Women living with Chronic Autoimmune Invisible Illnesses:

An autoethnographic study and narratives in Malta

Sharon Martinelli

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Declaration

I, the undersigned, declare that this thesis is my original work, and has not been presented in fulfilment of other course requirements to the University of Malta or any other University.

SHARON MARTINELLI DATE

Abstract

This doctoral thesis aimed to explore the experiences of women living with a chronic autoimmune invisible illness in Malta. Women diagnosed with chronic autoimmune illnesses have increased at alarming rates since the 1980s. Due to the subjectivity of the illness, medical professionals often dismiss symptoms as being products of anxiety, depression, or as being *all in their head.* Although research on chronic autoimmune invisible illnesses is vast across different disciplines, embodied and *enfleshed* research is limited. *My*story of the illness experience is presented alongside narratives of four other women collaborators. Evocative autoethnography, women's narratives and writing as inquiry was used to present the illness stories underpinned by a feminist, postmodern and social constructionist approach. This study was initiated from a personal, situated standpoint in believing that individual stories are socially and culturally contextualised. However, I was oblivious to the continuous evolving process, the meanings in motion from the co-creation of other stories.

I hoped to provide a platform for women's stories to be told, heard, and made visible, whilst embracing the embodied emotional attributions intersecting with gender, values, beliefs, culture and understanding(s) of health and illness. By using evocative writing, I hoped to embrace vulnerability, resilience and suffering more explicitly, through engaging in the process of *becoming* as well as knowing self and others as a form of healing and transformation. The stories were presented in the form of found poetry, retaining women's own words that were gathered during the respective meetings. Crystallisation was adopted to achieve depth and breadth of the material elicited through the already published research as well as the illness stories. Patterns were presented to provide a wide-angle perspective highlighting individual experiences through emotions, and expressions by using prose and poetry. As any autoethnographic research, the contribution to knowledge is believed to be multi-layered, depending on how the writing resonates with the reader and how the reader responds to the representation. Future research elicited from this thesis may include researching other genders living with chronic illness in Malta and to research the correlation that exists between identity, ableism, and chronic illness. Finally, on a practical level,

I hoped to extend the use of practice-based applications and research in supporting different individuals and groups in using writing as therapeutic healing practice for well-being.

Keywords: Chronic autoimmune invisible illness, feminism, autoethnography, subjectivity, Malta, embodiment

To my dearest mother Theresa

and my beloved sons Luca and Andrea

To my dear friend

Simone Buhagiar

Your smile lives on in my heart

"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"

~ Virginia Woolf, (1953)

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Glossary

Autoimmune illnesses occur when the body's immune system attacks and destroys healthybody tissue.

Chronic illness is the lived experience of the individual and family diagnosed with chronicdisease (Larsen, 2014).

Chronic diseases are defined as conditions that persist for more than 3 months or longerand require ongoing medical attention.

Contested conditions: contested conditions' is used to signify illnesses of controversial scientific status in which the patient experiences distressing physical symptoms but there isusually an absence of physical signs, clinical explanation, or medical diagnosis (Bendelow,citied in Fernandez, 2020, p.23).

Fibromyalgia (FM) is characterised by chronic widespread pain, unrefreshing sleep,physical exhaustion, and cognitive difficulties (Häuser & Fitzcharles, 2018).

Medically unexplained symptoms (MUS) is an acronym in popular usage in the medical and social science literature is perhaps more neutral and less stigmatising than psychosomatic symptoms, but still identify illnesses or syndromes, which cannot be definedin terms of organic pathology and are thus seen as abnormal and low in "illness hierarchy" (Bendelow, citied in Fernandez, 2020, p. 23).

Multiple sclerosis (MS) is an inflammatory demyelinating disease of the central nervous system (CNS). The underlying immunological abnormalities in MS lead to various neurological and autoimmune manifestations. There is strong evidence that MS is, at least in part, an immune-mediated disease. (Wootla & Rodriguez, 2012, p.1).

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a complex, chronicautoimmune medical condition characterized by fatigue and malaise that is worse after exertion, cognitive and immune dysfunction (Bested & Marshall, 2015).

Myasthenia gravis (MG) is an autoimmune disease characterized by muscle weakness andfatiguability of skeletal muscles (Lazaridis & Tzartos, 2020).

Rheumatoid arthritis (RA) is a chronic autoimmune inflammatory joint disease characterized by bone and joint destruction (Tobón et al., 2010).

Ulcerative colitis (UC) is a colonic disease characterized by chronic inflammation (Attalla,et al., 2019).

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It has been a long journey, interrupted by the COVID-19 pandemic and life itself. I could not have completed it without the help and support of many to whom I am grateful. I am thankful to the University of Malta (UM) for part financing my doctoral studies. I wouldalso like to acknowledge the Department of Counselling, the Faculty of Social Wellbeing aswell as the Department of Nursing, the Faculty of Health Sciences (UM) who provided the opportunity and supported my interest in pursuing my doctoral study.

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Lastly, but by no means least, I wish to thank the four women collaborators for agreeing to participate in my study and for sharing their stories. I am also grateful to other women who trusted me with their illness stories, both in my personal and professional capacity. Your voices have been heard and are valued – never forget this!

Prologue

Mystory…

No shame, no blame, no guilt,

A story of self and others.

I was 21 years old. I had just graduated from nursing school and was enthusiastic to start my career working as a State Registered Nurse in Malta's only general hospital, St Luke's. Unfortunately, the number of days working on the medical ward I was assigned to were very short lived as I was suddenly taken ill.

It was 29th June 1988, a Public Holiday in Malta, the feast of St Peter and St Paul, and the hot summer months had just started. All of my family had transferred to our summer residence near the sea, and I remained at home since I was within walking distance to the hospital where I worked. I woke up one morning to go to work as usual, but something was not quite right … as soon as I got up from the bed, I fell to the floor, my legs would not carry me. This was a very strange feeling! Why were my legs feeling fuzzy? Panic set in! I was petrified! I had no idea what was happening to me!

I vividly remember the warm tiled floor and how I had great difficulty reaching the fixed telephone set in the corner of the living room to call my mother since at the time there were no mobile or cordless phones. I remember how, in a matter of seconds my mind took me down memory lane. It seemed as if I was viewing a fast-forwarded film of patients I had cared for as a student nurse, patients who had *suffered symptoms similar to mine. It was very scary and puzzling!*

Within that same week we visited a neurologist privately, who provided me with a fast-track appointment. The neurologist logged my medical history and carried out a physical assessment. Following this, in an authoritarian tone, without any hesitation and form of empathy, the neurologist stated in a very conclusive manner, that it was probably Myasthenia Gravis. I was left numb. He was in a hurry; he had a party to attend and no time to answer questions. I was supposed to accept this information, pay, and leave the room quietly without further ado. It was all happening too fast, the world seemed to have stopped, I was weak and emotionally devastated. I couldn't believe that this is happening to me Why me? But then why not me? I felt numb!

I was hospitalised for further investigations, but I was immediately started treatment for Myasthenia Gravis. During my stay in hospital, consultants, medical doctors, and medical students referred to me as 'the case in bed 16'. The medical team spoke as if I was not in the room, as if I was deaf…. my presence seemed to be ignored, nullified, erased…. I felt objectified and invisible. My hospitalisation lasted about 5 weeks. The uncertainty and mixed messages were devasting. I was fatigued, my body ached, and I was suffering from hyper insomnia. The side effects of the medication left me feeling emotionally and physically broken. The lack of clarity and mixed messages were devastating and left me feeling vulnerable. On the one hand, Myasthenia Gravis was confirmed as my diagnosis and plans were underway for a thymectomy surgical intervention, whilst at the same time they could not make sense of the subjective and medically unexplained symptoms.

They associated my symptoms with psychological distress and insinuated that it was 'all in the head'. I felt betrayed, infuriated, ashamed, offended, and guilty.

It was as if it was all my fault and that I shouldn't be experiencing such symptoms. Their words and actions were not only hurtful but harmful too. All this did not make sense!

My family was not convinced of the diagnosis. They halted all plans for surgery and of their own accord and pocket, made necessary arrangements to fly me to the United Kingdom for a second opinion. We were secured a meeting with a professor in Oxford specialising in Myasthenia Gravis. I am aware that this is not the norm for most patients, and I feel greatly privileged and grateful that my family organised and funded the visit for this specialist without any hesitation. My parents are middle-class working people who always considered family, education, religion, and health as their top priorities. These intrinsic values formed the core foundations of us as a family unit. During the time of my appointment in the UK, many people were praying for my healing and wellness. The support from family and friends which I received was immense and very powerful. After many investigations in the UK, it was decided that I was not suffering from myasthenia gravis but post-viral fatigue syndrome (PVFS), also known as chronic fatigue syndrome (CFS) or myalgic encephalomyelitis (ME), an autoimmune invisible chronic condition. The latter is a condition I knew nothing about at the time and is a condition, which is still contested today. I was reassured that the symptoms I was feeling, that are the fatigue, the joint and muscle pains, the insomnia, the brain fog were synonymous with a known and now named condition. It was not 'all in the head' after all and it was not myasthenia gravis either!

PART 1

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Chapter 1: Setting The Scene – The Metaphor Of The Maltese Tile

The Maltese tile is specific and synonymous to the culture and context of Malta - embracing tradition, manifesting endurance, resilience, and survival. In this research study, I refer to the Maltese tile (Figure 1a) metaphorically. Each tile is synonymous to a memory, an experience reflecting a different story. Tiles might embrace similar features, colours, patterns but at the same time they are dissimilar and unique, just like the uniqueness of every story. Metaphorically, as a collective, the tiles represent the beauty of the bigger picture of collective stories, accumulated diversity, to create a larger whole, which is greater than the sum of its parts.

As a nurse, a counsellor and a reflexive researcher, my interest in researching women living with chronic autoimmune invisible illnesses in Malta is multidimensional. It originated from my situated understanding of the relationship between my own illness event coalescing with other illness experiences that I have witnessed with close family members and individuals who I have met in the therapeutic and medical field. *My*story is a true recollection of my own illness narrative and not a composite fictional story. Today, I am only moderately affected by the illness. In sharing my personal experience in an embodied, existential, and reflexive manner, I explicitly and intrinsically positioned myself at the core of the research, whilst implicitly locating the illness story within a wider context. Contextualising my position in this thesis ultimately guided my methodological choice. *My*story is not only my story of illness, but it was also aimed to serve as a ‘sensitising agent’ towards the collective narrative, be it oral, written or visual, of the ‘other’. Eventually, I also gathered the stories of four other women who live with a chronic autoimmune invisible illness. In listening to womens’ stories of health, illness, and chronicity, I anticipated that similarities and differences would be elicited, some of which would resonate with my own illness experience, whilst generating new knowledge and cocreate new stories.

Figure 1a

The Maltese Tile

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, most especially as a methodology in health sciences in Malta.*

This first encounter with my supervisor, destined new beginnings; the beginning of my doctoral journey, consolidating my research idea, the discovery of autoethnography, a form of narrative inquiry, drawing upon own experiences to examine the interplay between self and culture (Ellis, 2004; Adams, 2017; Bochner & Ellis, 2016), whilst also extending sociological understanding (Sparkes, 2000; Wall, 2008; Ellingson, 1998). This required a paradigm shift in my thinking, positioning, and conceptualisation of autoethnography as "a blurred genre that refuses categorization" (Holman Jones 2005, p. 765). I was novice to this notion 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 came to understand autoethnography as "a process and product [and how it uses] tenets of autobiography and ethnography to do and write autoethnography" (Ellis et al., 2011, p. 273). As I started to gain further knowledge on how to represent self-stories, I gained clarity, and this clarity has grown throughout the work that I have carried out on this doctoral project.

Laurel Richardson (1997, p. 1) asked how "specific circumstances in which we write affect what we write, and how, what we write affects who we become". To answer these questions, I needed to critically reflect different stages of my thinking and writing, using systematic introspection and emotional recall (Ellis, 1991) to generate new knowledge, in the process aspiring to broaden meaning within and beyond the context of the experience (Ellis, 2007). I do this in the writing of my doctoral study by evocatively combining narrative knowledge and pragmatic knowledge (Bruner, 1986). Furthermore, Grimshaw (1986) stated that “the reconstruction of knowledge is inseparable from the reconstruction of the self” (p. 164). In this process, besides continuing to invest in self-exploration and professional development, I hoped to provide the women with the opportunity to re-tell their illness stories as they continue to experience them. Most importantly, I hoped to be able to expose and honour the particularities of self and others living with chronic invisible illnesses in smaller countries and communities, specifically in Malta. In presenting the stories of living with chronic illness by adopting an evocative autoethnographic approach, a first of this sort in my country, I was aspiring towards the experience being transformative in its nature, both for the writer and reader. This was done in the hope of activating social change by bringing the individual stories together, to create a sense of ‘collective consciousness’ in the community (Etherington, 2020) for voices to be heard.

Origins, motives, and research idea

Researchers have identified different motives to why individuals decide to start a Ph.D. namely: a vehicle for enhanced career and credibility; an affirmation of self-worth and self-determination; an opportunity to explore and pursue topics, such as illness or for empirical and intellectual achievement (Numerof & Abrams, 2004). Although I might relate to some of these motives, none seem to fit well with me. My motives spanned from having an avid inquisitiveness to continue to invest in personal and professional development and being deprived from the opportunity to follow tertiary education in the 80s in Malta. At the time, measures implemented by Labour government against Catholic church schools (see Figure 1b) with the slogan *Jew b’xejn jew xejn* (translated from

Maltese to English as *free or nothing*) and the 20-point system discriminatory approach against such schools, together with the *numerus clausus* (translated from Latin to English as *closed number)* on most university programs, deterred my possibility to continue formal education at the University of Malta. Since I attended a Catholic school, opportunities for furthering education were impossible and alternative educational/career pathways and options were very limited to namely, nursing and banking. I chose nursing. I have been working as a nurse in the Primary Health setting since 1988. Looking back, I am grateful for the experiential learning gained whilst working as a nurse in community settings, both in the public and private setting. The reason for this is that this experience continued to fuel my motivation and interest to *never give up*, in turn culminating to pursue further tertiary education as a mature student in counselling. In 2016, I was assigned a lecturing post with the department of Nursing, Faculty of Health Sciences, University of Malta. Subsequently, I started my doctoral research with the department of counselling, Faculty of Social Wellbeing about women living with an autoimmune illness. Wearing multiple hats, as daughter, mother, nurse educator, primary health care nurse, counsellor and a person who had been diagnosed with CFS/ME, I embarked on this journey.

Figure 1b

A classroom

Genesis of research question

Prior to embarking on this specific research topic, I had explored other areas of study. I recall that revisiting my illness experience was not my first choice of preference. I had thought that my illness story was a story of the past. During the process of reflection on the genesis of the research question process, an *epiphany*, a dawning realisation seemed to materialise. Dawning is not only a re-labelling, but remembering the experience anew, whereby the emphasis of meaning changes, conceptualising it to 'what is happening now' (Beech, 201, p. 289) which, according to Goffman (1974) is similar to 're-keying' an experience. The experience implicitly and explicitly forms part of my life both on a personal and professional level.

The realisation of apprehending the role of 'time' was vital. The opportune 'time' had come, to revisit and to consolidate the illness experience, as well as interlinking the multiple identities that I embody during this journey - an insider, outsider, and in-between researcher. My current positioning and understanding informs previous experience, in the same manner that the original experience becomes the motivation for researching in the first place (Muncey, 2005). As Kierkegaard (1957, as cited in Muncey, 2005) suggested, life must be lived forward but can really be understood only backward. My research represents a reiteration of looking backward and looking forward, exploring memories, events and images guided by experiences, and reflections of self, others, and culture. Shim (2018) noted that it is only when enough distance from the lived experience has been established, that the researcher becomes empowered to share the story. In sharing the embodied experience, I, the researcher, became the story (Ellis, 2004). However, I could only relate now because time had elapsed from the experience, thus establishing distance, gaining emotional maturity and preparedness, to make sense of it with more clarity and openness (Ellis & Bochner, 2000).

Pre-existing expectations and personal conceptions of the actual experience served as my guide when entering this new research milieu. Although I was set on the research question, I still experienced a lot of uncertainties. I was confident that I no longer wanted to remain distant, removed, neutral, disengaged, “above-it” (Ellis and Rawicki, 2013) just like traditional and positivist type of research would have it. It was as though I was seeing light for the first time, both as being fully immersed, and also from a meta position, by viewing life experiences in retrospect through the presence of the *now* (Bochner, 2016). I became curious to understand the relationship of illness intersecting between, across and alongside the different variables of the cultural envelope. I embraced, rather than rejected, the epitome of illness beyond medicalisation. I wanted to explore the wider meaning of living with invisible chronicity rather than focusing on one specific condition. Specifically, I wanted to obtain a clearer understanding of what it means for women to live with a chronic autoimmune invisible illness.

Although I vaguely knew what I aspired to achieve through this project, I was not fully aware of the deeper meaning of my research focus. McLeod (2015, p. 33) stated that the meaning of any potential research idea is always embedded within a complex web of social, interpersonal, as well as personal relationships and meanings. Research ideas are born from four main sources: existing literature, policy and practice initiatives, personal contact or personal burning questions" (Mcleod, 2003 pg. 2). Similarly, Bochner (2001) challenged "the myth that our research is divorced from our lives, that it has no autobiographical dimension, that what we do academically is not part of how we are working through the story of our own life" (p. 138). Researchers from across the social science disciplines mainly counselling and psychotherapy (Etherington, 2004, McLeod, 2015) and sociology (Ellis, 1996; Ellis & Bochner, 2000; Sparkes, 1996) noted the links between life experiences and research. The birth of a research idea is multidimensional and multi-layered, primarily attributed to first-hand experience as a patient and secondly through reflexivity upon experiences, memories and observations situated from witnessing others.

The research question

The research question guiding the project is: *What are women's experiences of living with a chronic autoimmune invisible condition in Malta?* To address this question, I hoped to provide a space where women would feel validated and comfortable to share their illness stories as collaborators in this research rather than a form of data source. My aim was to look beyond the 'medicalisation' and pathology of a specific chronic disease, thus, beyond the biomedical aspect of the physical body. Instead, I was interested to understand how the women embodied the illness experience. The body, not just being what is enclosed inside the skin envelope (example different body parts), but even more so, acknowledging the interaction it has with others, the environment and society at large (Keane, 2008). Besides the attributes (characteristics), the antecedents (background) and the consequences of living with chronicity, I hoped to delve deeper into the psychological and cultural aspect of living with chronicity, the feelings, and emotions alongside the identity constructions that are specific to the cultural context of Malta. In asking this question, the ultimate intention was not to generalise but to provide a platform for stories to be told and others co-created. It is hoped that a deeper understanding on how intersecting factors of culture, age, gender, and beliefs influence and/or affect meaning, identity, and the embodied emotions is gained. Campbell (2017) captured an apt description of my journey, maintaining that "[w]here 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).

> *As I immerse myself deeper into the different layers of this project, I also expose different layers of self. I continue to ascertain the non-linearity of this process but embrace it as being dynamic and a continuously evolving one. Looking back at my early days of this journey, I realise that my initial research aims, were only a point of entry, written from a personal standpoint of what I thought and believed I knew. However, I soon realised that this was only the tip of the iceberg. The complexity, the breadth and immensity of this research, was much greater than I had originally envisaged, much more than that which could be read in books. Living and embodying this experience went far beyond what other people's words could capture.*
>
> *Metaphorically speaking, during the process of this journey, both on a personal and professional level, I compare my journey to the famous novel of Alice in Wonderland (1865) into the dark hole. It feels as if I am stumbling and spiralling into a 'dark hole', both in the thoughts and in the writing of my doctoral thesis, fearing the unknown, continuously moving (even when I felt stuck, I was moving) through space and time into the depth of this abyss. My straitjacket (intrinsic internal script)*

> *protects me from the cold and the sharp edged, humid rocks but at the same time suffocates and sabotages my freedom to explore untrodden spaces. My baggage is strapped tightly across my body - packed with experiences and some knowledge of health and illness, fears, uncertainties, mixed emotions but also hope and resilience. I am uncertain as to where I am going, which direction I will be taking. However, I feel I am constantly embodying and trying to make sense of the unfolding revelations of different realities, truths, and emotions during the trajectory.*

Research aims of the study (revisited)

This section highlights the research aims that acted as the driving force behind address the key research question of this study. I felt the need to revisit the aims I had written at the start of my doctoral study due to the development of my research and writing process. In this manner, I continue to embrace curiosity and a less known position. Some years down the line, in gaining more agency, I became less defensive and more evocative about the research focus, the aims, and the chosen methodology. The research aims of this study are:

- To provide a platform for women's stories of chronic autoimmune invisible illness to be told and made visible;
- To explore attributes (characteristics), antecedents (background) the consequences of living with invisible chronic illness;
- To delve more deeply into emotions, at the intersections of gender, values, beliefs, culture, health, and illness; and
- To embrace vulnerability, to understand the process of becoming and knowing self and others as a form of healing and transformation.

Sketching the framework

In the initial phases of my research, I sketched a rough map (Figure 1d), of what I thought could be the basis of my framework for this research project. In doing so, I realised that I was also documenting layers of self. Initially, I visualised the genesis of my research focus as a flat spiral circle with the *I* situated at its core continuously evolving, embracing memories, experiences and multiple selves in the process. However, during the research study, the image of the spiral pattern around the central axis called *columella* (Figure 1c) on a snail calcareous shell better represented what I was doing, documenting, and creating. Just like we construct different narratives and multiple layers of self, the shell of a snail, constructs different layers, which circle around the axis of the *I*, columella at the centre.

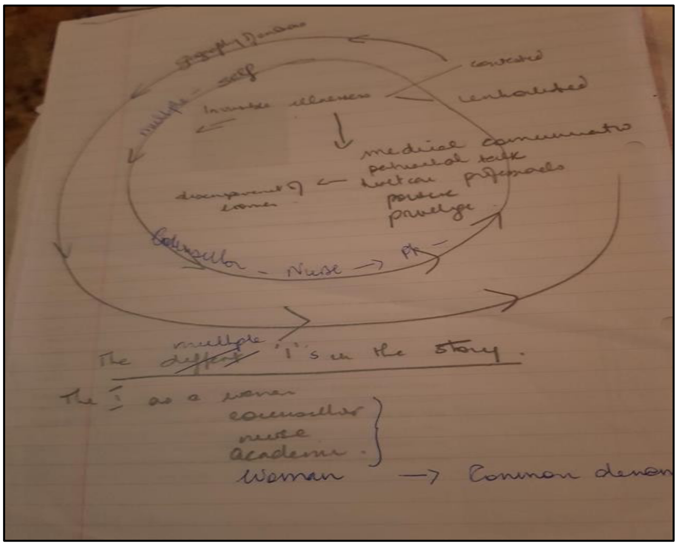
The different layers are representative of the different experiences, meanings, the multiple selves, and identities intersecting with other factors, including environment and culture, values and beliefs that influence and shape us over time. Similarly, as *my*story, alongside the women's stories, continued to unfold on the page, I realised how, as opposed to traditional objective research, subjective personal views and beliefs were intrinsically intertwined in my research process. Upon reflection, questions in relation to self and to others kept resurfacing, including: *Do women illness stories matter? How does culture, gender, beliefs, and age intersect with this research?* Women's subjectivity in relation to illness symptoms continue to be doubted and silenced, including ME/CFS, and fibromyalgia. The only difference between the time when I was unwell and now is that, nowadays there is more awareness, and communities are using different platforms to sound their voice, for instance through social media platforms, as well as through support groups and associations. Having witnessed care from both sides of the fence, meaning as a receiver and as a provider of care within a bio medical system, I strongly believe that each individual and their respective illness story matters. This belief underlines the research work that is presented in this thesis.

Figure 1c

The columella

Figure 1d

The columella sketch



Emancipation from the shadows

Presenting in the European Congress Qualitative Inquiry (ECQI, 2018) Scotland was the first conference where I shared an autoethnographic paper about my autoethnographic journey using the metaphor of the Maltese tile. When presenting this paper, I felt as if I was transgressing all comfort zones. During the conference, I attended as many autoethnographic sessions as possible. I wanted to hear more, to learn more about the writing and the performance of autoethnography. I specifically wanted to attend an autoethnography session chaired by Jonathan Wyatt. It was a majestic room full to the brim with students and renowned people from the field of autoethnography. The audience were captivated by the stories that were being told, very well- articulated by the presenters - a great performance. I was so grateful to be there, I felt a sense of belonging in this community. Three women had just finished their presentations – evoking emotions whilst generating a lot of thinking – the silence in the room could be heard.

Every time I attend such conferences (virtually and in person), the sense of belonging becomes stronger, and faces become more familiar. Paradoxically, at the same time, I recall feeling my 'straitjacket' becoming tighter. It was no different this time round. I felt I was suffocating. Is this projected anger? Displaced emotions? Emotional confusion? It was emotionally exhausting! However, at the same time, these same emotions generated hope – the hope that one day I would find the courage and ability to 'speak out', in a way wriggle myself out of this straitjacket and free myself, whilst giving myself the permission to be a misfit if that is what it takes… to be different, to be active in speaking, telling [un]tellable stories, my own and other people's stories. Speak vulnerability with agency.

I walked out of the room; my emotions seemed to have been shaken to the core! So much more seemed to be happening inside me beyond awareness. I could not breathe... I needed air. Is this the same 'SHARAM' – (shame) that was being spoken of? Shame of what? Or was it something else?

Walking back to the room where the sessions were running, I saw myself in the shadow walking before me, my shadow was becoming more visible. It dawned on me how, as a person, I always preferred to remain in the shadows, to remain invisible and yet, ironically, in using autoethnography, I am explicitly using a way of writing that exposes my invisibility. I do this consciously and without hesitation, similar to what needs to happen for women to come out from the shadow, to overcome invisibility in illness and of self - to become more visible? The shadow of a woman's face is blurred, identity is unrecognisable, however, it is not fictitious but real.

….my shadow walks before me, behind me ...
becoming smaller,
the road more visible and clearer,
time to come out,
time to come closer
to be Explicit…

Thesis breakdown

This thesis is being presented in three main parts. During *Part 1*, I presented *my*story of illnesses that sets the scene for this thesis. I introduce and present the background to the research focus, together with a review of literature of the cultural envelope and illness. I present a background of health and well-being, dovetailed with foundational aspects of chronic invisible illnesses experienced by women in Malta. The research approach and ethics are discussed in detail. The reader is walked through the process of conducting the research and the representation of the stories. Moreover, the *Part 2* of this study consists of the (re)presentation the stories in found poetry format using the women's own words. Here, I present and discuss material elicited, whilst navigating and thinking with stories shared, co-creating other stories alongside my own. During *Part 3*, the final part of this study, I draw the thesis to a writing close. In this part, I had the opportunity to sum up the main and most prominent patterns and present a collage of reflections elicited from collaborative and evocative work. The implications, knowledge limitations of this study are highlighted. Furthermore, a collage of reflections and reflexivity are presented to acknowledge the experience, the strengths, the doubts, the dilemmas, and the transformational process revealed through the writing.

Establishing terminology used

From the start, I grappled with using certain terminology and concepts that are used in conventional qualitative research (St. Pierre, 2018). Therefore, it is important that these are addressed to provide context and clarity to the language used throughout. Instead of the term *interviews,* the word *conversations* seemed more apt, and this specifically refers to the specific conversations that I had with the women involved in my study. Moreover, the more common term *participants*, that been modified into *collaborators* to emphasise the fact that the women's contribution to this study carried equal importance and ownership in the stories, humbly and bravely shared. Lastly, instead of *data*, the term material (see Chapter 5) was used. At times, however, the more common (conventional) terminology was used due to literature sources using them within the published studies. Similarly, the word *reflection* refers to recalling memories, whilst reflexivity delves deeper by critically analysing these experiences. Whilst both are used, it is important to note that they build on each other and work intrinsically, without eliminating each other.

By using an autoethnographic framework, more specifically an evocative autoethnographic approach, I present *my*story and the women's stories using different patterns, fonts, and formats. To create an overall, more visually aesthetic presentation, the following differentiations were drawn. Academic writing is presented in *Times New Roman (font 12)*, whilst my own reflections and poetry formatted entries are presented in *Calibri (font 11)* idented and italicised. Lastly, the woman's illness stories are representing in poetry format, yet presented in *Arial (font 11)* centred and italicised. In addition, periodically, the text is illustrated creatively through images, sketches, and poetry to emphasise the idea resonant to autoethnography of *showing*, not just *telling* (Ellis & Bochner, 2016; Denshire, 2014; Ellis et al., 2011).

Mind the gap!

In preparation for this study, I researched and read extensively through the literature relating to chronic disease and illnesses. The research in health and illness has always been at the interface of science and life. It has always been a topic of major interest, since illness *e*(a)ffects every one of us, without exception, at some point in time in our lives, no matter the age, sex, gender, or culture. Research on chronic illness is immense and presented in different forms, mainly scientifically, socially and/or through personal accounts adopting different methodologies and designs. A preliminary literature search was carried out mainly using the University of Malta (UM) resources and its e-library online access facilities. Furthermore, an online search for academic articles and dissertations submitted to date at UM was carried out. The search engines and databases accessed through UM e-library included: Hydi, ProQuest, JSTOR, Sage, EBSCO, PsychoInfo, Springer and Wiley online Library. Besides, ResearchGate, Google Scholar and Open Access to international dissertations were also accessed. Further literature was located through the manual search of reference lists, bibliographies of retrieved sources and related books that helped in understanding the topic in a more expansive manner. However, although a vast body of research on chronic illness exists both internationally and nationally, evocative autoethnographic studies on chronic illness remain limited even though “autoethnography is gaining acceptance as a legitimate research method in health science research” (Chang, 2016, p. 443).

Within the context of Malta, autoethnographic studies specifically related to women living with chronic autoimmune invisible illnesses were not found. The outcome of the search on chronic autoimmune invisible illness in Malta was very limited. The located studies included: spiritual coping in rehabilitation (Baldacchino, 2010, Baldacchino et al. 2013a, 2013b), self-management in diabetes (Buttigieg, 2016), fibromyalgia (Xhaxho et al., 2017; Farrugia, 2019), chronic pain (Portelli and Eldred, 2019), ulcerative colitis (Sammut et al., 2015). Ellingson (2016) stated:

> The erasure of researchers’ bodies from conventional accounts of research obscures the complexities of knowledge production and yields deceptively tidy accounts of research. Qualitative health research could benefit significantly from embodied writing that explores the discursive relationship between the body and the self and the semantic challenges of writing the body by incorporating bodily details and experiences into research accounts (p. 298).

Such *erasure of researchers’ bodies* was noted in the located literature pertaining to Malta. This research study sought to address this gap in the specific context of Malta. Ellingson (2006) stated that after more than a decade of postpositivist health care research, and an increase in narrative approach and writing practices, social scientific, qualitative health research remains largely disembodied. Researchers continue to remain in the shadows. Internationally, autoethnographic health research on chronic illness is also very limited. Some autoethnographic studies that have been carried out with regards to chronic illness include long-term cancer (Ellingson & Borogka, 2018), embodiment, cancer, and pain (Ellingson 2006, 2017), chronic kidney disease (Richards 2013), inflammatory bowel syndrome (Defenbaugh 2008, 2011), and chronic fatigue syndrome/myalgic encephalomyelitis (Farrell Delaney, 2020). As noted above, no autoethnographic research focusing on chronic illness were located in Malta. The gap in research and knowledge that relates to women living with chronic autoimmune invisible illnesses, using an autoethnographic approach, was identified through the literature search carried out for this thesis. I did not focus on one specific condition because my interest goes beyond the medical and pathological aspect of the disease.

In the next chapter, in line with the metaphor of the Maltese tile, I present different tiles as a background to the research focus of this thesis, including the Maltese cultural envelope intersecting with health, illness and women.

Chapter 2: The Maltese Cultural Envelope And Chronic Illness

This chapter delves into research literature to provide better insight of the lived experiences that women with chronicity face in Malta. The aim is to generate a more profound understanding of chronic illnesses and its intersection with elements that comprise the cultural envelope (see Figure 2a), including gender, culture, religion, body politics and emotions, across time and space in the form of narrative. In figure 2a I present snapshots of Malta and Gozo that are synonymous with our traditions, beliefs and identity.

Figure 2a

The Maltese cultural envelope

From the beginning, I was intrigued to better understand what living with chronicity meant for women in Malta, whilst also focusing on the embodiment of the illness and the emotional trajectory. I was interested to explore the geography of emotions, the shifting and bargaining of self and identity, the impact of these factors and the meaning given by the four women collaborators, alongside my story as participant in research. Therefore, I refused to focus on the pathology or medicalisation of a specific chronic autoimmune invisible *dis*-ease.

As from the start, I was more interested to understand the impact of invisibility and the chronicity on the person rather that the scientific aspect of the disease. Autoimmune illnesses are characterised as conditions where the host's immune system mistakenly attacks itself (Angum, et al., 2020). Incidentally, just like the metaphor of the tile I use in this thesis, where different patterns (stories) come together to form a new design, similarly the different factors that might contribute to the development of autoimmune conditions come together to form the *mosaic of autoimmunity.* A term originally used by Shoenfeld and Isenberg (1989) which refers to the interactions between genetic, hormonal, immunological, and environmental factors in the etiology of autoimmune invisible illnesses. There exist about more than 80 different autoimmune illnesses and often symptoms overlap making them difficult to diagnose (Watson 2019).

Myasthenia gravis, rheumatoid arthritis, inflammatory bowel disease and multiple sclerosis are recognized autoimmune illnesses that could be scientifically and objectively diagnosed. Recent scientific evidence shows that both FM (Kingsland 2021) and ME/CFS (Klimas 1999) are linked to immune systems. Both are disabling conditions without "objective diagnostic tests, clear-cut treatments, or established etiologies" (Sotzny et al., 2018, p. 602), rendering them i*nvisible*, and thus considered for this research.

My initial primary search was broad to gain knowledge on the topic prior to focusing on the specified research area. The most common keywords searched included: autoimmune, invisible, contested chronic illness, women, autoethnography, narrative, storytelling, and their respective synonyms. In the secondary search, I specifically focused on intersecting factors in relation to chronic illness mainly gender, culture, body, emotions in relation to illness. A comprehensive overview of the health and illness is given, followed by the presentation of main intersecting factors of chronic illnesses and women. Initially, an open search without limiters was carried out. Although peer reviewed articles published in the last ten years were valued, literature prior to that date also served as a value source due to the uniqueness of the stories. Despite their older publication date, the stories that were deemed relevant to this study were still considered valuable. The literature search was international, that is there was no selection of specific region or country. Although the study is intended to focus on Malta, the participants could be international, therefore not necessarily of Maltese origin, however, were required to be living in Malta.

The western paradigm

The definition of *illness* seems to fall under two main distinct agencies. Radley (1994) suggested that on the one hand, there is 'biomedicine' that adopts the methods of natural sciences and believes that the origins and treatment of disease are understood through concepts derived from physiology, anatomy, and biochemistry. On the other hand, Burr (2003) argued that there is the acceptance that psychological and societal factors can influence the susceptibility to disease. This interface embodies both personal and the political meanings. On conveying the personal meanings, illness becomes more realistic and intimate. The uniqueness of each woman, in this project and beyond, influences but does not revolve around the respective interpretation of the illness experience. I came to realize how interpretation is also influenced by our Maltese social and cultural aspects, which consequently are shaped and continue to shape our identities across time and space of the illness trajectory. Furthermore, the political aspect of illness in turn, embraces the medicalisation of illness and its structurally assigned expectations. Nevertheless, *my*story alongside women's personal experiences and how they are linked (directly or indirectly) to other women experiences was taken into account, which in turn were linked to a broader politics (Holman Jones, 2005).

Often, health and illness discourses are presented in binary thinking, that is either health or illness, abled or disabled, and normal or diseased; dualism that often "plague the western thought" (Moss & Dyck, 2002, p. 13). However, I tend to oppose this binary thinking, as if all were either black or white, good, or bad, rational, or irrational, thus eliminating the possibility of grey areas, which do not necessarily fit anywhere in particular. In view of this, I adopted a multi-dimensional lens and multi-layered focus for this project, shifting from dichotomous thinking to explore the liminalities and the areas in between, including mind and body, in turn, harvesting a broader and deeper understanding of my research focus.

Women and chronic illness

From the 1950s and 1960s, chronicity was reconstructed as a new experience, made up of a new set of expectations, dilemmas, and negotiation (Hankivsky, 2012). Chronicity has ever since become an integral part of our lives. The term 'chronic illness' is used by many and carries different meanings and inaccurate definitions, making it more difficult to specify and determine its social impact (Sidell, 1997). Demographic changes have incited a substantial growth in chronic illnesses today (WHO, 2005; EU Commission, 2012; Ambrosio et al., 2015). Both the World Health Organisation (WHO) and the European

Union (EU) identified that those chronic diseases are the leading cause of mortality in the world, representing 60% of all deaths worldwide, which is a burden not only on patients and their relatives' lives, but also on society. Furthermore, the WHO Global report (2005) indicated that out of the 35 million people who died from chronic disease, 50% were under 70 years old and 50% of these were women.

It is important to note that the EU has no legislative power in health. The organisation and financing of health care is the responsibility of national governments. In Malta, people living with chronic illness have been defined by the National Statistics Office (as cited in Cooke, 2014) as those with a "permanent condition that may require a long period of supervision, observation or care". The National Statistics Office (as cited in Cooke, 2014) also stated that "[o]ne fifth of the island's population suffers from a chronic condition". The census does not provide a breakdown of chronic diseases or gender. However, chronic health problems were especially prevalent among the elderly, with more than half of census respondents aged 70 and over declaring that they suffered from such conditions. Recognised, uncontested, chronic conditions in Malta sum up to eight-four (84), which include fibromyalgia and ME (Cooke, 2014).

Research has shown that women with chronic illness report more symptoms and poorer physical health than men and that women enter the health care system later and sicker than their male counterparts (Neil & Morrow, 2001; Read & Gorman, 2010). It has also resulted those men and women experience chronic illness symptoms in different ways and that a possible reason for their increased morbidity and mortality is related to the gender differences in interpreting and managing symptoms (Neil & Morrow, 2001) within one's own cultural identity. Furthermore, Kralik (2002) reiterated that the impact of chronicity in both men and women depends on both intrinsic and extrinsic factors. Women living with chronic illness described dealing with their illness as being a complex and profound life event, involving an ‘extraordinary’ phase of turmoil and distress and an ‘ordinary’ phase of learning to integrate chronic illness into their lives. There seems to be a gap in analysed research, most especially relating to factors that influence women’s system, perception, and response (Moss & Dyck, 2002), even more so, autoimmune invisible chronic illness in the Maltese context.

Researching women’s illness experience was a consequential choice due to my own embodied illness experience as a woman. By no means was it meant to ‘erase’ or undermine men’s experiences – men living with chronic illness might manifest similar or different experiences and challenges. There is growing recognition within the health sciences that gender awareness is crucial to avoid gender bias in research (Hammarström et al., 2014; Bondi & Fewell, 2017).

In the 1970s, health and illness were of vital concern to feminists and medical sociologists. Incidentally, it was in that same timeframe, that is between the 1960s and 1970s, that women’s liberation movement, sought equal rights and opportunities highlighting a greater personal freedom for women. Besides the legal right to vote, the women’s rights movement included politics, work, the family, and sexuality (Burkett, 2020). It was the time when they also distinguished the biological from the social – in feminist terms sex from gender (Annadale, 2005). Furthermore, Annadale (2005) noted that although vast research has been carried out both in the feminist and medical sociological field, gender is still everywhere and nowhere (p.62). Annadale also argued that feminists claimed that gender is a social construction, meaning that our ideas about gender are not predetermined by our biological sex differences. Gender meaning is inscribed onto women's and men's bodies and minds through past and present medical discourse, that eventually also influences interpretation, meaning and behaviour.

A qualitative study, involving in depth interviews carried out by del Mar García-Calvente et al. (2012) in Spain, analysed different perceptions by women and men, from different social backgrounds and ages, regarding their health, vulnerability and coping with illness. They discussed the main representations of both sexes to explicate determinants for gender inequalities in health. Results showed that women appraised their health as being weaker than men, many a time relating it to exhaustion. However, men tended to misconstrue their health, to honour the orthodox 'tough guy' stereotype representation of masculinity. Ironically, both males and females are socialized to believe that women are more vulnerable, whilst men are weaker at coping with illness echoing the paradox of 'weak but strong women' and 'tough but weak men' (Anderson, 2008). Men used biological arguments more than women, centred on the female reproductive cycle. Women used more cultural models and identified determinants relating to social stratification, gender roles and power imbalances (del Mar García- Calvente et al., 2012). In conclusion, gender constructions and socio-cultural influences impact the health perceptions of both women and men at any social level or age.

