uncovering intricate layers of self. Indeed, the journey I am writing about in this paper is marked by nonlinearity in thinking, writing, and being—a journey that remains in a constant state of evolution and dynamism.

Kierkegaard (1957, as cited in Muncey, 2005) famously suggested that life must be lived forward but can only be understood backward. This wisdom highlights the idea that we often gain a deeper understanding of our lives and experiences when we reflect on them in retrospect. This profound insight resonates deeply with my experience at different stages of my writing, for example, when it came to choosing my research topic for the doctoral thesis, when recalling and writing about illness experiences, when crafting the Creative Bridges presentation, and in writing this paper. As I delved into the realms of writing and thinking, I found myself, once again moving both backwards and forwards in time. I embarked on a journey informed by my experiences with illness, the act of writing and tacit knowledge (Etherington, 2004). This journey led me to delve into memories, events, reflections, and images, all of which enriched the narrative. Additionally, as time has elapsed since the completion of my doctoral thesis, I've noticed a shift in my focus and intention when writing this paper. My contemplation extended beyond the content of my research and its emergent material and patterns. I became particularly drawn to a profound exploration of the overarching impact of the process of becoming and transformation as my life story continues to unfold beyond the writing.

Entering the Cave

In my doctoral thesis, I cited Campbell (Campbell & Osbon, 1995) who eloquently captured the essence of my journey by stating that 'where you stumble, there lies your treasure. The very cave you are afraid to enter turns out to be the source of what you are looking for' (p. 24). Before embarking on my research project, I held the naïve belief that I had a clear understanding of what lay ahead—I thought I knew. However, what I did not realise was that I was venturing into the unknown, uncertain of what was yet to unfold in this uncharted path. As a nurse, a counsellor, educator, and a reflexive researcher, my interest in researching women living with chronic autoimmune invisible illnesses in Malta was multifaceted. This interest stemmed from my personal illness understanding of the intricate relationship between my own experience of illness (hereafter referred to as *my*story) and the illness experiences of close family members and individuals whom I have met in the therapeutic and medical field. In the prologue of my thesis, I shared my personal journey of illness, which included a misdiagnosis of myasthenia gravis followed by a diagnosis of post viral fatigue syndrome (PVFS), also referred to as chronic fatigue syndrome (CFS) or myalgic encephalomyelitis (ME)—a complex, chronic autoimmune medical condition characterized by fatigue and malaise that is worse after exertion, and cognitive and immune dysfunction (Bested & Marshall, 2015).

Coming to Autoethnography

I came to understand autoethnography as 'a process and product [and how it uses] tenets of autobiography and ethnography to do and write autoethnography' (Ellis, Adams, & Bochner, 2011, p. 273). By openly sharing my own experience in an embodied, existential, and reflexive manner, I intentionally placed myself at the heart of the research, while also implicitly situated the illness narrative within a broader context that goes beyond the boundaries of the page. Certainly, the contextualisation of my own perspective played a pivotal role in my choice to adopt evocative autoethnography as the methodology for my research. I was novice to autoethnography and found it quite revolutionary, both as an academic and on a personal level. In hindsight, I recall the excitement but also the hesitancy, knowing that '[w]riting both selves and others into a larger story goes against the grain of much academic discourse' (Denshire 2014, p. 832).

> I had not spoken about my illness story for a very long time, but once I was given the space and was being listened to attentively, it all came back, recalling both physical and emotional experiences: the pain, the fear, the anger, and the uncertainty. Emotions that were not visible but suppressed in what felt like a 'straitjacketed body'. Unconsciously, there was a great sense of relief through sharing my story. It was a powerful moment – on one hand appreciating how life experiences, cultural context, as well as beliefs affected me on a personal level, but on the other curious as to how I was going to use this experience to extend to the larger community. This is when I was introduced to autoethnography as an 'alternative method and form of writing'. Although I knew of it, I did not know about it. However, I was aware that I was embarking on a path that was less travelled at doctoral level across the Faculties of Social Wellbeing and Health Sciences respectively.
>
> Reflection excerpt (Martinelli, 2019)