A study by Dahlin and Harkonen (2013) explored gender gaps in subjective health in 28 European countries measured by reports of self-rated health and of limiting longstanding illness. Subjective health measures are commonly used as summary indicators of health, which predict mortality independently of many objective measures (Idler & Benyamini, 1997). Results have indicated to cross-national differences in gender gaps in subjective health, which proved hard to elucidate. Although individual level socioeconomic and demographic variables explain the gaps in some countries, the cross-national differences in the gender gaps remained. Findings reflected differences in European women's and men's health, although cross-national variation in reporting styles was also noted. Cross-national differences in women's socioeconomic position did not account for differences in gender health gaps. However, it was noted that, in some countries more than others, variables were deemed more important, possibly inferring that women's position can be less beneficial in some contexts due to inequalities in other spheres, such as caring and housework. This has highlighted the need for incorporating additional appropriate variables in future studies and analyses.

According to a report issued by the European Institute for Gender Equality (EIGE, 2016), the Gender Equality Index developed by the European indicated that Malta is fairing midway (46.8% out of 100%) with regards to equality between women and men. Malta ranks in 16th place when compared to the other 28 EU Member States. Furthermore, the gender equality score in the domain of health is high. There seems to be a satisfactory gender balance in access to services and overall health status in Malta. However, differences in health-related behaviours of women and men are not accounted for and will be added to the Gender Equality Index in the future to provide a more complete picture of gender equality in health.

Blaxter and Paterson (1982) stated that working class women described themselves as *healthy* if they were able to go to work and perform their usual everyday activities. They saw common ailments and *women troubles* as just part of normal life and reserve the term *illness* only for serious conditions. Similarly, Jackson (2019) in her seminal book Pain and prejudice: a call to arms for women and their bodies presented different studies that showed how untreated menstrual pain can progress to chronic pain. She ascertained that the implications are not only medical but affect society at large. Moreover, Jackson also stated that “[t]he messages that period pain is normal and the afflicted should suffer in silence are potentially setting women up for a lifetime of pain” (p. 429). She continued to state that normalising such pain could in turn, contribute to the delay going to the doctor and consequentially infer diagnosis. The main reasons why women delay going to the doctor included family, relational and caring responsibility, work, and employment; The socio- cultural beliefs and the normalization of pain silences and deters complaining; they fear that they won’t be believed. Furthermore, Jackson (2019) states that women have been socialised to gain self-worth through pleasing others, so focusing on their own health may be viewed as selfish, particularly when they’re caring for other ill family members.” (p.429). A person was not considered ill if they got on with their lives and did not dwell on their symptoms (Burr, 2003). Therefore, the interpretation of illness is not so much the experience of symptoms as the reaction to symptoms (Hardey, 1998, p. 33).

This becomes even more complicated when women suffer from invisible and/or contested chronic illnesses, when bodily functions fluctuate and become not so obvious to many people (Moss & Dyck, 2002). According to Parker (2018), for many individuals, including health care professionals, invisible illnesses might be classified as ‘deviant’ in behaviour, and may cause medical professions’ irritation and loss of power when faced with ‘pathologies’ they cannot track and remedy (p. 8). In turn, ‘patients’ might lose their ‘sick role’ identity, a theory developed by Parsons (1950). The concept relates to the social aspects of becoming ill and its’ related rights and obligations. On the other hand, Parker (2018) described illness as deviant since health is largely important for a functional society – which thrusts the ill person into the sick role. However, by the 1990s, the concept was contested and had almost disappeared from the research literature. Beyond the generational and theoretical changes that showed the irrelevance of the concept, two key factors were elicited: the negative politicisation of the concept and the shift of medical sociologists to a focus on applied health behaviour (Burnham, 2014).

Invisible chronic illnesses, labelling and diagnosis

Conrad and Baker (2010) argued that invisible contested illnesses are a category of disorders that "have particular social or cultural meanings attributed to them" (p.69). These are illnesses that many physicians do not diagnose or recognise as being distinctly medical. Some autoimmune invisible chronic illnesses may also be contested, including chronic fatigue syndrome (CFS), which is also known as myalgic encephalomyelitis (ME) or post viral fatigue syndrome (PVFS), fibromyalgia syndrome (FM), irritable bowel syndrome (IBS), and multiple chemical sensitivity (MCS). These illnesses are generally medically contested because they are not associated with any known physical abnormality. In fact, invisible illness showcases the tension that exists between the lay person and medical health professional knowledge.

Chronically ill people's needs and medical complaints, as well as their bodies are often erased and ignored by the medical community and society at large, since they exist only as symptoms. If symptoms cannot be objectively measured and solved, medical professionals often dismiss them as non-existent or declare them to be 'all in the head'. Dismissing the symptoms of the ill body erases the subjectivity of the ill person – the body as a whole consisting of body, mind, and spirit (Edley & Battaglia, 2016). Building on Derrida's concept of erasure, Defenbaugh (2008) analysed not only the invisibility of the illness but evermore so, the invisibility of the chronically ill body, suggesting the following:

> I was surrounded by meaning that had no meaning in my body… terms represented me but were not representative of me... my symptomatically ill body was erased and

> replaced by medical terminology. Similarly, I felt treated as an assemblage of symptoms rather than as a person, I felt objectified, erasing any form of subjectivity of me as a person and reduced to a 'chronically ill word' (p.1404).

Oftentimes, medical professionals question the authenticity of the symptoms, the mental stability of the sufferer, and in so doing, burden patients even more as they seem to need to 'fight to get their illness' (Dumit, 2006; Conrad & Baker, 2010), indirectly fighting to get 'their illness identity' (Charmaz, 1995) recognised by the authorities, health care professionals and lay people in general. Additionally, invisible illness suffers are weighed down by the cultural meaning of a medically invisible condition in an era of high-tech biomedicine (Brown, 2007). A survey conducted by the American College of Rheumatology between 1990 and 2010 has shown that generalist doctors, and specialists have relatively poor knowledge on the diagnostics criteria of fibromyalgia, chronic fatigue syndrome. This continues to be reflected worldwide, whereby some doctors struggle to treat such patients. On the other hand, patients desire a medical diagnosis as confirmation that their symptoms are *real*. Diagnosis is central to medical theory and practice and manifests the existence and legitimacy of the condition (Brown, 1995) and thus, then again, differentiates between normality and abnormality. However, this is where I question the *dominant biomedical discourse* on how they consider health to be (ab)normal. *Against which criteria is this measured?* Dominant biomedical focus is challenged by many patients' accounts of their experience, illustrating that a biomedical diagnosis and treatment plan is a tiny element in what is needed for *recovery*. Recovery from illness is very far from becoming *whole again*, but recovering their *self* (Parker, 2018, p. 7).

Hence, labelling the 'disease' in conventional medical models is considered crucial not only for the health care professional but also for the person living with the illness condition (Conrad & Baker, 2010). It not only legitimises the illness, but also the treatment, the health services provision, certification for unemployment, compensation claims and lawful testimony, as well as legitimising both the suffering and the medical professionals themselves. Diagnosing, by default, is validating symptoms, whether they are seen or unseen, which in turn affects the access to health care systems, the acknowledgement and response of others to their illness, as well as validating the identity of the sufferer. Paradoxically, at times, the inability to diagnose creates uncertainty and lack of predicament, which could also be considered as a blessing, because it may create a sense of hope (Conrad & Baker, 2010).

My culture

Malta's community, like any other country or context in the world, has its own specific particularities. Malta (see Figure 2b), an independent European country is made up of an archipelago of islands, which covers an area of approximately 316km^2, with a population of approximately 442, 283 persons (Malta Population, 2021). Sciriha (2005) maintained that Malta is listed as having one of the densest populations in the world. Despite its smallness, Malta has played a prominent part in history of the world due to its specific geographical position, centrally located between Europe and North Africa. The Maltese culture, including the growth of its own language, Roman Catholic religion, beliefs and values, education, and political views have evolved over time under each successive ruler, finally celebrating Malta's Independence from the British Empire in 1964 (MAVM, 2022). Further to this, as a result of this Independence, Malta has now become much more globalised and multi-cultural, with an ongoing influx of EU and non-EU citizens migrating to Malta (Sciriha, 2005).

Figure 2b

Malta on the map

Malta is an island that oscillates between modernism and tradition. This is partly due to its relatively strong Catholic morality, conservative beliefs and kinship ties that make it an ambivalent location; however, other religions are freely practiced (Mitchell, 2002). There are more than 360 churches in Malta, which amounts to one church for every 1,380 residents of the island (Allen, 2022). The basilica of Our Lady of Mount Carmel is one of the different churches found in the capital city Valletta (Figure 2c). Notwithstanding the fact that the Maltese society is predominantly Catholic, it is important to note the recent changes in legislation with regards to the introduction of divorce, same sex marriage and civil partnerships (legalisation of same-sex civil partnerships, after the enactment of Civil Union Act in 2014, following the legislation of same-sex marriages in 2017), indicating a more liberal, more secular society (Visanich, 2018) and distancing from the previously conservative one. I was brought up as a Roman Catholic, as all the members of my family. When I was unwell and was taken to the United Kingdom by my family for a second opinion, half of the village where I resided in Malta, were praying for my healing.

Figure 2c

Basilica of Our Lady of Mount Carmel, Valletta (Shabbar, 2021)

The period when Malta became a British colony in the late 19th century and early 20th century since 1813 for approximately 150 years is a very significant era in Maltese history. The British legacy still lives on in many aspects of daily life in Malta today, so it is hardly surprising that business, laws, and education have British overtones. Malta and Britain continue to exchange reciprocal benefits in the areas of health and social benefits due to long existing bilateral agreement dating back to 1975, between the two countries. To date, Britain remains the first port of call for medical expertise and assistance when Maltese people require it. Even post Brexit, Health Minister Mr Fearne (as cited in Camilleri, 2016) stated that "bilateral agreement, dating back to 1975, which states that Maltese nationals who are living or visiting the UK are entitled to the same NHS services British people". This argument is supported by Saliba Haig (2016) who argued that "the status of a Maltese citizen resident in the UK or a British citizen resident in Malta will remain mostly unchanged in the sectors of health and social security".

While embarking on this project, I questioned the intersection between women, illness, and culture more profoundly, and found myself delving deeper beyond the micro and macro elements that I was accustomed to in understanding culture and space. Trying to make sense of *me* as a woman within my own cultural space was not a straightforward task. Making sense of the illness experience(s), both lived and witnessed, in relation to the cultural meaning and how this, in turn, influenced my broader understanding of culture, space, behaviour and cognition. This propelled my thinking further by comparing and questioning the self to 'others' both within and beyond our shores. In doing so, I draw on the cultural understanding of Ettore (2006) and Grant (2010) who maintain that culture is drawn to locate the self in the world, by connecting the personal to the cultural.

Moulding the latter understanding of *culture* with the Maltese tile, the individual pieces of the puzzle are made up of cultural similarities and differences that are to be valued as independent from the consequential impact on its overall meaning. I failed to see the broader picture of meaning, up until my own *cultural turn* started to unfold, as if the lights in the room where being switched on, one by one, enlightening and informing me. A sense of realisation and consolidation of past and present events viewed through the cultural lens started to gain momentum.

> *Reflecting … Remembering … Recalling*
>
> *As a child and teenager, I felt cocooned, protected, nurtured, and moulded in my own family of origin. The catholic church education which I received all throughout my primary and secondary education harnessed similar values, social beliefs and social norms which were very similar to my family practices. The ethos of the girl's secondary school was run by the Malta Province of the sisters of St. Dorothy, instilled in me amongst many other things the importance of love of God, caring, being responsible and trustworthy. Similarly, I was also imparted with the importance of reflection, respect, repentance for mistakes and forgiveness. These*

> *cores issues moulded me into that young woman in the mid-80's who believed to be readily prepared and skilled to face the world. However, on a wider National level, I felt deskilled and unprepared when competing in an educational system that was very much exam oriented, discriminatory, and limited for choice of subjects. I recall the cultural shock I experienced when I started nursing training education, my cocoon had been burst. I felt no longer protected. I was thrown in the deep end. I felt unequipped to voice my own views, to critically reflect, to train and work in different social beliefs and norms, to sound my voice. Many a time I felt I did not fit. I felt the need to fit… to relearn, learn to try and fit in this unknown environment…*

As stated earlier, my own illness event occurred just after I graduated from nursing school. On looking back, I realize how the illness incident somewhat broadened my world view, nevertheless, on another layer. It was another learning curve; my own cultural turn had started. This instigated me to revisit how I manifested my own cultural and spiritual values and beliefs over time and question how the transgenerational attributes influenced and/or determined my own behaviour, thinking and positioning. On locating myself within the wider cultural frame and induced into the historical context of Malta, I became a participant in the story rather than just being an observer, understanding the impact on the cultural identity, gender role expectations, assigned meanings and interpretation of events, as lived and experienced, was an evolving process; a seemingly, unfinished process of making and remaking of meaning.

Chapter 3: The Research Approach

Then …

A while ago, I attended a conference where students were presenting their academic work. A senior lecturer, a tall smart person wearing a white starched shirt and fine suit, walked up to me, and asked, "So tell me, what is your research all about?" I was pleasantly surprised and taken aback by this question, since he is usually a very reserved man. I started to explain my research topic and my interests about women living with chronic autoimmune invisible illnesses. I told him that I was interested in exploring the emotions and feelings experienced during the illness trajectory through an autoethnographic research approach. However, as I was telling my story, I realised that he was not listening. He was looking through, above and beyond me, hovering over my head, looking at the crowd, in a detached manner, lost in his own thoughts. His demeanour portrayed a privileged aura and seemed to engulf the immediate space.

Now...

I was catapulted back in time, to when I was initially misdiagnosed with myasthenia gravis; taken back to when the medical entourage were not listening to mystory, where ailments were considered subjective and where objective data was all that seemed to matter. I recall feeling confused, erased from my known identity. I remember how frustrated I used to feel; the ambivalence of needing a diagnosis, thus believing their narrative, whilst at the same time rejecting how I was being treated and labelled, and as a result, questioning myself about whether the symptoms I was experiencing were 'all in the head', whether I was to blame? Wearing my researcher hat, I contemplated how just like the invisibility of the illness, it seemed as if I became invisible once again. It seemed as if, once again I did not fit in any category established by the institutionalised systems –

Then.... just like a cold shower, out of the blues, in a rather high pitched, supreme, and patriarchal voice says: "Yes, that is exactly what we need, we need 'Real Research' … And not research that has to do with feelings and emotions". His body reflected his words, his fist was clenched, swinging his arm to a ninety degrees angle, tightening the muscles of his arm demonstrating strength and power to prove his point. I was utterly shocked. I realised that he did not listened to what I had said. He was not really interested. He had his own agenda. Once again, I experienced the same feeling of alienation, which swept me off my feet. Once again I felt that I was being silenced by a white authoritarian man. I felt belittled, obscured, erased. Words failed me. I choked. I lost my voice! I literally felt sick to my stomach – suffocating, straitjacketed once again. be it health or academia. I did not perform as expected as a 'patient' and was considered 'deviant' in my behaviour. Now it seems as if it was happening again … Am I not fitting into the academic world too as a researcher because my research was being deemed as not 'real research'? It felt as if I was looking through the looking-glass and seeing the image of (other) woman made up of different selves .... I could see, hear, feel, and embody the invisibility, the silence, the emotions, and pain starring back at me.

Is this real research?

This event evoked similar feelings and emotions on different levels, experienced at different periods of time and in different socio-cultural contexts. This recollection empowered me to delve deeper into intense and transparent reflection, questioning my position, values, beliefs, and cultural background (Trahar, 2006). I once again experienced the gendered nature of feeling silenced and vulnerable by the patriarchal overtones, this time emerging from a privileged academic space. I tried to make sense of this incident in relation to the research focus as a researcher and researched. Making sense and interchangeably linking this particular experience through the different layers of the personal, cultural, and structural levels was essential in mapping the framework of the philosophical and theoretical underpinnings of my research. These included issues around the use of language, culture, sexism and the gendered word (worlds) (Tarrayo, 2014); the cultural politics (Ahmed, 2012) of the gendered aspects of emotions (Locke, 2002, Pease, 2012) and stereotypical connotations of being ‘weak’; male privilege and hegemony emphasizing women’s invisibility (Clarke 1983), feeling erased (Defenbaugh, 2008) not only in relation to health and illness but also in relation to the gendered concealment in academia (Annandale & Clark, 1996) with regards to research focus and method and researcher- researched relationship and vulnerability (Råheim et al, 2016).

All this continued to reconfirm the dire need to look beyond the linearity and the traditional forms of doing research, herein referred to as ‘real’ research, but to explore and adopt an alternative approach that positions the researcher within the research itself, whilst providing “the space and platform for voices that are too often muted and/or forcibly silenced to be heard, opening up and democratizing the research space to those seeking to contest hegemonic discourses of whatever flavor” (Allen-Collinson, 2013, p. 282). To do this, I needed to factually look back using an ethnographic wide-angle lens, focusing outward on the socio-cultural aspects of these parallel personal experiences, whilst in tandem looking inwards, exposing a vulnerable self in the different contexts (Ellis, 2004, p. 37) in health and academia. Against this backdrop, I questioned the meaning of 'fitting in' within a community, institution, and societal context as a woman? Equally, I was interested in how other intersecting factors might influence complacency to master narratives, namely age, gender, religion, and culture. I was curious to know whether these factors had a role to play and if so, how?

Searching the roots and influences

From the outset of my journey, I was in search of a methodology that best suited the way I wished to present and address my research focus, whilst being able to answer the research question appropriately referring to illness experiences (my own and also those of others) and views on onto-epistemology. Like Etherington (2004) "my view of reality or the nature of being or what is, and my understanding of what it means to know are intertwined. The world exists out there independently of our being conscious of its existence" (p. 71). Likewise, chronic illness, an "unwelcome presence" (Smith, 2015, p. 94) that tries to take over our lives, exists as an identified socially constructed reality (Conrad & Baker 2010) but we only become aware of it when it affects us directly or indirectly. A main ontological assumption in qualitative research, is that there is not a single truth or a single reality. This is in line with the postmodernist thinking, which guides my research. Although there is an awareness that that there is no one single truth, believing that there is Truth in 'master narratives' may still be an easy trap to fall into.

Often people with most power and knowledge determine the 'master narratives' (Foucault, 1972), whilst those with the lesser power and lesser knowledge may be considered as vulnerable and less assertive, most especially when making choices. Thus, power and knowledge can sometimes be used to oppress (Foucault, 1980), most especially if knowledge is withheld (Etherington, 2014) or for example when women living with a chronic illness, have the knowledge of what it means to live with the illness, but are silenced (Jack, 1991). This could also reflect a gendered mindset, mirroring the impact of gender and patriarchy on health and wellbeing which is not a new phenomenon. (Musoke et al. 2022).

Incidentally, women living with a chronic autoimmune invisible illness very often encounter such behaviour and attitudes most specially because of the subjectivity of symptoms which cannot be objectively measured, thus lack scientific explication. Hence, as women they are made to feel vulnerable and powerless (Cotterill, 1992). Additionally, due to the subjective nature of chronic autoimmune illnesses, which are many at times contested, patients are not always believed, thus causing them to be silent, and left feeling sabotaged by patriarchal authoritarian voices, which in turn may diminish their sense of agency. Feminist researchers have long been interested in women's subjectivity and validation of knowledge (Bondi et al., 2002; O'Shaughnessy & Krogman, 2012). The dynamics that keep women from speaking their experiences, reinforces powerlessness and highlights the social power structures, privilege, and oppression (Ahrens, 2006). This is synonymous to reiterating medical narratives, not out of choice, but in the hope of being validated and recognised by the same system. Consequently, in doing so, becoming a passive recipient of care. On the other hand, one may find agency and voice to question, to challenge and oppose the master narrative with the risk of being considered as deviant in behaviour. This can perniciously have repercussions on one's health and wellbeing, for instance, being ignored as a person, or else not being validated or recognised for the condition by the health system and/or insurance. In short, this is in line with what Ahrens (2006) stated that "[t]o speak and be heard is to have power over one's life, whilst when silenced this power is denied" (p. 263).

Living in a post-colonial country may dictate and determine, not only who we are, but also how we act, speak, and think (Ashcroft et al., 1998, 2007). In Malta, it can be argued that our ingrained transgenerational practices and beliefs may continue to submit to this continual colonisation, even up to this present day. As Smith (2010) maintained, the colonial experience continues to shape our modernity, our identity. According to Stanley and Vass (2018), post-colonialism problematises the duality of the coloniser and colonised and the accompanying structures of knowledge and power.

Therefore, colluding (consciously and unconsciously) could be resultant to cultural and gender transgenerational ramifications, which could affect meaning making and subjective truths of illness events. Even though we might be aware that different multiple truths exist, we might concurrently also know that one truth often takes precedence over the another. Besides culture, gender and the transgenerational aspect intersecting factors such as age, class, status, religion, and race may impact the meaning making, emotions and feelings as well as the quality of life.

In the process of writing, I became more sensitive to the fact that what I conceptualized as truth, the understanding and meaning I gave to my story then, was very much influenced and determined by these same intersecting factors which included my support system, the environment I lived in, the beliefs and values around illness, and the meaning given to health and illness within my own family system. Consequently, women living with a chronic autoimmune illness, experience illness narratives differently and/or similarly depending on the influence of the intersecting factors and how the individual makes sense of the ‘experience’, which in turn might affect the individual’s subjective truths. Thus, generalising in such circumstances would be a grave mistake.

Positionality

My experiences as a woman, counsellor and a nurse are pinnacle to my philosophical positioning, which essentially draws upon existential humanistic beliefs, such as the process of becoming, which implies movement, agency, and continuity (Etherington 2004) knowing oneself through reflection and 'influenced relatedness' through the 'other'. This process unfolds through critical reflexivity and writing (Richardson, 1997). The knowledge gained over the years is not only historic, self-proclaimed, gained through one's own life experiences, but also comprises of knowledge gained from other people's life experiences and narratives. Therefore, my research is informed by personal, professional, and collective experiences in the same manner that my practice is informed by research. I draw on steadfast belief of the importance and value of different subjective understanding and meaning making. Each person is more than the sum of their parts, someone who constructs a particular world from their unique perceptions of the world (Schneider & Orah, 2010). This philosophy merges with humanistic and person-centred values, which include individuality, rights, privacy, choice, independence, dignity, respect, and partnership. Thus, as participant in research and as researcher, I hail from the position that each person should be respected for their individuality, identity, choices, beliefs, and values, both in sickness and in health no matter the age, gender, or race.

Against this backdrop, the positionality of 'researcher' and 'researched' is considered as central in qualitative research (Ganga & Scott, 2006). The position that the researcher takes inevitably affects the overall outcome of the study itself; one may be considered as insider or native to the social group being studied or alternatively, an outsider to the topic. Additionally, Ritchie et al. (2009) suggested that in qualitative research, the apparent separation between *insiderness* and *outsiderness* is becoming more blurred and that it is more appropriate to define the researchers' stance, by their physical and psychological distance from the phenomenon being researched, and less by their paradigmatic position. Furthermore, Ganga and Scott (2006) continued to affirm that the change in positioning between the private and public self can affect dynamics. They argue that when conducting insider research, the boundary between private and public self is different to conducting research as an outsider, since private life is closer to when conducting research as an outsider. They claim that such positioning could influence the social dynamics of the interview in qualitative research. In this regard, researchers often struggle with the power dynamics when conducting such interviews (Zavattaro, 2021). However, in my opinion, affecting dynamics is not necessarily a negative thing if it is done with purpose, awareness, and ethical mindfulness.

Where do I stand?

Therefore, where is it that I stand in relation to my research? Subjectivity, duality and intersubjectivity are longstanding debated topics in research. Corbin-Dwyer and Buckle (2009) highlight a gap in literature on the experience, value, and challenge of inhabiting dual roles when researchers are members of the group they are investigating, or actual participants in their own study. I find it unsettling, and thus refuse, to position myself in such a claimed 'duality', taking sides with either/or, insiderness/outsiderness. Furthermore, dichotomous thinking is evidenced strongly between the qualitative and quantitative divide. Even in qualitative research, polarities mark differences between interpretivists and realists (Atkinson et al., 2001; Bochner & Ellis, 1999).

Corbin-Dwyer and Buckle (2009, p. 61) claimed that qualitative research no longer allows the researcher to remain a true outsider to the experience that is being analysed, and since as researchers we may not qualify as complete insiders, we might then need to occupy the space between – the liminal space, the *in-between-ness* (Beech, 2011). In doing so, we move away from the dichotomy of *us versus them*, *researchers versus researched*, *insider versus outsider* (Ellingson & Ellis, 2008). Therefore, rather than choosing sides in binary positions, we can incorporate “a hybrid insider/outsider position” (Paechter, 2013) or negotiate “fluid identities” (Razon & Ross, 2012) assuming “multi positionalities” (Ryan, 2015), occupying a position of “betwixt and between” (Beech, 2011) whilst embracing private, social, academic, and professional roles and positions that occupy a paradoxical identity. Incidentally, *in betwixt and between* is a phrase that anthropologist Victor Turner used to capture the essence of his theory of *liminality,* a central feature of the framework he developed in the late 1960s to analyse rites of passage within tribal, sociocultural systems, a transformational process, a becoming (Cook-Sather, 2006), a realm of pure possibility (Turner 1967, p. 67). Autoethnography’s liminality refers to the *in betweenness* that oscillates between art and science, between rationality and emotionality. However, Bochner & Ellis (2016) stated that although the *in betweenness* could “be a good place to occupy, because that’s where novel and creative ideas arise, [u]ltimately, liminality ends in recognition” (p. 67).

Unlike Turner (1967, as cited in Bochner & Ellis, 2016, p. 67), Bochner and Ellis (2016, p. 68) claimed that autoethnography is not a passage to something else, but a way of life that others would want to embrace. Therefore, it would be safe to declare that my positionality during the process of this research is surfing the “in betwixt-and-in-between” (Beech, 2011) as a nurse, a counsellor and an educator so as to gain a deeper understanding of self and identity, to be creative, to give meaning to life, to understand what we do with meanings of illness. I do this whilst possibly experiencing messiness, chaos, and confusion, aspiring to find positive meanings, a ray of hope. However, it is not a means to an end; it is a continuous process of becoming through showing and telling. I experience how writing autoethnography, self and others (directly or indirectly implicated), works on the consciousness of the writer and the reader (Poulos, 2021), which in turn supports the process of becoming, healing, and transformation (Etherington, 2004; Wright, 2018; Wright & Bolton, 2012; Richardson, 1997; Goodall, 2000; Ellis, 2004; Bochner & Ellis, 2016). Similarly, the in betweenness, is also experienced by persons suffering from chronic autoimmune illnesses. The liminality of fitting in, recognised and validated for their (contested) illnesses. Often this falls between *socially recognised* and *medically approved* categories, thus illuminating both the experience of illness and the process of recovery. Reconfirming what was previously implied by Bochner and Ellis (2016), recognition and recovery is not a means to an end, but a transition into a post liminal phase, a new experience, a new liminality, a new identity characterised by straddling boundaries between illness and wellness (Brown et al., 2007).

A critique on researchers' roles and positioning has developed in response to a greater consciousness of *situational identities* and to the perception of relative power (Angrosino, 2005, p. 734). By extension, it is essential that as participant in research, practioner, professional who is adopting an autoethnographic approach, the position I claimed is non-singular and non- binary but instead one that is fluid and "unapologetically eclectic" (Ellingson, 2017). This is in line with the research approach chosen for this thesis that draws upon experiential and acquired knowledge from different disciplines that sometimes lie in between or on the borders of the research field.

> *I continue to question the notion of different identities, multiple selves, how they merge, interweave, come together and/or function separately? On one hand, I claim to oppose binaries, (which I do), whilst at the same time I realise how my thinking can be selectively situated depending on which hat I'm wearing, from which identity self I am functioning, for example when I process personal attributes and experiences or when I tap into the knowledge gained from my professional capacity*

> *as a nurse, counsellor or educator. Paradoxically, multiple selves are not separate parts but are a representative of the whole – all that which makes me the person that I am. Therefore, the different aspects of myself as woman, daughter, nurse, counsellor, educator are not separate parts but an inseparable whole. I am and have been the same person all along comprising of the scientific and the humanistic aspect, the personal and the professional. I, as the researcher and participant in research was the same person in and outside of research. The space between personal and professional disciplines becomes more blurred, intersecting and intwining boundaries to cocreate new spaces, new understandings whilst continuing to embrace the whole.*

I draw on Edward Soja (1996) who referenced the "third space", which is the experience of intersecting boundaries that in turn produce, and co-construct other lived spaces and experiences. Therefore, I do not believe that shifting my position between nursing and counselling, an insider, an outsider or staying in the 'in betwixt and in between' in the third space or on the borders, depending on the context and need, makes me a better or worse qualitative researcher. It just makes me a different type of researcher, which I heartily claim.

In search of a methodology

From the initial proposal stage of my research, I was convinced that qualitative research was deemed to be the most apt method of naturalistic inquiry to research illness experiences, as it is considered to be less intrusive than quantitative investigations (Bowling, 2014). The combination of the chosen theoretical framework, my positioning, and the research aims guided my search which led me to narrative inquiry. As mentioned earlier, my view of narrative inquiry drew upon feminist, social constructionist and postmodernist ideas and practices, which were all reflected through my research practices and relationships. I value different forms of knowledge, including the experiential, subjective knowledge acknowledging that every story matters, whilst reiterating that there is no one single truth and that no story is privileged over the other. According to Mishler (1999), 'narrative inquiry' is an umbrella term that covers a large and diverse range of approaches. This was chosen because it captures human experience over time, taking into account the relationship between the individual experience and the cultural context (Clandinin & Connelly, 2004). Narrative inquiry research referred to narratives (written, oral, visual) that are systematically gathered, either its raw *data* or its product, (Bleakley, 2005), are analysed, and represented as told, and ascribed to experiences (Josselson, 2006). Etherington (2004) maintained that it is a method that challenges traditional and modernist view of truth, reality, and knowledge, whilst also presented a multiplicity of truths that cultures claim for themselves (Ettore, 2016). Thus, I chose this approach over other qualitative methods primarily because of its emphasis on people's lives and how they were constructed by the stories that they had shared about themselves, others, and their relationships (O'Shaughnessy et al., 2013; Andrews et al., 2008). Besides this, it embraced the empirical, existential, and phenomenological experience of health and illness. Yet, unlike many qualitative frameworks, it offered no automatic starting or finishing points.

My goal was not to expose scientific knowledge, which in its broadest meaning embraces systematic knowledge, but to explore the detail and intricacies of the micro stories through narratives using multiple forms of knowing and representation. We cannot measure knowledge scientifically, most especially personal experiences. However, although I indicated that I would be using a narrative inquiry during the proposal stage, I did not specify what type of narrative inquiry I would be using, namely life story research (Etherington 2009), life history (Cole et al., 2001) biography (Hollway & Jefferson, 2000), collective biography (Davis & Gannon, 2012), autobiographies and autoethnography (Ellis et al., 2011; Reed-Danahay, 1997). One thing for sure was that at that stage I needed to shift my paradigm, from the way I was trained to do research to using personal life story using different ways of representation. In his article *Narrative Virtues*, Bochner (2001) "speaks back to critics who regard narratives of suffering as privileged, romantic, and/or hyperauthentic". Furthermore, Bochner (2001) explains:

> The narrative turn moves away from a singular, monolithic conception of social science toward a pluralism that promotes multiple forms of representation and research; away from facts and toward meanings; away from master narratives and toward local stories; away from idolizing categorical thought and abstracted theory and toward embracing the values of irony, emotionality, and activism; away from assuming the stance of the disinterested spectator and toward assuming the posture of a feeling, embodied, and vulnerable observer; away from writing essays and toward telling stories. (pp. 134-135)

This article particularly consolidated my philosophical positioning together with how I wanted to carry out the research. I came to understand different possible options of narrative as a method. It appears I had gained the rightful permission to carry out research differently by being introduced to (a) narrative autoethnographic writing (personal experience, reflexivity and conversing with others); (b) data gathering, which included art-based approaches (used in the broadest terms); as well as (c) promoting multiple forms of representation, such as images, poetry, and prose. Denzin and Lincoln (1994, 2000, 2005) described key moments in the history of qualitative research with autoethnography falling under the fifth moment that concerns experimental and participatory research. As a method, autoethnography challenges the dominant false contradictions and hierarchies in academic and political culture that continue to regard intellectual knowledge as superior and patriarchal. On the other hand, the emotions, feelings, and embodied research are regarded as *informing experience* rather than knowledge, and often deemed inferior, thus satisfying the *feminine*, *non-scientific,* and *not real research* associations. Consequently, I was aware that I would be challenging the 'diehard' objective and scientific ways of doing research, which is usually assigned to illness. Relying exclusively on knowledge generated through objective investigation, would only acquire partial knowledge about the impact of living with an invisible chronic illness, often executed by male medical professionals to women patients. In such an instance, I propose a more inclusive and expansive approach, including research conducted from, and informed by, introspection, the subjective and embodied standpoint of women. In this way, it was hoped that a collective account of the personal, relational, and social impact of the illness experience would reach a greater and diverse audience, which would have been difficult to capture and document in objective studies.

Even though narrative approaches are increasingly being used in illness research (Kralik, 2002), the trend in using autoethnography is still limited (Ettorre, 2006; Ellingson, 2006; Richards 2008) but slowly increasing (Niemeijer & Visse, 2016; Bertrand, 2021). However, the use of evocative autoethnography in health research is still considered transgressive and critiqued. Chang's (2016) main critique in this regard was that it "may evoke emotionally compelling responses from readers but offer insufficient sociocultural insights about the illness phenomenon (p. 443).

Nonetheless, during the writing of this study, autoethnography as a method in health sciences in Malta is untrodden ground. I felt as if I was *breaking bad*, misbehaving, and defying the rules (Bochner & Ellis, 2016) by not conforming with the traditional, conventional, scientific way of doing health research. In using such an approach, I was aware that this could disrupt the politics of traditional research relationships and traditional forms of representation (Ellis et al., 2011). I was aware that as participant in research, alongside another four women, I formed an integral part in the process, and this was a notion that went against the assumption of positivistic research methods who assume that researchers need to be neutral, impersonal, and objective (Atkinson, 1997; Delamont, 2009). Yet, scholars who deem autoethnography as a widely acknowledged research method and process recognised that this is no longer tenable (Denzin & Lincoln 2005; Richardson & St. Pierre, 2005; Bochner & Ellis, 2016). The choice to use such an approach was precisely because it acknowledges subjectivity, reflexivity, emotionality, and embodiment giving space for the researcher's influence on research, rather than assuming they do not exist (Ellis et al., 2011). Further to this, qualitative health research remains largely disembodied. More autoethnographies in health research would be beneficial to help bring the body back into research (Ellingson, 2017) to gain agency and power to give voice in health systems that are usually patriarchal, male dominated systems. Most health research erase the researchers' bodies and in so doing conceal intricacies of knowledge production presenting tidy accounts of research (Ellingson, 2006). By this stage, I had reached a phase where I refused to do research in a disembodied manner or to ignore the subjective illness experience(s). I aspired to represent narratives in different formats (writing, prose, found poetry, dialogue) creating *new tiles,* thereby cocreating and representing illness stories of lived experiences in a discursive manner in known and less known territories. Incidentally, according to Metta (2013):

> concepts of voice and feminism and feelings of agency are in many ways connected to our multiple subjectivities as women and as feminists. Feminist scholarship has long confronted the problem of language and women's historic silence. Women have been systemically excluded from public life. Treated as objects in a masculine discourse and language reflects women's exclusion. (p. 61)

Narrative inquiry, evocative autoethnography and writing as inquiry are similar in principle and values, and together they provided the tools required to look inwards, outwards, and forward in the writing of the thesis. I needed to sketch my writing trajectory to make sense of my thinking. Figure 3a presents a rough pencilled sketch whilst Figure 3b is a summarized version of the writing trajectory. In using personal narrative writing and evocative autoethnography as a legitimate source of knowledge, I aspired "to soften the hard of hearing, hopefully to make them receptive, open the eyes and awaken the heart" (Sellers, 1994): *them* referring to anyone who still believes that this is not *real* research by giving space for silence to become a whisper or a shout if needs be. In hindsight, choosing the scientific path, colluding with the known, could have reduced a great deal of uncertainty and would have probably been less messy.

Incidentally, qualitative research is still precariously positioned in messiness once cleanliness, definitiveness and singularity are challenged (Preissle, 2011, p. 685). This was another reason to persevere; to be different and to show difference in presentation.

Figure 3a

Sketch of the writing trajectory

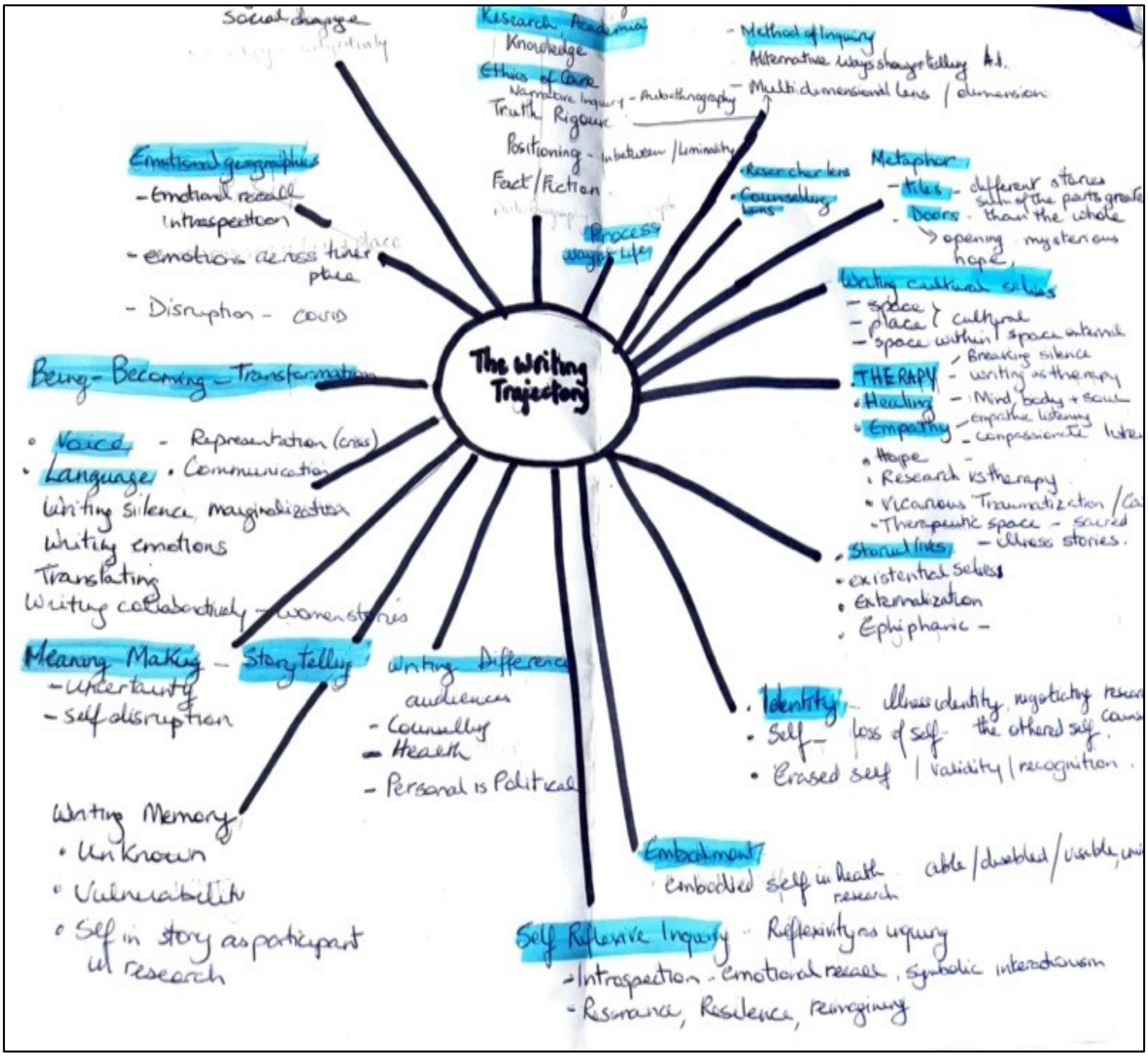


Figure 3b

Writing trajectory

It all starts with a story… coming to narrative

> *Storying is a human phenomenon, a fundamental part of being human. There is so much to say of our living realities, if we are provided a secure space, time, and a compassionate listener. This is how it all started, recalling, and relating my illness experience, whilst unconsciously embracing the collective story – my story seems to merge with other stories. Chronological time does not seem important. I considered my illness experience a historic story, which was no longer relevant, deeply buried in my subconscious even though I periodically still live it especially when taken ill or when over fatigued. I believed it to be a story that was not relevant any longer. However, when revisiting and relating this story retrospectively, I realise that this was*

not the case: I do not only recall events, but also, emotions. It is not something that I had envisaged, predicted, or accounted for. Words flowing freely – I cannot hold them back, I need to explain, to make sense of it all. Narrating stories, positioning them within cultural and social contexts, whilst also embodying the story and writing about it, is another unprecedented experience.