Employing an autoethnographic framework introduced several firsts for me. Among these firsts was the creative presentation of my work, incorporating the use of the first-person narrative ('I'), poetry, and images, and openly sharing my reflections on the page. This demanded a departure from traditional methods of research and presentation that I was accustomed to. I presented *my*story and the women's stories using different patterns, fonts, and formats, each representing a different voice: the academic writing (Times New Roman font size12) and my reflective writings (Calibri font size12, indented and italicised). The woman's illness stories were represented in poetry format (using Arial font size12, indented and italicised) to create an overall more visually aesthetic presentation.[1]

Reflexivity of discomfort.

Body speaks…unbeknown knowledge,
writing body self[ves]
remembering memories,
recalling emotions,
unless spoken or written,
remain invisible, unofficial, untellable,
unheard…Painful.

(Martinelli, 2020)

Another first was presenting personal reflections alongside academic writing. Despite my familiarity with reflexive writing due to my nursing

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[1] The quotations and poetry from the author's journals are formatted in *LIRIC Journal* style for this paper.

and counselling background, I still experienced writing myself onto the page as a participant in research and including excerpts of my reflections to be challenging at times. As opposed to other methodologies, the feminist research movement encouraged researchers to be visible, to use the first person and tacit knowledge. This required stepping out from the absence of the researcher, thus shifting the focus inward, to question the self, others, and the research process (Altheide & Johnson, 1998; Ellis & Bochner, 2000). Additionally, in autoethnographic research, writing is characterized by its truthfulness, vulnerability, evocativeness, and therapeutic nature (Ellis, 2004). The reflections and first-person narratives often exposed a vulnerable self:

> [I]n using myself as subject, treating my own experiences as a primary source amongst other things, I explicitly exposed, and made visible – doubts, vulnerabilities, resilience, losses, emotions, and feelings.
>
> Reflection excerpt (Martinelli, 2021)

However, it is important to note that, as Smith and Sparkes (2007, as cited in Defenbaugh, 2013) argued, personal stories are both personal and social at the same time:

> The 'I' and the 'we' intertwine, merging fact with fiction, rationality with emotionality, vulnerability with resilience, and visibility with invisibility…a platform for words and stories to be told and heard – a personal and collective space advocating compassion and (self)care.
>
> Reflection excerpt (Martinelli, 2022)

In my endeavour, I aimed to empower women in the broader society, particularly those who may feel marginalised due to their invisible illness (as explained earlier) by integrating diverse perspectives, including women participants' narratives, personal stories (*my*story), and academic literature. By democratising academic knowledge as advocated by Wood, McAteer, and Whitehead (2019), I sought to make scholarly insights more accessible and relevant to those affected. This approach, also known as the *emancipatory* approach, aligns with feminist principles that guided my research. Through this lens, I hoped to promote empowerment, subjectivity, human rights, and equitable power dynamics (Denzin & Lincoln, 2005).

The Other Women Collaborators

In addition to the autoethnography of *my*story, I included the narratives of four other women whom I referred to collaborators rather than just participants in the study. These women were purposively selected to share their narratives. The inclusion criteria for participation specified women aged 22 to 55 living with chronic invisible autoimmune illnesses for at least two years and residing in Malta. The exclusion criteria included children, older adults, and persons living with acute or chronic psychiatric or neurological illnesses and/or terminal illnesses. Coincidentally, the selected individuals were 20 to 30 years of age, mirroring my own demographic during my personal experience with illness.