The story[ies] keep evolving depending on the timing, the context, the audiences to whom I speak and write, attributing different meaning, discovering multiple truths, and reconstructing experiences in the process.

Narrative knowing, upon which narrative inquiry is based, premises that, as human beings, we come to understand and give meaning to our lives through [stories] (Andrews et al., 2008). Bruner (1986) identified scientific and narrative ways of knowing as being fundamentally different; science is concerned with establishing truth, whilst narrative's concern is to endow meaning. Narrative became an established approach not only in the fields of anthropology (Skultans, 1998), sociological (Frank, 2005) and psychology (Crossley, 2000), but also in politics and education. In recent years, narrative was also deemed particularly appropriate for health research because of its ability to draw upon the understandings of illness through socio-cultural and environmental influences. Thus, this incorporates all the dimensions that impact the individual's health experience (Green, 2013). Narrative approaches illuminate illness experiences as they provide a *window* into understanding how individuals store their experience within the context of their broader lives (Riessman, 2008) focusing on affective, relational, ethical, and imaginative aspect of experience through time, especially chronic illness (Bleakley, 2005). Narrative is considered as a distinct form of discourse through its retrospective meaning shaping or ordering of past experience (Denzin & Lincoln, 2005). Unlike scientific discourse, narrative highlights the uniqueness of each human action and event rather than their common properties (Bruner 1986; Polkinghorne, 1988).

Experience centred and event centred approach to narrative

In narrative research, both an event centred approach and an experienced centred approach are assumed to be individual, internal representations of phenomena (events, thoughts, and feelings) to which narrative gives external expression. Event-centred work (Labov, 1972, as cited in Andrews et al., 2008) assumes that these internal and individual representations are relatively constant. These types of narratives are not a comprehensive, preferred way of telling stories; they may be gender and culture specific, defined as a method of recapitulating past experience, but focusing on syntax and matching verbal sequence clauses (Squire, 2005). Labov (1972, as cited in Andrews et al., 2008) restricts the event centred approach to salient events including sex, death, and moral injury. In fact, narration was based on the selection of certain ‘reportable’ events. Telling about specific events can cast a special light on one's past or present life (Bruner, 2009). Yet, it is often only retrospectively that we come to understand and give meaning to events (Polkinghorne, 1988); memory is always selective. The selecting of events, the organisation of them and the description of the relationship between these events are deemed basic elements in narrative.

Experience-centred research focuses on the meaning of narrated experience, and stresses that representations vary over time, across circumstances and environments. A single event may produce different stories, even from the same person (Andrews et al., 2008). This approach assumes that narratives are sequential, meaningful, and unique; definitively human, thus re-presenting experience, reconstituting it, as well as expressing it displaying transformation or change (Andrews et al., 2008, Bochner & Ellis, 2016). Narratives are considered to be a reconstruction of stories that cannot be duplicated or repeated across time or places, since words do not mean the same things twice and social contexts are different (Andrews, 2004).

Meeting up with women participants, recalling memories together felt as if we were revisiting a ‘snapshot’ in time: each of us uniquely positioned in whatever was happening in our lives at that specific time (Etherington, 2004, p. 77). Reflection and storytelling is an ongoing process (Frank, 1995), “linking the past to the present and the present to the past” (Mcleod, 2003, p. 37) and a continuous process of transformation and becoming (Clandinin & Connelly 2004; Etherington, 2004). We continuously evolve through our own stories. Different scholars consider individual narratives as being *agentic* because we determine what gets included and excluded in the *narrativization (*Clark, 2018, p.11). We construct past events and actions in personal narratives to claim identities and construct lives. Each illness story is told with a purpose; *how* it is told, *who* it is told to, *how* it is received and interpreted, as well as *when* it is told (Etherington 2004, p. 8). Similarly, to health and illness, more specifically, chronic illness, meanings are not fixed but they evolve and are influenced by same illness trajectory.

In this regard, Denzin (1989) also noted that meaningful stories of personal experience, might address a life turning point, such as living with an illness and its consequences. Illness narratives contextualise experiential and interrupted lives, and consequential change in relationship with the social world (Bury 1982; Charmaz, 1991; Frank, 1995).

Illness narratives

The illness narrative is a story told to give coherence to the distinctive events and a long-term course of suffering. In this thesis, these stories were collated in collaboration with the women (Bleakley, 2005). The plot line of each story, including the specific use of language and metaphors, reflected personal and cultural experiences in meaningful ways

(Klieman, 1998). In the last few decades, there has been a notable growth of interest in illness narratives namely through the work carried out by Kleinman (1988), Mishler (1984), Frank (1995), Sparkes (2000), Riessman (2008), Plummer (2001), Charon (2006), Bochner(2001), Richards (2008) and Ettorre (2006). On the other hand, Atkinson (2009) and Thomas (2010) critique the use and validity of illness narratives. The range of illness narratives include documentation of medical histories, fictional narratives, autobiographical accounts of illness, autopathography, co-constructed narratives in conversations, visual and narrative representations of sick people and disease in art, photography, film, and other media as well as visual modalities (Esin & Squire, 2013). There is increasing literature within the field of social science on the illness narrative genre that recognises the subjective reality in adaptation to illness, of *how* it is perceived, enacted, and responded to by the 'self' and others (Riessman, 2008). The value of narratives in constructing meaning and coherence out of disorder created by illness is well documented (Bury, 2001) and an attempt to provide a voice to the experience that medicine cannot describe (Frank, 1995).

Relating stories, can also be empowering when making sense of experiences (Hyden, 1997), as well as providing therapeutic benefits, connecting the body to the self (Ettorre, 2006), revealing embodiment and emotionality (Ellingson, 2017), and inscribing bodily dysfunction (Ellis, 1996). Further to this, Bury (2001) identified "three types of narrative form" consisting of (a) contingent narratives; (b) moral narratives; and (c) core narratives. He defined them as follows: 'contingent narratives'… address[ing] beliefs about the origins of disease, the proximate causes of an illness episode, and the immediate effects of illness on everyday life; 'moral narratives' that provide accounts of… changes between the person, the illness and social identity, and which help to (re) establish the moral status of the individual or help maintain social distance; and 'core narratives' that

> reveal connections between the layperson's experiences and deeper cultural levels of meaning attached to suffering and illness. (p. 163)

Moreover, Frank (1995) identified three primary illness narratives: (a) chaos narrative (powerless, out of control), (b) quest narrative (a challenge to be confronted) and (c) restitution narrative (whilst medicine might return the body to its former self, it depends on the sufferer to resolve the illness). Kleiman (1988) stated that "[m]uch illness-related storytelling is oriented to making sense of the trouble by answering questions like 'why me?', 'what caused it?', 'what can I do to get better?'" (p. 80).

One story may contain all three elements. Furthermore, in the field of medicine, Charon (2006), Greenhalgh (1999), Fioretti et al. (2016) developed *narrative medicine*, an approach where clinical practice is informed by the theory and practice of reading, writing, telling, and re-reading stories.

However, Parker (2018) debated that a narrative medicine approach, sets itself against an "algorithmic 'diagnostic' framework" (p. 7), viewing illness not as a discrete, confined event but as "interrupting and reforming life and identity, a life and identity that can only be comprehended in a rich or 'thick' text" (p. 7).

Critiques of the value and use of illness narratives have been presented over the years, often questioning their authenticity and the context of real time interviewing as well as the lack of social structure (Riessman, 2000; Atkinson, 2009). According to Thomas (2010), this is due to positioning patients' stories as testimony rather than perspectives, treating narratives as social facts to be interpreted.

It was also debated whether narratives are genuine representations of life experiences. Discussions circled around whether narratives are jeopardised by relational aspect between researcher and participant (Polkinghorne, 1995), who owns the story once it is told and written (Creswell, 2014). On the other hand, Bochner (2001, p. 147) highlighted the fact that stories generally reflect the struggle between personal, cultural, and political. He stated that ill persons usually need to negotiate a cultural script of bodily dysfunction, together with the unique meaning and the "situated knowledge" (Haraway, 1988, p. 581) and understanding of the experience. As from this start, I too hoped that the narratives would not just reflect, but contribute to the experience, co-creating other stories and in so doing creating a political and activist element to the research.

Furthermore, another issue worth mentioning is the issue around broken narratives. What happens when speech is 'disordered', incoherent, silent, or silenced, do gaps in narrative and when words fail to convey the illness story? The overarching question being what happens when there is insufficient linguistic representation due to illness? The essential purpose of illness narratives is to incorporate illness into the greater framework of life (Andrews, 2010). Illness narratives, in such an instance were considered to become broken narratives. It can be argued that all illness narratives can potentially become broken narratives. Kokanovic and Stone (2018) maintain that the latter could take place in the form of interruption by master narratives, lack of embodiment and empathy, inability to articulate language, inappropriately assembling and disassembling memories.

Writing evocative autoethnography

According to Ettorre (2017), "[n]arrative methods generate useful ways of creating knowledge about selves, individuals, collective agency, and the interior language of emotional vulnerability as well as at times, wounding, which is at the heart of autoethnography" (p. 1). Autoethnography is used in a variety of disciplines, including anthropology, sociology, education (Reed-Danahay, 1997; Ellis & Bochner, 2000; Etherington, 2004) and in recent years in health research (Ellingson, 2017; Chang 2016; Ettore, 2017; Richards, 2008). The term *autoethnography* has been used by many researchers going back as far as Hayano (1979). Ellis and Bochner (2000) define autoethnography as an: Autobiographical genre of writing and research that displays multiple layers of consciousness, connecting the personal to the cultural. Back and forth auto ethnographers gaze, first through an ethnographic wide-angle lens, focusing outward on social and cultural aspects of the personal experience; then they look inward, exposing a vulnerable self that is moved by and may move through, refract, and resist cultural interpretations. (p. 739)

Autoethnography refers to the research and writing of a story, as well as a method as well as a process, that connects the autobiographical to the cultural, social, and political through the study of a culture or phenomenon of which one is a part, integrated with traditional and personal experiences (Ellingson & Ellis, 2008). Ellis (2004) and Holman Jones (2005) state that it is an approach to research and writing that combines characteristics of autobiography and ethnography seeking to describe and systematically analysed (*graphy*), through personal (*auto*) and cultural experience (*ethno*). It reflects on and interprets personal experiences and interactions with others as a way of achieving wider cultural, political, or social understanding (Harreveld et al., 2016).Thus, in so doing, challenging canonical and traditional ways of doing research and representing others (Spry, 2001) treating research as a political, socially-just, and as a socially conscious act (Adams & Holman Jones, 2008).

For this project, I specifically chose an evocative autoethnographic approach to carry out my study, which has been at times referred to as *heartful autoethnography* (Ellis, 1999) as opposed to an *analytic approach* (Anderson, 2006). The decision to use an evocative approach was primarily due to my own experiential relationship with illness. As stated, previously, I did not want to undertake research as a “disembodied researcher” (Ellingson, 2017) or produce a theoretical autopsy of the story[ies] (Smith 2017) to serve as a means of scientific truth. I opted to present a layered narrative, using my personal experiences, alongside experiences of four other women, whilst drawing on relevant literature.

Furthermore, the conversations held with women were both mutual and discursive dovetailed with the overarching intention to promote relational equality, minimising power, and privilege, whilst conscientious of accusations of solipsism, self- indulgence and/or narcissism (Spry 2001; Sparkes 2000; Anderson 2006; Delamont 2009). This criticism ignores the dialogic relationship of self and culture the “I and we” (Holman Jones et al., 2013) and the vulnerability. A range of personal, public, and political issues were discussed, which included doubt, uncertainty, hope, and resilience, thus contributing to a narrative plurality of truth. Consequently, the conversations contributed nuanced insights to cocreate richly textured narratives (Smith, 2019) of living with chronicity situated within the personal, and wider socio-cultural context, in so doing, expanding views of self and other for future of possibilities (Anderson & Glass-Coffin ,2013).

Similarly, to Allen and Piercy (2005), who refer to autoethnography as a “method of being, knowing and doing” (p. 156), I too aspire to present accessible and meaningful research to reach a wider audience beyond academia. The intention is to sensitise the readers to the micro stories of chronic autoimmune invisible illnesses that are hardly spoken about, contested and many time shrouded in silence by using alternative forms of representation (Ellis, 1999; Ellis & Bochner, 2000) invoking an epistemology of emotion (Denzin 1997, p. 228), creating emotional resonance with the reader (Bochner & Ellis 2016, p. 70).

Writing as Inquiry, writing as therapeutic

Writing in all its forms is a way of knowing (Richardson, 2000), a method of inquiry and a process. Traditionally, mainstream researchers avoided expressing emotions on the page, and even when they used their own experiences they did in a separated manner (Ellis, 1997). Writing has formed an intrinsic part of this autoethnographic project and process from beginning to end (Adams et al., 2015).

Further to this, Giorgio (2009) stated that:

> [w]hen writing to heal ourselves, we help others to heal, we make our personal political. Speaking one's truth or truths, through an autoethnographic lens, allows us to address the tensions between truths, whether personal or epistemological, in a political and hopeful act. It is political because it opens others' eyes to new realities of oppression and traumas; it is hopeful because it offers a chance for change (p. 165).

Like in most autoethnographic writings, my thesis includes an exploration of an epiphany. Exploration of personal experiences, complexities and fragilities are presented in the space, and the liminalities we live in. On one hand, the writing helped me see the emancipating power of narrative, as well as the transformative power in writing the self, which sometimes was the means to transform personal stories into political realities (Ettorre, 2017; Spry 2001). Writing can be presented in various ways and formats, including first-person narratives, thus exposing a vulnerable self. I used the *I* at different instances, even though, at times, I found this quite challenging. I presented my writing in different representations including text, poetry, using metaphors and dialogic writing. Other forms of artistic representations and mediums used include short stories and scene writing (Ellis, 2004; Muncey, 2005; Wall, 2006; Tillman, 2009).

The open-endedness of autoethnographic inquiry is grounded in the "obdurate reality" (Blumer 1969, pp. 23-24) of change but also supports a belief in agency and the hope of healing. This is in line with the social constructionist position, which underpins my research resisting finality and closure. More so, Anderson and Glass-Coffin (2013) pointed out that this is possible because autoethnography lies at the intersection of discourse and experiences of "self and other, insider and outsider, native and colonist" (p.73) and reflects an understanding of "self and society as relational and processual" (p.79), opening and encompassing different future possibilities.

On speaking and writing about personal experiences, and as a result, autobiographical narratives, I projected myself as both subject and object. This was done by not solely placing myself in the field as participant in research, but by also becoming the field through the writing and interactions (Mayan, 2009). This was quite a revolutionary process. Steering through private, public, and therapeutic discourses, reflection and written interaction is a process of discovery of self and other (Richardson, 2000). The writing served as a means of self-discovery, to gain more knowledge about the topic that served as a catalyst for change (Lapadat, 2004; Wright & Chung 2001).

> *It seems never-ending. It seems as if I reached rock bottom, a culmination of exhaustion, numbness, and a total paralysis in feeling and writing. Ironically, this same inability to continue to write my thesis is provoking deeper and more profound reflectivity and rhetorical questioning. The more I want to write, to meet deadlines, to put thoughts into writing, the more I freeze and spiral deeper into the world of silence – an unknown desolate space. I am becoming more and more detached, distant, isolated. It feels messy, dark, unstable, and very frustrating – I am speechless. Words fail me or rather, I seem to fail words. I struggle to understand the complexity of what is happening. However, I am aware that during this period, even though I am finding difficulty to write, my mind is on overdrive mode – it is the same silence that is informs me and instigates me to question the unknown. In a way, it feels as if I am looking at the reflection of the 'other' self through a mirror, a meta position that seems obscure and blurred.*

During this Pandemic period, I form part of the National Public Health Infectious Disease Prevention and Control COVID-19 case management team. It feels like a defeat. Numbers of positive cases keep increasing. We are all mentally and physically exhausted. We have no knowledge of how this story is going to unfold. Deaths, grief, physical and emotional exhaustion, tension, and anxiety have become the rule of the day. It seems and feels as if I'm losing ground, juggling between work (as a nurse and an educator), my doctoral studies and my family. I am fearing for my health and the health of my family, most especially my elderly mother. I 'm finding difficulty to rest and sleep; I'm feeling very deflated and demotivated; my lifestyle is erratic. It seems as if I am entering a stage where I am no longer functional. I feel I am breaking down.

At the same time, it seems as if my internal critic, is 'not permitting' me to feel this way – this is not my script. I need to be strong! I'm desperately searching for meaning. I am currently seeking support from a professional therapist, who invited me to experiment with alternative therapy techniques including EDMR, visualisations, affirmations. I visualise myself wearing the therapist's hat – what would I ask and tell my clients? What about self-compassion? Self-care? What helps healing?

I am invited to use my imagination to re-enact a repeated dream, the experience of falling into the void of the black hole. During this experience I realised that the process was accompanied by clear metaphoric anecdotal visualisations that explained my feeling, which in the absence of words, served a clear purpose – I could not find a voice in this abyss. It felt as if I was standing on moving geographical tectonic plates, the ground was unsteady. Looking ahead, moving forward was the only option. The space in between was unknown. Writing it down is helping me make sense of this confusion.

Silence informed my thinking and writing. Language in all its formats has been key, that is a means to create a particular view of reality and of self (Richardson & St Pierre, 2005). In therapy we refer to this as *process*. This process helps us to discover different layers of self, expanding knowledge and promoting healing. Like writing, healing, is an ongoing process and not a means to an end. A process is still unfolding. The process of healing is not linear, it is intersubjective, rhizomatic – a condition from which a sense of self arises (ToyoSaki et al., 2009, p. 562). Therefore, writing as inquiry, writing as therapy, writing to heal, writing self, writing the other, writing the space, and feminist critical writing are transformative processes – not finite or conclusive, but an evolving process 'in motion' that assists in discovering more of what we believe to be known, whilst unveiling and bouldering unknown edges (Wright & Wyatt, 2017), both for the author, participants and readers who become witnesses (Ellis & Bochner, 2006), as a result bringing into being new meanings and subjectivities:

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.

Speedy (2012, p. 28) referred to the geographer Massey (2005) who describes space as “dimensions of multiple trajectories, a simultaneity of stories-so-far” (p. 24). Massey depicted the trajectories and dimensions that crisscross the spaces and silences between autoethnography and therapy. As stated earlier, in speaking and writing autobiographical narratives, I became both subject and object in the respective space. Making sense of the different trajectories and dimensions was complex, tangled and only started to take shape and form once verbalised and even more so, once written.

When discussing positioning, I spoke about the outsider and insider position in research, inhabiting the third space in between, embodying multiple selves across the geography of emotions. However, the meaning and understanding of the dimensions of space was not static, it kept shifting and becoming more obscure, elaborative, and uncertain. It unfolded and became clearer through writing. The use of personal experience, the dimensions and meaning of the space in between, go far and beyond any margins and parameters of the page and premeditated boundaries. Although writing revealed some form of clarity, I found the theory behind all this was still very complex. I used the metaphor of standing on a geographical tectonic plate, continuously moving, no possibility to turn back (historical time), but the only option was to move forward. Plate tectonics theory explains how major landforms are created because of the Earth’s subterranean processes, and the same process happened in the writing. The space in between, the liminal space, the third space was, and still is, a vulnerable marginalised place that went beyond binaries (either/or), difficult to cross borders, to conceptualise and/or to claim. It was a transitional space of uncertainty. Assumptions and understandings were questioned and debated. Inhabiting and embodying the crossroads in a space that provided the opportunity for new knowledge and understanding (Wright & Bolton, 2012) to be discovered, and creativity to emerge (Bochner & Ellis, 2016) felt as though I was embracing new horizons. However, it is a space that needed further exploration through writing, adopting a broader and more focused lens, looking into the spaces between research, writing, therapy and talking. This is what this study has embarked on.

How feminism informs my research approach

During the 1970s and 1980s, after being "conspicuously missing" (Gilligan, 1994, p. 17), women's voices, became louder, heard, and made visible "in society and in research, challenging the dominant discourses of patriarchy, recognizing that women's views of women's lives needed to be placed alongside the views of men" (Etherington, 2004, p. 26). In doing so, women researchers started to question women's ways of knowing and relating (Gilligan 1982, 1994; Chodorow 1995; Belenky et al., 1997) that were found to be different from those of many men (Alcoff & Potter, 1993). In psychology, Gilligan and Chodorow (1997) pointed to relationships and caring as different ways of knowing, whilst Belenky et al. (1997) identified five ways of knowing. These included: (1) Silence, women experiencing themselves as mindless and voiceless; (2) Received knowledge, able to receive and reproduce knowledge from external authorities but not creating their own; (3) Subjective knowledge, perspective of truth and knowledge conceived from subjectivity; (4) Procedural knowledge, using objective measures to gain knowledge; and (5) Constructed knowledge by valuing both subjective and objective strategies of knowing. In addition to this, Etherington (2004) stated that "[r]esearchers began to address power issues, not just in relation to women's issues, but also issues of concern to other oppressed minority groups espousing greater equality and transparency that required different ways of collecting and representing data" (p. 26). Furthermore, Leavy (2012, p. 516) claimed that feminist writing provided another avenue for accessing those hard-to-get-dimensions of social life, revealing a multiplicity of meanings and way of knowing. Personal narrative research is acknowledged as "a primary methodology for feminist research in that it introduces 'marginalized voices into record'..." (Maynes et al., 2008, as cited in Stern, 2015, p. 85) because life stories are embedded socially, structurally, and relationally, and provide unique insights into the connections.

Providing a platform for voices to be heard is synonymous to giving a sense of power and autonomy. The issue of power is also reflective on the type of relationship that we garner during the research process with participants, which should be one of consultancy and collaboration rather than a source for data retrieval by remaining an *objective*, detached observer (Schwandt, 2001) and privileged as the knower. Various feminist researchers have advocated for the recognition of subjectivity as important for social inquiry into human condition (Johnstone, 1999). Skinner et al. (2005) identified several characteristics which are common in feminist research, whilst asserting that there is "no single unified feminist theory" (p. 10). One characteristic points to addressing the traditional academic expectation of researcher objectivity and researcher reflexivity. Postmodernists contest the assumption that objectivity is at all possible because they believe that the methods and procedures employed in research are ultimately, and inextricably, tied to the values and subjectivities of the researcher (Bochner, 2000). However, there is a risk in the objective research endeavours that the raw immediacy and subjective meaning making of the research participants may be diluted, lost or (mis)interpreted during the collection and analysis of data. Prioritising researcher objectivity may also fail to demonstrate respect for the personal account, and may unintentionally, and paradoxically, contribute to the silencing of women's voices. Often, objective approaches, may fail to recognise or accurately present the meaning of participants' complex and intuitive self-knowledge and their changing perspectives on their own experience(s). Pillow (2010) highlighted that once objectivity is open for question, subjectivity is also open to scrutiny by questioning "how research relations and researcher subjectivity impact the doing of research [becoming] equally important" (p. 272).

Across the various research disciplines, reflexivity and subjectivity have been debated at length (Roth & Breuer, 2003). Reflexivity helped to strike a balance in the relationship between participants as collaborators rather than simply posing as data gathering subjects. In doing so, this has continued to inform dialogue and writing to attain meticulousness, by not solely manifesting *what* was discovered, yet *how* it was discovered (Etherington, 2004). It was through reflexivity, that a clearer understanding of my position in relationship to self and others within the broad socio-cultural context was established.

Reflexivity has also helped to inform certain dualities and liminalities to bridge the gaps between, for instance, the insider and outsider, researcher and researched, the knower and the known, visibility and invisibility. Additionally, reflexivity, embodiment, subjectivity, *tacit* knowing, and intuition were considered equally important contributors to knowledge (Etherington, 2004) and have been a primary methodological vehicle for this inquiry, as in research using autoethnography, autobiography and/or narrative inquiry (Ellis & Bochner, 1996). However, it was essential that through reflexivity, our own limits of knowledge claims about contexts, subject, and findings in research have been recognised (Adams et al., 2015, p. 22). Similarly, it was as important to recognise that subjective knowledge is of equal value. It has not only given precedence to one way of knowing, but it has also enlightened other aspects, including reason over emotionality; embodiment over intuitive knowledge; as well as voice and agency over silence.

Despite this, Wall (2006) stated that qualitative researchers have generally been accustomed to using the concept of reflexivity as a *token reflection*, stating how their presence as a researcher has influenced, or could have influenced the research process. A reflective excerpt is added in a study that claims to be neutral and objective as opposed to being intrinsically intwined in the study. However, as a methodological tool, reflexivity is routinely used in critical and feminist research, amongst other fields to better represent, legitimise, or question data (Pillow, 2003 p. 176). Hence, as opposed to other methodologies, the feminist movement of research encouraged researchers to be seen using the first person, using indwelling *tacit knowledge* (Etherington, 2004). This meant stepping out from the absence of the researcher, thus, shifting the focus inward, questioning the self, other and the process of research (Altheide & Johnson, 1998; Ellis & Bochner, 2000).

As a counsellor, reflexivity, and reflective practice constituted an integral part of our training, both for our personal and professional development. This practice has now become so ingrained that it has become a way of life, adopting reflexive sensitivity across different disciplines and in different contexts.

According to Etherington (2004), reflexivity is

> an ability to notice our responses to the world around us, other people, and events, and to use that knowledge to inform our actions, communications, and understandings. To be reflexive we need to be aware of our personal responses and to be able to make choices about how to use them...aware of the personal, social, and cultural contexts in which we live and work and to understand how these impact on the ways we interpret our world (p. 19).

Without exploring and making sense of my own subjective experience, and my existential self as a woman, a nurse in a doctor's world, a researcher and academic coming from a positivist discipline (health sciences), as well as a counsellor. Thus, failing to acknowledge and embrace all this, I would have failed transparency, to engage fully in the research process and to understand the multiple identities that represent the fluid self in relation to the research (Lincoln et al., 2005).

Moreover, Sandelowski (2002) asserted that many qualitative researchers have taken account of "them*selves*" (p. 108) in their research, but these *selves* are rarely represented as *embodied selves*. Therefore, although embodiment might be acknowledged in theory, it is not necessarily reflexive in research practice. Conversely, Ellingson (2006, p. 298) strongly believed that qualitative health research would significantly benefit from embodied writing that explored the discursive relationship between the body and the self, as well as the semantic challenges of writing the body by incorporating bodily details and experiences into research accounts, resisting the mind–body split, in principle, but to infuse their research with the vitality that comes from embracing knowledge production as deeply embedded in sensory experience (Ellingson, 2016, p. i).

Reflexivity

...Discomfort.

Body speaks…

unbeknown knowledge,

writing body self[ves],

remembering memories,

recalling emotions

Unless spoken or written,

Remain

invisible,

untold,

unheard

...Painful...silence....

Writing is speaking the body

When researching personal experiences, the relationship between researcher and participant is repeatedly brought to the forefront and consequently the issue of voice arises. The voice of the researched and that of the researcher are essential to move inquiry and knowledge further. In their book *We only talk Feminist Here*, Lipton and Mackinlay (2017, p. 40) refer to the feminist academic writing practices of Helen Cixous (1976) and Sara Ahmed (2014), two female writers based in different periods of time in search of ways to work within/against the in between-ness of women's experiences. In fact, Cixous (1976) maintained that "[w]omen should break out of the snare of silence" (p. 88). Along the years feminist writers have written *themselves* on the page, across different disciplines, transgressing traditional ways to create change. For instance, Behar (1996) who positioned herself as a "woman of the border: between places, between identities, between languages, between cultures, seeks to research and write in a 'feeling-as- sensing-as- knowing way that matters" (p. 162); Richardson (1997) presents feminist essays including concepts of "reflexivity, authority, authorship, subjectivity, power, language, ethics, representation" (p. 2); and Ellis (2004), who combines the self, fiction, and ethnography to write about the material, emotional, and affective dimensions of social experience, contesting the binaries of creativity and analysis. In sum, it is through narrative that voice, agency, subjectivity, reflexivity, and embodied writing (Ellingson, 2006) are expressed. These elements are foundational for this research, which in turn can be perceived as a feminist act, in resisting domination and encouraging silenced voices to speak out and be heard (Stern, 2015).

Furthermore, Lipton and Mackinlay (2017) discussed the paradoxical concepts of voice, feminism, and agency, and how they are "connected to multiple subjectivities as women and as feminists" (p. 61). The notions around silencing, and silence in relation to women's voices, agency, and empowerment were critically interrogated. Over the years, feminist researchers have confronted the issue of language and women's historical silences. Historically, women have been excluded, or treated as objects in masculine discourse and language. The humanist view of *agency* and *self* are synonymous, and used interchangeably with words such as freedom, autonomy, rationality, and moral authority (Davies, 1991). Voice and the act of speaking are considered acts of empowerment in a world were women's voices have been expected to remain silent. It is recognised that there exists a hierarchical and inherent imbalance of power in any relationship between professionals and clients, particularly medical professionals, and patients. This is not only manifested through authoritative behaviour, but also through communication or the lack of it. Unwell patients are reliant on the medical professional's knowledge, skills, and expertise. Persons with a chronic autoimmune illness are no different. This power relationship can become further compromised, due to the size of Malta, as an island. Due to this, the space and proximity (also relational proximity) become more and more restricted, with only one main National General hospital, which arguably limits choice of consultants, treatment, and care. Further to the environmental and spatial factors that could influence limitations of choice, other intersecting factors, such as age, gender, sexuality, race, belief, socio-economic status, as well as education of the professional and the ill person, may also act as contributing factors to the complex dynamics of power relations in any given professional relationship (Applegarth, 2018).

The literature examines different ways in which women's voices are silenced, distorted, marginalised, and excluded from the public domain. The *voice* metaphor in feminist literature has been widely discussed. In fact, Carol Gilligan (1982) reveals several assumptions about the role of the *voice* in feminist work, from a perspective of psychological theory and women's development. Gilligan, who worked with renowned psychologists, Erik Erikson, and Lawrence Kohlberg, two white privileged men, noted that the voices of women were missing in their research, so she decided to explore this further and include different voices. She was particularly interested in the stories about decision making when coming to crossroads. Gilligan (2018) was not only interested in the decisions taken at crossroads but, more importantly, questioned the person's use of *I* when taking a moral decision about what would be the right thing to do. She continued to explore ideas about how women were taking decisions that were up, close, and personal, thus putting oneself "*on the line"* (p. 26), while remaining consciously aware that they must stand by the choices that had been taken. This led to her questioning agency, morality, culture and meaning making. Moreover, Gilligan (2018) states that "if we said what we really thought and felt, we would not be listened to; we would be corrected, told how we should think and feel or what was the right way to think and feel about ourselves and about morality" (p. 27). Therefore, Gilligan presented a different way of framing *self and morality* and, in essence, questions the significance, gender equality, relationality, morality, and the contribution of women's voices at large. Emphasis is not solely based upon what is written. What is even more pertinent is the unspoken, untellable stories – the silencing.

She explicates the different views between women's voices whose discourse revolves around relationships and interdependence when compared to voices of psychological theorists, who, in contrast, speak about separation, autonomy, and independence. The intersection between psychology and culture depicts psychological resistance to collude with the overarching cultural framework and subsequently undermining basic human capacities by splitting reason from emotion, mind from body, and self from others. The resistance to and incoherence of these binary distinctions further exposed the tension between human psychology and culture of patriarchy. Even though we are all born with a voice, with the presumed ability to communicate our experience, and with the desire to connect and engage relationally (Gilligan 2018), voices are still being smothered.

The social construction of chronic illness

> *My experience as a child in the seventies was a different story from most of my friends at school. All my friends' mothers were 'stay-at-home' mothers, whilst my mother, who was born during the 2nd world war, always worked as a teacher and so did her sibling sisters. Today, I reflect on how this has shaped and moulded my thinking and behaviour. I have grown up in an environment where family, work, education, health, and religion played an integral part of our identity and formation of values and beliefs. I have not only learnt stories of self-control, resistance, commitment, and strength, but also resilience – resilience to working and living with chronic invisible illnesses (my mother living with RA since the age of 25 years and my late father who suffered from cardiac related problems). As a child I could not really conceptualise the notion of illness or pain because I was being given other messages. I do not recall my parents ever claiming to be 'sick' – although both parents had every reason to do so. Rain or shine, they continued with their responsibilities – work, family, and community participation. Besides being a primary school teacher, my mother was also very involved in church activities; teaching catechism in the local parish church, animating and reading liturgy during mass, and giving communion to*

> *the sick people in their own residences. A common phrase I remember being used is that 'only sick people stay in bed!'*
>
> *Illness and pain never stopped her/them from working both at home and/or professionally. My mother confronted chronic illness and defeated weakness, she defeated the culture of the 'stay-at-home mother'; she was in control, fervently combatting the powerlessness of her arthritis.*

Over the years, I scrupulously integrated the belief that the understanding that women are strong, committed, resilient and in control abhor weakness, fragility, dependence, and control were fundamental in the founding of values, principles and beliefs sculpted in my personhood. Further to this, "Butler argue[d] that we act out our gender according to prewritten scripts, scripts that make our actions culturally intelligible" (Moss & Dyck, 2003, p. 11). This was my mantra**,** my acquired knowledge, in both my personal and professional life. When revisiting and reflecting on my own personal internalised script, I realised that not only had I theorised illness in relation to the cultural envelope, mainly focusing on gender, culture, and age, but also in relation to other intersecting factors, including identity, emotions and meaning. The social construction of illness and diagnosis is a central theme to medical sociology.

Brown (1995) highlighted the difference between the social construction of medical knowledge and the social constructionism of illness. The social construction of medical knowledge mainly deals with professional beliefs in diagnosis, referring to the ways of knowing based on dominant medical frameworks focused on diagnosis.

In the last 60 years, the social construction of illness has become a major area of research in medical sociology contributing to the understanding of the social dimensions of illness. Reality does not just exist out there to be discovered, but it is created by individuals, the human agency in people's exchanges of meaning (Brown, 1995). Conrad and Barker (2010) contend that, in terms of illness, patients' perspective does not only assume the role of the patient but is also affected by the social factors that shape the illness experience. Three influential findings have been discussed by Conrad and Baker (2010):

> First, some illnesses are particularly embedded with cultural meaning— which is not directly derived from the nature of the condition—that shapes how society responds to those afflicted and influences the experience of that illness. Second, all illnesses are socially constructed at the experiential level, based on how individuals come to understand and live with their illness. Third, medical knowledge about illness and disease is not necessarily given by nature but is constructed and developed by claims-makers and interested parties. (p. 67)

These findings do not counteract scientific and medical perspectives, but rather indicate that diseases and illnesses are equally social products as they are medical-scientific ones. Conrad and Baker (2010) argued the importance of considering social and cultural meanings and attributions, alongside biomedical and experiential dimensions of the patients' health. The way that the illnesses are perceived, experienced, portrayed, and responded to by society are also influenced by the cultural meaning.

The postmodern open door to autoethnography

Additionally, the essence of the postmodern philosophy continues to reaffirm that there are many ways of knowing and inquiring and no one way is privileged. Neuman (1994) stated that "[i]t distrusts abstract explanation and holds that research can never do more than describe, with all descriptions equally valid … [Any] researcher can do no more than describe his or her personal experiences" (p. 74).

Postmodernism consolidates the idea that there are different ways of knowing and inquiring and that no one way is legitimate (Etherington, 2004) including partial, local and/or historical methods (Richardson, 2000a). It moves away from binary thinking, not by eliminating the traditional scientific method, but by questioning its dominance, thus demonstrating knowledge that can be gained and shared in many ways (Wall, 2006). Many feminist writers now advocate for research that starts with one's own experience (Ellis, 2004). In fact, this is very much in line with my philosophical standpoint, which was the main reason behind choosing autoethnography as the research approach for my thesis.

Autoethnography is not solely a method founded in postmodern ideas, but also a product, “a way of life” (Bochner & Ellis, 2016), in thinking, speaking, and writing reflexively and evocatively. In fact, autoethnography is used increasingly for diverse research topics, e.g., sexual violence (Javaid, 2019), pornography (Murray, 2017), anorexia (Holmes, 2014), trauma, poverty and Covid (Douglas, 2022).

Like Wall (2006), the emphasis of my research was to create a space for the sharing of unique, subjective, and evocative stories (p. 148) of illness and experiences that contribute to the larger illness narrative to generate reflections on what could be different because of what we have learned. Nonetheless, before attempting to delve deeper in the writing of this research project I needed to inform, familiarize myself and comprise the ethics in doing autoethnography.

Chapter 4: Ethics In Autoethnography

Ethics in essence, is larger than research. Ethics is the essence of morality (Gilligan, 1983) whilst research is an extension of a researcher's life (Ngunjiri et al., 2010). Doing autoethnography, writing and performing our own lived experiences to understand how culture and context shape our experiences, requires unlimited attention to ethical issues (Tullis, 2013, p. 244). Using ourselves as the primary focus of research, as researcher, informant, and as author (Clandinin & Connelly, 2004; Tolich, 2010) may lead to complex ethical dilemmas, most especially if storytellers are from marginalised and vulnerable groups.

The combination of writing and representing my own story alongside other women's illness stories was a complex process. As a woman 'insider informant' to this research, reflexive engagement was essential, not only because I have taken an autoethnographic approach, but also because of the multiple roles that I embrace. As previously mentioned, as an insider informant, I was conscious that I needed to be constantly aware of my own privileged position as a researcher, who, wittingly or unwittingly, may silence, or distort the viewpoints of the women that I was striving to support. Furthermore, feminists and autoethnographers alike acknowledged that the personal can indeed be political (Holman Jones, 2005) conceding people's personal experiences as being influenced by broader power, and political relations. In this way, a woman's personal experiences are not solely her own, they are linked to other women's experiences, and therefore, they are linked to broader politics. Similarly, the stories that we tell of ourselves or others, are always richly peopled and populated with others, be they named and/or unnamed (Cavarero, 2000; Speedy, 2008).

The ethical issues involved in autoethnographic research have been discussed widely and contested over the years (Tolich, 2010; Tamas, 2009; Andrews, 2017). Tolich (2010) and Tamas (2009) have been particularly critical of how some autoethnographers have managed ethical standards in research. In terms of addressing ethical concerns within their research, there is no simple solution, no one best way, and no holy grail available (Winkler, 2018, p. 242). Although in some instances guidelines could be helpful, in other instances they might have the tendency to become foundational principles, hence deemed as "universal standards against which to make judgements" (Sparkes, 2002, p. 224). Andrews (2017), Ellis (2007) and Etherington (2005) are of a similar opinion that ethical practice is an ongoing process to be evaluated throughout the project. Hence, rather than relying on guidelines as standards, doing autoethnography involves a continuous effort to evaluate ethical considerations and to make critical choices for oneself and others (Hernandez & Ngunjiri, 2013).

The following section discusses the different ethical dimensions and foundations considered for this research project namely (a) the procedural and the practical dimension (b) the relational ethics and (c) autoethnography as an ethical method.

a) The procedural and the practical dimension

Guillemin and Gillam (2004) described two dimensions of ethics. The first dimension is the procedural ethics with respect to this research. The ethical aspect of my thesis was regulated by the University Research Ethics Committee (UREC) of UM. This committee ensured procedures, which address issues regarding informed consent, confidentiality, rights to privacy, deception avoidance and protecting human subjects from harm. The procedural dimension of ethics is the initial stage of obtaining permission from UREC within the Faculty of Social Wellbeing (UM) to ensure the approval of such research project. I had a great sense of duty to ensure ethical correctness, such as taking measures to safeguard women *participants*, whilst remaining aware of potential concerns to guarantee research integrity (Guillemin & Gillam, 2004). Developing ethical procedures that outlined the study's aims and activities, whilst specifying the risks to, and benefits for the participants, was a multifaceted and complex task most, especially because the language used in the respective procedural documentation of UM and certain requisites, did not concur with autoethnographic research. Lapadat (2017) noted that research ethics reviews as conducted through research ethics boards are not often especially helpful with respect to the ethical aspects of doing autoethnographic work. This contention resonated with my own experience when compiling the application to seek clearance from the routine UM ethics clearance procedural body.

Christians (2011) referred to 'doing autoethnography' as a negotiation of bureaucratic ethical research processes in an institutional context, in which ethical practice is seen through a modernist social science lens. Furthermore, Christians (2011) argued that the value-neutral and utilitarian ethics practised by research boards are more effective at protecting the institutions themselves rather than research participants. The application itself leaves little opportunity to address particularity, situatedness, power relations, the way that ethnographers are implicated in their research. All these issues are key to the conduct and ethics of autoethnography (Lapadat, 2017). Indeed, my own experiences stand as testimony to the above. For this reason, I dedicated a lot of time and attention to completing the ethics application for UM. The questions on the application for ethics clearance were answered with ethical mindfulness and correctness, as well as in the best possible manner and knowledge at that moment in time. Measures dealing with informed consent, confidentiality, rights to privacy, deception, and safeguarding participants from potential harm, were extensively discussed with the supervisory team and experienced researchers in Malta, in view of embracing the specific context of Malta and the associated challenges related to carrying out autoethnography locally. Incidentally, the goals of ethical preservation and principles based on the commitment to participants' well-being, autonomy, fidelity, justice, and self-respect constitute the baseline, and are intrinsic, to both my professional disciplines of nursing and counselling i.e . The Code of Ethics and Standards of Professional Conduct for Nurses and Midwives (2020) and The Code of Ethics & Policy (Malta Association for Counselling Profession, 2011).

However, I felt that acquiring ethical clearance in autoethnographic research was not so straightforward (Connolly, 2007). At such an early stage, it was difficult to imagine or ascertain, determined possible outcomes for myself and others', since they were yet, unknown to all, including myself. Researchers, Cutcliffe and Ramcharan (2002) noted that, at this stage, it is difficult to account for all ethical aspects of an emerging design and predicting or controlling the research environment, which changes from participant to participant. Consequently, I also considered "ethics of consequences" (Etherington, 2007), and considered the positive and negative consequences of participating in research, and "process consent" (Ellis, 2007). In so doing, I aimed to minimise harm and maximise benefit by remaining ethically mindful (Guillemin & Gillam, 2015) from the start and throughout the study.

Ethical research requires much more than clearance from the UREC. Like Ellis (2009, p. 310), I believe that ongoing active awareness should not cease simply because a committee grants permission for the research to proceed. The second dimension is *ethics in practice* or *situational* ethics. This refers to the facets of ethics in research that deal with the process which may sometimes be unpredictable, and/or encounter indirect occurrences. Guillemin and Gillam (2004) described the translation of ethical principles into ethical practice, as well as ethically important moments (p. 262). These moments also include the difficult and unpredictable situations that can arise when doing research for example when recalling illness experiences, one might experience compassion fatigue and vicarious traumatization (Fox, 2019). Whilst McNamee et al. (2007, as cited in McEvoy et al., 2017) acknowledged that the power and emotional relations, cultural sensitivities, behaviour, and the ongoing nature of consent, are often respected in qualitative autoethnographic research, Bowtell et al (2013) argued that "ethical mindfulness and reflexivity are vital tools for noticing and processing ethical dilemmas in qualitative health research" (p. 652).

Therefore, in the writing of this project I was committed to remain consistent, reflexive and ethically mindful of the ethical aspects and challenges throughout the entire research process, from the time clearance was received from the committee, all throughout the meetings with the women and any time after, in this regard.

i. The conversation process

A preliminary informative and introductory conversation was planned with each of the women. The women's contact details were passed to me through third parties with their consent. An email was sent to each respective woman, and they were given the option to meet or to speak over the phone. This was an informal introduction, which was not being recorded or transcribed. I spoke to each potential contributor on the phone. The women were given a brief outline of the research and the process. Any questions and/or queries were answered in the best possible manner. Ethical obligations were also discussed.

The information sheet (as requested by UREC) was sent to each woman in the language of their preference - Maltese or English (see Appendix A). The sheet included information on ethical measures, mainly concerning consent, confidentiality and preserving anonymity, as well as measures to safely secure personal information and data in line with the Data Protection Act. Details of the measures to be taken to ensure safeguarding, storing, and discarding recordings were also given at this stage. In order to secure data protection, contact details were kept separately from transcripts and representation of their stories. Pseudonym names were used from the start.

Safety measures also included offering psychological support services offered by a professional therapist in the eventuality that they would require emotional support during the process of telling their stories. The women were informed that they were free to withdraw consent at any time during this process. Consent was discussed at length, including ongoing ‘process consent’, meaning periodically checking their ongoing consent during the research process (Etherington 2004; Ellis, 2007).

ii. Consent and autonomy

Upon agreeing to participate and collaborate in this research, an appointment was arranged for the first conversation at a time and place of their preference. The conversation was held in a private clinic that was very welcoming and located centrally. Prior to starting our initial conversations in our first face to face meetings, a general overview as described in the information sheet was once again discussed with each respective woman. Each woman was given the time to read the information once again, to ask about any possible queries or implications (if any) in accepting to participate before signing the consent form (see Appendix B). McLeod (1994) acknowledged that this kind of research can be rather intrusive, “complex and demanding” (p. 62) and may reconnect participants and the researcher, with issues and experiences, which could have been disturbing. Therefore, as highlighted in Tolich’s (2010) guidelines, it is imperative to inform and respect participants’ autonomy, voluntary nature of participation, withdrawal, and document the informed consent processes. They all agreed willingly to participate and collaborate in this research project.

Moreover, I practiced ‘process consent’ (Etherington 2000; Ellis 2007) periodically to not only to ensure willingness to continue to participate but also to give them the opportunity to withdraw at any stage in the research process. Instances of illness fluctuations or flair ups and/or other events like the COVID-19 pandemic enhance fear, reinforce the sense of loss of control and/or agency. Consequently, it was very important for me to ensure that all necessary measures possible were taken to safeguard and minimize any ‘risk of harm’ (Lapadat, 2017). In so doing, I wanted all the women participants to understand that this time sharing their stories was destined to be a different experience. Unlike the experience of their illness, where the women claimed that they felt they had no say in the process, no voice or control, I wanted them to experience the process with a difference. They were valued as equal partners in the research, they had control, choice, and a voice. They were in control to choose whether to continue collaborating in this research project or not, and if so, they had a choice and a voice in which stories to tell for the purpose of this research.

Additionally, consent in autoethnographic research does not stop with the person being interviewed. When relating stories of experiences, we cannot avoid implicating others (Ellis, 2007) in the telling, writing and performances. For example, when relating our illness experiences, we could draw in other family members. Tullis (2013) stated that it is, therefore, just as important for others to consent to participate or appear in a text. The ‘others’ in autoethnographic research could include partners (Ellis, 1995), friends (Richardson, 2007), family (Tamas, 2011). In this research project, I often needed to refer to my mother to fill in the gaps when memory failed me, most especially during the period of my illness event. She was informed and involved in the process as from the very start of this research project. Her contribution both verbally and written were very valid and valued throughout the process. As stated earlier, ethical mindfulness and reflexivity were practiced with great sensitivity, most especially when discussing different material that was elicited from the stories with my mother. I was sensitive to the fact that even though verbal consent was gained, process *consent* was checked every so often during the writing of this thesis to ensure that the questions asked did not disturb her tranquillity or elicit any negative thoughts and feelings. Furthermore, although at times I referred to past experiences and related memories (Richardson 2000), at no time was there any need to gain retrospective consent from other third parties. It is important to note that the issue of *others* and *ethical correctness* is highly debated in autoethnographic research. Chang (2008) referred to others (third parties) as visible and invisible participants whilst Andrew (2020) referred to others as persons who also have rights of consent and protection. According to Tolich (2020) these third parties are not always informed of their involvement in the story, let alone about ownership of the story, both in writing as well as when publishing such work.

Besides the issues of authorship, Tolich's (2010) perspectives also included choice and restrictions when choosing topics for autoethnographic research, and subsequently gaining permission and consent. However, Grant and Young (2021) critically resisted and viewed these perspectives as a form of epistemic violence. They accused Tolich's perspective as being authoritarian and silencing, thereby claiming that violence was being replicated, this time with the researcher. They compared this behaviour to that imposed on abuse survivors to silence them, thus denying them the right to tell their stories. They highlighted the fact that whilst, it is imperative that *all* voices are heard, in practice, there are significant power imbalances and societal prejudices that maintain epistemic injustice in many aspects of the system.

Similarly, on another level, chronically ill women are especially vulnerable to epistemic injustice, power and inequality owing to gender politics, contested, and stereotyping of illnesses, together with certain structural features of contemporary health care practices. They also find difficulty to relate their story, many a times resulting in emotional distress. In fact, much of the literature focuses on the emotional distress that such experiences generate, grounded in the epistemic dimension (Kidd & Carel, 2017). In a way, this is another form of challenging the master narrative, which many of us do, and thereby refuse to be silenced.

iii. Confidentiality and anonymity

According to Denzin (1989):

> [W]e must remember that our primary obligation is always to the people we study, not to our project or discipline. The lives and stories that we hear and study, are given to us under a promise…that we protect those who have shared with us. (p.83)

The women were informed about all the measures taken to safeguard confidentiality and anonymity, mainly related to recordings and the storage of transcriptions, as well as how to keep records secure (Tullis, 2013). Further to the previously mentioned measures, others included the alteration of information, the creation of composite characters technique (Ellis, 2007), and the fictionalisation of parts of a narrative to disguise time and place (Ellis, 2004). Such measures were adopted and respected in this study. More so, the women were asked to choose a pseudonym and title for their story.

I was cognisant to the fact that the safeguarding measures concerning confidentiality and anonymity of participants was going to be challenging due to the limited size of the population and the smallness of the country. Research in "small, connected communit[ies]" (Damianakis & Woodford, 2012, p. 708), as well as "geographically bounded and tightly knit" communities (Ellis, 2007, p. 8), heightened the risks of unintentional identity disclosure, which was magnified when involving myself as participant in research and the women participants from such a small community as is Malta. Moreover, it was also possible for participants to know each other through connections that “transcend shared geography” (Damianakis & Woodford, 2012, p. 709), such as professional or personal networks, including health care professionals or support groups. Locally, this risk is enhanced since there is only one main National hospital. There are few consultants in specialised fields of autoimmune illnesses.

Also, due to the smallness of our population there are only a few support groups/associations for each specific condition who tirelessly represent and support people living with chronic autoimmune invisible illness in Malta. Therefore, the probability of recognizing the persons due to the limitations of place and space was high and consequently, so was the possibility of fracturing relationships (Etherington, 2007). This increased possible potential for exposure required careful planning and deliberation. The ultimate aim was to safeguard and minimise risk any potential harm or consequences most especially for the women participants who continue to live with the chronic illness in Malta.

In autoethnographic research, this was not merely a risk for participants, but also for me, as the researcher, to be open to vulnerability, visibility, and recognisability. Anticipating this type of personal vulnerability is a foundational aspect for autoethnographers (Tullis, 2013). I was aware, and fully cognisant of the risk, that as the author and participant in research, similar to Attard (2017) who echoed (Butler 1995, p. 42), I claimed my position and did not shy away from using the *I* in research, even though I could easily be identified from my different professional communities I work in and form part of, as a nurse, a counsellor and educator. Notwithstanding all this, the choice to use autoethnography was made with full awareness of the possibility of making myself personally, and professionally vulnerable (Ellis, 2009), and took full responsibility of the consequences.

iv. Ethics of reciprocation

When completing the ethics clearance application forms, I explained that besides meeting up with the women participants at least twice for face-to-face conversations, an additional conversation would be held for the women to validate the representation of their stories. The representation of the women stories written in poetry format were eventually sent to each participant for review, to include any missing information or remove any details that they did not wish to include to be published. As promised, they were in control.

Going back, giving back to the women their own stories, was considered as being "ethically and/or politically necessary" (Grinyer and Thomas, 2012 p. 223). Some researchers refer to this as *intentional ethics of reciprocation (*Kirsch,1999), and consider research as being just, representative of their voice and ultimately beneficial to the women. In drawing upon multiple perspectives (women's stories, *my*story and academic literature), representing their stories by using their own words in the form of found poetry, academic knowledge is democratized, thus reinforcing the view that the marginalized have a moral right to own and control knowledge produced by them (Baker et al., 2004 as cited in Swartz, 2011). Therefore, it was not simply relenting the 'findings' but giving them back the ownership, the opportunity and control to review their stories, and remove or add any parts to satisfy them for accuracy in interpretations (Ellis, 1999; Tamas, 2011). This approach to research is also referred to as the 'emancipatory approach' (Denzin, 2005) which draws on feminist arguments adopted for this research namely promoting empowerment, respecting subjectivity, valuing the ethics of human rights and equal power (Swartz, 2011) which includes the relationship between researcher and researched.

b) Relational ethics of care

Eakin (1999) posited that “all identity is relational” (p. 43); no person is an island, and we live relational lives. We are relational beings. We live and interact daily with different members of the community family members, friends, colleagues, and others. Thus, autoethnographies are not wholly our own because, oftentimes, they involve relational others (Ellis, 2007; Tullis, 2013). Writing autoethnography and illness stories required an ethical approach that honours and respects participants’ stories, whilst staying true to the meaning of the story (Giorgio, 2013, p. 413). Doing autoethnography involved a *back-and-forth in time* and *in between* experiences, examining both the vulnerable self as well as the broader context of that experience (Ellis 2007). When we write about ourselves, we also write about others. Relational ethics was also referred to as “ethics of care” (Gilligan, 1982; Christians, 2000; Noddings, 2003) and the “ethics of responsibility” (Ellis, 2009). ‘Ethics of care’ occupy a central position within the moral philosophy and feminist theory (Hankivsky, 2014, p. 252), which, in research, required attention to the way I related to the participants at every stage (Etherington, 2020). Similarly, “dutiful ethics are considered as an acceptable baseline for moral and ethical conduct, whilst ‘care’ requires that we act in ways that are additional and part of our duty” (Ellis, 2017a, as cited in Etherington 2020, p. 6).

An ethic of care recognised and values mutual respect, dignity and connectedness between researcher and researched (Chang, 2013, p. 111). As a researcher, I was responsible for providing a true representation of stories and in the writing. Relational researchers viewed “relational concerns” (Ellis, 2007, p. 25) as important as research. For instance, Tamas (2009) grappled with the “ethics of the autoethnographic voice” (p. 1) and Roth (2009) questioned who has the right to tell the story. Simon (2014) depicted relational ethics as being “an ethics-led activity” (p. 16) as opposed to methods-led and stated that doing, writing, and reading research are all dialogical activities with ethical responsibilities. According to Tullis (2013, p. 53), doing no harm is sometimes an imagined state rather than a known reality, particularly if the researcher has no direct contact with ‘others’ who are brought into the story. During my conversation with women, the relational ethic of care was practiced throughout the process. This included practising compassion, empathy, mutuality, attending fully to the women whilst sharing vulnerability and listening deeply to the stories.

c) Autoethnography as an ethical method

Ellis (2007) stated that “autoethnography itself is an ethical practice” (p. 26). Mendez, (2013, p. 238) maintained that writing autoethnography entails being ethical and honest about the events described, as well as transparency in representing the stories. Writing autoethnography often raises discussion about potential harm to the autoethnographer and is a potential ethical dilemma. In writing, individuals may easily forget themselves, whilst attention is paid to protect the other. On the other hand, Denshire (2014) highlights that one of the strengths of autoethnography is its ability to present an intimate, yet transgressive account by writing the absent body(ies) and voices into their practice, challenging institutional and professional power relationships. Therefore, according to Poulos (2008), it is about the ‘ethics of revelations’; what one should do rather than what one should not do (p.53).

As noted earlier, whilst great attention was paid to protect others (most especially family members), I was also aware of my own participation in the story, since whatever I wrote could have consequences (Ellis, 1999). Despite this fact, it did not stop me from writing my story. Admittedly, however, I was not fully cognisant of the process that would unfold through the writing. Bochner (2007, as cited in Denzin & Giardina, 2016) compared the public sharing personal of stories to “opening our veins” and bleeding.

(p. 197) However, my experience was somewhat different. Since time had elapsed, I was looking at the experience from a distance with a critical eye. In fact, I was now looking beyond the actual illness event itself. I was looking into the cultural and societal connotations around my story in relation to health and gender. These were facets, which I would have probably never explored if it were not for the methods approach being used in this study. The challenge was not in the recalling, re-living and re-telling of my experience, as well as others, through their own stories, yet through the desperate *want* to voice my experience through a successfully- articulated and well-written study.

The issues discussed in this section illustrated the complexities of application of ethical research practices, because of the nature of autoethnography and the multiplicity of my roles. Tullis (2013), Ellis (2007) and Etherington (2020) recommended that ethical issues should be considered throughout the process of writing. Indeed, this is what I aspired to attain throughout the project. Ethical research is not solely accomplished by checking boxes, completing forms, creating pseudonyms, or drafting an ironclad informed consent form. This was a major learning curve, contributing to my process of seeking ethics clearance, and moreover, carrying out research ethically Therefore, it was essential to make autoethnography's ethics more visible (Tullis, 2013), which is why this section was so extensive. In the next section I will walk you through the design and discuss the process step by step. Each step is punctuated with a detailed rationale when deemed necessary.

Chapter 5: A walk through the research process

The terminology chosen for this study needed to be decided at the preliminary stages of this research. From the outset of this study, like St. Pierre (2018) struggled in using certain terminology and concepts like interview, the field, and data, I preferred to consider the women 'participants' as 'collaborators' in the research. The women were invited to tell their stories and in so doing other stories were co-authoring other stories (Adams & Holman Jones,2018). With this in mind, I decided that it would be more apt to use the term 'conversations' instead of 'interviews'. I deemed conservations to be more appropriate because of the nature of the study and the importance of the relational aspect of these conversations, with the aim being to minimise the risk of repeating power and privilege. However, at times the word 'meeting' was occasionally used to facilitate ease of reference.

The intention behind drawing on other women's stories was not to extract data to eventually analyse them, but to support any propositions or to elicit any theories. The women whose stories of living with chronicity are represented in this study go way beyond data collection about their illnesses. As Frank (1995) highlighted, I aimed to "think with stories rather than about stories" (p. 23). Instead, the stories are the material used for the co-creation of other stories. As the women collaborators claimed, "IT is not me" similarly, sharing *my*story goes way beyond the sharing of the illness event.

At the proposal stage, the Faculty of Social Wellbeing doctoral committee, UM, recommended that I should recruit a minimum of 8-10 women participants for my research. According to Creswell and Creswell (2018), the number of participants depends on the qualitative research approach. Due to the in-depth nature of illness narratives, together with the anticipated intensity and sensitivity of the stories, I felt it was premature to stipulate the exact number of participants. However, experts from the field of narrative inquiry recommend that researchers should avoid using more than four participants (Clandinin & Connelly, 2004). In this autoethnographic study, I am not only the researcher, but also participant in research, alongside the four identified women. Indeed, many autoethnographies use only the researcher's story. My decision to include other participants were various but mainly since, besides being novice to autoethnography, writing an autoethnography solely using self-as-data was a risk because of the small-scale island on which this study was based on. Therefore, the choice to include other women was also a way to counteract possible accusations of being self-indulgent and/or narcissistic (Spry, 2001; Sparkes, 2000, 2013).

Eventually, together with my supervisory team, it was decided to focus on fewer participants, given the richness and complexity of the stories experienced and shared. I hoped to be able to connect to a certain a level of "relational depth… entering into the world of an Other, and a sense of being welcomed and valued there" (Cooper, 2005, p. 89) to give the women the time and space for holistic and compassionate listening, whilst validating their respective individuality through their stories, as originally told. In so doing, I was adhering to what had been promised when they agreed to participate. As from the beginning of this project, my intention was to treat the women as collaborators in research for the co-creation of stories, and not as objects and/or subjects for data collection. Therefore, the importance in taking this decision was based on the quality of the experience rather than the quantity in numbers.

Mearns and Cooper's (2005) working definition of relational depth is "a state of profound contact and engagement between two people, in which each person is fully real with the other, and able to understand and value the other's experiences at a high level" (p. 36). Such human encounters are, at times, also described to be similar but not limited to a therapist-client relationship. Even though the research relationship evidently differed from the therapeutic encounter and the scope of the outcome is different, it was envisaged that similar skills would be adopted, for instance, empathy and compassion, the space and the relational depth would be both a genuine and respectful one. Both instances were intended to provide a safe platform for stories to be told. Moreover, the in-depth mode of relating, in which two individuals experience a great sense of connectedness and mutual collaboration with each other has been discussed by many. Buber (1947) wrote about moments of genuine dialogue in which "each of the participants really has in mind the Other or Others in their present and particular being and turns to them with the intention of establishing a living mutual relation between himself and them" (p. 37). Furthermore, Ellis (2007) emphasised the importance of recognising and valuing "mutual respect, dignity and connectedness between researcher and researched, and between researcher and the communities where they live and work" (pp. 4-5).

In hindsight, the relational aspect I aspired to advocate in the conversations with the women was not only an ethical one, but it also reflected core aspects of the feminist approach that I adopted for this study. By participating in these conversations, the women had an opportunity to tell their stories (many of them for the first time), listened to and shared with a larger audience. Subsequently, this was an opportunity to use their own voices, to relate their truths, underpinned by a desire to perform their powerful, agentic, and autonomous selves and identities through the telling of their stories (Speedy 2008, 2016; Etherington 2021). These fundamental values and beliefs about the relational aspect with the women helped me navigate the process of writing this thesis. Even though they were not captured in the writing of the application, they resonated all throughout the process.

Selecting the women collaborators

Initially, three entities were chosen for the identification of women as *participants* namely, primary health Care, community care services and non-governmental associations associated with chronic illnesses, that is, the ME/CFS association. However, these entities did not prove to be as resourceful as was hoped for. Request for permission was presented and clearance was gained from the management of each respective entity. Background of the study and other information for selection of *participants* was given to an identified person from each respective entity. An information letter was also given both in Maltese and in English and handed out to any persons that showed particular interest in contributing to the study (see Appendix A). However, unfortunately none of these entities identified any *participants*. Therefore, purposive sampling was adopted as an alternative measure to identify women to participate in the study. Women that fit the selected criteria were "purposively selected to represent rich knowledge about the research questions" (Gubrium et al 2012, p. 248).

The inclusion criteria for the selection of the women to be eligible to participate in this research study included women aged between 22 and 55 years who have been living with an autoimmune invisible chronic illness for at least two years, thus confirming chronicity, and who lived in Malta. Other age groups were not considered because of the respective specific needs of the homogenous groups, namely: children, who face distinctly different challenges associated with developmental stages and parental relationships; older persons who could be influenced by attributes of old age, frailty, and other comorbidities. The autoimmune invisible chronic illnesses that were considered for this study included contested and non-contested autoimmune illnesses namely: Fibromyalgia (FM), Chronic fatigue syndrome/Myalgic encephalomyelitis (CFS/ME), Multiple Sclerosis (MS), ulcerative colitis (UC), and Rheumatoid arthritis (RA). Incidentally, these chronic illnesses are most prevalent in women (Jackson, 2019; Whitacre, 2001). Furthermore, whilst cardiovascular disease including heart failure, hypertension and/or other metabolic chronic invisible illnesses like Type II diabetes might be considered as hidden, they are not autoimmune. Yet, although Type I diabetes is autoimmune condition there were no women selected for this research with such a condition. Although these conditions might share similar experiences they were not considered for this specific project. However, it would be interesting to follow up this group in future research. Also, other exclusion criteria included women diagnosed with acute or chronic psychiatric illnesses, neurological illnesses that could affect cognitive processing, and/or other terminal illness.

The four women were purposely identified through colleagues and friends who were aware of the research focus. The women who fit the selection criteria were invited to participate in research project. All four women accepted the invitation. The respective contact details were eventually forwarded to me with their consent. Primarily, I communicated with each person by email and forwarded the information letter for their perusal (see Appendix A). Once the women confirmed their agreement to participate, plans for sequential meetings were made individually. Two consecutive meetings were organised with each participant. The second meeting happened after approximately two weeks from the first encounter.

Getting to know the women

> *(Personal notes 2019 – post first interview)*
>
> *I was feeling very anxious preparing for my first interview, even though I thought I was prepared, I honestly don't think I can ever be prepared enough. I was privy of Francesca's story or how it was going to affect me. It felt like I was walking into the darkness, the unknown with caution and curiosity. I experienced that same*

> *feeling prior to meeting a new client in a therapy room, having minimal information – tabula rasa, not knowing. Francesca enthusiastically accepted my invitation to relate her illness story. A story of living with fibromyalgia, a roller coaster of uncertainty, doubt, fear, achievement survival and pride – she repeatedly stated that she would not have had it any other way.*
>
> *On asking her a single introductory question, I could see Francesca, who was sitting at the edge of the armchair, feet firm on the ground, she couldn't wait to tell her story. Whilst she was talking, I could see that she was choosing important goalposts in her illness narrative timeline starting from the very beginning. The beginning was when she felt the first symptoms… the before and the after. It seemed as if she made sure that I was being given every detail and the full picture of her story. It amazed me how she seemed to have this dire need to explain specific details about emotions, cultural context, family support. She made sure she explained the meaning she gave to the condition (IT) and discussed in detail the loss of the healthy self – the disrupted self. However, at the same time shared the realisation and discovery of the new and unknown; a genuine, authentic self in the making who in her opinion was hidden. The space seemed to give her the opportunity to 'talk about IT' freely and was no longer feeling trapped, ashamed, and guilty to do so. I witnessed a strong woman determined to live her life in the best way possible…herstory was mystory, ourstory.*

The four women who agreed to share their story were all aged between 20 and 30 years old at the time of the meetings, meaning that they were the same age that I was, when I was unwell. Alas, although individuals might be of similar chronological age, it is essential to note that age, in itself, is a social construct to better represent an individual's feeling of 'place within the life span (Rubin & Rubin, 1986). Ultimately, we all live different life experiences and associate different meanings, no matter the age. In turn, these experiences influence our personal and social identity. Life experiences might differ between individuals of the same chronological age due to different intersecting factors including gender, class, culture, religion but also the presence or absence of a chronic illness (Kundrat & Nussbaum, 2003, p.331). All the women readily related their embodied, emotional, existential experiences of living with invisibility and chronicity (FM, MS, RA, and UC). The women claimed that collaborating in this research process also experienced psychological benefits because the opportunity to voice their story and be heard was powerful. This kind of outcome is documented in literature (Etherington, 2007; O'Shaughnessy et al., 2013). They were responding to an introductory single question (see Appendix C); it was their performance and their time to speak. I, the empathic listener was their audience. It was as if I was being handheld, drawn into their space, their world of pain, suffering, silencing, secrets, yet also a world of resilience and hope; a space that I, myself was familiar with. The stories that were told were grounded in embodied experiential knowledge. They were generated through intentional self-reflexivity and awareness (Poulos, 2021) for the purpose of this conversation. They were not only telling a story, but they were speaking out their heart about particular life stories, an embodied story that could not only be heard, but also visibly seen through their whole body. On listening to their stories, I was transported back in time, invoking, and evoking diverse feelings and emotions unifying a mutual sense of belonging. In turn, this generated further reflexivity, deepened empathy and imagination which was vital for research, therapy, and life itself (Andrews 2017), thus pushing for new interpretations of human experience.

Francesca started experiencing unexplained pain in her legs and fatigue in her late teens. Up until she was diagnosed with FM in her mid-twenties her life was put on hold.

However, she claims that the illness experience revealed her *authentic* self and gave a meaning to her life:

IT gave me a
reason meaning of Life.
The ME of now
…Less is More

Jessica developed symptoms of MS in early twenties but was diagnosed in her late twenties – she says that she keeps her condition as a hidden secret to protect her mother's health and wellbeing:

a secret to my mother
only few people knew
longing for normalcy
loathing pity

Erica developed symptoms of RA before she was 10 years old and was diagnose in her early teens. She learnt to listen to her body and planned her life conscientiously and according to pain:

I plan and do things according to Pain.
No medication restored normality
I still need to rest, to make conscious decisions
… to plan

Jasmine developed symptoms of UC in her early twenties – refused the condition to become her identity. Her positive outlook in fuelled her motivation to optimistically continue with her life in the best possible manner:

‘To get on with it…. get on with life!’
‘IT doesn’t define me.
IT is NOT me!
IT is just a part of me’

The research process explained

Hereunder, I present the process that was followed once the women collaborators were identified. The stages of this research process included (i) initial conversation; (ii) the single question; (iii) the second conversation; (iv) transcribing and translating conversations; (v) member validation; (vi) rigor and validation; and (vii) post meetings.

Initial conversation

As explained in the previous chapter a preliminary informative and introductory conversation was organized with each woman. Conversations were destined to be informal and were not recorded or transcribed. I spoke to each potential contributor on the phone. The women were given a brief outline of the research and the process. The aim was to answer any burning questions and/or to clarify queries. Information sheet were sent to each participant in their preferred language. Ethical obligations as written on the provided information sheet was discussed namely: issues around consent and process, confidentiality, and anonymity, as well as safeguarding measures to secure personal information and data (verbal and written) in line with the Data Protection Act. Personal safety measures for the women participants were also highlighted offering professional psychological support services in the eventuality that they would require emotional support during the process of telling their stories. Furthermore, the women were also informed that they were free to withdraw consent at any time during this process.

The single question

Three meetings were planned for each woman. In the first meeting a single narrative inducing question was asked to elicit a life story narrative, based on Wengraf (2001), a model of meeting three times adapted Shaughnessy et al. (2013). The question was asked in their language of preference (Maltese or English), inviting the women to tell their respective story (see Appendix C). *"I am interested in listening to people's experiences and meaning of living with a chronic illness as part of my research project. Could you please tell your story, the events, experiences that have been important to you up till now and that left an impact on you as a person*?"

The intention to use single inducing narrative questions was to allow the women choose freely on whatever they wanted to speak about, from their own perspective (O'Shaughnessy al., 2013). The first meeting enabled me, as a researcher and participant in research, to establish a collaborative relationship and gain a preliminary understanding of the story being told.

The second conversation

The second meeting was organised after approximately 3 weeks from the first meeting. This specific time was allocated to give me enough time to transcribe the first conversation. At the same time, I did not wish to leave too much time from the first conversation to the next. The second conversation was as significant as the first conversation, as it consolidated the collaborative relationship further. During this conversation it felt as if we were resuming an established relationship rather than starting out as strangers, as happened in the first meeting (Holloway & Jefferson, 2000, p. 44).

In the second conversation, I asked the women about any reflections they might have had on the first interview and invited them to elaborate, clarify, change, or add any detail that they had shared during the first conversation. This conversation was aimed at eliciting further aspects, that is, the “thickening” (Geertz, 1967) of their narrative in the areas they wished, to compliment the first interview or to seek further knowledge and generate new stories, if they wished to do so. I met three of the women twice in face-to-face meetings, where each conversation lasting approximately 1 to 1.5 hours each.

I had met each participant, individually, giving my full attention to that respective participant, whilst considering my own journey within this intriguing process. Alas, I only managed to meet the fourth participant once in a face-to-face meeting. We could not organise a second face-to-face meeting due to COVID-19 pandemic restrictions. However, we communicated by email as a follow up to the first conversation.

Transcribing and translating conversations

Each conversation was recorded and later transcribed and translated with the women’s consent. Minimal notes were taken during the conversation. My intention was to give my full attention listening to the woman relating her story and not get lost in keeping interview notes at that moment in time as a source for data collection (Wall, 2006). More so, I was interested in the verbal and non-verbal communication, how they embodied relating their story and keeping aware, how I was embodying hearing their story being told. At times, I found this process to be emotionally taxing because stories told resonated with my own experience, memories, and emotions. These precious gestures cannot be recorded in any interview audio recordings.

The audio recordings of the first two conversations were transcribed and translated into English as per requirement of the UM. A sample of each conversation is presented for reference and authenticity (see Appendix Section 2). Transcribing is far from a neutral act. Transferring words from an audio recorder onto a page is an act of translation between two vastly different media (Ellingson, 2012, p. 529). The spoken and the written words are stripped of most non-verbal interactions. Mishler (1991) argued that transcribing oral to written speech is like transcribing from one language to another, and that it may be impossible to express ideas accurately. I experienced this in the literal sense both it in transcribing from audio to written text, and also translating the transcribed conversations from Maltese to English. At times, I found it difficult to find the appropriate words in translation and thus, retained the Maltese words.

Member validation

The third meeting was intended as member validation process also referred to as member checking. It was intended to serve as a means for the women to check the meaningfulness and accuracy in the poetic representations of their stories and, to ensure that the translation made justice to their conversations. Ethical aspects of the member validation process were taken into consideration every step of the way. The third meetings were not held face to face due to COVID- 19 pandemic restrictive measures. The women opted to communicate by email.

Even though, they were informed about the process at the start of the project, I was conscious that some months had passed since our conversations. I was very sensitive to the possible disruption that the COVID pandemic might have caused on the women, their families and/or their health. An email was sent to each respective woman and asked whether they wished to receive the representation of their stories. They all accepted the invitation to view the representation of their stories written as found poems. When using member validation or member checking in this autoethnographic research, I was mindful and sensitive to the fact that the women participants could be reading their own stories with possibly no one to support them. They were once again offered the possibility to opt out, if they wished to do so. At this instance, as stated earlier, my main aim was to minimize any risk of harm to each woman collaborating in this research. I had invited them to write to me once they read their stories and to add any comments if required. The feedback I received were positive and only minimal changes were required. I was aware that participants may have different reactions to whether or not they wanted to read the stories that had been written based on their personal experiences. Reasons for these may have been due to (i) a lack of time on their hands; or else (ii) a sense of awkwardness. Moreover, it may have also been the case that the participants were in a different place emotionally, since the conversations had taken place some months prior to receiving the written text, mostly because of the pandemic. However, according to Tullis (2013), the experience could also create a "space for dialogue" (p. 254) and an opportunity for "nuanced interpretations" (p. 254).

All participants agreed to view the representation of their stories written as found poems. I each sent the representation of their conversations in found poem format rather than prose. It is a genre of poetry in which the content of the poems is "found" and extracted from the same conversations. Found poem is consistent with alternative ways of representing qualitative research (Reilly, 2013; Prendergast, 2004, 2009). Richardson (1997, 2001) viewed poetic texts as relevant forms of representation for research interviews and conversations, which also capture the vitality required in life writing (Etherington, 2004). The contrast between the narrative and the poeticised extracts invites the reader to listen carefully, impacting far more than communications transcribed verbatim could allow (Reece & Speedy, 2014, p. 54). As one of the participants wrote after receiving and reading her own words on paper:

> *Kemm hu stramb taqra ħajtek lol. Id-dettalji huma kollha tajbin. Dalgħodu jien u naqraha għedt, "Imma… jien għaddejt minn dan kollu?" ... Jien naħseb għalija l-iktar ħaga importanti huma l-kliem li kien qalli ħabib li*

> *speċita m'għandix inħalli din l- kundizzjoni tibdilni. Kienet qaltli, "Illum mur u ibki xortik, imma għada ejja u ejja l- istess inti". U meta, rari, jaqbduni d-dwejjaq, niftakar f'dawn il-kliem u ngħid, "jien irrid niġġildilha!"*
> *(Maltese version)*
>
> *How strange it is to read your own life lol… All the details are correct. This morning as I was reading it, I said to myself "But…. Did I pass through all this?" … I think that for me, the most important thing were the words a friend of mine had told me once, that I should not let 'IT', the condition, change me. She had told me 'Today go and cry your misfortune but tomorrow come back and let the same person come back.' And when, very rarely, I feel sad remember these words and I say to myself "I need to fight it!"*
> *(English version)*

Like Reilly (2013), the decision to conduct member validation by forwarding found poems was a decision I took to establish 'veracity through empathetic validity' (Dadds, 2006). In this instance, empathetic validity is an alternative measure to trustworthiness (Reilly 2013, p. 3). Forwarding these found poems, helped to maintain the women's active involvement and voice in their representations, without my constructions or influence. I was adamant to represent their story rather than my interpretation of their story. I used their own same words as found poems and I made sure to safeguard their identity as well as ensure anonymity in the excerpts. I invited the women to feel free to include any information, comments or remove any detail as they deemed best. In the email sent to the women, I also invited them to choose their own name to use as a pseudonym throughout my study and a title for their own story.

This process was a purposeful social invitation in which women determined the images of themselves that they wished to become public, constructing their own realities and actively participating in “the social inquiries that shape their lives” (Cho & Trent, 2006, p.336)

Adopting crystallisation

To gain methodological rigor, I adopted a crystallisation approach rather than triangulation for validity for postmodernist texts (Richardson, 2000). Further to this, Richardson and St Pierre (2005) argued that

> [c]rystals grow, change, and are altered, but they are not amorphous. Crystals are prisms that reflect externalities and refract within themselves, creating different colors, patterns, and arrays casting off in different directions (p. 963).

Similarly, Ellingson (2009) continued to build upon this concept by combining multiple forms of analysis and multiple genres of representation (p 4). Crystallisation provides depth, enhances “thick description” (Geertz, 1972), and utilises different ways of producing knowledge as well as includes more than one genre of writing or representation (Ellingson, 2009, p. 445). Crystallisation is in line with feminist thinking, mainly that the researcher’s reflexive understanding is inherently valid and taken into consideration throughout the research process. Furthermore, Ellingson shuns positivist claims to objectivity and a singular truth. ‘It embraces, reveals, and even celebrates knowledge as inevitably situated, partial, constructed, multiple, and embodied (p. 446).

Post meetings

Moreover, the entire experience with these women, was and still is, an ongoing learning curve. For this reason, I invited them to include any feedback in the form of comments, reflection, or else constructive criticism about the process that they had contributed to. The women were also invited to communicate by email or otherwise, if they wished to add any further feedback after the three individual conversations had been carried out. However, none of the participants took up this invitation. I would be very curious and interested to understand their hesitancy in writing their thoughts and feelings. In fact, I would be intrigued to find this out through a follow-up project soon.

The different steps taken in the process of this research were explicated at length supported by a rationale when deemed necessary. In the next section I shall be delving deeper into the layers identifying implicit and explicit tools that were used for assembling and representing the tiles in the process.

Chapter 6: Assembling and representing the tiles

This chapter identifies and discusses different sources that have informed my writing and knowledge to assemble stories. Like Bochner and Ellis (2016), I drew upon different tools, including the individual tiles (see Figure 6), to interchangeably move across the self, culture, and descriptive research writing by taking an autoethnographic approach. My aim was to use different sources including the use of self-as-data, contributing to my inner source of knowledge, whilst also embracing stories of the other. Stories of self and other intertwine, namely through thoughts, memories, perceptions, emotions, behaviours, relationships, identities, events, situations, stories, discourses, and larger socio-cultural and historical contexts (Ellingson & Sotrin, 2021, p. 108). Systemic introspection, reflexivity, emotional reconstructions, and affectively resonant writing (Ellingson & Ellis, 2008, p. 110), together with written notes, memories, and recorded material were multiple measures used to reflect transparency and authenticity. All of these were addressed in the process of research and writing.

Figure 6a

The individual tile

Personal Reflections

Entry 1

… in my training as a nurse, 1980s reflexivity was not given much attention… as if reflections, emotions, and care should not be strung in the same sentence… or maybe I do not remember… In hindsight, I realise that whilst practicing as a nurse working in the community, often times working alone, my reflexive thinking was never captured in writing. It concerned the other, caring for the other, thinking of the other, whilst keeping myself out of the picture. However, I resumed writing and journaling when I started my Master's in counselling course at the UM…when going backwards and forwards in time, I might forget the detail, but I can remember the feeling… allowing myself to come back on the page even if for my eyes only.

Entry 2

Intrinsically, I am an introvert, quite a reserved person - my relationship with feelings and emotions is just as reserved. I believe that repressing emotions is a coping style, I had adopted as a child - sometimes denying my own affective responses – something I became aware of through my writing.

Writing in the form of 'raw poetry' rather than prose helps me to express myself better… I am aware that I sometimes leave gaps, sometimes those gaps reflect my thinking process… I refuse to fill in the gaps, the empty spaces! Writing thoughts and feelings does not come easy and find it quite laborious and emotionally taxing… I realise that it is a process, I test my own waters, I choose words to describe my feelings and emotions … Also, I have control over what I chose to write, to discard and what to put on the page. However, I am aware that I do not have control over the cathartic effect of the writing … the becoming … I realise that it is through *reflexivity…introspection and emotional recall that I approach my research thinking in the past but writing in the present … merging self and other.*

Entry 3

When I think about the start of my journey, … I realise how I struggled to understand how journal writing was going to support my research. I remember thinking about this but not conceptualizing it to the full…. I knew research differently –It was all about studying something, someone else… how was research going to benefit from my journal writing or vice versa…. Then, I was privy to the unfolding story however, I still immersed myself deeper into writing … questioning how I was going to bridge writing to my research… little did I know that writing was already doing that for me – I was told that it's a process not solely a product – I could not understand this to the full... I can do so now because I am experiencing it.