The women shared their embodied experiences of living with invisible chronic autoimmune conditions, highlighting the psychological benefits of sharing and voicing their stories. They expressed vulnerability and occasional feelings of marginalisation stemming from their experiences of living with an invisible chronic illness. This entailed finding a balance between self-silencing and acknowledging the importance of asserting agency. Our conversations revealed similarities in our experiences such as societal expectations for women, the subjective nature of the invisible illnesses, and need to validate one's authenticity, all within the context of patriarchal dynamics in health systems. These exchanges fostered a sense of solidarity. Notable differences also emerged, particularly in how each of us asserted agency and reclaimed our voices. Ultimately, these conversations served as sensitising agents—they were a catalyst to the creation of new and collective narratives, enhancing our understanding of living with an invisible illness and the resilience required to navigate it.

Three consecutive meetings were planned for each participant—a model adopted by O'Shaughnessy, Dallos, and Gough (2013). In the first meeting, a single narrative-inducing question inspired by Wengraf (2001), was posed to elicit a life story narrative. The first meeting helped to establish a collaborative relationship and gain a preliminary understanding of the story being told. In the second meeting, the women were encouraged to elaborate, clarify, change, or add any detail that they had shared during the first conversation and/or discuss any reflections. For the third meeting, we could no longer meet in person due to COVID-19 restrictive measures, and the women were given the option to meet virtually and/or write, communicate, via email. They all opted for the latter. The third meeting was intended as a member validation process.

After transcribing the interviews, I used their own words and presented their stories in the form of found poetry (Prendergast, 2006; Reilly, 2013). Since some time had passed from the time of the meetings and I was sensitive to the possible disruption that the COVID-19 pandemic might have caused for the women, their families, and/or their health. I remained mindful of the possibility that the women participating in this study might be reading their own stories without any support available to them. Thus, I adhered to the ‘ethics of care’ (Gilligan, 1982; Christians, 2011; Noddings, 2013), which holds a central position within moral philosophy and feminist theory (Hankivsky, 2014, p. 252). In research, this required careful attention and responsibility in the way I related to the women collaborators at every stage (Etherington, 2020). Therefore, I once again conducted a ‘process consent’ (Etherington, 2004; Ellis, 2007) to ensure ongoing consent and confirm their willingness to continue participating. I reiterated their option to opt out if they wished to do so. My primary concern at this stage was to mitigate any potential harm to my participants. All the women reaffirmed their agreement to proceed with the study.

Going Back, Giving Back

Going back, giving back to the women their own stories, was considered as being ‘ethically and/or politically necessary’ (Grinyer & Thomas, 2012 p. 223). My doctoral research endeavour aimed not only to present elicited material but also to empower the women by returning ownership over their words. Each poetic representation of their story was shared with the respective participant. This was achieved by crafting their words into found poetry and giving them the opportunity to revise and/or rewrite their own narratives. The women were invited to review the meaningfulness and accuracy of the poetic representations of their stories, ensuring that the translation from Maltese to English accurately reflected their original intentions. Furthermore, by presenting the women’s stories in poetry format, I believed I was honouring the pain, doubts, uncertainties, and ambiguities of the experience (Bondi & Fewell, 2017) thereby giving a voice to the voiceless (Denzin, 2009). As mentioned earlier, it was a measure to advocate for social justice to those women who felt that their voices were being silenced.

Denzin (2014) with reference to poetic representation maintained that

> The poetic representation of lives is never just intended to be an end in itself. The goal is political, to change the way we think about people and their lives and to use the poetic-performative format to do this. The poet makes the world visible in new and different ways… The poet is accessible, visible, and present in the text, in ways that traditional writing forms discourage (p. 86).

The contrast between the narrative and the poeticised extracts invites the reader to listen carefully, whilst offering and impacting them far more than communication transcribed verbatim could allow (Reece & Speedy, 2014, p. 54). This participatory approach ensured that the woman had agency and control in shaping their own stories, accentuating the collaborative and empowering nature of the research process even further. I had encouraged them to communicate and write their respective comments and reflections once they had read their stories. The women chose to use email as their preferred mode of communication although they did not include any new information or insights.