Autoethnographers, and qualitative researchers commonly postulate that reality is neither fixed nor entirely external but is created by, and moves with, the changing perceptions and beliefs of the viewer (Duncan, 2004, p. 30). The above reflection entries are a sample of the personal writing on the move, dilemmas and uncertainties shown in the writing, reflecting the ambivalent processes of the subjective self-alongside writing the research project. Writing is another way of knowing. It is through the writing that we discover and evaluate different aspects of ourselves, our topic, and our relationship to it (Ellis 2004; Richardson; 1994).

Furthermore, Denzin (2014) specified that autoethnography has incorporated reflexive inquiry practices and taken them a step further, whilst shifting the focus of inquiry from the other in the field to the situated self and one's own personal experiences.

Autoethnography is defined by Denzin as “reflexively writing the self into and through the ethnographic text; isolating that space where memory, history, performance, and meaning intersect” (p. 22). Further to this, Wright and Ranby (2009) stated that writing personal notes as “myself as the first other” (p. 58), is not only a therapeutic exercise that promotes significant physical and mental health improvements (Pennebaker 1997a, 2018), yet it is a vehicle for transformation whilst deepening and broadening reflection, thus enhancing the value of knowing.

Similarly, Guillemin and Gillam (2004, p. 247) noted that reflexivity can often be the key to revealing the complexity of contextualising the self, the research and the intersubjective processes that take place. It is an active ongoing process, which requires critical scrutiny and interpretation, not just in relation to the research methods and the material that is elicited and co-constructed, but also to the researcher, participants, and the research content. In this regard Winkler (2018) asserts that being critically reflexive involves ‘continually reflecting on one’s own responsibility, and whilst doing so, making sure to do no harm to others who become written into the text (p. 242). This process of reflexivity and care deepens empathy and creativity in the researcher (Andrews, 2017). This is vital for qualitative research as well as life itself. Therefore, the value of any written document or artefact for research purposes depends on its evocative potential, its ability to either open the research for deeper reflection on relevant experiences or relationships, evoke compelling images, emotions, or understandings in other readers (Anderson & Glass-Coffin, 1998, p. 68).

Memories and truths

When writing, I sometimes recall experiences that unconsciously resurface without any anticipated awareness. However, there are certain periods in my life

> *where I fail to recall the detail; my memory fails me. Funnily (not so funnily), I try justifying this loss of memory and foggy brain on stress, exhaustion, and menopause.*
>
> *However, I never attribute the loss of memory to any other reason including my event of chronic fatigue. For me to make sense of the gaps in memory, I ask family members about the sequence and detail of instances and events to help me join the dots and clarify. Also, writing seems to help memories become somewhat clearer.*

Autoethnographers often consider memory as a primary data, another kind of knowledge (Bochner, 2007). The introspective and reflective method heavily relies on memory to achieve deeper understanding and meaning of the human condition (Poulos, 2021). Autoethnography relies on memory work of lived experience and remembered events. Subjectivity and temporality play a significant part in memory (Bochner & Ellis, 2016). The four women recalled their illness story, which they related during the individual conversations. I recalled *my*story through the writing. However, memories are not one-time linear happenings but a much more complex endeavour. The topical is interwoven with the chronological (Ellis, 2004).

According to Pelias (2021, p. 123), digging into the personal is what allows the self to unfold, create itself again and again in its multiplicity of forms, exposing what is hidden and elusive, thus making public the unspoken and forbidden. However, it is not always easy to fit language to experience. Bochner (2016) maintained that:

> We learn that there is always a cleavage between experience and words, between living through and narrating about, between the chaos and fragmentation of living a life and the smoothing orderliness we bring to it when we write, between what we

> remember now and what we say took place then, between how we mourn and work through the past and what shape our grieving gives our future (p. 197).

According to Bochner (2016), recalling stories and writing could be painful, however, it is not painful because of reliving the events in body and mind, but most especially, the obligation to produce a truthful account of the past. The truth is that we can never fully capture experience; what we tell is a story of the past (Ellis, 2004). In telling my illness story, I wanted to be faithful to the past, also drawing on other people's memories. However, I was also cognisant that what I remembered of my past was partly influenced of who I am now. It is not only the recollection but what we do with that recollection, the meaning we give to it and most importantly what that meaning does to us (Mate, 2011), and how we process that becoming.

Arthur Frank (2000) has challenged the popular myth that in autobiography, the self writes the story. In this autoethnography, the story writes the self. I am a woman with a foot in both camps; my writing is informed by practice and experience, and it is the same practice and experience that is informed by research. Incidentally, Denzin (2013) proposed five standards of autobiographical truth, which include, sincerity, subjective truth, historical truth, fictional truth, and aesthetic truth. The account of my personal story is subjectively true, authentic, and sincere. From the very beginning of this research process, my aim was to be as transparent as possible, and not to deceive the reader by relating a happy ever after story.

The ultimate scope was to create awareness, validate and extend sociological understanding (Sparkes, 2000). Although *my*story is anchored in historical data, I remember memories and events in retrospect. Bochner (2017) stated that "[t]o remember is to recall something forgotten – a place, an event, a person, a situation" (p. 72), however, positioned in the now since "we can never return as we were to the past as it was" (p. 73). I can only read the past through my experiential reality (Ellis & Bochner 2016, p. 241). Metaphorically, I referred to fictional characters and objects, that are the tile, the dark hole, to facilitate imagery and visualisation in illness, a topic that is not readily spoken about unless experienced to portray comparison fictional (literary) truths, in the evocative reflective, embodied accounts and poetic pieces. It was a means to reconnect with the readers, in a less formal, yet more relatable manner.

The autoethnographic conversations

Anderson and Glass (2013) stated that "[a]n autoethnographic interview involves, a dialogue between our past and present selves, at times with others as well, in which memories and understandings about the past are constructed anew" (p. 69). The autoethnographic interview may seem an oxymoron (self-contradictory) since the purpose of interview is to obtain new information from somebody else (Anderson & Glass-Coffin, 2013). It is considered as an extension of the active interview approach. During the writing of this thesis, introspection, self-reflection/reflection, as well as self questioning/questioning were a constant process reflected in the writing. Self-interviewing and self-questioning are considered continuous processes and thus, not a one-time event.

Holding conversations with the women collaborators has proven to be a very enriching experience on many different levels. Hearing them relate their stories, made me realise how we interpret and relate worlds from our respective world view, the powerlessness and vulnerability in adversity. Through their stories they provided depth to the narrative and broadened knowledge (Chang, 2013) giving detail to what matters beyond medialisation, making themselves seen beyond the invisibility of their illness.

Compassionate interviewing

> *July 2019, an autoethnography workshop in Roskilde University, Denmark. I had the opportunity to discuss my queries with Carolyn Ellis face to face, during the workshop and in between the sessions. We discussed at length different issues related to ethics and analysing autoethnography. Primarily, I wanted to understand better how interviewing others fits with autoethnographic research?*
>
> *How was I going to refer to the 'participants and interviews? I was not sure how to refer to the women participating in this research, women collaborators? Coparticipants? Also how was I going to refer to the 'interviews' as meetings? Conversations? And also, issues pertaining to analysis when using autoethnography. I questioned her understanding of dual and/or multiple relationships with participants living in smaller countries. It was a long and interesting discussion. Carolyn referred me to her published research on autoethnographic research and introduced me to 'compassionate interviewing'.*

In her publication entitled *Manifesting compassionate autoethnographic research: Focusing on others*, Ellis (2017, as cited in Ellis, 2013) refers to an interview carried out with a holocaust survivor Jerry Rawicki. According to Ellis (2017), "[t]his manifesto addresses how an autoethnographic perspective can be applied directly to the experiences of others in compassionate research" (p. 54).

It offers 10 premises as a guide to researchers, which she developed during her research with Jerry. I referred to the guidelines and adapted them accordingly when holding conversations with the four women, namely the detail when meeting up with the four women; the ethical considerations and sensitivity to cultural differences, whilst keeping in mind the rights, beliefs, and cultural contexts of the collaborators, as well as their position within patriarchal or hierarchical power relations (Denzin, 1997; Etherington, 2007).

Their stories unfolded during a give-and-take conversation rather than in the traditional format of question-and-answer interview, where the participant may be referred to as the subject. Instead, I fostered a mutual relationship with my collaborators, and thus, termed them as such to represent this equal autonomy with ownership of their story. During the conversations, I was not solely a research instrument or tool (McLeod, 2015), but an integral part of this research and so were my lived experiences. This, therefore, helped to deconstruct the authoritarian and privileged notion of a researcher. From feedback gathered after our conversations together, the women unanimously stated that they did not feel objectified or ‘researched’, but more like collaborators in research. These conversations were mutual and balanced based on fundamental humanistic principles and values, which helped develop a relationship of camaraderie, positioning self as empathic and compassionate. These guidelines were also reflective of the feminist approach adopted for the purpose of this study. The rationale I presented above gives a clear overview as to why I choose to use compassionate interviewing rather than for example thematic analysis interview. I strongly believe that ultimately, the outcome of the study would have still been valid and less messy, but it would have been different story. The structured interviewing process to elicit themes, my positioning as the researcher, the dilemmas as insider and outsider to research, the theoretical and methodological frameworks would be different and therefor provide different toolsets to guide the analysis would have been taken a different format (Maydell, 2010).

Representation of the stories

So…Where have you arrived with your research?

Did you start your interviews?

How are you analysing your data?

Are you discussing your findings now?

How is it going?

These are the most common questions I am repeatedly being asked. To this, I would reply, "My approach is slightly different… I am using autoethnography?" Oftentimes, I am left with these same persons looking back at me, quite blankly: "Autoethno… what?" I feel somewhat disheartened, not understood, and not following the norm of what is expected from the academic realm. The product is not structured and still evolving, still being written…. still in process. I am aware that the approach in writing, analysis and discussion is different, but it is still very confusing. I was doing my best to think 'with' the stories rather than 'of' the stories, to be as transparent and authentic to myself, the women collaborations, and 'other' women living with a chronic invisible illness who I have come across in my personal and professional capacity, as much as feasibly possible.

According to McMahon (2016), the term evocative autoethnography can also be referred to as emotional autoethnography, that is a literary approach to research that seeks to show rather than tell the reader about the subjective experiences (Sparkes, 2021, p. 266). This, in sum, was my guiding mantra behind presenting stories and creating different tiles. When the time came for me to write the women's stories using their own words, I was still unsure how I was to represent the story(ies). I started experimenting with other creative ways to represent the stories. When transcribing and translating the text, I created what I called raw poetry, instead of prose, to preserve the authenticity of the stories that the women told.

I came across Laurel Richardson (1997; 2001) who proclaimed poetic texts as relevant forms of representation for research interviews and conversations, which Etherington (2004) later described as having the ability to capture the vitality of life writing. Richardson (2002) further elaborated how "[p]oetic representation play with connotative structures and literary devices to convey meanings; poetry commends itself to multiple and open readings in ways conventional sociological prose does not" (p. 216). I am not a poet and do not consider myself to be one, however when writing this research,

I found myself many times writing in poetry format, detached words, micro writing (sometimes intentionally, and other times unintentionally), which when put together projected my embodied feelings and thoughts more than any prose would have ever done. Thus, once again I felt as if I were "disrupt[ing] the taken for granted" (Kinsella, 2006, as cited in Denshire, 2014, p. 839). I wrote in poetry form, most especially, when I felt stuck unable to express myself, when words failed me and/or rather when I failed words to write in prose form. Further to this, Richardson (2002) stated that:

> How we write has consequences for ourselves, our disciplines, and the publics we serve. How we are expected to write affects what we can write about; the form in which we write shapes the content. Prose is the form in which social researchers are expected to represent interview material. Prose, however, is simply a literary technique, a convention, and not the sole legitimate carrier of knowledge (p 877).

In 2020, I attended a virtual yearly international autoethnographic conference held in Bristol (UK). During this conference, one of the presenters highlighted research on found poetry (Prendergast, 2006; Reilly 2013). I had never yet come across the notion of reconstructing existing texts into poetry form. Without knowing, this is how I was representing the stories. I became curious to learn more about art-based approaches and delved deeper into reading the works of various authors who used poetic representation, including Richardson (2002), Faulkner (2009), Ellingson (2017), Speedy (2017), and Wright (2018). Incidentally in 2017, I had attended a research conference held by the Department of Counselling (UM), where Prof. Jeannie Wright had presented a co-written a paper alongside Ravi. K. Thiara, entitled Breaking the silence and shame of sexual abuse: Creative writing for therapeutic purposes. The authors presented women's stories who suffered sexual abuse in poetry format, which were written in stanza form, thus eloquently capturing the experience more powerfully, in turn, eliciting emotional response (Speedy, 2008). Similarly, by representing women stories in poetry format, I felt I was honouring pain, doubts, uncertainties, and ambiguities of the experience (Bondi & Fewell, 2017). Through the use of this format, I felt I was enabling a voice to the voiceless (Denzin, 2009); a form of social justice to the women who have had their voices silenced, and in so doing making the personal political.

According to Jackson & Mazzei, (2008) in conventional qualitative research "voice has frequently been privileged because it has been assumed that voice can speak the truth of consciousness and experience" (p.1). Thus, in doing so, such studies tend to assume the 'authentic' voice of individuals, as factually reflecting the realities of both the participants and the researchers (Grant, 2013). However, the intended meaning when using the phrase 'enabling a voice to the voiceless' in this context was not merely to privilege women's voices or to free the authentic voice, but to give space for the different voices to be told and heard. Therefore, the drive to make voices heard was neither a means to create 'transcendental and/or universal truths'. On the contrary, each woman's individual story[ies] and subjectivity were valued and represented using their own words in found poetry, reflecting different and multiple truths.

Additionally, 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 writings 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). Having said so, I was aware that poems make a difference according to how they are read, by whom they are read and when they are read. The elapse of time, the context, and the biographical identity all play an important role on the evolving meaning and perspective, most especially when revisiting one's own story written on the page. Ellis and Bochner (1992) highlighted that "[t]he act of telling a personal story is a way of giving voice to experiences that are shrouded in secrecy... becomes a social process for making lived experience understandable and meaningful" (pp.79-80).

An ongoing assumption that continues to be argued is the belief that qualitative researchers can directly capture lived experience (Denzin & Lincoln, 2004). In qualitative research, lived experiences are analysed, interpreted, written, and presented as understood by the researcher, thus creating inevitable gaps between reality, experiences, and expression of that experience (Bruner, as cited in Denzin, 1997). Yet, in reality, interpretations can never accurately capture or represent what was meant, said and/or written in text (Riessman, 1993). Besides, Tierney (1997) further delineated that “events and stories do not always unfold sequentially” (p. 30), thus making the link between text and experience more complex (Denzin & Lincoln, 2005). Moreover, in chronic illness, the lived experience is not a one- time event, it is an experience that continues to be lived and therefore, the story as well as its representation are continuously evolving.

Thinking with stories

Storytelling is both a method of knowing, a social practice, and a way of telling about our lives (Richardson, 1990). However, Ellis (2004) argued that autoethnographies do contain analytic elements in the sense that “when people tell stories, they employ analytic techniques to interpret their worlds” (pp. 195-196), knowing that this form of analysis does not sit comfortably with the realist or analytic tradition. Furthermore, Ellis & Bochner (2006) asserted:

> If you turn a story told into a story analyzed... you sacrifice the story at the altar of traditional sociological rigor. You transform the story into another language, the language of generalization and analysis, and thus, you lose the very qualities that make a story a story (p. 440).

Therefore, in doing so, we would be sacrificing the story into another language of generalisation and analysis, and thus losing the very qualities that make a story, a story. Some narrative researchers take illness stories and analyse them as data (Frank 2005), while other researchers re-present the data of life experience in narrative form as product (Riessman, 2002). However, one must also be aware that there might also be common and/ or different types of narratives across individuals. These stories are deemed knowledge per se, which may also reflect, or constitute, the social reality of the narrator (Etherington, 2004) and convey a person’s life and experience in depth, richness, and texture. Giving space for people’s illness stories to be told empowers them as storytellers to share their stories and provides an opportunity for them to gain a historical and socio-cultural view, discover how individuals create different meanings, and how these meanings continue to influence their own and their families' lives.

Polkinghorne (1995) distinguished between the analysis of narratives and narrative analysis. The distinction between the two is, the stance of the story analyst and the stance of the storyteller (Smith & Sparkes, 2009; Bochner & Riggs, 2014), respectively. A story analyst refers to the researcher who places narratives under analysis and produces an abstract account of narratives. The stories are subjected to a narrative analysis (e.g., thematic narrative analysis) and results are communicated in the form of a realist tale. However, when a researcher is the storyteller, like in evocative autoethnography, the story is the analysis (Smith 2019, p. 5). Richardson (2000, 2005) refers to creative analytical practice (CAP), an umbrella term for research that is cast into storied forms, such as creative non-fiction, ethnodrama and autoethnography. Evocative autoethnography has been criticised for its rejection of traditional analytic goals, such as abstraction and generalisation (Anderson, 2006). Shifting between telling to showing, storytellers move away from abstract theorising, toward the goals of evocation, intimate involvement, and engagement with stories (Smith & Sparkes, 2010). Whilst Bochner (2001) noted that the call of these stories is for engagement within and between, not analysis from without. In fact, Ettorre (2016) stated that:

> When telling an autoethnographic story, the story is not only mine – it is also co-owned with those in my story, sharing this borderland space. I am telling a story without borders, and yet I am an insider and an outsider – a living, embodied crossroads of words, flesh, emotions, interpretations, and humanity (p. 6).

The approach to narrative inquiry that I have taken, changes the activity of theorising from a process of thinking about to one of thinking with. In fact, Frank (1995) stressed that:

> To think about a story is to reduce it to content and then analyze the content… To think with a story is to experience it affecting one's own life and to find in that effect a certain truth of one's life (p. 23).

Despite the latter, Webster and Mertova (2007) expressed that narrative inquiry itself "does not strive to produce any conclusions of certainty" (p. 4). This is in line with the postmodernist lens adopted in this research, which gives space for a multitude of truths and a multitude of approaches to knowing

Transparency and trustworthiness

In using autoethnography, I experienced the research as being rigorous, theoretical, analytical, and emotional (Ellis et al., 2011). Although there exist different approaches of doing qualitative research, there is also diversity in the ways to justify or legitimise and evaluate each approach. However, whilst approaches differ, the ethical obligations remain a constant. More specifically, as discussed earlier, autoethnography has its own specific requirements as a method, a product and a process. Douglas and Carless (2013) summed the ethical dimensions in autoethnography very aptly, and refer to them,

> as not being static but continue to expand to include not relational ethics, but moral ethics, ethical mindfulness, an ethic of trust, an ethic of care, and an ethic to look out for the well-being of ourselves as well as the other as we engage in emotionally laden journeys (p.99).

My aim from the start was to be as transparent and trustworthy in my writing, as much as possible, whilst adhering to all ethical obligations when writing this thesis. In essence, laborious reflexivity and introspection, were key to ensure accountability, transparency, and trustworthiness. In this regard transparency is important because it that what is invisible visible. I strived to do this by showing as clearly as possible how decisions were taken every step of the way, whilst documenting why the different factors that led to my choices were imperative and the least, I could do (Etherington, 2004). Examples of these decisions include my position as a woman researcher and participant in research being ‘unapologetically eclectic’, refusing to stick to binaries whilst harnessing a position of ‘in betwixt and in between” though claiming that my personal standpoint as a nurse and a counsellor as being one in the same person, and not either or; the ethical correctness and decision making in relation to relational ethics, ethic of care and process consent when including my mother and other women in the research, alongside other ethical measures are discussed in Chapter 4.

As stated earlier, although memories may account as research by definition, yet they may not reach conclusions or recommendations; uphold or falsify hypotheses; inductively generate models to be tested; or invite validity and reliability checks (Bleakley, 2005, p. 538). Alas, this is not the way I was doing research anyway. Ultimately, the aim of this study is that the research evokes meaning to the readers, that is, serves “to attract, awaken, and arouse them, inviting readers into conversation with the incidents, feelings, contingencies, contradictions, memories, and desires that our research stories depict” (Bochner 2012, p.159). As discussed, in autoethnography, the issue of truths are not literal truths, they are emotional, dialogic, and collaborative truths (Bochner, 2012, p. 161).

The intention of this research was not to generalise; however, it was hoped that when reading this evocative autoethnographic story alongside the narratives shared by the women collaborators, the readers determine whether the story resonates with them or with someone they know (Ellis & Bochner, 2000) and elicit similarities and/or differences. In this regard, evocative autoethnography has been criticized for the very fact that it relies on a direct emotional response from a reader rather than offering analysis, grounding in theory, and methodological rigor (Duncan, 2004). Yet, it has been argued that autoethnography is more authentic than traditional research approaches, precisely because of the researcher's use of self, with the voice of the insider being more true than that of the outsider (Reed-Danahay,1997).

In their seminal work conducted in the 1980s, Lincoln and Guba (1985, as cited in LeRoux 2017) proposed the application of a set of specifically developed evaluation criteria. These criteria replaced the quantitative assessment criteria of reliability and validity with the parallel concept of 'trustworthiness' comprising four aspects – credibility, transferability, dependability, and confirmability. These aspects were later referred to by Denzin and Lincoln (1998, as cited in Smith, 2006) as the key concepts that increase the trustworthiness of qualitative research (p. 209). However, it has been noted that even though traditional criteria could be important and useful in providing guidelines (Tracy, 2010) it is not always easily applied to autoethnography (Holt, 2003; Bochner 2000). In order to determine the trustworthiness of autoethnography, Ellis et al. (2010) state that primarily, the goal of autoethnographic research should be agreed upon before criteria, to assess that its authenticity could be framed. According to Ellis et al. (2010) certain autoethnographers view researcher and writing as socially-just acts rather than a preoccupation with accuracy which according to Le Roux (2017) indicates that these researchers "take a different stance towards the subject matter of social science and establishing its validity" (p199).

Prominent research in the autoethnographic field, namely Ellis, (2000), Bochner (2000) and Richardson (2000a) amongst others, have recommended differently on the use of different criteria to serve as guidelines, to monitor and to gauge autoethnography. Ultimately, in order to ensure trustworthiness, I drew on Le Roux's (2017, as cited in

Sparkes, 2021) five main criteria, embracing the notion that research is ethical throughout (p. 270). Therefore, these criteria consisting of subjectivity, self-reflexivity, resonance, credibility, and contribution served as the compass in the writing of this thesis.

Here, I draw the first part of the thesis to a close after giving a background to the research focus together with a review of literature of the cultural envelope and illness. The method approach and ethics were discussed at length. Ultimately a walk through the process was presented, closing with an assemblage and representation of the tiles, drawing on the different toolsets used in the process of writing this thesis. I therefore invite you to the second part of the thesis, 'to open the eyes and awaken the heart (Sellers, 1994) whilst navigating with the stories.

PART 2

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Chapter 7: Navigating with stories

The experiences presented in this section contribute to metaphor of the tile, where each different tile represents a different story but put together, they co-create a new design (see Figure 7). In bringing the stories together, an assemblage of illness narratives evolved. In this instance, “the concept of assemblage includes but goes beyond the literal meaning of bringing together a range of heterogeneous elements in different modalities to offer different perspectives on a phenomenon” (Denshire & Lee, 2013 p. 221), particularly referring to different emotions, embodied experiences, meanings, and cultural connotations. However, besides the spectrum in bringing different perspectives together, I would also like include depth by drawing onto the concept of layering of the stories. Whilst navigating with women stories of illness, experiences of self and others merge and interweave rhizomatically, and not solely in parallel, with other collective stories, thus providing multiple voices of telling the story and sharing of experiences. Just like Wright (2009, p. 627), I bring together patches of writing, whilst navigating with stories, bringing them together with pieces of reflective writing as a method of inquiry (Richardson, 1994; 2000). This approach is synonymous to the writing of this project. The intended audience of researchers, practitioners and persons interested in illness stories are invited to see the different facets of experience, allowing space for their own individual response to develop. In my writing, I explained this contestation in the context of stories, which I have presented and the emerging collective story, that is my eclectic collection display of tiles.

Figure 7a

Bringing the tiles together – creating a new design

Navigating with care

Listening attentively and empathically, bearing witness to other people's suffering, navigating with their stories is difficult bodily work for both the teller and me as the listener. In tandem to listening to the women's stories, personal feelings and emotions kept resurfacing. Suppressed events, which I had thought of as 'past' were rekindled, bringing to the forefront once again the social injustices and patriarchal power experienced as a patient by white male professionals. Listening to the women tell their story was a wakeup call of my unconscious, a loud shout echoing into my silence… After the meeting, I realised how, for many years I had curbed and silenced my thoughts and feelings believing that it was best thing to do, as if it was my fault and responsibility, my weakness. The should and should not keep revisiting my thoughts… should be ashamed… should be grateful...should not mention … should

> *not be unwell. I recall the internalised critical voice, convincing, judging and condemning me for my behaviour and actions. My moral compass, religious values, and intergenerational beliefs of how a woman should 'behave' determined my actions, my way of life - to be 'good' daughter and woman as expected by society… to be 'selfless' and care for others as my duty of care...to maintain relationships...to be productive … to be … to be …*

Listening attentively, empathically, and compassionately to the women's stories, reflects a feminist ethic of care (Preissle, 2007; Gilligan 1982). However, compassion in such instances should not only be directed at the participant women collaborators. On hearing their stories, I became even more aware of the importance of practicing self-compassion to be able to communicate effectively and safeguard ethics of care. Ellis and Patti (2014) presented compassion as a holistic mindful practice of caring, not only for self, but also for other by listening deeply and attentively and authentically empathising and caring about the other person. As the listener, I was part of the storytelling process (Frank, 2000). It is through the story relations (Frank, 2000) that we revisit realities, question power and injustices, and negotiate our existential being and our identities (Richards, 2005) as women. Moreover, Bochner and Ellis (2016) maintained:

> Since the present is itself a passing moment, vanishing swiftly into the infinite past of memory, every look back is a gaze from a different moment, a different perspective, and a different remembering self. We live in-between, perpetually moving forward into experience and backward into memory (p. 92).

In narration, the women and myself seemed to need to chart our autobiographic story in a temporal framework highlighting epiphany and situated moments around the illness event when it all started, when the curtain came down, depicting the liminal moments of experience of life pre-diagnosis, to life after diagnosis of the illness. Every story told seems to be marked in a temporal framework as if it were *a reckoning in and with time*. It was as if they were drawing an imaginary line between wellness and illness, remembering 'when it all started', acknowledging, and saluting the past as if it were a farewell apotheosis, saying goodbye, on exiting from the kingdom of the well, whilst entering the kingdom of the unwell. A foot in the door, looking over their shoulder remembering and recalling, welcoming me into the intersubjective space 'to see' and experience with them, whilst moving forward into the present. Our only view of the past is in the present, in hindsight (Freeman, 2010; Bochner, 2017).

> *On hearing the women speak, I too walked through that open door into the past revisiting my own situated moment when I thought IT had all started. However, on reflecting deeper into my own biographical timeline prior to the illness diagnosis, I started to join the dots, another epiphanic moment – this is when I realised that the story had, as a matter of fact, started much before my body showed any signs. I was too young and too immersed in my youth to make sense of the story then, I was still discovering my own independence and developing a sense of self.*

Reading through a thought-provoking book by Mate (2011) entitled *When the Body says No*, helped me make sense of the sequence of events, articulate, and put words to the untellable and unrecognisable feelings and behaviours. Similarly, narrating illness experiences was a visibly challenging endeavour, which could not always be manifested and communicated through language and/or body(ies). It seemed as if they were continuously juggling the binaries of the socially constructed understanding of health and illness, whilst revisiting and recalling experiences. They seemed to need to refer to medical language terms and jargon to describe, justify symptoms and objective testing as recipients of care. In doing so, I believe it was a way to signpost themselves and the condition within the dominant biomedical system (that focuses mainly on a malfunctioning disembodied body) for objective acknowledgement and validation. In the same breath, claiming symptoms to be *true* and *real* instead of, imagined. Concurrently and paradoxically, adamantly refusing to be pitied or categorised as a *less able-bodied* reflected by social model, which in theory disregards the physical body. Therefore, in telling the story(ies), the aim was to "bring the body back to where we can speak of it humanistically" (Ramanathan & Makoni, 2007, p. 283). Furthermore, bringing the body back into research did not only include bodily experiences, but also the emotional, and socio-cultural experience as a whole person rather than as separate body parts (Ellingson, 2017). However, the story leading to the fictional demarcation line before the illness event remains untold. This was not the focus of the thesis since the focus however, it would be an interesting study to follow up. The stories shared in the next chapter all started when the illness made itself known to the body, to the women (e.g., through the pain, fatigue, myalgia, joint paints, severe bowel movements and in my case not being able to walk).

Chapter 8: Stories

Francesca’s story: ‘Everything happens for a reason ... it’s true’

The beginning

Excruciating pain
labelled Fibromyalgia,
without
adequate investigation

Unconfirmed diagnosis
Without a name
or confirmation…
Waiting, ... hoping… (pause)

A new illness experience
slowly becoming more
familiar with
IT

Listening to the pain…
Resting…
my life stopped …
IT still became worse.

Medical providers baffled
when encountering IT,
Imaginary hallucinations,
a psychological disruption

Interpreted as being
‘All in the head’,
referred to psychologist
for the ‘pain’…. they said

Accepting the PAIN
was the toughest part
Not giving in to
FATIGUE

…not stopping ……
……not resting
Interrupted youth
My life was on hold

My bed was my refuge
Doing nothing…
Waiting
Waiting for time to pass

...hoping that the pain
would go away
Longing for another year….
to start afresh

IT manifested itself
In different ways
Different symptoms…
My legs the weakest

All 16 points were on fire…
Fibromyalgia?
ME?
Complex regional pain syndrome?

A second opinion in UK,
instilled courage and hope
longed for a diagnosis
... longed for certainty.

Diagnosis was confirmed,
nothing else to do
but…
to learn to live with IT

Mental turmoil
'IT's not all in the head'
IT is real...
invading my life

They spoke of IT
As being imaginary,
as if I was making it up
as if I was not there…

Is it doctor's privilege?
An unprecedented right
to make you believe what
they want me to believe.

Next phase

I wanted to fight IT.
Met many sufferers,
demanding validation,
and acknowledgement.

Experienced IT otherwise.
...work, support, family,
and friends,
gave IT a different meaning

Family, a motivator and a burden.
Protecting them
to protect myself,
by hiding the pain.

Self-blame
triggered a lot of pain
when told that
IT is imaginary

Sometimes thoughts
spiralled to darkest depths
Fearing the worst….
to become bed bound again.

A continuous struggle
to make the right choices
to minimise consequences
all year round.

Unexplained medical
occurrences
…. Contested condition…
labelled as Fibromyalgia.

Mental turmoil
"IT's not all in the head"
IT is real……….
invading my life

Imma ma nbiddel xejn (I wouldn't change anything)
IT made
ME
The person that I am today

IT changed ME...
revealing, a truer self.
I am proud of the person
I have become.

A note to self and others…
all things are possible ...
a question of perspective,
it's a choice.

Moving on embracing time.
Self-efficacy, self-worth….
Not knowing,
if IT, will stop me.

Pain is still very present.
Self-taught to manage IT.
… I dream and long
for Pain free days.

Worst fear is loss of control,
powerlessness,
dark memories,
stopping me from doing and being.

A stronger voice,
Accepting, not loving myself
but, liking…
is good enough

Craving normality.
Questioning normality?
A different meaning
To different people.

The story could have been
told differently the story
Of a weaker woman, less
Determined Passive

Living IT on a daily basis
Not easy to explain,
Nobody asks knows
IT is not seen

Not easy to relate…. (pause)
the emotions,
loss, anger, pain…. shame
fatigued…Albeit proud.

Realisation phase

I am not wonder woman
I need to slow down….
Listen to my body…
Find a balance….

I voice IT,
IT is there.
IT is NOT my identity.
IT is not ME

Looking ahead….
nothing could stop IT.
IT changed Me….
Everyone…. Everything.

Protecting loved ones
not knowing, showing,
silent…. hidden secret.
IT was not over.

Refuse overprotection
I changed, things changed,
I protect them (my family)
to protect myself

Discovered the voice
Found the space
To live and work
tirelessly… No stopping.

Celebrate triumphantly
every achievement
Not allowing IT to stop me,
to change me

My identity is not fibromyalgia …
IT is there
But I am all that
makes ME

This urges ME
to continue to Fight IT,
Not permitting IT,
To take ME over

I see IT as exterior
controlled, contained
restricting the space for
IT to flourish.

Pain cannot always
be controlled physically,
Mentally the effect of
pain is too difficult

A great discontent
When I sense failure
Because I had the joy
To savour success.

IT revealed the true ME.
I live and appreciate life
through a different lens
I live the now

IT gave me a reason
meaning of Life.
The ME of now
… Less is More.

Today, I focus inwardly,
It’s a chain…a choice,
Behaviour, emotions
mind, body, and soul.

Jessica's story: The curtain comes down

I was diagnosed with
Multiple Sclerosis after
six years of multiple
visits to A&E

first symptom, blurred vision
the clock on the
bedside table showed
hazy, distorted time

visited A&E regularly
and repeatedly was sent
back home without a
diagnosis or cure

the first diagnostic
hypothesis
was optic neuritis
I feared vision loss

after many months
yearned for a diagnosis
ophthalmologist gave
reason for vision loss

panic, fear gripped me
optic neuritis? ...
possibility of blindness
... other complications?

unstoppable tears
was my intuition correct?
was it multiple sclerosis?
reality drew closer

at hospital, doctors didn’t
hear me, I was ignored,
patronised, I was being
careful….IT got worse

started medication
everyone was there
support …
never failed.

vision cleared with
medication, however,
uncertainty continued to
prevail

married at a young age
wished a large family
… hope started to fade
a distant forlorn dream

two years later,
the curtain came down again
partially covering my
eyes, blurred vision

was told, I do not have IT
repeated visits to A&E continued
no diagnosis reassurance
was recommended as treatment

a visit to a neurologist
I was not crazy
I was resolute that
I had IT

readmitted to hospital
a worser experience
no improvement
I was really in a bad state

three years later
another episode
tingling... pressing,
tightening of both legs

this was not normal
what was happening?
did not tell
did not wish to alarm

negative MRI brain
…. different prognosis
sensitive to touch?
inflammation?

is this the reality of MS
the ugly truth revealed
I feared...a lingered truth
kept on hold…. was exposed

a lot of fear,
a lot of questions
confused, shaken,
panic stricken

what was going
to become of me.
how and what am I going
to tell my family?

a secret to my mother
only few people knew
longing for normalcy
loathing pity

demanded another MRI
against doctor's advice
I was told not to assume
… but I was convinced

The MRI spine
the beginning of the end
IT finally revealed itself
White on black

a white patch
medics still hesitant
IT was now definite
IT was to be named

the neurologist confirmed
what I already knew
information on treatment
to keep stable...not to cure

to tell my family
...the tallest challenge of all
guilty… that IT ruined
plans of the people I loved

the ultimate diagnosis
was only a formality
I had prepared for this
...I knew IT

treatment started
adamant not to let IT
change my life
I needed to plan my future with IT

I did not feel the ground
beneath me, numb feet
not feeling anything
adamant to challenge IT

I refused to decide
about bearing children
an informed decision
my choice and not because of IT

I did not allow
fever, joint pains, nausea
stop me to live my life
my work had to continue

I prefer to keep IT a secret,
not only unknown but
invisible and without
a voice

I prefer they don't know
...refuse to be seen
a victim, I did not want pity,
I wanted control

a secret to my mother
to protect her,
interpreted fatigue as laziness
'if only she knew'

juggling with secrecy
to protect others…coping
with uncertainty and
powerlessness

I look ahead,
follow my dreams
self-invest, study
prioritising self-care

although powerless on
things I cannot control
adamant to continue
as normal as possible

to remain the same person,
same self
independent… before
and after diagnosis

although I know of IT
people query and doubt
the diagnosis
hidden, invisible

emotionally I was
supported by many
except my mother
whose support I longed

I was told to be me
not to let IT change who I am,
to retain my identity….
to win I

I dread to worsen IT
challenged IT, aspiring for
normality, ability,
stamina, body-image

I feel I can control
my own hurts and pains
but feel powerless and lost
... other people's pain

chronic illness
experiences are different
however,
stories of IT are similar

added expectations as a
woman... societal demands,
roles and responsibilities
to live up to

the worst feeling…
I was not normal,
not believed, feeling shattered,
silenced, broken

I relate my story without
stopping… breathless
in motion…I keep going
just as I do life.

Erica’s story: Never give up

I was not 10 years old yet
Helping with home chores was something
I normally would not have minded so much but…
I remember the days when it was hard
Getting out of bed in the morning
or the pain to stand up...
Notwithstanding the pain
I continued to help with home chores,
I continue to go to school.
Life seemed to roll on very slowly...

I recall there was little awareness
of Rheumatoid arthritis (RA)
Visited different doctors for a diagnosis….
I was given ointment to rub my painful knee
And ... experienced no difference.
The pain continued to increase in intensity.
The RA started from the left knee
which spread to different parts of my body
over a short period of time…
…. ankles, toes, fingers, neck and jaw…
there came a point where …
I could barely move without pain.

More doctors... different opinions
repeatedly treating the acute symptoms
… the problem persisted.
I was admitted to hospital
Many tests and finally…. a Diagnosis,
Juvenile Rheumatoid arthritis.
I was still very young,
did not know what this meant.
The consequences, the repercussions….

I remember my family were very worried.
It was a very difficult time.
I did not attend school
I was in and out of hospital.
I needed help with personal needs
I spent time in wheelchair and used crutches
…very difficult days.

I compared myself to my friends.
Many things happened quickly
I could not play with them as before…
I felt alone… What could they say?
We were so young...
I could only watch them.
I was always a few steps back.
At school, I missed out nearly 2 years.

I was given steroids, painkillers.
I started to swell – became all bloated.
A drastic change to my body, my image
I was very sad.
I was not sad because of the arthritis, or the pain.
I was sad because of my appearance... (pause)
Medication regimes kept changing,
constantly increasing dosage... but…
I could not stop the steroids.
Hyper insomnia – I could not turn in
bed My whole body ached
They were very difficult times.

I was taken to U.K for a consultation
Medication once again was increased
There was more awareness,
more questions answered ….
a lot of ambiguity, uncertainty
of what the future holds for me.

I started secondary school.
I still could not do things
like the rest of my friends.
I was always lagging behind.

Even though I had a lot of support
from family and friends
I felt limited - physically and emotionally.
I was sad…. It took me long to accept I was different.

Yet, secondary school helped me mature.
I was given the space to fend for myself.
I was very conscious of my image.
A personalised diet by nutritionist,
reducing steroids helped shed weight.
I started feeling better, more confident,
with the support of my family.

During this period,
I had slight problems with RA medication.
I felt nauseated after taking medication.
Doctors told me 'It's all in the head'
Was I conditioning myself?
The nausea persisted.
For four years, I was injected once weekly
I used to dread the weekend... (pause).
It's as if I had no say in it,

They made me take the medication.
I felt that the doctors were not understanding me.
Then, medication was changed to orally.
I rebelled and stopped the medication.
I threw them all away. I was in control!
The nausea stopped…. I was right!!
The RA medication made me feel unwell
I was not imagining it…. (silence)

I missed out on a lot of school,
it was difficult to recuperate missed time.
But…persevered to achieve.

I had no voice, no control!!
I went to college, even though
these were difficult times -
I was proud of myself!!
Refusing medication led to
unbearable pain.
I decided for myself…
I wanted to fight back,
I wanted to continue to study,
I wanted to reach the next level…
and the next... and the next...
This, I managed with the help and support
of my family, friends and colleagues.
...The pain persisted.

In my relationship,
I felt it was my responsibility to tell him
About my illness story.
Nobody knew of IT because IT is not seen.
It was difficult and I was scared….
I did not know how he would react.
Pain was controlled
The real suffering had passed,
although uncertainty remains.

Religion gives me a sense of purpose
The religious community
gives me a lot of courage
helps me spiritually and emotionally.
It gives me energy
and I do not feel alone.
I feel loved and with a scope in life.

I empathise with the suffering of others;
I realise that I am not alone
There were others suffering too… (pause)
This helped me come to terms
with the meaning of illness and pain

I plan and do things according to Pain.
No medication restored normality,
I still need to rest,
to make conscious decisions…to plan.
I am a multitasker.

I do not like missing out on things… and on life.
It helps me to continue moving on …
but sometimes it's a challenge.
It seems as if I needed to recuperate
on missed out time, things, and opportunities
…to prove myself to others and myself.

I am very self-critical...
Without being too presumptuous...
My condition grounds ME. (strong voice)
Makes me think…why not me?
A roller coaster of emotions,
sometimes I feel good, privileged
but sometimes, something
happens, and I reconsider my
position.

My reasoning was always
'If you feel healthy, do it'
Take advantage of that moment…
There might come the time
when I would not be able to do so.
I state this with conviction and belief
Because I know what it means when

it's taken away from you …. (exhaling deeply)

I was scared (pause)…pregnancy, children
As a child, I always dreamt of a big family
Doctors did not give me much information
Pregnancy not advised because of the medication…
...that is why I stopped it.
And replaced it with healthy eating
and natural remedies…
This did not work.
The pain returned…
I did not manage to control it.
This was very meaningful to me.
I could not be normal…. (silence)
I did not want to put my baby at risk…

I accepted the situation...
This is how things are…nothing to do…
Then came the heavy bleeding
…which persisted…
Endometriosis!!…. "Now this?"
I recalled the victim in me…
I became very frustrated,
It was the same excruciating pain ….
I did not realise how painful it was,
I had become accustomed to the pain……
I was hospitalised again.

Tolerating pain
is good because
you get along with your life,
but I also endangered myself,
I continued with my life
as if all was
'Ok'... but it wasn't...
I think of the future...

but not much,
I live day by day.
At times,
I wonder what the future holds.
Whether I am going to suffer?
Whether I am going to bear children?

Presently, I focus on the now,
I still have the freedom to plan my time
My story in the future,
might be a totally different one,
it might be difficult more than I think,
And it might not....
It’s not the end of the world
I’m not disheartened
It is something that I wish
If it will be God’s will, it will happen
If not… (pause)

Jasmine' story: 'IT doesn't define me, IT's just a part of me'

Let me start from the very beginning.
In my late teens,
I started experiencing issues with my bowels,
I visited the bathroom multiple times…
and…there was blood!!

Before the blood, I thought it was a virus
I thought "uwija issa jgħidili" (Now it will pass)
...or whatever... however,
it didn't get any better
…blood persisted…

what's happening?
something that
sounded like ellelle
I couldn't recall the name….
elllelle … ellelle

As if I was talking gibberish (mimicking sound)
...not knowing
the correct name,
I went to the doctor told him

Jasmine: I have IBS! - irritable bowel syndrome, (that's what I knew).
It runs in my family, and this is what I think it is

The doctor did a few tests
and agreed that it could be IBS

Doctor: 'It can be regulated by diet'

Jasmine: 'Ok great!'

Went home and told them
"It's IBS ta!!"
At home they knew... they said...
"No…. It is not IBS,
It's Ulcerative colitis!".

I returned to the doctor
To clarify the detail

Doctor: 'That's a completely different story'

Jasmine: 'I made a mistake in the name' (very chirpy)

Doctor: 'We need to do more blood tests and endoscopy'.

Diagnosis confirmed ulcerative colitis
IT was getting quite severe.

Doctor: 'You need to be very careful'…

I was started on medication straight away,
… suddenly... my life changed.
I was healthy, before I got diagnosed.
Suddenly, a barrage of appointments,
blood tests started to happen...
I was immediately started
on high doses of medication
…mesalazine, enemas…
and then steroids.
I was like 'ok let's do this!!"
But... nothing changed.
It just kept getting worse
…and worse!

Doctor: It's quite bad and your blood levels are very low (mimicking voice)

I became anaemic
took iron supplements
… and then…. the steroids
I was aware of the side effects of steroids,
which included weight gain

Jasmine: If it means, me getting better, even though I put on weight,
I was ok with that! 'ejja ħa mmorru' – (let's do this).

I was taking a lot of medication.
Then...I did not realise
how bad it was affecting me…
At higher secondary,
I remember I had a class
on the fourth floor,
I had to go up four flights of stairs
and could only make one flight
…I did not know that...
it was because of the anaemia….
I locked myself in the bathroom, (giggling)…
I cried...
I called my friend

My friends were very supportive,
I was very lucky.
they had never heard of IT….
like me… they were learning about IT
as it was happening….
Wherever I went….
I became obsessed
on bathroom location.
When I walk in a place,
I would say, they would say
"the bathrooms are there"
…. It got to a point

Jasmine: 'Ok... this is how it is, there is nothing much I can do

I will deal with it the way it is
So… after I had that cry …
…...I was like
let's see how we can live with IT (speaking in plural).
I am quite like this …
I cry a bit… (clap hands) …
Get up and move on...

Jasmine: 'Ok this is the situation lets deal with it'.

There were obviously the bad days too.
I remember one time I was at a party and
my friend gave me a very tight hug… I
hadn't seen her in ages,
she hugged me from my stomach
... and I was like …
(Simulated a choking shallow voice)

Jasmine: ... STOP …. STOP!...

she was not aware,
…. So, from now on,
hugs above the chest ONLY
After that hug,
I said ...

Jasmine: ok… I need the bathroom
…NOW' …

My friends and I were running around
looking for the restrooms
…we could not find them.
…we were like
'What… they hid them?'

Jasmine: ‘I’m going home ... there is a situation happening
...so, I said bye’ (chirpy)…

I waited for someone to pick me up
what’s wrong’?
What happened’?

Jasmine: a friend hugged me ……nothing to do.

I might as well see the funny side to it… (giggling)
what’s happening to my life?

Jasmine: Now you cannot hug me cause of the consequential problems (giggling jokingly saying).

When I find myself at a low point...
I always try to see the positive side of things
… and persevere.
It takes the toll out of me,
but I always
try to find solutions for things.

One of the things that I hate the most
out of this chronic condition (emphasized tone of voice)
…I had to stop eating certain food
I really loved.…
‘ohh… that was the worst part of it’
At the very beginning when I was diagnosed,
I had to cut out on all dairy products
…that was a horrible experience
…because I am a very big fan of dairy and cheese…
When symptoms persisted without change,

Doctor: if you want to eat cheese ...eat it because there was no difference

That was the best news ever!!
Then there were... the steroids...

Jasmine: Maa, the steroids (inhaled deeply)

when I started the steroids…
I put on a lot of weight
I was surprisingly exercising a lot,
I had a lot of energy...
Also, I was eating a lot of carbs.

I was swollen because of the steroids
but then also due to overeating.
I never really realised because
I was seeing myself every day,
but my family saw it I was not well.

Besides the weight gain,
my mood was horrible,
no one could win me –
if anyone touched me,
I would scream…
I was always angry at everyone…
no one could contradict me....

not because I was in a bad mood…
I think it was because of the medication …
because at that point,
I had already come into terms with IT,
and I was feeling much better with the steroids.
...despite all the side effects…
the symptoms stopped.

It's not her, it's the steroids,' they claimed.
So, part of me was like
I can get away with anything

but also. too tired,
and hungry to do anything.
Sometimes, I used it as an excuse...
… when challenged.
I would say…

Jasmine: You want it? Take it! you can have it (giggling)…

It was hard on them also because
things were changing, not just for me
but also for everyone around me
…. seeing me lose so much weight and
then put on weight …
eating the entire
universe and then eating nothing (pause)…

Jasmine: Emm (x'kont se ngħid?) … emmm …(pause)? Ehh... where was I...

Then the worst part was having
...the colonoscopies…
the preparation before….
I hated it (speaking with disgust) … and
even the actual intervention ….

I always have a lot of things going on
to plan an entire day
where I can't do anything……
plan nothing but to sit at home
and just drink the disgusting prep...
it's a laxative but nauseating at the same time.
The next day...
jiena niekol ħafna (I eat a lot).
I wake up hungry.
I just want to eat.
I'm cranky, I'm tired, I feel empty….
Now, I've been in remission years,

I stress out very easily.
Stress does not help.
When I feel, I am going to stress too much…
I know that I need to cut things down
… To STOP!

Nudging memory - I wonder

I nudge my memory… I try to remember,
to recall sequence of events...
my brain has selectively chosen what to remember,
what to forget... I focus hard
I wanted to understand, to make sense
not only how I lived the experience but also
how others close to me were living IT.
I do not remember the exact details,
but I recall the emotions fear, doubt,
uncertainty and powerlessness
I feared the unknown… I felt lost.
It was as if I was being experimented upon,
giving a diagnosis without adequate investigations
…However, all is a blur

After numerous tests,
I recall a big sense of relief
on receiving a different diagnosis in the UK
The validation was the best news I could ever receive,
even though I was not sure of the future-
I experienced a sense of freedom
A sense of hope……. giving me permission to feel Normal…
I was not mad after all.
The pain was real and justified.

The fatigue was real.
The fear and uncertainty were real.

Only now can I look back
at this interruption and disruption of my life and face IT.
Reclaiming my life back was not a dream but a possible reality.
Investing in my relationship, planning a family,
motherhood depended on the outcome of the diagnosis.
Even though invisibility was here to stay
I could live with that.
I needed to respect my body.
I needed flexibility in my working patterns.
I needed time to recuperate, to regenerate.

My life was interrupted for months
I was feeling useless... not living to my known script….
Not productive, feeling worthless, energy less,
powerless…… I was walking a fine line to keep a
balance between…
sanity and despair, losses and gains, ability, and lack of ability….
Desperately holding on - refusing to let go.
Desperately needing to ‘show’,
I am back!’

So, what am I missing?
My memory seems to have erased detail…

How I wish I could go back
and capture instances, moments, discourses…?
I wonder

How did others experience this disruption?
Never really spoke about it… it is the past!
I wonder
How my parents, my siblings lived IT?
I wonder
I feel guilty even just thinking about it
Life continues…… things happen….
The myalgia lifts its head every so often.
I learnt to manage it as best I can

Not easy, not seen, not there
Living up to my roles as woman:
A wife, mother, employee, daughter
I feel fortunate to be able to continue with life.
Things could have been much different.
I wonder

The underlying fatigue is a constant
The periodic joint and muscle pains –
Sometimes revisit and remind me
that they are still there
I push myself and refuse to be weak

Family, work gives me a sense of purpose.
A meaning... A Sense of self worth
Gives me my identity…
Being needed?
Is this what makes me visible?
I wonder

What if?
What if the diagnosis was otherwise?
Not questioning, believing, and accepting the first diagnoses?
Undergoing the planned thymectomy?
What if I did not have the support I had?
the possibility for a second opinion?
What if I had taken another path in life?
I wonder

Speaking to invisibility
Speaking to the unknown
I imagine different possible scenarios
What meaning would I give it?
What would be my sense of purpose?

I speak to resilience…
Holding on
Determined to move not to stay put,
I do not want or need pity,

What helped me then and what helps me now?

I wonder

'It's a spectrum,' says a doctor

A condition that may be discussed in a broader spectrum,

It could be 'short-lived', but it could return unannounced,

referring to the Chronic fatigue

'Broad spectrum'? I question

'You cannot really measure it objectively -

'it's subjective to the person" he continues....

The Psychological state of the person...

Stress does not help,

may affect exacerbation of the condition.

'But the pain is real' I claim,

speaking in defence of myself and the other

I wonder

A lot of questions….

How does the body react to stress and anxiety?

How does stress affect autoimmune illnesses?

Therefore "IT is not all in the head",

IT is felt all over the body.

The mind (head) is part of the body!

The language used to communicate

empathy and validation were cathartic…

You remember he said

“When they told you it was not Myasthenia Gravis....

Psychologically you started healing”

I add….

“It’s not only when they told me but

how they told me and how they made me feel”

That I remember….

That… gave me hope

I remember the feeling –

the feeling of relief…

being believed...

putting a name to IT.

I was ready to face IT.

No matter what IT was

Chapter 9: Loss of words … lost in translation?

A phone call

Unknown number

A radio invitation - Hesitant, weary

Trespassed comfort zone

Broke the silence …gave the whisper a louder voice

Accepted invite

Confident,

Heard but not seen

I was speaking to my interviewer, using my mobile phone, before we started the recording for the radio programme. I had been invited to an educational radio programme "Konnect FM", aired by the University of Malta to discuss my autoethnographic research about women living with chronic autoimmune invisible illnesses. We were holding the interview using my phone because I was in self quarantine awaiting a COVID-19, PCR test result. I could only hear my interviewer; I could not see him. Similarly, just as the audience reading published text are unknown and unseen, I did not know my audience either. I was becoming somewhat agitated!

S: I'm panicking! I cannot seem to find the correct translation of some words

Interviewer: Which words are you talking about?

S: Two most used words in my English written text, which are "self" and "care". I cannot find the right translation of these words in Maltese that reflect the same meaning of these words… can I say them in English?

Wall (2008) affirmed the aim of writing and, in this case, audio recordings, were to speak a language that the audience could understand, so that, what was being said could be heard. Unlike all other presentations (e.g., International conferences, including European Inquiry for Qualitative research, Scotland and Narrative Research, UCL), which were presented in English; the radio interview was to be presented in Maltese. Besides the fact that the University of Malta requests that theses to be written in English language, and all the literature is in English, it was the first time ever that I was presenting my project to an unknown audience using the Maltese language and in Malta.

Although Maltese is the native language spoken by most of the population in Malta, it is not the only language used by the population on the island. I, like many Maltese, claim to be bilingual and/or even plurilingual, equally fluent, using Maltese, and English simultaneously as the first language and sometimes Italian switching effortlessly between languages according to the context and the audience. In the 19th century, when Malta became a British colony, one of the main features was the attempt to change Malta's everyday school language from Italian to English (Cassar, 2003). I attended Private Catholic Church schooling throughout my primary and secondary education, which provided a faith-based education. In the early 80s, I remember how we were only allowed to use English Language at school. Similarly English language is recognized as the official language in presenting theses and assignments at the University of Malta. Likewise, at home we speak and switch between languages. This ambivalence in language use is transgenerational, intrinsically ingrained, inherited through our history of invasion and colonialisation over the years (Borland, 2005).

In preparation for the interview as well as during the translation of the collaborators' conversations, I aspired to retain the same meaning when translating words from English to Maltese and vice versa. My aim was to present and translate the women's stories in an authentic manner, whilst ensuring to translate both the spoken and unspoken words as accurately and vibrantly as possible. Both the radio interview and translating the illness stories turned out to be a greater challenge than I would have ever expected. These events brought to the forefront the complexity, the intricacies and responsibility in using symbols and modes of communication when switching languages. A broader meaning beyond the linguistic language was elicited, accentuating power, and revealing the sociolinguistic and psycholinguistic connotations. It is not just a matter of switching between one language to another, but how the same message is communicated and interpreted in different languages (Ashcroft al. 1998). I continuously experienced difficulty and frustration in choosing the most appropriate word, symbol, metaphor when translating, in writing and when speaking. At times, it felt as if I had forgotten how to speak and write both in Maltese and English. Incidentally, as stated earlier, in preparation for the radio interview, I struggled in finding the appropriate translation for the two very commonly used words in this study, which are care and self. The translation of the word care in Maltese could be referred to as *kura*. However, in my opinion, *kura* only comprises the medical and physical aspects of care, whilst the meaning of care within the context of my study is more expansive and holistic and goes way beyond medicalisation and the act of pathologising. The other word I struggled with is the self. The self is being significantly central to autoethnography in combining biography and ethnography. The closest translation of the self to Maltese was Il-Jien, as referred to by Dun Karm Psaila, a renowned Maltese National poet and author of the Maltese national anthem, in his poem *Il-Jien u lil hinn Minnu* (1936), which was translated into Beyond self by Cachia (1962) and *I and Beyond* it by Friggieri (2017). Nevertheless, I did not feel that the identified translations manifested the intended meaning. Therefore, in that instance I decided to retain the English version and did the same when translating conversations with women

> *During the time of this interview, I was feeling physically and emotionally exhausted as well as burnt out. On the one hand, as educator and academic member on the placement committee under the nursing department, we are facing numerous issues and problems with student placements in hospitals due to COVID-19. On the other hand, I am living through the tension and anxiety of COVID19 first-hand, whilst also working with the Public Health COVID-19 response case management team. It is as if I am swimming in the ocean with no land insight Ironically, I unconsciously or consciously, was finding it difficult in translating two important and separate words, 'self' and 'care'… Upon reflection, I realise that language and meaning of such words were much broader and deeper than the translation of the text. It is the time where self-care is being forgotten but very much needed.*

Languaging IT

Interestingly, Christians (2004) stated that "[h]uman beings are the one living species constituted by language" (p. 240). Language is an important feature across all stories. It is through narrations (Defenbaugh, 2008) that, chronically, ill persons have a voice and share their lived experiences with others. When languaging the illness, all women incidentally used the same pronoun to name IT. They spoke about it as if there was another person in the room. Through the externalisation of IT, and thus, disassociating themselves from IT, they seemed to create a physical, emotional, and psychic distance from the illness. Externalisation is a concept used in narrative therapy. Externalising measures and practices locate problems, outside the individuals (Carey & Russell, 2002). In therapy, the problem becomes a separate entity and thus, external to the person or relationship that was ascribed as the problem (White & Epston, 2004, p. 88). If these same conversations were held during a psychotherapy session, IT would most definitely been given a chair. However, whilst the women conversing used explicit language to highlight the distance between the illness and themselves, it seemed as if they needed to safeguard their identity from IT. Francesca adamantly stated that she is not fibromyalgia:

> *'IT is NOT my identity IT is not ME'*
> *I see IT as exterior….*
> *... controlled…contained*
> *restricting the space for …IT to flourish*
>
> ~ Francesca

Whilst conversing, the women were switching between languages effortlessly. They were selectively choosing the most appropriate word(s), phrases and/or metaphors they deemed most fit to describe their feelings, emotions, and ailments. Maltese language was commonly used when describing emotions or when using specific phrases (e.g., ejja ha mmorru; translated into English as let's do this). Language and communication in its broadest and widest forms, including metaphoric expression, which allows us to increase the range of meanings in our languages (Edwardes, 2019) offer the possibility for a highly evocative and effective means of expressing bodily felt emotions that are not easily rendered by literal communication (Angus & Mio, 2011). Similarly, I had found difficulty in translating certain words and/or phrases when transcribing and when invited to speak on the radio interview, the women also seemed to encounter similar difficulty to language emotions, pain, and fatigue. Sometimes they reverted to describing the experience using medical terms and/or medical jargon, which by now, had become part of their vocabulary as opposed to using lay terms. Using medical terms seemed to help facilitate expression. Listening to the recordings once again helped me to gain a deeper understanding of these details, which I might have missed on hearing the recordings the first-time round. On re-listening to the recordings, attention was given on how the story was told, the gaps, the silences, the emphasis on the choice of language used, and taking note of how I embodied this experience.

Living IT?

As counsellor and a nurse, communication and language formed an intrinsic part of my training and practice. However, no amount of training or experience could have ever prepared or forewarned me for what was yet to come. The embodied cathartic affect, the presence and resonance perpetuated in listening to and writing about the illness experience, and all that it entailed, was another story being co-created (Etherington 2020; Clandinin & Connelly, 2004; Ellingson & Sotirin, 2020). In this project, IT has been objectified, and used interchangeably, by the women during conversations, namely referring to: (a) The illness condition in relation to their identity; and (b) the existential experience of living with the illness.

As noted earlier, upon carrying out a brief search using UM's e-library online platform, only a limited number of studies related to lived experiences seemed to have been carried out in Malta. Further to this, all the local studies, including the qualitative studies, excluded the body self of the research and the researcher. Up to a few years ago, I too conceptualised lived experiences based on interview responses, claiming neutrality, determining main themes without reporting anything beyond the existence of recordings. The experience of writing this project, using autoethnography as 'a process and a product' made me realise that I can never go back to researching and documenting lived experiences as a disembodied participant or researcher (Ellingson, 2006, 2017). Incidentally, Denzin and Lincoln (2000) referred to different moments in qualitative inquiry, particularly the fifth moment as the "postmodern moment of experimental ethnographic writing" (p. 17); a moment that triggered the crisis of representation, undermining the assumptions that lived experiences are merely captured and represented in the written in the texts and in so doing destabilised the positivist aspirations for validity, generalisability, and reliability (Gannon, 2017, p. 5). Consequently, in using autoethnography, personal narrative, reflexivity, participant in research and subject of inquiry as well as author (Ellis & Bochner, 2000), I abandoned the known way of doing and freed myself from the notion of objectivity in the writing of this thesis.

In adopting a social constructionist lens, I consider that the recordings from the interviews about the lived experience were not collected but were made at one point in time in the lives of the women participating in the conversations to co-create another story rather than to extract data (Ellingson & Sotirin, 2020, p. 100). According to Denzin (2014) narrative text freeze events and lived experiences into rigid sequences […] the ambiguities and complexities of life situations seldom appear in the analysts' text. The experience outside of the text is not included (p. 36). When we retell our stories, we think afresh, integrating new knowledge (Etherington 2021). The women's experiences were represented by stories of ambivalence and ambiguity. This paradox was reflected in the manner how IT was referred to as an ambivalent intersubjective love/ hate experience.

On one hand, IT was used as the illness condition that disrupted their lives and consequently their identity. Unfortunately, oftentimes, health care professionals reinforced the illness identity, by referring to the patient (e.g., the fibromyalgia patient or the MS patient, or even worse bed number x), thus consequently objectifying, medicalising, and erasing the identity from the person. One of the collaborators stated that this was even more painful than the illness itself, labelled Me as the Fibromyalgia. On the other hand, the women embodied IT and was manifested through their bodies accentuating an intersubjective sense making (Ellingson, 2017) to discover their authentic selves. The understanding of intersubjectivity between illness and self includes the lived space, body, time, and other (Van Mannen, 1997). According to phenomenologists, intersubjectivity is not only corporeal, embodied but also intercorporeal, that is a primordial relation with others through our bodies (Dolezal, 2015, p. 238).

This research process proved to be a learning curve and a life changing experience, which has been demonstrated in phenomenological ways, both the centrality of shared human lived experience and intersubjectivity and limits of intersubjectivity (Allen-Collinson, 2013, p. 293). In remembering and reconciling past to present illness experiences, the paradox of the existential life re-emerged, which although is not life threatening, is evolving unpredictably. Bremer et al. (2009 p. 328) described how, in recalling memories, the past and present may become intertwined and as we try to make sense of experiences and traumas, we re-evaluate our body, health, and life. In the process of re-evaluating our existential body selves, our identity in relation to illness, issues around normalcy, appearance, stigma and ablism become intrinsically and existentially important, as expressed by the women collaborators:

the ultimate diagnosis, was only a formality, I had
prepared for this eventuality, I knew IT
I was told to be me, not to let IT change who I am,
to retain my identity to win IT
~ Jessica

I voice IT, IT is there, IT is NOT my identity,
IT is not ME
IT revealed the true ME. I live and appreciate life
through a different lens. I live the now
~ Francesca

My condition grounds ME. (very assertive)

Makes me think why not me?

~ Erica

IT doesn't define me, IT's just a part of me

~ Jasmine

Chapter 10: Contextualising the traditional and modern woman in Malta

Dingli (2021) maintained that "[n]arratives are often either constructed by authors in retrospect… history is one of the most incorporated things in existence, in that it is abstract and belonging to the world of memory and consciousness rather than the physical world" (p. 64). How does our past affect our present, and how can it in turn affect our future? Life is not experienced in a linear way. Aspects from the past are transgenerational and expressed (consciously and unconsciously) in the way we act and think, both as individuals and collectively. Hence, I felt it was essential to provide a sample of periodic background information about women in Malta collected from diverse sources (i.e., newspaper features, academic studies, and published articles) to understand how specific social, political, educational, and cultural background continues to influence choices, behaviour, and personal agency through the years.

In a feature on the *Independent newspaper* called Female Medical Staff in Hospitaller Malta, Camilleri (2022) stated that during the time of the Order of St. John in Malta (1530-1798), whilst the management and administration of its hospital, known as the Sacra Infermeria, was almost entirely male-dominated, women also played important roles in the medical scene, which included the administration and running of female hospital and caring for female patients (i.e., midwifery, childcare, and pharmaceutical responsibilities). Having said this, in her Master of Arts dissertation, Mifsud Bonnici (2015) looked at Women in the Eighteenth Century Malta Legal and Social Aspects. She gathered information from 1401 public deeds in the mid-18th century that involved women. Her main aim was to dispel some misconceptions concerning the legal and social status of women who were believed to be under the complete control of the men in all the fields (i.e., political, social, religious, and economic). The research showed that women's legal and social status (even if limited when compared to men) provided them the opportunity to be proactive. Even though law was restricted, women participated in the economic life of the community mainly in trade parallel to men. The study by Mifsud Bonnici redefined the image of women in Malta during that period. Women's participation in the economy, as well as in other tasks, is proof the that ordinary working lives were not only limited to bringing up families. Mifsud Bonnici (2015) wrote that "one can hopefully refrain from envisaging all women living in eighteenth century Malta either as dutiful submissive wives or holy nuns at one extreme end, or as permissive prostitutes or wicked witches at the other" (p. ii).

More recently, Visanich (2018) examined some of the shifts in personal agency in the life domain of young women oscillating between the ambivalence of traditional and modern, by comparing a group of young adult women to another with 50 years difference who had continued their studies to tertiary, non-compulsory education. It resulted that there were various structural and cultural factors that had a direct impact on the women's personal agency in Malta (a Southern European country) namely, the church, legislation, and education. The main outcomes of the study highlighted that the context cannot be divorced from the process of individualisation. Despite the increasing advancement of the individualisation process, the social and cultural conditions, such as the strong family ties, and moral regulations, are still very present and continue to influence young women's life choices.

Additionally, Visanich's study explored ways how socio-cultural conditions were simultaneously negotiated and resisted. The main strategies included: (a) the understanding of marriage, as being neither western nor traditional, but conceptualised as a bridge between youth and adulthood, a means to move out of the family home, and to build a family; (b) employment was not necessarily deemed to mean personal agency or equitable gender roles, but was also considered as a measure for collective income procurement; and (c) a paradoxical dimension that even though opportunities were vast, anxiety, guilt and uncertainty were experienced because of the multiple roles of caring for family, whilst juggling career and repeating their mother's behaviours in caring duties.

An exhibition was held at Spazju Kreattiv, St. James Cavallier (Valletta, Malta) to celebrate women's day in March 2022 named *The ordinary lives of women*. This exhibition acknowledged and highlighted different achievements of women across the world. However, the achievements noted in this exhibition were by no means meant to reflect equality with men. It was a reminder that women make up half of the world's population and their struggles are the world's struggles. This exhibition recognised women in everyday life situations, as well as how their contribution to humanity (i.e., cleaning, caring and maintenance tasks) are, oftentimes, undervalued. The exhibition also recognised the resilience of ordinary women who have been pushed to extraordinary acts when their rights and lives were threatened also adopting a revolutionary stance when required. Whilst this exhibition focused on women, it is imperative to note that it is not restricted to women, but also to society at large.

In Article XIV, the European Union Agency, Constitution of Malta (1991) maintained that:

> The state shall promote the equal right of men and women to enjoy all economic, social, cultural, civil, and political rights for this purpose shall take appropriate measures to eliminate all forms of discrimination between sexes by any person, organization or enterprise; the State shall in particular aim at ensuring that women workers enjoy equal rights and the same wages for the same work as men.

Paradoxically, although Article XIV of the Constitution of Malta (1991) attempts to promote equality in paid employment, women's employment rate in Malta stands at a low of 32.8% when compared to other European countries (Legal notice, 2021). Therefore, although there might seemingly be more gender mechanisms in place (e.g., the gender parity bill approved by the Maltese parliament 2021), to counteract the gender imbalance that was manifestly absent, continues to devalue the role of women's contribution in their everyday lives, which still forms part of most women in Malta. Against such a backdrop, the process of individualisation for women continues to be a contradictory and ambiguous one. The association between femininity and domestic duties, including caring duties, remain firmly ingrained in the fibre of the Maltese society. The struggle of maintaining a balance between the private (i.e., caring duties, the physical and emotional well-being) and public lives of women is still very much a reality at present.

Contextualising illness uncertainty

> *Looking back on my illness episode, I vividly recall and relive the embodied feelings, the doubts, and ambiguity at the crossroads in decision making. When I was initially diagnosed with myasthenia gravis, I remember thinking that my life literally depended on my choices and decisions yet to be taken…. Thoughts that passed through my head and where never shared… I prayed and hoped that my diagnosis/life would unfold differently. In a way it did. But this is not the story everyone tells.*
>
> *Although the uncertainty and the hope may be similar, but the outcome, the individuation of how we live the outcome, and what we do with the meaning, is a very personal journey, nonetheless a collective one….*

In view of the above, I question how health and illness fits into women's ordinary lives. How do women with chronic illness construe health and illness in a world where patriarchy still reigns, and women are still being silenced? Is the illness behaviour representation still being dovetailed by similar social, political, and cultural attributes? The process and degree of individuation and agency whilst living with IT, is yet another issue that could influence juggling the multiplicity of selves in between the liminalities of traditional and modernity. Bury (1982) explained that:

> [i] llness, particularly chronic illness, is an experience in which, the structures of everyday life, it's taken-for-granted features, and the tacit stocks of knowledge upon which they rest are profoundly disrupted… involves a recognition of pain and suffering, possibly even death, which are normally only seen as distant possibilities or the plight of others. (p. 169)

In this project, when I spoke to the women collaborators, they seemed to be very well-informed about the medical aspect of their illness. It was not a question of making sense of, or how to cope; they have been doing that for a few years. What they seemed to be contending with was the uncertainty of the future and how they were going to live it in the best means possible. They were in a position where they had already made necessary adjustments to their lives, including the need to change workplace, listen to their bodies, rest when they needed to do so and plan their daily lives in relation to their needs. The symbolic significance they each gave to their condition was reflected in the way they regarded themselves, their identity post-diagnosis and how they perceived others (Williams, 2000). The symbolic attempt to repair ruptures between body, self, and society, seems to have made them more resilient, and provided them with new insights into the meaning and experience of chronic illness (Williams 1984; Hyden 1997). The search for coherent authentic self, seemed to be an ongoing endeavour, alongside the illness, goes beyond bodily alienation, medicalisation, the loss of the known self and biographical disruption (Charmaz,1983; Williams 2000; Bury,1982) or the disruption of the embodied self (Leder, 1990).

Throughout this research process, the questioning of the self in relation to the illness was not an easy journey. Being diagnosed in the 80s with ME/CFS, a contested illness was considered a relief than being diagnosed with myasthenia gravis. However, since symptoms were moderate, I questioned the truth of my diagnosis, the possibility of being misdiagnosed for a second time, and then questioned my authenticity as if it were all my fault. Similarly, the women claimed that the search for the authentic self was a continuously evolving trajectory in tandem with the illness unpredictability. Making sense of a coherent embodied self was evidenced in a multitude of ways, reflecting socio-cultural factors with the ultimate aim to prove their worth, namely on (a) a personal level, by comparing themselves to other female siblings or friends, hence discovering their new selves in relation to the other, sometimes were, thus left feeling disheartened with low self-esteem, because they refused to bargain for less; (b) on an educational level, by expressing the need to continue to invest in their own education and make up for the lost time when their life was on hold due to the illness. Incidentally, this is similar to mystory, the women participants were in employment and were continuing with their studies, investing in their professional development, during the time when the conversations were held; (c) in employment - working relentlessly to prove their worth, abhorring the idea that they were less abled; and (d) on a cultural level – they made sure that they did not miss out on things and that through their actions and behaviour, they could still abide to cultural expectations as women (e.g., caring for their family members by protecting them by keeping secrets about their illness and medication and/or to fulfil their dreams of caring for their own family).

There are two essential forms of identity, the social or public identity as perceived by others and personal/private self-identity as perceived by self (Kelly & Millward, 2004). Sociologists have viewed illness as identity disruption (Charmaz 1993, Karp 1996), whilst others strived to maintain a sense of self despite their illness (Sanders et al., 2002). Inspired by the lifespan ego-development research carried out by Erikson (1968), identity is viewed as how the individual integrates a sense of coherent self into daily lives and guides choices and values across the life span. This gives rise to a sense of continuity and coherent elements that contribute to psychological wellbeing (Erickson 1968; Schwartz 2001). The women collaborators experimented and compared themselves in relation to others, to better comprehend the impact of the illness on their identity to regain a coherent sense of self (Leventhal et.al., 1999). They did this by integrating illness in their everyday lives, by listening to their bodies' needs (resting and taking necessary medication) or absurdly pushing their limits, their bodies further, by for instance, working longer hours at work. In so doing, this attempted to not allow the illness to take over part of their identity Charmaz (1995) but conceptualising the illness alongside them. Just as 'I was ready to face IT. No matter what IT was', the women also externalised IT, refusing to be known by the illness 'IT is not ME'.

> *Further reading about education, politics and religion in the 19th and 20th century Malta, and more specifically this article, helped me to gain a deeper understanding on how and why I think, act, and behave in the way that I do. Besides fluctuating between the youth of my past, the adulthood of my present, I was also recalling the stories related by the collaborators who are young adults in the present.*
>
> *I felt as if I was swaying backward and forward between traditional and modern; I could relate to their stories of family and moral obligations, the limitations*

in education and career choice due to legislative restrictions, leaving my parental home when I got married to build a family of my own, whilst at the same time experiencing guilt and anxiety, juggling roles in caring for my family and elderly parents, whilst also continuing to invest in my own education. It also brought to the forefront how we/I continue to repeat certain family patterns, embracing certain values and beliefs as well as making them as our/my script. Moving on to the present, I am still juggling with multiple selves, roles and responsibilities as a daughter, mother, nurse, counsellor, and researcher. It made me realise how actions and behaviours are oftentimes dictated by overtones of my past, as well as intergenerational attitudes related to religious, educational, cultural, and political beliefs. I believe that the difference now from then, is that there is more insight, knowledge and information that is easily accessible, therefore choices and decisions are taken with awareness.

Chapter 11: Tellability and untellability

Goffman’s work on stigma explored possibilities and consequences, deconstructed binaries of visibility vs. invisibility, tellability vs. untellability, being unnoticed vs. being exposed or exposing oneself, demonstrating categories as being situational and/or collaborative (Goldstein & Shuman, 2012). Moreover, “Goffman [1963] distinguished between the discredited, that is, individuals recognized as belonging (sometimes by associations only) to a stigmatized group, and the discreditable, that is, individuals who are vulnerable to stigmatization” (Goldstein & Shuman 2012, p. 115).

Traditionally, researchers studied and interpreted chronic illness experience from two main vantage points: the stigma that society imposes on those judged to be different or the success in adjusting to the illness (Joachim & Acorn 2016, p. 38). The stigmatisation is deemed as not being within the control of the individual but depended on the societal and cultural norms. In illness, conceptualising stigma as not belonging, or fitting with the normal and healthy population, which could lead to questioning one’s sense of coherence and authenticity.

Stigma discourses often promote a sense of difference. Authenticity is one of those differences. Therefore, whilst women with chronic invisible illness could strive to be as authentic as possible, stating their illness realities and sometimes chaotic personal stories could come at a cost, not only risking visibility of their true selves, but also stigma. In relation to this, Goldstein (1991, as cited in Goldstein & Shuman, 2013) explored that:

> the representational politics surrounding untellability and stigma, especially in those situations in which trauma or mental and physical challenges result in ‘chaotic narratives’ that only serve to further stigmatize individuals (p. 118).

Also, Smith and Sparkes (2007, as cited in Defenbaugh, 2013) argued that personal stories are both personal and social at the same time, thus, “revealing a hidden, chronic illness is a risky and vulnerable act” (p. 159). On one hand, one risks remaining socially stigmatised, and on the other, one must continuously conceal or legitimise their invisible illness identity since, oftentimes, they do not look unwell. It is a choice and a risk that not everyone is ready to take. This issue could be even more accentuated because of the smallness of our island and close relational proximity. Additionally, revealing the illness is, in a way, accepting the illness identity bestowed by medical professionals. All of the women collaborators rejected the notion that the illness condition is their identity; ‘IT is not me’.

Not telling and concealing IT, is in a way, holding on to the known self(ves), whilst at the same time going to great lengths to look normal, even when the sense of multiple self keeps altering (Defenbaugh, 2013) due to the illness. Therefore, the choice to tell or not to tell is dependent on the teller, the content, and the audience. According to Frank (1995), when people tell their own unique stories of illness or disability, they compose these stories by adapting and combining narrative types that cultures make available to them (p 75). Untellable narratives are connected to what hooks described as questions about who is “worthy to speak and be heard” (hooks, 1992, p. 345). Moreover, Goldstein and Shuman (2012) expressed that:

> Stories become untellable because the content defies articulation, the rules of appropriateness outweigh the import of content, the narrator is constrained by issues of entitlement and storytelling rights, or the space the narratives would normally inhabit is understood by the narrator as somehow unsafe. (p. 120)

In addition, the decision to tell, and not to tell, could ultimately also depend on being able to continue with life in the best manner possible, even if experiencing physical and emotional turmoil, (e.g., not divulging pain, keeping secrets, or working exceedingly long hours) to prove their ability and worthiness. The following is an excerpt from Jessica's story:

> *I relate my story without stopping…. breathless*
> *in motion…keep going just as I do life*
> *I continued with my life as if all was "Ok …*
> *My life changed*

Furthermore, Philips (1990) considered an outcome of disability resultant to the illness as labelling (e.g., the identification of a person as lazy or seeming well from the outside and questioning the pain). Jessica was not lazy but was suffering from iatrogenic effects from medication she was prescribed for her illness:

> *a secret to my mother*
> *…to protect her,*
> *interpreted fatigue as laziness*
> *…. if only she knew*

Philips (1990) stated how stigma is caused not by the illness or the disability itself but by the difference between what is socially desirable and what, in fact, is. Behaviours of a divided self (i.e., the public and the personal self) are a natural response to these exterior expectations by outwardly presenting themselves as normal, whilst hiding the suffering. This conditioning lends itself well to the narrative of invisibility, disability, gender, and normalcy. In society, it is understood that health equates with normalcy and "illness is perceived to be a deviant, abnormal state" (Hayden, 1993, p. 264).

This self-constructed understanding of health and illness sets the stage for concealing one's illness identity. Many researchers view normalisation to enable people living with a chronic illness to resume roles and responsibilities according to societal norms, to live or pretend to live, whilst coping with symptoms and minimising the disability (Strauss et al., 1984). The effort to conceal pain (i.e., physical and emotional) and the resilience to continue with life, as well as to study and work, may equate to feeling normal and productive, and thus conforming to societal expectations. Sometimes, this effort is done at the cost of putting one's own health at risk (e. g., self-silencing, stopping medication to minimise side effects). Normalisation, in this instance, bracketing off the consequences of the illness, the treatment required and consequently mitigating their private and public identity. In the world of binaries, the illness and its embodiment could be deemed as a polarised position to being normal.

Nevertheless, seeking and hoping for normalcy, or the return to normalcy, could indicate a positive psychological approach and resilience to illness experience. This is reiterated through Jasmine's story, when she expressed:

> *When I find myself at a low point…*
> *I always try to see the positive side of things*
> *and persevere...*
> *IT takes the toll out of me,*
> *but I always managed up to a certain point.*
> *I try to find solutions for things*
>
> ~ Jasmine

In-niċċa

Many streets in Malta are adorned with architectural niches (see Figure 11a) or in-niċċa in Maltese, also known as street shrines (see Figure 11b). These niches were brought to the Maltese islands in the 16th Century by the Knights of St John. These stone niches were either carved or built into the facades of public or residential buildings across the islands of Malta and Gozo. One of the most common statues that one can find in these niches in different villages across the island is the statue of Mary holding baby Jesus with reverence to the Catholic faith, accentuating the centrality of family.

Paradoxically, the fundamental Christian beliefs and values on the family continue to be proclaimed in Church's liturgy, on Family of Jesus, Mary and Joseph and presented as the model and inspiration for all Christian families, and all families at large (Eminyan, 2004). Also, the overarching position of the Vatican and the Catholic church holds the Family and safeguarding life as central (Vella Bardon, 2012).