Unfortunately, due to time constraints, it was impossible to delve further into the writing process. Moreover, it was not feasible to convene as a group during the study period mainly because of ethical clearance and COVID-19 restrictions. Nevertheless, as a continuation of this research, I aim to follow up and bring all the women together. This would provide the opportunity to expand upon the elicited material as a group, co-creating new insights and knowledge.

Before embarking on my doctoral thesis, my perception of knowledge was fundamentally different. I was trained to do health research differently and viewed knowledge as being objective, something external to me as the researcher, and I was not accustomed to factoring in the internal processes, my own subjectivity, reflexivity, introspection, and emotional recall.

However, right from the outset of my doctoral journey, my goal was not to uncover explicit and scientific knowledge in its broadest sense (which is also important), but rather to immerse myself in the intricate micro stories through writing as inquiry and narrative exploration. I had yet to experience the transformative power of embodied writing (Ellingson, 2017) to generate new knowledge. To do this, I employed various forms of writing, understanding, and representation. Echoing Lather (2013), I now realise that through the writing, I was generating distinct knowledge and approaching the knowledge differently.

Writing as Becoming

Laurel Richardson (1997) posed a fundamental question: ‘How do the specific circumstances in which we write affect what we write, and how does what we write affect who we become?’ (p.1). To answer these questions, I engaged in a journey of critical self-reflection, employing systematic introspection and emotional recall (Ellis, 1991) to illuminate fresh insights. My aim was to extend the relevance of my experiences beyond personal boundaries, echoing Carolyn Ellis's sentiments (2007). I blended narrative and pragmatic knowledge inspired by Bruner (1985), crafting an evocative narrative that transcended merely recounting, delving into practical aspects. As Grimshaw (1986) astutely noted, 'the reconstruction of knowledge is inseparable from the reconstruction of the self' (p.164).

> Looking back on my experience, I realise how subjectivity, introspection, reflexivity, emotional writing helped me to deeply examine my own feelings and experiences in relation to self and others. It's been a simultaneous process of looking inwards and outwards, forwards, and backwards. I often joked that it felt as if I was going to the therapist on a daily basis– but in truth, I was serious. It felt as if I was continuously peering through a mirrored looking glass.
>
> Reflection excerpt (Martinelli, 2022)

Thus writing my doctoral thesis was not just an academic endeavour; it became a transformative journey, moulding my evolving identity. Through this process, I came to understand that the act of writing inherently reshapes the self and there exists no ultimate interpretation, for once written, there is a sense of 'isness' (Richardson, 2002) that defies conclusive understanding.

Similarly, in relation to the writing, Pelias (1999) aptly suggested that 'once written it will become a historical claim, a writing event, simultaneously embodying, making theory an experience visible to others' (p. xi). I deeply resonate with this notion, as revisiting my doctoral writing in crafting this paper feels like revisiting history. Yet it also embodies a great appreciation for the evolving knowledge and evolving self that feels constantly in motion—a continuous process of becoming, where the boundaries between the researcher and the researched seem to merge and blur.

Transformative Writing: Journeying Beyond Boundaries

In all its forms, writing serves as a mode of knowing (Richardson, 2000), an avenue of inquiry, and a dynamic process. Like many traditionally mainstream researchers, I refrained from expressing emotions on the page, even when drawing from personal experiences, I kept them separate (Ellis,1997). However, throughout my project, writing played an integral role. Giorgio (2008) astutely observed that when we write and we write to heal, we extend healing to others, making it a political and hopeful act (p. 165). In my exploration of autoethnographic storytelling, I started to appreciate its unique ability to understand better the complex relationships between personal and epistemological truths, culture, and the realm of politics. Within the political dimension of illness, I witnessed (in both my personal and professional capacity) the intricate processes of medicalisation and the societal expectations inherently woven into it. Beyond my own personal experiences, I delved into the potential connections, whether direct or indirect, with the experiences of other women and questioned how the illness experience impacted women's ordinary lives. These interconnections, as outlined by Holman Jones (2005), are integral components of a broader political context. Embracing this approach has afforded me a more holistic understanding of how individual narratives intertwine with larger socio-political forces and structures concerning illness and healthcare.