Figure 11a

In-niċċa

Figure 11b

Close up of a street shrine

Galea (2020) claimed that Malta remains a conservative bastion in Europe, most especially when debating reproductive rights, which brought to the forefront issues of national identity, morality and sovereignty in a post-colonial state that continues to grapple with traditionality and the modern. However, anthropologist Scicluna (2018) commenting on a play that was held in Spazju Kreattiv, named *De-terminated*, that reinforced that the meaning of things and/or ideas can never be understood in isolation. Hence, understanding the socio-cultural context is essential (Allen-Collinson, 2012). In a society like Malta, where family connections are very strong (Abela, 2000) conservative views on gender roles prevail (Sollars, 2018). Scicluna (2018) stated that the concept of an embryo is, on one hand, intrinsically linked to the concept of family and relatedness, whilst on the other hand has to do with body politics, thus elicits debates around gender, feminism, and women's rights. In Malta, the significance of relatedness is very profound because the Maltese society is built on connectedness between family and friends (Grima, 2006). Yet, demographic changes and progressive society might be slowly influencing and changing social norms, affecting family relation and behaviour, whilst beliefs and values seem to remain ingrained.

Undoubtedly, there exists a distinct difference between the time period when girls got married at a young age and rarely invested in their own careers with nowadays, when women's lifestyle has been altered due to shifts in society's development. Women and their respective families' self-worth were measured by the number of children they bore and raised. Nowadays, women might consciously choose not to have children or consider having children to be only one, relatively small, but still an important aspect of their lives (Zammit, 2019). Scicluna (date) also stated that the absence or loss of a child remains an extensively sensitive topic and that the deep-rooted connections are still embedded in our collective unconscious as a population. For the record, it is important to note that Malta remains the lowest birth rate in all the EU, with 1.14 births per woman recorded in 2019 when compared to the EU average of 1.53 births per woman in 2019.

In this study, the fear of being discredited because of their conscious choice not to bear children (potential risk due to illness) was deemed to be more painful and stronger than feeling stigmatised for the illness condition itself. I cherished the fact that the women felt comfortable to discuss such a topic, which is generally considered as taboo. Whilst recalling their personal illness stories, they also revealed negative emotions that they had experienced besides pain, including, grief, shame, and anger. Through the writing, similarly, to what Letherby (2003, p.13) maintained, I appreciated how 'the emotional, the sense of self, and the physical were tied intimately into the social definitions of womanhood and responsibility. Gabor Mate (2011) noted that:

> while we dread being blamed, we all would wish to be more responsible—that is, to have the ability to respond with awareness to the circumstances of our lives rather than just reacting. I stand to believe that ultimately, we all hope to be the authoritative

> person in our own lives: in charge, able to make the authentic decisions that affect us. However, there is no true responsibility without awareness (p. 20).

The women in this research took responsibility for their decisions whether to tell or not to tell (willingly or unwillingly) about their invisible illness in both personal and professional contexts. On one hand, this could reflect conscious decision making, awareness and agency, however, on the other could reflect silencing due to different factors including gender, societal conditioning, and patriarchal attributes. An act of collusion and resistance at the same time.

Chapter 12: Silent whisper

Silence is considered a phenomenon on its own merit and goes beyond spoken language. Spoken language is commonly regarded as words put together in the background of silence. Solnit (2017) expressed that “[s]ilence is golden… Silence is the ocean of the unsaid, the unspeakable, the repressed, the erased, the unheard (p. 2). For instance, in therapy, we listen and observe the person’s non-verbal communication (i.e., posture, facial expression, and body movement). Silent prayers, or moments of silence at a public solemn event, are practiced in many cultures by people of different religions, and by those people who do not have any religious affiliations. Yet, embodied silences could be interpreted as a form of resistance or oppression (Edley, 2000).

Figure 12a

The silent city

Growing up, as a child and as a teenager, I understood and interpreted silence in different formats and used words interchangeably, depending on the context:

Be silent, Timid,

Quiet, Stillness,

Keep the Peace,

Not seen,

Erased (emotionally and physically)

Submissive

I feel that silence could easily be interpreted as a conscious act or measure to be respectful, hence, not to defy authority and/or societal expectations. This I believe is intrinsically influenced by my upbringing and the Catholic education schooling in the silent city (Figure 12) in the 80s in Malta.

It could also be an unconscious act to protect self. Looking back, as a 16-year adolescent I remember me as being quite shy and timid, and brought up to respect authority. However, ironically, I also remember being very active and vociferous reacting to political oppression and "Turbulences of the 80s" (Azzopardi, 2015) when our Catholic church schools were closed down, and we as an age group were discriminated from furthering our education at university. In fact, at this time, when Malta was on the brink of civil war, I was protesting out on the streets without fear.

Yet, in relation to mystory of illness, I thought that being silent about IT was a conscious decision. In hindsight, I realise how conditioned I was by my internal script. Silence is an emotional coping mechanism, catalyst for suppressing feelings and emotions. I believe that it was a moral and existential decision as a young female aspiring for normalcy. It was both an act of collusion and resistance at the same time.

It was my way of coping. Upon reading the article titled, Saying the word:

Voice and Silence in an autoethnography about illness by Rose Richards (2005), and more specifically, another article called Making Peace with the unspeakable, made me reflect deeper into my own story of silence, something I had not really given much thought prior to the writing of this project. I realized that for 30 years I hardly ever spoke about my illness event let alone questioned IT. Through my writing and reflection, I start to discover lacunae in my life story that I had smothered deeply in my subconscious…Why do we silence stories? I wonder…is it a form of protection or care of self and others? It is through reflection, that I am becoming more aware on how I embodied this silence into numbness and invisibility along the years. Awareness brought the numbness back to the forefront. It is as if I just wanted to erase the 'unwell' self from my memory, from my life history. I wanted to form part of the kingdom of the 'well'; to be 'normal'; to feel and be seen as 'normal', even though every now and again my body manifests otherwise.

I subconsciously erased most of the detail and sequence of events leaving fractured spaces - gaps in mystory. I reverted to family members to help me fill in the gaps of those periods of my life where my memory (selectively) failed me. However, in the process of writing, I come to understand that selective memory loss and silence goes far deeper into the layers of the self than the instance of the event. If given a voice, memory would also have volumes to say. However, I also realise that the inner voice is not congruent to what I am thinking.

Even when I have a flare up of joint pains, myalgia and fatigue, the silence of naming it for what it is, is inaudible…. deafening. I refused to allow myself to be seen as vulnerable, fearing discreditation and validation. I justified pain and fatigue by self-blaming, as well as justifying exhaustion and burn out to overworking myself and stress. At times, it seems as if I was drive myself insanely to the edge, as if it is the only option, close to self-sacrificing sabotaging, my own health. Furthermore, I *became curious to understand the conscious, unconscious, and moral decisions being taken at the intersections of being silenced or self-silencing and how, in turn, these decisions or actions are affecting me or affected me as woman and my relationships with others.*

Illness…is IT personal? Political?

According to Datan (1989):

> Illness is a central tenet of feminism that women's invisible, private wounds often reflect social and political injustices It is a commitment central to feminism to share burdens. And it is an axiom of feminism that the personal is political. (p.175)

During the process of writing, I experienced an intense urgency to deconstruct, that is make sense of my own self silencing, guided by the phrase that "the story is in the silence" (Richards 2005, p. 6). I found myself repeatedly connecting or trying to make sense of the personal in relation to the cultural and social (Ellis, 2004) through the writing. This made me recall the slogan, "the personal is political" (Hanisch, 1968), which was made popular by the second wave feminists conveying the political dimensions to private life. The late Nancy Datan, a feminist psychologist, who died from breast cancer, wrote these words calling for development of feminist theory and practice around issues of breast cancer. This slogan has continued to influence feminist theory, including Soloway & Hooks (2016) and Holman Jones (2005).

Reflection on the silence questions seemed endless, and at times unanswerable.

How do we internalise experiences that make us feel disempowered, intimidated, repressed, and consequently, choose to remain silent? Is silence the language of emotions, i.e., shame, blame and guilt?

Does silence affect health? How do societal, cultural roles, expectations, and power impact women's silence to become a whisper or even a shout?

According to Solnit (2017):

> If our voices are essential aspects of our humanity, to be rendered voiceless is to be dehumanised or excluded from one's humanity [….] the history of silence is central to women's history. (p. 2)

Self-silencing has been widely studied in the context of certain illness, including depression, eating disorders, cancer, AIDS, chronic fatigue syndrome, premenstrual dysphoric syndrome, which have helped to bridge the link between gender and health (Maji & Dixit, 2019). According to Jack (1991), sociocultural norms of traditional femininity depicted that for a woman to be considered good, she should curtail their own thoughts and feelings, to give way for the others' needs, including self-silencing and suffering in silence. Thinking with mystory and other women stories, it became even more evident how gender and social construction of illness unconsciously condition our thinking and behaviour throughout our lives. Keeping silent is a multifaceted measure, which could also include an identity issue to safeguard the socially constructed ideology of fulfilling hierarchical, patriarchal, and societal expectations (Gilligan, 2010). The contestation of certain invisible illnesses, the internal script and cultural understanding of gender stereotype roles and responsibilities, as well as the social context we live in, are all factors that influence our decision-making when in between, at the borders or at crossroads.

Jack (1991) foundational work on self-silencing theory was based on her longitudinal study with clinically depressed women. She conceptualised self-silencing comes from a motivation of maintaining relationship with others since women's self is relational in nature. Furthermore, another motivation from self-silencing comes from existing gender norms of the society, which portrays women's character as more docile and submissive (Maji & Dixit, 2019). In relation to silencing and self-theory, incidentally,

Jack and Dill (2010) stated how "women detailed how they began to silence or suppress certain thoughts, feelings, and actions" (p. 5). This ultimate aim was to avoid conflict, safeguard relationships, as well as personal psychological and/or physical safety. This is not independent of the social structure but is strongly rooted in the gender norms as dictated by culture in attempt to "fill a gender role marked by passivity, body shame, fear and vulnerability, and niceness" (Jack & Ali, 2010, p. 141). Yet, Ussher and Perz (2010) differentiated between women's self-silencing, which is used as a coping strategy and external confirmation of women's caregiving role, whereas men self-silence to conform to the strong macho man gender norm of inexpressiveness.

Similarly, the women participants' understanding of self-silencing could be interpreted as a measure to collude with gender roles and societal expectations, by abiding to the cultural and moral transgenerational script (Abela, 2000). The politics surrounding the gendered role and socio-cultural expectations are also experienced in everyday life. In medical settings, the social control that occurs most especially in relation to medically unexplained illnesses, continue to place patients in a passive and powerless role that is often aggravated between male doctors and female patients (Borges & Waitzkin, 1995). Ellingson and Buzzanell (1999) stated that the biomedical standpoint and the medical discourse continues to reinforce gender roles.

Also, "the power of doctors to make decisions and exercise authority over patients is part of this gendered construct" (Ellingson & Buzzanell, 1999, p. 157). This biomedical, asymmetrical relationship places the doctor "as the holder of knowledge, authority, activity, and dominance" (p. 157). In so doing, the medical team (knowingly or unknowingly) influence and may increase the patients' sense of vulnerability and powerlessness. This power and authoritarian behaviour strips off and disempowers the patients of their self-efficacy and self-worth, which is a form of intrinsic epistemic injustice, by denying them from capacity as a knower (Fricker, 2006). At times, keeping silent, not questioning care, or not voicing ailments could be detrimental to wellbeing. This could also include suppression of negative emotions, including anger, frustration, shame, and guilt, from fear of not being believed, validated as a person, or even worse labelled as being hysteric and that it's *all in the head*. Suppressing such negative emotions could be interpreted as a restriction in the body from responding to the authentic self. Resultantly, this could evolve into a divided self, which could gradually lead to passive withdrawal or displacement of anger where women feel angry at one part of their self and respectful to others on the other part (Maji & Dixit, 2019, p. 9).

The family

This double bind and self-sacrificing could also be reflected in the family context. In his influential book Values of Women and Men in the Maltese Islands, Abela (2000) demonstrated how, when compared to a European perspective, people on the Maltese Islands, share basic value orientations, however, prioritise matters regarding religion, politics, work, and family. Amongst other results, he presented the analysis of the four waves of the European values. This study, which was carried out over a span of fifteen years, indicated that the Maltese people still valued and retained a strong attachment to the family (Grima, 2006; Cutajar, 2001). Many Maltese families place high value on the strong relations with immediate and extended family members. The proximity of family connections are both physical and spatial due to the smallness of the island. Maltese people will go to various lengths to maintain harmonious family connections and to support each other when the need arises, both in sickness and in health. Illness is a stressful enough event for all persons concerned and involved. Penn (2000) regarded illness as a "relationally traumatizing experience" (p. 33), not only for the person with the illness but for all the family. Keeping IT a secret to spare family members from further pain and devastation, with the ultimate intention to protect them, is generally a conscious moral decision taken with full responsibility, even if it means self-sacrificing one's own health condition. A decision, an act of care to protect self and others from further emotional dishevel by enduring pain and suffering, carrying their own cross, which symbolises suffering, hope, endurance and love. A balancing act between the relational aspect manifested through loyalty, altruistic, empathy, compassion and addressing one's own internalised needs, negative emotions of guilt, shame, as well as self-blame. In fact, two of the women collaborators expressed their thoughts on this, by expressing the following:

I prefer to keep IT a secret,
not only unknown but invisible
and without a voice…
I prefer they don't know

~ Jessica

Protecting loved ones not knowing,
showing, silent…. hidden secret….
IT was not over

~ Francesca

Chapter 13: Feeling and emotions

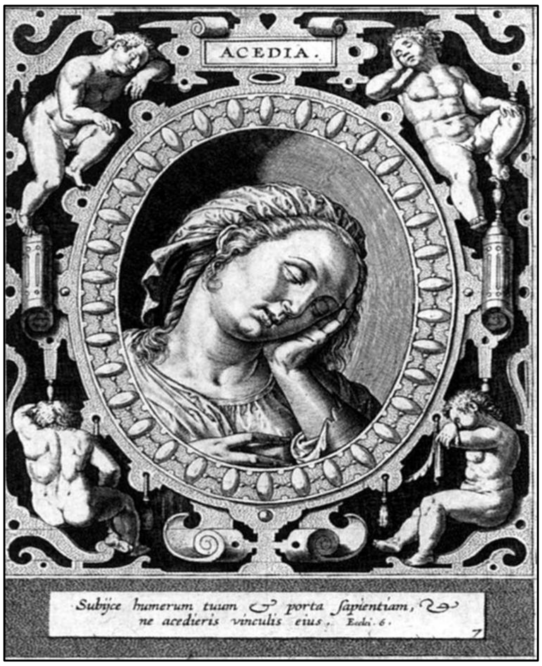
One evening during lockdown, I was scrolling through the posts on social media and came across the word Acedia. It was a word I had never come across or heard before. Acedia is the lost name for the emotion, which was compared to the same feeling experienced during the COVID-19 pandemic. John Cassain, a monk, and theologian in the 5th century wrote about the Acedia (Figure 13a), which refers to a mind 'seized' by emotion.

> *I, sincerely believe, that the COVID-19 pandemic and long COVID have taken feelings and emotions to a level beyond explication. The COVID-19 pandemic is, or should be, should serve as, a wakeup call on many different levels, including emotional, physical, and mental health. Ironically, the COVID experience for persons already living with chronic illnesses is a reminder of their reality(ies). The naming of emotions became more explicit, and tangible. Negative emotions, such as fear and sadness, alongside their psychopathological associates, anxiety and depression, together with uncertainty and powerlessness, like skeletons in the closet, seemed to have been let loose. Additionally, social isolation increased a permanent sense of stress, exhaustion, listlessness, hopelessness, a longing for connectedness and a desire to return to 'normality'. We are all trying to stitch our future to our past, just as is done with persons living with chronic illness.*

Widespread incidence of long COVID continues to rise all across the world. Long COVID symptoms resemble chronic illnesses' symptoms, which include headaches, muscle and joint pain, fatigue, anxiety, and multisystem inflammatory syndrome. However, this time round, these symptoms are not contested and are being recognised due to COVID-19. An article written by Ellingson (2021), a feminist and a person who experienced chronicity first-hand envisaged a repetitive story that societal invisibility, stigma, lack of financial and social resources will remain a reality, and emotions will continue to be silenced.

Figure 13a

The lost emotion – Acedia (Wierix & Galle, 1553 - 1619)



In short, the COVID-19 pandemic, just like chronic illnesses, which ironically is also referred to as the *silent pandemic* due to its prevalence, brought to the forefront emotions as “embodied existential modes of being” (Denzin,1984, p. 138). Those same emotions that do not solely underpin the biological experience of our bodies in the kingdoms of wellness and illness, but they also link the relation between the personal and society at large, which are also culture specific. Interpretation, emotional expression, and norms change over time. The conceptual link between emotions, body, gender, and cultural responses continue to remain a recurrent issue (Bandello & Williams, 2002). It is argued by Williams et al. (2000) that:

> Emotions lie at the juncture of some fundamental dualisms in western thought such as mind/body, nature/culture, public/private (p. 15) …Williams (1998) Emotions, in other words, are thinking, moving, feeling 'complexes' which, sociologically speaking, are relational in nature, i.e., communicative, intercorporeal and intersubjective. (p. 124)

Emotions are felt through the body, the site of emotional experience and expression (Davidson & Milligan, 2004, p. 523). However, Davidson and Milligan distinguish between language and emotion as if they were two separate domains; the language system of linguistics and communication and the emotions, which are made visible through body. Incidentally, Davidson and Milligan (2004) stated that the articulation of emotion is "spatially mediated in a manner that is not simply metaphorical. Our emotional relations and interactions weave through and help form the fabric of our unique personal geographies" (p. 523). Similarly, whilst conversing with the women, they too, intentionally or unintentionally, spoke of emotions using terminology related to space in relation to the body taken from Davidson and Milligan (2004), for instance*, spiralled to darkest depths*, *depths of despair*, *tallest chall*enge and referring to significant others as being *close*, or kept at a *distance*.

Moreover, Ahmed (2004, 2013) makes a distinction between the internal emotional experience manifested through subjective feelings and emotional expression, which include the external manifestation of emotions. In so doing, she differentiated between affect as being relational to the bodies, the *within* and emotion as the relation connected to subjectivity and cognitions, which should be questioned more as a feminist discourse. Furthermore, Ahmed (2017) stated that "our emotions can be a resource; we draw on them.

To be a killjoy is often to be assigned as being too emotional letting your feelings get in the way of your judgment. Your feelings can be the site of a rebellion" (p. 246). Similarly, Letherby (2003) reaffirmed how the display of emotions is gendered. It seems less acceptable for men and women respectively to display certain stereotypical emotions, for instance when women are considered as more emotional and caring to display anger, and men are considered to be more in control to display distress (Hochschild, 1990).

Listening to the illness accounts elicited a myriad of emotions. In certain instances, the emotions experienced created such void that it felt as if the mind was 'seized by emotions' and found difficulty to conceptualise and/or name it, thus the reference to Acedia. Whilst in other occasions the emotions elicited were very strong emotions, and at times even distressing. Many a times this was compounded by the fact that what they were relating resonated with my own feelings and experiences. Besides feelings of empathy, I also experienced feelings of anger, most especially when they were discussing how they felt objectified, erased, not believed, as well as deviant. I was angry at the status quo of the biomedical model. However, at the same time, I also experienced feelings of admiration at how these women manifested agency, in the way they spoke and responded, as well as how they embodied emotions in coping with illness. Hence, they attested their realm beyond agency (Hay, 2010) through their actions. Incidentally, when comparing this to my own understanding of cultural expectations, my behaviour and reactions to illness at the time of diagnosis, I still recall how oppressed and powerless I used to feel, lacking any form of agency, let alone a voice. In hindsight, I believe that this increased the suffering. I was, once again, reminded of how objectified I felt (i.e., as if I was the problem). I was lost in the omnipresent authoritarian system of medical patriarchy. Subsequently, I started to question other factors that influenced my lack of agency and my encrypted beliefs on existential vulnerability:

A note to self

And others… all things are

Possible… a question of

Perspective, it's a choice

The story could have been told

differently …the story of

weaker/stronger women,

determined/less determined ... passive/defiant

Religion and emotions

The research of Christian religion and emotion has been an important part of theological writing, through centuries of the western world (Corrigan et al., 2003) since emotions play a fundamental role in religion (Fuller, 2007). Over the years, the relationships between the individual, society and the Church have been undergoing rapid change all over the world including Malta has also been affected by these changes. Over the years, various factors have influenced the character of the Maltese population; one of the main factors being the Catholic religion, an important protagonist in the construction of the identity of Maltese society and of individuals. However, the fabric of Maltese society has been radically and progressively changing, the role of religion has also been modified (Vassallo,1999). The relationship between the individual, society and the Church in Malta have been experiencing rapid change. The tensions between the influence of the Church and the secular pull of society is ever present in different domains including the political and the personal (Psaila, 2012).

Amongst other emotions, shame, and guilt are used interchangeably making little differentiation between the two. Shame relates to self (internal and external), whilst guilt generally, relates to others (Burgo, 2013). Internal shame is related to negative self-evaluations and self-directed affects (Gilbert, 2000, p. 176), whilst external shame relates to what has recently been called stigma consciousness and awareness (Pinel, 1999, p. 5). Gilbert (2000) argued that guilt is focused on harm or hurt done to others. Women claimed to experience both shame and guilt in relation to self, but mainly in relation to others, for e.g., feeling ashamed, being unable to engage in activities like siblings or friends because of the pain, fatigue and body image, whilst feeling guilty from stealing time, attention from their family and siblings, together with financial repercussions on all the family due to their illness. Upon listening to the women's illness stories, I could relate to similar negative emotions of shame, guilt, anger, but also those of empathy, compassion, and resilience, despite the events happening at different time periods.

Healing, suffering and spirituality

The words *healing* and *curing* are two terms that carry various meanings and connotations for different people. They are used widely and interchangeably by both, lay and professional persons across different disciplines. These are two words that have different etymological history. The verb to cure comes from the Latin word *curare.* According to the Oxford English dictionary (date) to cure means to 'take care of'. The Maltese word for cure is *kura* (derived from *curare* - a word of Italian origin; originally taken from Latin), which denotes medical treatment. However, in Maltese, the word *curing* is also referred to as *tfejjaq* with the noun being *fejqan*. Yet, according to Aquilina (2006), the Maltese dictionary states *fejqan* is to *heal*, showing that there is a duplication in meaning and words are used interchangeably. Therefore, whilst *curing* is specifically intended to control or eliminate disease, the meaning of *healing* is more complex and at times inaccurate. The verb to *heal* is a very traditional word in the English language and is closely related to the word holy (sacred); *haeloz* and *halig in* old English (Gordon, 1979).

Healing describes a process that facilitates health and restores a sense of wholeness, harmony and balance between the mind and body (McGlone, 1990). Finding a balance between mind, body and soul is not a linear, quick fix, or straightforward process. On the one hand, the medical profession claims to heal the body physically by preventing illness, treating, curing, and eradicating disease, whilst the psychological healing aspires to make whole that which has been broken, and the spiritual healing involves meaning, reconciliation, and transcendence (Egnew, 2005, 2009). Ultimately, we all hope for a cure, to receive a diagnosis (be it what may), as long as IT is given a name, and even though uncertainty of prognosis prevailed, starting treatment was an initial hopeful step towards getting life back:

Treatment started
Adamant not to let IT
Change my life … I needed
To plan my future with it
~ Jessica

In so doing, patients collude to medical model of *treating* disease and long to receive treatment primarily to seek *relief* of symptoms, to make *IT* better and get on with life (e.g., pain relief in fibromyalgia or steroids in UC and RA or medication for MS). Medication relief in chronic illness is not a means to a cure. Sometimes, the ramification of the same medication may affect the person's holistic wellbeing. For instance, whilst medication could on the one hand relieve, alleviate, and control pain as well as inflammation, on the other hand it could affect weight gain (i.e., effecting body image) and also determine choices of fertility. Such aftereffects effect the psychological and emotional wellbeing, therefore, although curing, healing is deterred:

Was I conditioning myself... the nausea persisted…?
I rebelled; I stopped medication ...I threw them away….
I was in control...
Besides the weight gain, my mood was horrible…….
Medication was a contraindication to pregnancy…
that is why I stopped!

~ Erica

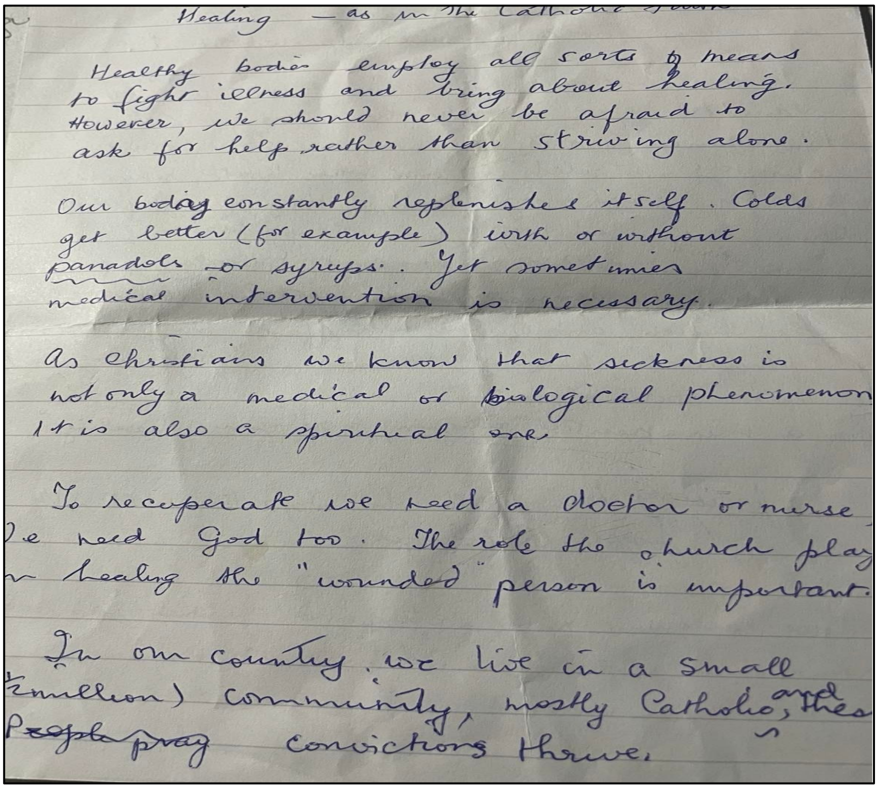
Healing is defined in terms of developing a sense of personal wholeness that involves physical, mental, emotional, social, and spiritual aspects of human experience (Egnew, 2005 p. 258). The healing journey does not necessarily lead to a finite objective, to an ultimate recovery or cure, to a happy ending of a story, but a journey of self-discovery and self-development. If we were to look beyond the physical and view the person holistically, the symptom is deeply embedded in personality. Holistic healing involves the transcendence of suffering, which could present a threat to the integrity of personhood involving physical, mental, emotional, social and the spiritual aspects of human experience. Suffering is transcended when meaning is attributed to personal wholeness (Egnew 2005).

I was curious to understand the spiritual meaning attributed to healing in our family. Who best to ask other than my own mother, a devoted and practicing Catholic who has been living with chronicity for more than half a century? I wanted to understand how illness was viewed through the religious lens. I was mindful to ensure ethical correctness in asking and sharing her point of view. I asked her whether she preferred to talk or to write her thoughts. Being the reserved person that she is, she preferred to write it down. "I prefer to use pen and paper, rather than the computer" *she said, "…. words come easier". It felt less intrusive for both of us. She wrote in her own time, choosing what to write within the boundaries of the page.*

I asked permission to present the handwritten note. Figure 13b is a photo of the first part of the note that she wrote. In her note my mother expressed her thoughts about illness, healing, and spirituality, including a Catholic lens to her writing, she wrote:

Figure 13b

Healing - handwritten note



Healing — as in the Catholic

Healthy bodies employ all sorts of means
to fight illness and bring about healing.
However, we should never be afraid to
ask for help, rather than striving alone.

Our body constantly replenishes itself. Colds
get better (for example) with or without
panadols or syrups. Yet sometimes
medical intervention is necessary.

As Christians we know that sickness is
not only a medical or biological phenomenon
It is also a spiritual one.

To recuperate we need a doctor or nurse
e need God too. The role the church play
n healing the "wounded" person is important.

In our country, we live in a small
½million) community, mostly Catholic, and these
~~People~~ pray convictions thrive.

Healthy bodies employ all sorts of means

to fight illness and bring about healing.

However, we should never be afraid to

ask for help rather than striving alone.
Our body constantly replenishes itself – colds

> *get better (for example) with or without*
> *panadols or syrup. Yet sometimes*
> *medical intervention is necessary.*
>
> *As Christians we know that sickness is*
> *not only a medical or biological phenomenon.*
> *It is also a spiritual one.*
>
> *To recuperate we need a doctor and/or a nurse.*
> *We need God too. The role the church plays*
> *in healing the "wounded" person is important.*
>
> *In our country we live in a small*
> *(1/2million community), mostly Catholic and*
> *these convictions thrive.*

My mother's letter continued to read….

> *As is the case of COVID 19 pandemic,*
> *people pray fervently as well as take the*
> *necessary health measures to eradicate it.*
>
> *Another instance that comes to mind was*
> *when my daughter was wrongly diagnosed*
> *as having myasthenia gravis,*
> *yet a second consultant out ruled it.*

During the time of her second consultation,
the parish priest of our local community organized
a day of prayer. At this time, a frame of the
Sanctuary of Our Lady of Good Health
in St Francis Church, Rabat was brought
to the church of St Massimiliano Kolbe,
the village church in Bugibba,
specifically on the day of prayer (see Figure 13c).

These prayer meetings are not unusual.
As retired Pope Benedict XVI,
a profound spiritual leader in his own right and a
theologian and bible commentator said,
"Healing is an essential dimension of the apostolic
mission of the church and of Christian faith in general...
a therapeutic religion, a religion of healing"
(Jesus of Nazareth by Pope Benedict XVI – Joseph
Ratzinger).

Figure 13c

Il-Madonna tas-Sahha (Our Lady of Health)

The Doctrinal Commission of the International Catholic Charismatic Renewal Services (ICCRS), recognise different categories of healing, namely: (a) physical healing - the healing from physical sickness and disability; (b) psychological healing - the healing of wounds to the human psyche, including emotional wounds; (c) spiritual healing – referring to the healing from sin that restores a person to a relationship with God. In spiritual healing, there is the belief and the full trust for God to alleviate pain and to heal sickness. Pain, in this instance, goes beyond the physical symptom of pain experienced due to the illness. Ill health is a requisite that goes beyond bodily needs and the self, that is, to heal the person in his/her totality and hence with a dimension of eternity (Congregation for the Doctrine of the Faith, 2000). Hence, spiritual healing is not only the healing of the soul, but also the full trust and belief that through the interception of God, physical healing is prayed and hoped for, not necessarily as a cure but asking for strength to accept the illness with dignity; acceptance in carrying their own cross, symbolically meaning carrying one's own suffering.

Figure 13d

Ward shrine of Our Lady

Prayer-based healing is not new and resembles Catholic healing practice (Reynolds, 2018). A core feature of Catholicism is the belief in a direct and personal relationship with the divine represented by the saints and the Virgin Mary (King, 2014, p. 9). As a student nurse in the mid-80s, I remember the different wards at St Luke's hospital, (which was our previous National Maltese hospital) were each full of religious symbols. It was customary to have a crucifix in every ward and a table stationed at the entrance of the ward always adorned with religious statues and artifacts, mostly of Our Lady (see Figure 13d), as well as holy pictures of other Saints always embellished with fresh flowers. This table was a makeshift sacred space decorated with statues according to specific religious calendar holy days (e.g., Christmas and the birth of Jesus, Our Lady of Sorrows, and the risen Christ in Easter). Although it was the feast of St. Peter and St. Paul, this makeshift sacred space did not have any of these statues but was decorated with the statue of Our lady. This space served as a source of consolation and strength to both patients and relatives.

However, as stated earlier, the process of secularisation of the western world has also affected Malta. Nowadays, in Mater Dei (The Mother of Christ) Hospital, which replaced St Luke's hospital in 2007, is very much devoid of such religious symbols (Calleja Balzan, 2008) There are no makeshift sacred spaces in the ward, except for a wall hanging cross or a small religious statue discreetly placed. This decision was justified in the name of respecting religious diversity.

Chapter 14: It's all in the head

It's all in the head! snap out of it!

Trying to remember …

I remember very well overhearing this phrase! Two newly qualified houseman male doctors discussing me, bed number 16, in the corridor just outside my room space, whilst I lay still in the hospital bed with just a curtain separating us… waiting, hoping to hear some good news. All other noise in this big ward seemed to have been muffled by the intensity of this conversation happening around, yet about me, just on the other side of this curtain separator. They spoke as if I was not there. They were questioning the reality of my symptoms, attributing them as being psychological. This came as a surprise and shock; they confirmed my unvoiced fears and dread of not being believed. They never actually ever discussed this issue with me. It was their predicament trying to give a diagnosis to the unexplained pain and fatigue. Today, I realise that it was an explicit act of power, privilege and cowardness. The inability to diagnose without objective results but to interpret the subjectivity of the ailments.

On hearing this phrase, I recall, my immediate first reaction was that I was at fault, questioning my truth and the reality of the symptoms – was I exaggerating my symptoms? Was I going mad? I started to blame it on myself… Was I to blame? Was I responsible? Yet, the symptoms were real, they were very present and debilitating– the chronic fatigue, the restlessness, the pain and myalgia in joints and muscles, the breathlessness on exertion, the foggy brain, the hyper insomnia…. Although at that time, I did not really understand the meaning of what was happening, I still recall the feeling of anger and the insult. It felt unfair, lame, and incorrect. At the same time, I felt ashamed, powerless, and vulnerable to voice my experience or state the truth

> *about how I felt, fearing further humiliation from not being believed and not validated.*

In 2021, feminist cultural historian Elinor Cleghorn, a person who also suffered from CFS, published her book entitled *Unwell Women: A Journey through Medicine and Myth in a Man-made world*. It addressed the space between what science represents and knows, however also presents how the patients feel. This literary book was ground-breaking and pivotal for me. It helped me relate my illness event to historical background as I gained a better understanding of western medicine and the mistreatment of women in relation to invisible illnesses and symptoms, including pain and fatigue. In the 80s, unexplained illnesses were rising across the western world in women between 20 and 40 years old (Cleghorn, 2021, p. 391). Incidentally, my illness event happened during the same period.

Pain and fatigue are the most common, invisible, and sometimes medically unexplained symptoms endured in many chronic illnesses. A study carried out by the clinical psychologist Dr Dorothea Lack (1982) revealed that women had to wait longer than men to be referred to pain clinic. According to the results of the study, women were also more frequently offered minor tranquillisers and antidepressants than further diagnostic tests, whilst the men received more insurance compensation for pain treatment. Additionally, when reporting pain, the language also differed. According to Jackson (2019), women have reported to be complaining of pain rather than experiencing it, and at times this comes across as dramatic and emotional when describing pain, especially in a male-dominated medical environment (Jackson, 2019).

Pain is a universal experience. However, it remains poorly understood and often ineffectively managed (Notcutt, 2011). The belief that women were more sensitive to pain, and that pain was influenced by their emotions was persistent throughout 80s. In 1992, ME/CFS and Fibromyalgia (illnesses mostly prevalent in women) were listed as "affective spectrum disorder" (Hudson et al., 1992; Hudson & Pope, 1994), a diagnostic category of overlapping physical and psychological conditions, which implied that pain and fatigue are caused by mental ill health.

In their study, Hoffmann and Tarzian (2001, p. 23) stated that medicine's focus on objective factors and its cultural stereotypes of women combined, leave women at greater risk for inadequate pain relief and continued suffering. If no lesion, fibroid, or tumour could be found, then the origin of the pain was often assumed to be in the patient's mind, and not her body (Cleghorn, 2021, p. 377). Studies supports the fact a bias towards the underestimation of women's pain is related to gender stereotypes (Jackson, 2019; Zhang et al., 2021). Gender biases in pain estimation may be an obstacle to effective pain management. Such gender biases may be an obstacle to effective pain management from medical professionals. Furthermore, Ware (1992) stated that not being believed, patronised and having one's symptoms trivialised as discomforts of everyday life, resulted in women internalising these belittling dismissive attitudes and began to either blame themselves or to believe that illnesses must be imaginary, and thus, *all in the head.*

In turn, this feeling of "alienation result[s] from a decision to keep the illness secret, and the shame of being wrong in one's definition" (Ware, 1992, p. 347) of reality. In so doing, silencing, resulting in the erasure of the self and deconstruction of agency, is at stake. Even though three decades have passed, this type of language and behaviour, with all its attributed implications, is still being used to date. The women collaborators have experienced same feelings of anger and powerlessness and thoughts, questioning both coherency and betrayed, when hearing the phrase, *It's in the head:*

I was not crazy

~ Jessica

Medical providers were baffled
when encountering IT
Imaginary, Hallucinations,
A psychological disruption

Interpreted as being
All in the head
Referred to a psychologist
For the pain… they said

~ Francesca

Doctors told me “It’s all in the head”
Was I conditioning myself?

Therefore, “IT is not all in the head,”
IT is felt all over the body.
The mind (head) is part of the body

~ Erica

This notion is ingrained at the heart of the old myth of sick femininity, where illness is pathologised, and the medical culture has perversely defined some illnesses as “invisible”, “mysterious” and assigned the “imaginary” status, hysterical” and “it’s all in the head” continue to demean the women besides add insult to injury (Hattrick, 2021). Cleghorn (2021) stated that because of such an attitude, women continue to be dismissed as neurotic, anxious, depressed, hypochondriac and even hysterical.

The impact of illness identity in relation to the understanding of having a mental illness is synonymous with being incompetent and inadequate, which could also impact agency, hope and self-esteem (Yanos et al., 2010).

Back to the future

Several years down the line, the phrase continues to be repeated as claimed by the women during conversation. Whilst writing, I wondered, what would I answer if I overheard this phrase again today? How would I react? How would I feel? Would I speak up or be silenced again? I wonder I imagine a conversation with the same male doctors, 30 years down the line. I wonder - a fictious dialogue with a doctor:

S: So… It's all in the head you say? I wonder, what your understanding is of this phrase. You seem to use it very lightly, nonchalantly; However, I am confused…what exactly do you mean by it …. IT being all in the head?

Doctor: I'm referring to the symptoms that patients complain about in circumstances when medical symptoms cannot be objectively measured, analysed, seen…. so really and truly symptoms are subjective and lack scientific evidence.

S: Well, I guess it all depends on your understanding of scientific evidence. Could it be that your understanding of evidence reflects your western medicinal training – objective evidence? You speak of the condition in a very dehumanised manner. You speak of body parts rather than the person. It's as if the head, or the mind are separate *from the person from the body as it were a fixed entity that lives on its own merit. Likewise, in using a preposition the, rather than a pronoun your/his/her, further changes the meaning and objectifies the person. It's as if the head, and the mind are independent from the person.*

Doctor: (pause) …What do you mean?

S: Our minds are not separate from our bodies as aren't any of our organs – we are one whole being and not separate body parts. Also, my understanding of IT being "all in the head" is dismissive, labelling, medialising, pathologising symptoms as independent claims, whilst ignoring the unity of the person as a holistic person. A very binary way of thinking; healthy/unhealthy, black/white, obedient/deviant.

Doctor: Well, isn't that what is expected of us to pathologise, to analyse, to determine by elimination? To give a diagnosis... Would you be happy if you came to me, and I did not provide you with an answer?

S: I have my reservations on that… I would be happier with an honest answer rather than giving me a diagnosis to fit me into a box… and close the lid. I refuse to be put into a box. I am not the diagnosis, and the diagnosis is not me… e.g., if I have cancer, I am not cancer, and it's the same with Fibromyalgia, CFS, RA and MS. However, stating that IT is all in the head is not only separating the mind from the body, but also alleging a mental connotation.

Doctor: Western medicine training categorises disease as either 1) genetics; 2) external invaders (e.g., bacteria or viruses); and/or 3) resultant lifestyle choices. Anything beyond that is difficult to explain.

S: The philosophical undertones of the medical model seem to be delineated and dependent on objective and measurable pathology, biology, physiology, and analysis, thus leaving little or no room for subjectivity and for external factors like the social, environmental, and economic, separating further the mental from the somatic.

Doctor: As doctors we consider psychosomatic disorders as conditions in which the person suffers from significant physical symptoms causing real distress and disability. Sometimes they are manifested out of proportion and cannot be explained by medical tests or physical examination. They are hard to qualify as medical disorders as they don't obey any rules. Often, they are stress-related and there are personalities that are weaker than others.

S: Does this presentation differ between man and woman? Would your prognosis and advice differ?

Doctor: No, it shouldn't really make a difference, but maybe, these autoimmune invisible illnesses are more common in woman more than man; maybe it is because women are more sensitive… to stress.