> Reflecting on my illness episode, I vividly recall the embodied feelings, the doubts, and ambiguity at the crossroads in decision making. …. Although the uncertainty and the hope may be similar with other women's experiences…the individuation of how we live the outcome, and what we do with the meaning, is a very personal journey, nonetheless, a collective one….
>
> Reflection excerpt (Martinelli, 2020)

In delving into autobiographical narratives and sharing personal experiences, I found myself occupying dual roles and/or multiple roles—as both the subject and object of the narrative, the researcher and the researched, the nurse, and the counsellor. This immersion went beyond being a participant in research; it transformed me into an embodiment of the field through my writing and interactions, thus echoing Mayan's insights (2009). The navigation through private, public, and therapeutic discourses transformed the act of reflection and written interactions into a profound journey of self-discovery. Drawing on the wisdom of Lapadat (2017) and Wright & Chung (2001), this process expanded my knowledge and positioned it as an effective catalyst for personal, and perhaps broader societal, change.

> I'm adamant that I do not want to pathologise or medicalise the illness experience, I'm very cautious in keeping the nurse's voice at bay. However, when looking at the geography of emotions, and compassionately listening to women's illness stories, I do not inhabit fully the counsellor role either – it is not the scope or the space to do so.
>
> Reflection excerpt (Martinelli, 2020)

In hindsight, I realise that I continued to project the same ambivalence in multiple roles. I did not inhabit fully any role; I refused to fit into binaries, the dichotomy of either/or, one/the other, negative/positive, amongst others. I once again found myself betwixt and between. I sounded different voices that were elicited from a multitude of experiences. These voices merged with other women's voices. Although I was writing *mys*tory alongside other women's stories, I realise that it is not always clear whose voice I was sounding, because it could have been a composite voice.

By now, writing had evolved beyond a mere act to a dynamic process of inquiry, therapy, healing, and self-exploration. Engaging with others in the study, exploring the spaces within and around us, this journey has translated into transformative processes. What I have come to realise, especially highlighted in the crafting of this paper, is that the transformative processes are not finite or conclusive; they're an ongoing, evolving journey that is always in motion. Drawing inspiration from Wright & Wyatt (2017, p. 83), this ongoing exploration aids in uncovering the depths of what we think we know while revealing and challenging unknown edges.

As the author, the participants, and readers become witnesses to this journey (in alignment to Ellis & Bochner, 2006), new meanings and subjectivities emerge, contributing to the ever-evolving narrative. Lather and St. Pierre (2013) further emphasize that it's not solely about the act of writing: it's about the act of *thinking*. They assert that 'thinking differently changes being' (p. 631) highlighting the transformative power inherent in the process of contemplating and expressing thoughts through writing.

Thinking, writing, feeling,
therapy, wounds, healing.
Unspoken words
Loosely flowing, merging into
each other
Fading into silence
I sit down to write – words fail.
Or I fail words.
The silence fills the
space…
Patiently…
Waiting,
Longing,
To write
Paper, pen……

Scribbling
Flooding emotions
Gripping mind, body, and soul
Etching words
Gently caressing the wound…
                                        …. to heal.

(Martinelli, 2021)

Thinking with Stories

In my writing, I aspired to embody Richardson's (1990) and Bochner & Ellis' (2016) idea that storytelling is not just a method of knowing, but a social practice—a way of sharing our lives. Shifting from telling to vividly showing, I aspired to move beyond abstract theorising. My goal was to evoke emotions, foster intimate involvement, and truly engage with the stories being told, aligning with the principles of narrative inquiry. This transformed my approach to theorising, evolving from contemplation about the stories to an active and immersive process of thinking *with* stories.

Frank's (1995) perspective resonates deeply—thinking *about* a story is like dissecting its content and analysing it from a distance. However, thinking *with* a story is a more immersive experience, where the narrative becomes intertwined with one's own life, revealing profound truths (p. 23). As I delved into the stories, the material that emerged was rich and diverse. It touched on language use, contextualising the narratives of the traditional and modern women in Malta and the exploration of emotions and feelings, often highlighting the perception of the condition as 'being all in the head'.

Hoffmann and Tarzian (2001) emphasized how medicine's focus on objective factors alongside cultural stereotypes often results in inadequate pain relief for women. When no physical cause is found, women's pain may be dismissed as in the patient's mind rather than acknowledged as legitimate (Cleghorn, 2021). This bias, backed by studies (Jackson, 2019; Zhang et al., 2021), hampers effective pain management by medical professionals. Additionally, Ware (1992) observed that women who face disbelief, patronization, or trivialization of their symptoms often internalize these attitudes, leading to self-blame or a belief in imaginary illnesses. This internalization can foster feelings of alienation and shame, prompting individuals to keep their illness secret and doubt their own reality (Ware, 1992, p. 347). Hence, the phrase 'It's in the head' elicited feelings of anger, powerlessness, and betrayal among women collaborators, questioning their coherence and agency, and contributing to their silencing and erasure of self. As one woman stated:

> Doctors told me…
>   ‘It’s all in the head’.
>   Was I conditioning myself?
> But
>   ‘IT is not all in the head,’
>   IT is felt all over the body.
> The mind (head) is part of the body

The Use of Language

> [T]he experience of writing goes beyond the use of language, or the discursive story written on the page. Often times, words failed me, or I failed words for diverse reasons, which included difficulty to express myself ‘well enough’, fear that my writing did not satisfy academic expectations or that the writing was not literary and aesthetic enough, therefore not satisfying autoethnographic criteria and the constant of shifting between languages (in thinking and writing Maltese and English) to find the ‘correct’ translation of some words/phrases, e. g., ‘the self’ and ‘care’. These were only but a few of the challenges that I continued to experience in the use of language.
>
> Reflection excerpt (Martinelli 2021)

Sarah Wall (2008) posited that the essence of writing lies in conveying messages in a language accessible to the audience, ensuring effective comprehension and understanding. This implies that language surpasses the act of speaking in one’s native tongue. In the context of conversations, language played a pivotal role in the crafting of illness narrative. It served as a powerful tool in shaping a distinct perspective on both reality and self as highlighted by Richardson & St. Pierre (2005). Our choice of language and the narratives we weave can serve as catalysts, fostering inclusive and empowering dialogues around illness, particularly when the ailment remains unseen by others—most especially when it is invisible. Instead of succumbing to silence, we can let language transform into a potent instrument. Through it, we articulate our experiences, challenge societal stigmas, assert our agency, and advocate not only for ourselves but also for others. In the journey of crafting my thesis and listening to the stories of the women collaborators, a clear revelation emerged, namely how this same process empowered us to share our stories, voice our needs, and potentially play a role in driving positive change. It stands as a testament to the profound transformative power of language and storytelling. The act of storytelling proved to be a potent tool for advocacy and creating awareness, facilitating connections, and ultimately making a meaningful impact on the discourse surrounding illness.

In our conversations, the women unconsciously and separately each used the same pronoun to personify their conditions, referring to 'IT' as if there were another presence in the room. This act of externalising 'IT' enabled them to create a tangible, emotional, and psychological distance from their illnesses. However, even though they employed explicit language to accentuate the separation between themselves and their conditions, it became apparent that the motivation extended beyond creating a divide. They were also driven by a desire to safeguard their identities from being overshadowed by the illness and to avoid being solely identified through the lens of their health challenges. As one of the women participating in this study expressed it,

> IT is NOT my identity, IT is not ME'
> I see IT as exterior. . . to me.
> Control . . . contain,
> restricting the space for
> IT to flourish.

Navigating Identity: The Symbolic Significance of Chronic Illness

Navigating the labyrinth of personal experiences unveils concealed and elusive aspects of the self, transforming the unspoken into the public domain (Pelias, 2021). Yet, language often grapples with the daunting task of truly encapsulating these experiences, facing a chasm between living the experience and narrating it (Bochner, 2016). The challenge goes beyond the simple recollection of memories; it extends to the intricate process of attributing meaning to these experiences and comprehending their profound impact on one's sense of self (Maté, 2011).

> [I]n writing this project 'I' (a daughter, woman, nurse, counsellor, and person who had been diagnosed with CFS) together with the women collaborators represented in the stories, brought forth their 'own' self, multiple selves, and different identities (e.g., the illness identity, the relational identity, the public/private identity), including the subjective selves that continue to evolve. In questioning selves, we open to a multitude of questions.
>
> Reflection excerpt (Martinelli 2021)

The symbolic significance that each participant attributed to their individual circumstances had a profound impact on how they perceived themselves, their identity post diagnosis, and their outlook on others (Williams, 2000). This symbolic quest to mend the ruptures between their bodies, sense of self, and society seemed to bolster their resilience and offer fresh insights into the meaning and experience of chronic illness (Williams, 1984; Hydén 1997). For both the women participants and me, the pursuit of an authentic and cohesive sense of self unfolded as an ongoing and parallel journey alongside the trajectory of illness. As one women participant claimed,

> I voice IT, IT is there,
> IT is not ME.
> IT revealed the true ME.
> I live and appreciate life,
> through a different lens.
> I live the now.

This journey transcended challenges such as bodily alienation, medicalisation, the loss of the known self, biographical disruption (Charmaz,1983; Williams, 2000; Bury, 1982) and the disruption of the embodied self (Leder,1990).

Throughout the research process, the exploration of self in relation to illness proved far from straightforward. In my personal experience, being diagnosed with ME/CFS—an ailment shrouded in controversy—in the 1980s initially felt like a relief compared to a diagnosis of myasthenia gravis. The moderate nature of my symptoms led me to question my own authenticity in relation to illness, almost feeling ashamed as if I were to blame. For many, the pursuit of an authentic self within the context of chronic illness is a deeply personal and ongoing journey, an ever-evolving endeavour in face of adversity. This journey closely mirrors the unpredictability of the chronic illnesses. Ultimately, embracing one’s authentic self in chronic illness involves accepting and embracing both the strengths and vulnerabilities that come with it, cultivating resilience, and finding ways to live a fulfilling and meaningful life despite the challenges.

> A note to self…and others…
> All things are possible…
> A question of perspective,
> It’s a choice…. or not?
> The story could have been told differently,
> the story of

> weaker or stronger women,
> determined or less determined,
> passive or defiant,
> …. Yet, in every narrative resilience shines.
>
> (Martinelli, 2022)

Reflecting, Re-evaluating, and Moving Forward

Bruner (1985) emphasises that narratives are fluid and constantly evolving; all stories are partial, and meanings are never fixed. The past is not frozen but shaped by context, audience, and retelling (p. 153). In recounting life and illness stories, the focus of my thesis and the writing of this paper is not solely on describing past experiences, but on understanding the impact that making meaning continues to have on the individual's experience. Moreover, in sharing illness stories the aim is to engage readers in the emotional journey, inviting them to participate in the joint creation of meaning (Pollock, 1998, p. 8). Rather than romanticising outcomes, the intention is to reveal ambivalences and contradictions. Through sharing *my*story alongside others', the boundary between private and public life blurs, allowing readers to connect and 'experience the experience' (Ellis & Bochner, 1992, p. 98).

Reflecting on whether I could have approached things differently now that I've gained more awareness is challenging. Any potential changes could have altered my experience significantly. However, given ethical clearance and the lifting of COVID-19 restrictions during that period, one thing that I would have done differently is to bring the women collaborators together informally and as equals to discuss, write, and continue to expand on material elicited from their stories, further co-creating other stories. As mentioned earlier, I hope to have this opportunity in the very near future. Moreover, in every study there are limitations which once again can only be identified in retrospect. Some limitations in my study included the following:

1. Being a novice researcher using autoethnography and the first student to use such an approach at the University of Malta for a Ph.D. study. This novelty may have created some limitations in writing and when talking about my project with my colleagues. At times, it felt very overwhelming and limiting. I am thankful to my doctoral supervisors, advisors, and the international autoethnographic community.

2. At times, I felt *homeless,* a nomad trying to fit in, to belong to the two different disciplines that I come from; I felt that I was not totally immersed in either the counselling or the nursing department. Instead, I found myself hovering in the in-between.
3. During the COVID-19 pandemic, while working with the case management team in the Infectious Disease and Prevention Unit of the Public Health Department and with the Department of Nursing, I faced significant limitations in my doctoral journey. The high stress, anxiety, and long working hours led to physical and mental exhaustion. The emotional toll and uncertainty of COVID-19 were exacerbated by the parallel emotional processes involved in writing my thesis. There were moments when I felt lost for words, when everything seemed irrelevant, and giving up felt imminent. One of my final reflections of my thesis which I believe is still relevant today in the crafting this paper—I realise that the process continues to unfold as stories continue to be told. I had claimed that

> Like Alice (in wonderland), I felt totally immersed in the 'deep hole' of the unknown, even though it was my choice to walk this path, honestly speaking, I was oblivious to the process and the transformation of self in this journey. On recalling experiences, I relived and re-identified with my inner child's known experiences, feelings, and emotions during this journey, which were my known reality, whilst I continued to question and remained curious to search for meaning. I embraced the path and assigned 'meanings in motion' as I continued to delve deeper recalling memories, capturing specific moments and emotions of past experiences. As I relate *my*story, I embrace the child and the woman I am today, thus placing meaning within the context of my life, the whisper of silence echoed through the deep hole into open space, in the hope that it would be heard by the 'other'.
>
> Reflection excerpt (Martinelli 2022)

So, what now? What next? Where do we go from here? Does the writing stop here? In my oration during the graduation ceremony, I referred to Amanda Gorman's (Fox 11 Los Angeles, 2022) words from her poem 'What is the way forward?' which is still very relevant:

> Today we are writing our own path,
> not with wrath but with will.
>
> The way forward isn't the road we take,
> The way forward is the road we make.

So let us make our road a worthy one! I stand by what Virginia Woolf (1953) stated about Michel de Montaigne's essays, that I hope to 'continue to communicate a soul...to go down boldly and bring to light those hidden thoughts which are the most diseased; to conceal nothing; to pretend nothing' (p. 66).

Conclusion

In conclusion, the present moment serves as a culmination of an intricate dance between the research journey and the process of writing this paper. The ongoing exploration of scholarly works has not only informed the content but has been a continuous source of inspiration in shaping the narrative. Simultaneously, the act of translating these insights into written form has been a dynamic process of synthesis and reflection. In writing this paper it became more evident that the research journey and the writing process are intricately intertwined, each influencing and enriching the other. The iterative nature of this endeavour is manifested in the symbiotic relationship between recollection of memories, exploration of ideas and their articulation on paper. In the present moment, insights gained from the research journey resonate within the crafted narrative. Additionally, the act of writing acts as a driving force, prompting ongoing inquiry, refinement, and exploration of ideas.

The simultaneous engagement with both the research and writing highlights the dynamic nature of academic inquiry, emphasising the continuous interplay between understanding and articulation in the ongoing process of knowledge creation. Essentially, the present moment represents a critical juncture where the synthesis of the research journey and the writing process gives rise to a cohesive and insightful narrative, marking not just the end of a project but a point of transition into the broader conversation of scholarly discourse.

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