S: Therefore, what does that mean? Do you believe that autoimmune illnesses go beyond genetics, lifestyle changes, viruses, or bacteria? Or maybe that there could be a *link between body and mind? Could it be result of a more intrinsic and ingrained cause where is the body literally turning on itself due to diverse reasons - auto-immune? Could it be that diagnosing yet another woman, manifesting unexplained ailments, irritates you and you dismiss it? Or maybe it is because it is presented by a woman, who, according to you is probably stressed and/or weak to handle emotions? Or pin it to a personality issue, as you stated? Ah! Maybe, after all, you actually believe that emotions and stress could influence the presenting ailments, but instead of acknowledging them as authentic manifestations giving them the merit that they deserve, you prefer to dismiss them and associate them to mental health attributes.*

It may be all in the mind because the mind, i.e., the head, is not separate from the body. Is it possible that stress has something to do with the onset of the condition? Could direct or indirect trauma, or elevated stress, result in medically unexplained illnesses? Could it be that the body, i.e., the person, is reacting against its own self to visibly show and shout out to a world that it does not want to listen? What separates health and illness? How can we separate mind from body, individual from environment? So many questions seem to remain unanswered...

Nearly two and a half millennia ago, one of Plato's dialogues, Socrates (as cited in Mate, 2011) stated that you cannot split mind from body. The Cartesian dualism of viewing the mind and body as separate entities persists within the field of medicine. Medical medicine seems to continue to embrace the belief, which inevitably acts to the divorce mental and physical states and tends to attribute single symptoms to single causes (Bendelow & Williams, 2002, p. 155). As stated by Plato (as cited in Mate, 2013):

> This is the reason why the cure of so many diseases are unknown to the physicians of Hellas; they are ignorant of the whole. For this is the great error of our day in the treatment of the human body, that physicians separate the mind from the body. (p. 31)

This dualism laid the foundations of positivism, logical thought based upon empirical, unbiased, impersonal, and unsympathetic observation and measurement (Mehta, 2011, p. 203), which eventually determined the biomedical model. Therefore, it is no wonder that the link between the mind and the body continues to be dismissed. The dualism between mind/body and health/illness continues to mould and dictate our beliefs and thinking, often, considering ailments as separate from body parts, and in isolation from the whole being and extrinsically from the environment (Mate, 2011).

Additionally, over the years there has been substantial research that proves the link between emotions and physiological changes as affecting the immune system (Mate, 2011; Klimas & Konery, 2017), also referred to as *psychoneuroimmunoendocrinology.* This science validated the unity of mind and body, showing that the emotion-processing centres of the brain are inextricably linked with the nervous system, the immune system, and the hormonal system (Mate, 2005).

Further to this, Suzanne O'Sullivan (2004) argued that the body has a multitude of ways through which it can express emotions. Although biomedicine is characterised as not recognising the relationship between the body and the mind, this may not always be the case, and there is acceptance that somatic symptoms can be manifested in response to emotional and psychosocial distress or reaction to life events or social situations that are stressful to the individual. Therefore, she claims that mind and body links need to be seen not only for our understanding of illness, but also for our understanding of health. Therefore yes, IT is in the head/mind, but it is also in the body, because it is an embodied process.

When the body says no

> *I met pain and fatigue, many years ago in different forms and sorts. I knew it was there but could not really understand it... listened to other people's stories of pain. I could empathise but I could not really conceptualise it. However, when I started experiencing musculoskeletal pain myself, it was only then that I conceptualised the pain, the sharpness, and the numbness of it… The shift from witnessing to experiencing. Pain was devastating, fatigue was exhausting… how do you explain it to others? How do we respect our bodies? Is it possible for the overwhelmed mind to manifest itself as a diseased body? What if we are unable or unwilling to perceive, interpret or react to what is happening to us or around us? How much do we really listen our bodies?*

Similarly, Leder (1990) maintained that:

> [w]hilst in one sense the body is the most abiding and inescapable presence in our lives, it is also characterized by absence. That is, one's own body is rarely the thematic object of experience…the body, as a ground of experience…tends to recede from direct experience. (p.1)

Moreover, Ahmed (2017) argued that:

> [b]odies speak to us. Your body might tell you it is not coping with what you are asking; and you need to listen. You need to listen to your body. If it screams, stop. If it moans, slow down. Listen. (p. 247)

Physical symptoms and manifestations, for instance pain and fatigue, may be the signals our body is giving us. Whether we choose to listen to them or not remains an individualistic decision and prerogative. From the stories told, pain and fatigue were not considered as a justified reason to stop.

In fact, it seems as if there was a need to defy the symptoms and continue with their lives. Additionally, Mate (2011) highlighted how the role of repressed emotions (originally a defensive act for self-preservation), stress and how the meaning we give trauma, could affect our bodies by disorganising and confusing our physiological defences. Research has shown that such repression could eventually result in the development of disease, most especially autoimmune illnesses, where the body manifests itself by literally going against itself. This discussion did not surface during our conversations. It could have been because it was not deemed the primary focus of this research, it was not presumed relevant to the context of the stories being told or else because this part of the story was best left untold. This area of research would be another potential perspective to follow up at a later stage.

At the start of this project, I quoted Grimshaw (1986) who stated that "the reconstruction of knowledge is inseparable from the reconstruction of the self" (p. 164). Writing has proved to be an asset and served as a bridge between knowledge creation, transformation, therapeutic and reconstructive both a personal and professional level. The intricacies between research and therapy became more blurred it is for this reason that I felt the need to explore this matter further.

Chapter 15: The intricacies of research and therapy

How was I to represent the life story experiences, the embodied and enfleshed emotions that were generated during our conversations on the page? At the beginning of my research, when compiling the ethics form, I had claimed that I would be recording, transcribing, and translating the conversations, but little did I know, at that point in time, that there is more to the literal language of the story being told. This was not a simple and straightforward task of translation. How was I to transcribe the embodied emotions generated by both collaborators, and myself as the empathic listener? How was I to write the unsaid, the silence? In hindsight, I realise how naïve I was in thinking 'about' the stories and not 'with' the stories. Initially, I had failed to put into the equation the embodied and emotional affect elicited, whilst engaging reflexively and introspectively.

As a trained counsellor, I believed that I was adequately equipped with the appropriate skills and knowledge (i.e., experiential and acquired), to lead the conversations successfully. According to Etherington (2004, p. 109), counselling training provides us with skills, theories, and understandings of moral and ethical issues that we can then use to inform the process of building and maintaining a range of relationships in different contexts, including research. These meetings were not destined to serve as counselling sessions, nor were they to serve as an avenue to listen to confessional tales (Van Manen, 1988). In fact, the intention of the meeting, the relational ethics and the contract were different (Andrews, 2017). Nevertheless, the meetings were meant to be different from the traditional researcher-participant interviews looking for evidence or data collection for interpretative purposes (Denzin, 2013; St. Pierre, 2018; Altheide & Johnson, 2011).

Together, we privileged and cocreated stories rather than theories (Etherington, 2004). I listened to the stories being told with “reflexive embodied empathy” (Finlay, 2005, p. 271), compassion, and reflexive acuity. The women collaborators in this research were considered as equal partners, the experience was continually and equally shaped, both “experience-near and relational within the ongoing intersubjective system” (Stolorow & Atwood 1996, p. 182).

Research has shown that when participants tell their stories to attentive listeners, the act of narration in the presence of sympathetic witnesses, provides the space for participants to hear themselves during narrating, making stories freshly meaningful for both themselves and the researcher who is listening to them (Frank, 1995). The women collaborators claimed a very similar experience, even more so, when they eventually read their own transcribed text in format. Therefore, I was not surprised that the women claimed these conversations served as therapeutic opportunities and experienced them as being cathartic. They were given the space to share their story and were emphatically listened to with genuineness and in a non-judgmental manner (Birch & Miller, 2000). According to Speedy (2008), “[t]here are parallels between these research modalities and the conversational territories inhabited by counsellors, psychotherapists and the people consulting them” (p. 142).

The therapeutic value of sharing of stories has been discussed widely across different disciplines both in theology, psychology, and research. Talking to another person can be cathartic (Hutchinson et al.,1994) by making people feel better in sharing their stories and experiences, increasing self-awareness and/or finding a sense of purpose. For instance, within the field of counselling and therapy (Speedy 2012; Wright 2009; Wyatt

2021); the therapeutic value of writing (Pennebaker 1997b, 2004; Wright, 2018; Williamson, & Wright 2018); and in autoethnographic research, writing is truthful, vulnerable, evocative, and therapeutic (Ellis, 2004). Additionally, within the religious domain, speaking to a priest, religious advisor for solace or advice or through the sacrament of confession in Catholic church (Devassia & Gubi, 2021), could also be understood as therapeutic, relieving and cathartic - a means to find internal peace and spiritual healing as well as religious guidance. Although the intentions and scope of therapy, research and confessions are different, they may hold certain similarities, using the same skills, mainly the sense of empathy, empathic listening, compassion, and spirituality. Yet, in research there exists a fine line between therapy and autoethnographic research (Andrew, 2017). As Bochner (2001) claimed:

> Illness narratives need to be told not only because the telling of the story can give therapeutic benefits of redemptive understanding but also because of the political consequences of connecting the body to the self, revealing embodiment and emotionality as legitimated and significant mediums of lived experience and inscribing bodily dysfunction with positive meaning and value. (p. 148)

Whilst research and therapy both share a similar commitment to meaning making, meanings are not necessarily interpreted in a homogenous manner. In research, more specifically in autoethnography, subjectivity of meaning making is essential, most especially in relation to socio-cultural and political foreground. Writing personally, for research purposes, is not common practice, though the “crafting of such stories requires much analytical labor” (Bondi, 2012, p. 11). Telling about specific events can cast a special light on one’s past or present life (Bruner, 2009). We become the stories through, which we tell about our lives. We become historians of our own lives (Mishler, 2004), which could be fragmented and are not necessarily a linear narrative (Speedy, 2017). In the telling of stories, we are gathering knowledge about the past and not necessarily knowledge from the past (Bochner, 2007). Those sharing and writing illness narratives do not ask for pity (Defenbaugh, 2011), rather they ask the readers for empathic understanding, to “feel and care” (Ellis & Bochner, 1996, p. 24) with and about the narratives. The meaning elicited from shared stories told in research environment may generate broader social meanings.

Once published, the meaning elicited from the story is beyond the control of the writer or owner of the story, in a sense, handing over control to the reader, to construe their own meaning of the story (Moore, 2012). Vulnerability is placed in the hands of the readers for their own interpretation (Ellis & Bochner, 2000) of the story being told. Whilst in therapy, the meaning making is a personal process and thus, the way in which it affects one’s life experience depends on the individual and the therapist in the room. Illness stories may be told or presented as disjointed, disembodied and/or fragmented experiences. The researcher might fall into the trap to elicit generalised meanings, intentionally or unintentionally objectifying the person, presenting a neat coherent story, theorising, and conceptualising meanings as a privileged researcher rather than opting to present reality and messiness, through an inconclusive story. Whilst in therapy this linearity, fragmentation, and messiness is discussed at a deeper personal level; it is understood to be a process and not a conclusive act.

Wherever our focus lies, we all have our own stories to tell. These stories are reshaped by the new meanings forged through the research, the telling, the conversations in which we engage. Introspection, reflexivity, and symbolisation are transformative measures where we come to understand our own otherness. Hence, in the process of writing, I continued to reflect on my own thinking processes through introspection (Ellis, 1991). I, systematically, continued to question how recalling, writing, and speaking to other women was influencing my telling and their telling of the story. The myth of the researcher as a neutral, detached observer has been subject to extensive criticism (Denzin and Lincoln, 2000). However, Ellis et al. (2011) believed that counter narrative promotes the researcher as active and immersed within the field.

It is hoped that in sharing personal narratives, narrating life experience disrupted by chronic illness, the focus of this research, provided the possibility of turning something, possibly chaotic, into something meaningful. In line with the postmodern perspective, neither therapy nor research, represent singular, universal truths of those who participate in them. It is essential to highlight the difference between the autoethnographic telling, the writing and the life experience as is being lived. The representations of lived experience, or rather the living of the experience, still have value, be it for therapeutic, research or personal reasons, no matter if messy, incoherent, or lacking in meaning (Speedy, 2012).

PART 3

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Chapter: 16 Patterns

Lockdown

Isolation

Time stood still

Fragile worn hands

Clicking away in the silence

Notwithstanding pain

Day and night

Stitch by stich

Knitted patterned

multicoloured squares accumulated

each four squares created a design

crafting

the COVID blanket (see Figure 16).

Figure 16a

The COVID Blanket

Endings turn into beginnings

Denzin (2014) maintained that:

> [a]utoethnographies and biographies are conventionalised, narrative expressions of life experiences […] conventions, which structure how life experiences are performed, told, and written about, involve […] the existence of others […] family beginnings, […] turning points […] known and knowing authors and observers […] objective life markers […] real persons with real lives [...] turning point experiences and truthful statements distinguished from fiction. (p. 7)

This thesis started by introducing *my*story of the illness experience in the prologue, whilst also looking beyond, guided by the research question "*What are women's experiences of living with an autoimmune invisible chronic condition in Malta*?" Women diagnosed with chronic autoimmune disease have increased at alarming rates since the 1980s. Medical professionals often dismiss symptoms as being products of anxiety, depression, or as something else that exists all in their head. For instance, the Centers for Disease Control and Prevention (CDC) dismissed the 1984 outbreak of CFS/ME in the Incline Village, Nevada-area as psychological "hysteria" (Hamilton, 2018).

The volume of research pertaining to autoimmune invisible chronic illnesses is extensive across different disciplines. However, research that goes beyond medicalization and pathologizing of the disease remains very limited. Studies that adopt an arts-based approach researching chronic illness using evocative autoethnography and narrative as used in this study are still extremely limited internationally, and the first of its kind with the local research field. Experiences from my personal and professional life, alongside the narratives of four women collaborators, served as the foundation of the study. In hindsight, I realise how naïve I was at the initial stages of this project, in believing that I was adequately equipped and informed about the research focus and process. The writing process has taught me that the story is never fully, exhaustively and/or completely told (Elbaz 1989), similarly, to how chronicity continues to happen, we continue to evolve, continuously becoming, alongside our stories. Sartre (as cited in Denzin, 2014) suggested that the "writing of life, is constantly being created as it is written. Hence the meanings of the patterns change as the meanings are found" (p. 9).

The thesis was divided into three parts. The *first* section provided a contextual background to the research focus and the research question guiding the project. In this section, the research approach, the process, ethics, and representation were discussed at length. The use of crystallization was discussed as the preferred framework, rather than triangulation, to examine relational topics using multiple lenses and a variety of genres (Richardson 2000; Ellingson, 2009). The *second* part of the thesis evocatively presented stories written in found poetry format, elicited from the original text of the conversations held with the four women collaborators. After transcribing the conversations, I translated the conversations in Maltese into the English language when the need arose for the purpose of this thesis (see Appendices Part 2). Whilst navigating and thinking reflexively with stories rather than about stories different interesting material was elicited. This material brought to the forefront women's untold, unvalidated and silenced affective stories of living with chronic illness. The third part brought the thesis to a close.

In line with a feminist approach and postmodernism, the material presented was not deemed as exhaustive or finite, i.e., that there is more than one single truth. Above all, the intention was not to generalise or to theorise, yet to present the stories as they are, to bring together a sense of *collective consciousness* as a contribution to knowledge about chronic autoimmune invisible illnesses to the forefront, most especially highlighting the emotional, relational, and socio-cultural aspects specific to the Maltese Islands. Consequently, this thesis hoped to prompt and encourage further thinking, and in turn, awareness, across different disciplines and to extend sociological understanding with the prospect of actively contributing to a heightened societal awareness of invisible illnesses.

Criteria as compass

In the initial years of writing this thesis, I was very defensive in using evocative autoethnography. I felt that I was transgressing all the traditional norms. I was writing in the first person, I was participant in research, and I was the first researcher to use autoethnography with a focus on health at doctoral level at UM. Therefore, I was grappling with a lot of firsts! The disadvantage in being a first was that I felt I was paving and walking on untrodden territory. I also feared that I was not doing it right. My doctoral supervisory team, as well as other experts in the field of autoethnography, acted as my compass and source of support. For this reason, whenever possible, I joined discussions and workshops online and attended in person, namely with CCRI University of Edinburgh and Lapidus Living research community. These opportunities included the following: (a) a short autoethnographic course organized by Roskilde University Denmark, presented by Carolyn Ellis and Arthur Bochner, symposiums; and (b) conferences organised by International Congress of Qualitative Inquiry (ICQI) and European Congress of Qualitative Inquiry (ECQI), International Autoethnography and Narrative conference (ICAE) in Bristol, and International Symposium on Autoethnography and Narrative (IAANI) in Tampa, Florida. I made acquaintances and formed my own community of friends with like-minded people and networked with researchers, scholars, and authors whose published work I was reading and referring to throughout my research and writing journey. These included Carolyn Ellis, Kim Etherington, Laurel Ellingson and Rose Richards. All these authors were pinnacle to the writing of this thesis.

Over the years, autoethnography has been criticised for a variety of reasons. It has been criticised for not being scientific, for not having theory or hypothesis, as well as for not being sufficiently artful (Ellis, et al., 2011). Furthermore, critics claimed that autoethnography lacked reliability, generalisability, and validity (Denzin, 2014), which according to Ellis et al., (2011) have different meanings to the autoethnographer. Full recognition of this ongoing debate, set the backdrop to my writing. Even though, at times, I had difficulty in remembering, (selectively or not), I did my utmost to be as transparent and credible when relating and/or recalling events, relying on family members who helped me to fill in the gaps when memory failed me. Autoethnographers have claimed that narrative truth is based on how a story is told, used, understood, and responded to (Denzin, 2016, p. 70). When writing, I hoped that my work had verisimilitude, i.e., that it evoked a feeling of authenticity, coherency, and believability to connect to its readers. I gauged this by sharing pieces of my work with experts in the field and close friends. Ultimately, generalisability would be determined on how the readers respond to the representations that I presented in my thesis (Ellis et al., 2011).

Therefore, when writing this autoethnographic project, as claimed earlier, I needed to make a paradigm shift in my way of thinking, and this included the use of language when writing. It was necessary for me to steer away from traditional positivist criteria that I was accustomed to. I felt literally thrown into the abyss of the unknown. Ironically whilst shifting away from the positivist structure, I grappled with the lack of structure of writing autoethnography. It felt messy and I felt overwhelmed. I questioned whether my literary writing and aesthetic representation were good enough. I read and referred to different criteria elicited by renowned scholars in the autoethnographic field, namely Ellis, (2000), Bochner (2000), Richardson (2000a), amongst others when I started writing my thesis. Ultimately, I drew on Le Roux's (2017, as cited in Sparkes, 2021) five main criteria, embracing the notion that research is ethical throughout (p. 270). Moreover, these criteria served as the compass for my work.

Subjectivity - The I in the story; through reflexivity the self was visible in this research, alongside the four women collaborators with the aim to retell a noteworthy personal relational experience, whilst self-reflexivity, focused on the evidence of intense awareness of my role and relationship to the research, which was situated within the Maltese historical and socio-cultural context. Reflexivity was used all throughout the writing of this thesis, and all reflexivity leans towards self-awareness, self-exposure, and self-conscious introspection.

Resonance – When writing this project, the audience, that is, the readers were kept in mind. The aim was that the readers may enter and engage with the experience or connect with the story, both on an intellectual and emotional level, creating a sense of communality between the researcher and the audience.

Credibility – In my writing, I was mindful that my writing aspired towards having verisimilitude, plausibility, and trustworthiness in research. The process was permeated with transparency and trustworthiness.

Contribution –This study generates knowledge particularly about the embodiment and emotionality of women living with a chronic invisible illness. This heightened awareness is catalyst for practice and education across disciplines identifying areas for activism and further research within, and beyond the field of health and counselling.

Contribution to knowledge

The contribution to knowledge of this thesis is considered to be multi-layered. As any other autoethnographic piece of writing, it all depends on how the writing resonates with the reader and, in turn, how the reader responds to the representation of the stories. Factors that might influence interpretation, include the (a) perspective that one has adopted; (b) discipline from which the research is carried out; and (c) personal standpoint that one experiences the material from. By discovering a feminist voice through telling *my*story, alongside the four women collaborators, the main intention was to draw body selves, and wholeness into health research. Their wholeness included acknowledging the affective aspect of emotions and the embodied experience of living with chronicity. The woman is central to this project, placed metaphorically at the central axis of the columella surrounded by different evolving layers of consciousness. In representing the women's stories through found poetry (represented from their own transcribed words), was a tantamount effort to gain a more expansive clarity of the meaning of wholeness (including emotional aspect), and to minimise the distortion of the women's experiences of living with a chronic autoimmune invisible illness.

Autoimmune illnesses affect about 4.6% of the world's population (Bender et al., 2021), and are mostly pervasive among women worldwide. In medicine's long history of paternalism and ambient sexism, women's ailments continue being dismissed and/or disbelieved (Hamilton, 2018). Therefore, it would be beneficial if women continue to be supported and, above all, feel empowered to exert greater control over their health and wellbeing by gaining more control, through agency and voice. The presentation of *my*story, alongside the women collaborators' stories, was an opportunity to show, providing visibility to the invisible (persons, as well as their illness) and emotionality (without shame or guilt) to be reported with precedence over rationality. Creating and supporting different virtual and physical spaces for individual and collective voices to be heard, validated, and treated as equal was enabled, and amplified in this thesis. I am hopeful that this will now go on to inspire any individuals, including researchers, educators, and professionals to help promote women's voice and the importance of validating chronic illness experiences, rather than being treated as other. However, it is important to note that:

> voice without control may be worse than silence; voice with control has the capacity to become a less perishable form of power because in essence it allows voice to enter a more genuinely reciprocal dialogue… [which] provide[s] a more enduring challenge to the power relations of research, knowledge production and the public sphere (Gready, 2009, p. 147).

The importance of providing and supporting a space that is conducive for stories to be told through establishing collaborative and non-exploitive relationship, is also another important issue that was elicited from this study. The women collaborators claimed that the opportunity to share their story without the fear of being judged, in a safe space, to an empathic listener, was resonant to a therapeutic experience, even though this was not a therapy session. The subjectivity and invisibility of illness characterised by the lack of objective evidence and measures, may lead medical staff, employers, friends, and family members to question its subjectivity, truth, as well as doubt the reality of symptoms. This was found to compound the isolation experienced by the woman who suffers from chronic illness. The conduct of this research study revealed that tellability is a central activity that may minimise human suffering and self-silencing patterns.

In 1992, the WHO and International Statistical Classification of Diseases and Related Health Problems (1993), also referred to as ICD, recognised fibromyalgia syndrome as a disease, including it in as Rheumatism, unspecified. Even though the European Parliament (2009) requested that there is recognition of the syndrome as a disabling disease, this was not followed up by any initiative on the part of the Commission and the Council. The debate and research are ongoing. Similarly, in Malta, although medical and health authorities officially recognise ME/CFS and fibromyalgia as a chronic condition, it is still not registered as a disability. Hence, it does not fall under the Social Security Act and persons who are diagnosed with it do not benefit from invalidity or disability pensions. A Maltese community of chronic illness activists are slowly becoming more vociferous, using different media platforms, including social media and through collaboration with associations. In so doing, the activists are challenging the status quo, standing up for their rights for issues regarding medication, employment, and work-related issues and advocating further the recognition of autoimmune illnesses as a disability is discussed.

Muscat (2021), a Maltese Member of European Parliament, went as far as arguing that in such illnesses, disability should be recognised on a European level. Whilst Scicluna (as cited in Calleja, 2019), at that time, the commissioner for the Right of Persons with Disability suggested that:

> as a state, we should assess such individuals on a social impact level i.e., what they can and cannot do in the society, rather than just from a medical point of view by for example, applying the International Classification of Functioning [ICF].

This thesis has shown that the issue, therefore, goes way beyond recognition of the disease as a disability in view of enabling eligibility to access social benefits. At the very least, I believe that this thesis has brought to light that in Malta, the silence around the unique emotional and embodied experience of living with chronic autoimmune invisible illnesses is deafening. Lack of validation, patriarchal overtones, family loyalties, shame, and pride are only a few of the reasons for this silence. The need for attention and research in this regard has been stamped.

It's all in the head, hypochondriac, and fertile imagination are common labels given to women who present with symptoms hoping to receive a diagnosis to be able to continue with their life. Symptoms that are often disproportionally dismissed by the medical community as products of anxiety, depression (Hamilton, 2018) or overreacting, a phenomenon referred to as *Yentl syndrome* (Reilly, 2018). Female bodies and their health continue to be stigmatised and at times underserved. Culture and gender continue to frame behaviour around subjectivity, pain, and fatigue, ailment claims that cannot be objectively measured. This thesis has illustrated how women, alongside *my*story in this study, objected to such behaviour from the medical professionals and did not welcome the labels, the illness as the identity and even more so, the gendered connotations. Expressing how one feels is synonymous to a double-edged sword; *damned if you speak, damned if you don't*. In fact, sometimes, they preferred to conceal their claims rather than have their symptoms downplayed or labelled. It would be a true breakthrough if the medical world were to hear what women and their bodies had to say and turn its energies, time, and money towards listening to answers, which reside in women's bodies, and in the histories that bodies have been writing (Cleghorn, 2021). Furthermore, medical health care professionals would benefit from training across a humanistic aspect, to look beyond pathologising and medicalisation, to be able to listen, and to validate women's embodied stories to collaboratively determine needs in the management of their health in a holistic manner. Whilst counsellors appear to have a big role to play, as part of the interdisciplinary team, in supporting persons with chronic invisible illness, and this study clearly affirmed this.

What now? What next? The implementation...

What now? What next? are questions that are posed to me by different people across different disciplines. To answer these questions, I had to revert back to where I had started when writing this project, the research aims, the research gap, the research question whilst also taking into account the whole transformative process in the writing of this project. Taking all this material and knowledge into account from the now whilst looking ahead to future exploring areas and opportunities for implementation in practice, education, research and also in the wider socio-political context.

In the area of practice and education

- My primary goal would be to create a space (online or face-to-face) to bring together adult persons who are directly or indirectly living with chronicity. This therapeutic space would serve as an opportunity for embodied and emotional stories to be told and shared freely, without feeling restricted from verbalising emotions solely through the use of language. The aim is to introduce the use of different creative art-based modalities which may include art, writing and/or poetry to facilitate creative expression intended to foster healing and mental wellbeing.
- The issue of tellability/ untellability, as well as silencing and voicing, struck a chord both on a personal as well as on a collective level. When reflecting on how this research was different when compared to other research about chronic illness, I also took into consideration how, where and with whom I should start sharing, discussing, and advocating the material elicited from this research. I consider this step as being a very delicate one because of the evocative and emotionally laden aspect. Once again tellability/untellablity is revisited with caution.
    - Initially I was very selective on who to speak to, namely I would choose representatives from the medical health care professional team, more specifically, those who embrace and practice the biopsychosocial and spiritual approach to care, and who equally value the emotional aspect when caring for individuals rather than just treating body parts.
    - I would also share the knowledge gained with my fellow counsellors and other kindred professions in the Faculty of Social Wellbeing.
- Organise discussion forums across the health and social disciplines with the objective of shedding light on the wider meaning of living with chronicity beyond

the bio medical aspect but including the affective aspect and gendering of chronic illness.

- Create opportunities and spaces for sharing and discussing, with individuals and groups who are living with chronicity, using different media platforms including social media with the intention of reaching a larger audience, to provide support and promote healing.
- Actively participate with local associations to ensure that women's voices are heard, and that women's embodied stories are validated to collaboratively determine needs in the management of their health in a holistic manner.

Further opportunities for Research

- In line with the feminist approach that strives for equality, the goal of extending the research with other genders living with chronic illness in Malta;
- As a post study to this research, I would really be interested in bringing the women collaborators together again, informally, and as equals, to discuss and to continue to expand on material elicited from their stories, and to co-create other stories;
- Worldwide, a large lacuna continues to exist between chronic illness and disability as a facet of identity and ableism intersecting with sexism. A study in this regard, which includes the Maltese context and post-colonial culture, would hopefully develop a wider understanding of the intricacies of these intersections. Furthermore, the study could also be extended to other countries, for comparative purposes and to look beyond the shores and boundaries of the Maltese Islands;
- Exploring another facet of the cultural envelope would be an interesting follow-up to this study, since in this research, socio-economic status in relation to health and chronic illness was not addressed (Calixto & Anaya, 2014). I would be very interested in researching how young women living with chronic illnesses navigate

work, relationships, and the pressure to seem just fine in a productive and capitalist world. Therefore, exploring what it means to be a sick woman in today's world would be relevant.

- Another source of knowledge that would benefit persons living with autoimmune illnesses is research on the issue of productivity and capitalism, intersecting with invisibility and disability. The need for this research study was brought to the forefront most especially during the COVID-19 pandemic and after that, due to long haul COVID.
- Lastly, this research study has touched upon how the body cannot be separated from the mind and that the mind is an embodied process. Feelings and emotions have been widely researched looking from a different lens, the neurobiological perspective (Damasio, 2004), the cultural politics of emotions (Ahmed, 2013), and the relation between trauma and memory (Van der Kolk & Fisler,1995). The relation between trauma, suppressed emotions including anger and stress, and autoimmune chronic illness (Mate, 2011), as well as the value of expressive writing (Pennebaker & Smyth, 2016, Lowe, 2006, Wright, 2018) and writing for wellbeing (Poole et al, 2020) could potentially also be an interesting study to carry out for further research. This curiosity became even more pronounced as patterns became more explicit in the process of writing as a participant in research. Furthermore, reflexivity and introspection continued to increase interest to delve deeper into the relationship between the four issues, i.e., trauma, suppressed emotions, autoimmune illness together with the value of writing as therapeutic healing practice for wellbeing.

Limitations of the thesis

When writing this evocative autoethnographic study, certain limitations were experienced mainly:

- I consider myself a novice researcher using autoethnography, and I am the first student to be using such an approach at the University of Malta for a Ph.D. study. This novelty may have posited some limitations in writing, and when talking about my project with my colleagues. At times, it felt very overwhelming and limiting. I could not knock on many doors in Malta to bounce ideas. As stated earlier, during the initial stages of my research, once I tried to explain my research to a (male) consultant, and in another instance to a (female) lecturer and was told that research on feelings and emotions is not real research. I was left feeling devastated, questioning whether I made the right choice, but at the same time resilient to move forward with my decision.
- Being the first to use autoethnography for a PhD in Malta and to base my doctoral study within the counselling department, whilst working as an assistant lecturer with the nursing department under the Faculty of Health Sciences was experienced as another limitation. At times, I felt homeless, a nomad trying to fit, to belong to the two different disciplines that I come from. Although I was adamant to move away from the scientific, positivist approach, I felt that I was not totally immersed into either the counselling or the nursing department. Once again, I found myself hovering in the in between.
- Further to this, since the research approach and the use of autoethnography was new to many, it felt as if I was forbidden to speak about it. I found my home and autoethnographic community outside Malta. For the first few years, I was very defensive when talking about my doctoral studies with my colleagues or with other doctoral students. This I feel inhibited my process, so much so that I only felt

comfortable to present my work in settings away from Malta. Additionally, if it were not for the support received from my supervisory team, international advisors and experts, close friends, family members and my therapist it would not have been possible to finalise this project.

- COVID-19 was another limitation experienced in my doctoral journey. In the two and a half years of the COVID pandemic, I was working with case management team, the Infectious Disease and Prevention Unit, Public Health Department. Working long hours, led to physical and mental exhaustion due to high level of stress and anxiety, most especially when the numbers escalated. However, the emotional impact and uncertainty of COVID was experienced to being even more devastating because of the emotional parallel processes experienced in the writing of this thesis. There were instances when I was lost for words, when all seemed irrelevant, when I was going to give up. Once again, the support system was what kept me sane.
- At the beginning of this project, I underestimated the power of writing. Writing was transformative, and at times healing. However, writing also elicited negative feelings and emotions when remembering and recalling past (forgotten) events, leaving me numb and unable to speak or write any further. Although I was aware of possible vicarious traumatisation, I believed I was over it and I had the skills to deal with any possible trauma resurgences.
- In choosing to use evocative autoethnography, the literary skill of writing is crucial and an essential criterion for assessment. I struggled with writing in this way. The support from expert people in the field, including my supervisory team were crucial at this point. I felt that besides being expected to produce a PhD level of writing for this academic project, I also needed to be a poet. Why should doctoral students have to be

under that kind of this pressure? Writing workshops claim that it is not a work of art, however in the autoethnographic community, I feel that there is a lot of competition.

- Finally, the smallness of the Maltese Islands constituted another limitation. When deciding on my research focus, starting with my own story, to use autoethnography, where I was going to be a participant in research and the decision to include other women collaborators to address the research question was debated and discussed at length with my supervisory team. I had believed that different possible ethical risks and repercussions in having only one main hospital because of the smallness of our communities would be a major obstacle in.

A collage of reflections

> *'You are nearing the end' ... 'It's the last push!' …*
>
> *I have been hearing these words for quite a while now... yes, I'm nearing the end, I think, the end to submit my work, maybe? However, ironically, I do not feel this as 'being the end'! How is the 'end' supposed to feel? … How do you end an autoethnography?*
>
> *Contrary to what I believed; I do not feel this is the end... I imagine myself walking down the alley into another beginning, whatever and wherever that may be, but it's not finite. The whole process was an inquiry – starting from the part where I naively thought I knew, however, I did not know where I was going?*
>
> *The back and forth of ending, letting go is synonymous to the feeling of hope… not knowing…uncertain…hoping….*

During this reflection, I wish to share a few of my thoughts and feelings that I experienced during the writing process of this thesis. I feel I owe this to whoever accompanied me along this journey. At instances, I also reference my reflective writing to substantiate some of the points being presented here. Woolf (1953) expressed that "[t]hrough this writing I hope 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).

> *Looking back on my experience, I realise how subjectivity, introspection, reflexivity, emotional writing helped me to deeply exam my own feelings and experiences in relation to self and others - the simultaneous process of looking*

> *inwards and outwards, forwards, and backwards, 'was similar to going to the therapist on a daily basis,' I joked. It was not a joke, I was serious. It felt as if I was continuously looking through the looking glass.*

Moreover, Ellis (2016) maintained that "[w]e come to understand others through our self-understanding, and we come to understand ourselves through understanding others, so it's a two-way street" (p.7).

Reflexivity

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.

> *The biggest challenge in the writing of this project was to write in the first person. The 'I' in the story, included my own personhood, my own self. I refuse to represent the knowledge of and about a subject that exists solely in the written text. Although I write in the 'now', I am conscious that once the story is written it would belong to the past.*

According to Pelias (1999) "once written it will become a historical claim, a writing event, simultaneously embodying, making theory an experience visible to others" (p.xi).

The experience of writing

In hindsight, the experience of writing goes beyond the use of language, or the discursive story written on the page. Oftentimes, 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 bilingual Maltese and English) to find the 'correct' translation of some words/phrases. These were only but a few of the challenges that I continue to experience.

On another level, the experience of writing was a tumultuous roller coaster – it was embodied, evocative, fidgety, inconclusive, nerve wrecking, anxiety-charged, nauseating, and at times a devastating process. It is impossible to physically count the number of times per day that I would become distracted, stop, get off my chair, take a walk to the kitchen (fridge), wonder away (physically, mentally, and emotionally), and then go back to my chair, drawing my 'body and mind' back on the page. This same ritual continued to happen also in my dreams. At times, I found myself trying to justify or blame my distraction on my foggy brain, my noisy neighbour, my furry friend Jack and on a multitude of other reasons.

Writing the other

When writing this autoethnographic project, my driving force was guided by the other (family, friends, patients, and clients). According to Jackson (1989), the understanding of *others* can only proceed from within our own experience, and this experience involves our lived histories. Elbaz (1989) expressed that:

> Autoethnographic texts are always written with the other in mind […]the presence of an other in autobiographical and biographical texts means that they are always written with at least a double perspective in mind: the author's and the other's. The eye of the other directs the eye of the writer (p.14).

At times, I felt that through reflexivity, introspection, emotional recall, and writing, I was bringing to the forefront what has been silenced and/or not spoken about for many years i.e., trauma, repressed emotions, and beliefs. Lather and St Pierre (2013) stated that it is not only about the writing but also about the thinking – "thinking differently changes being" (p. 631). Furthermore, according to Richardson (2002), the self that writes the story is changed by the process of writing and there is no final version of interpretation because once written there is an "isness" (p.91) to it.

Transformation and tension

> *Stories can conform and stories can transform. My experience of writing as inquiry has been transformative but has also created a lot of tension. On one hand, writing in prose and poetry helped me to express myself better – 'I was opening up by writing it down'; sometimes writing the unspeakable – writing pieces, which were kept for my eyes only. In my writing (on and off the page), I experienced a cathartic outpour, which seemed to unleash itself like a flood around me. I explained the process as if going to a therapist daily, sometimes visiting deeply personal experiences, at times trying to catch myself from falling. Also, writing is what helped me to capture instances, moments, feelings, and emotions. This was very evident during COVID, a period when I was lost for words, which if they were not written would have been lost as another moment, memory, or experience. It was through the writing (private and public), that I continued to discover my 'authentic self' by being*

transparent without restrictions.

On the other hand, 'opening it up and writing it down' caused some tension, stimulated some negative feelings by writing about past experiences. If I were wearing a therapist's hat, although I would encourage the client to use writing as therapy, I would however, ensure that the person feels ready to share, as well as being supported. In writing, sometimes thoughts invade your thinking and there is no holding them back. Even though, I had years of experience, and years had passed from the illness event(s), I naively believed that I was well-prepared as a nurse and counsellor, however, in reality, nothing could have prepared me enough for this experience.

A journey through the fog

The below is an excerpt from a letter I wrote to my foggy brain whilst in Qbajjar, Gozo during one of my getaway doctoral writing days:

… I've attempted to write to you a couple of other times, but you keep taking control over my mind, my whole body over and over again. I get up... sit down... make a cuppa… try to focus… sometimes I manage…. other times you invade... and all becomes a blur. Even in writing this letter, the memory of the detail fails me, however, the feeling still embodies me and hovers around my space. I have tried to medicalise your invasion, blaming it on menopause, chronic fatigue, physiological changes due to age, stress and anxiety or blame it on being a result of my own incompetency, not being good enough, knowledgeable enough...the imposter syndrome that keeps gate-crashing my thoughts and feelings and of course, COVID too…

I cannot really put my finger on it. However, I know that you are here to stay. One day a friend of mine…teased my thinking and asked, "What or who is your *foghorn?"*

I can share that my metaphorical lighthouse that kept saving me from you, was composed of different persons. Together, they were my collective source of support also including family, colleagues, and friends, my supervisory team, external advisors, and my personal therapist.

Doubt

Self-doubt loyally accompanied me in my writing trajectory. I was told that 'doubt was part of the process'; 'doubt is good'. I felt doubt consuming my being. Upon reflection, I realised that doubt was multi-layered, intersecting with my research focus and process. On one hand, I self-doubted my own personal capabilities and abilities, continuously questioning whether I was academically 'good enough'. This doubt seemed to be an ingrained pedagogical culture; my own personal script tattooed deep in the layers of my skin which I cannot remove no matter how hard I try.

On another layer lies the doubt, uncertainty and ambiguity that prevail in chronic illness; not knowing how the illness trajectory is going to unfold, always waiting, and hoping to remain in control, 'above it'. Staying as healthy as possibly can be, to continue with life 'as normal' as claimed by most of the women; the contestation of invisible illnesses due to the lack of objective evidence, subjectivity, invisibility, and medically unexplained symptoms cannot be generalised, and therefore, sometimes doubted as being 'all in the head'. Paradoxically, and yet on another level, I was using autoethnography as a method approach, which Bochner (2017) depicted as "a genre of doubt" (p. 67).

Conversely, in using myself as subject, treating my own experiences as a primary source amongst other things, explicitly exposed, and made visible doubts, vulnerabilities, resilience, losses, emotions, and feelings. My initial reaction would be an attempt to try to quieten, silence the internal critic that is creating this doubt, thus inadvertently self- sabotaging, tightening the straitjacket and further exposing a vulnerable self. Similarly, in a parallel process, women might experience same self-doubt when they are not believed, validated for their illness, be it due to gendered politics of illness, power, and patriarchy, we might feel constrained 'to fit' into a bio-medical system as passive receipts of care, silenced, and disempowered… hijacked.

The 'I' and the 'we' intertwine, merging fact/fiction, rationality/emotionality, vulnerability/resilience, and visibility/ invisibility. In both instances compassion, connection, recognition, and validation rather than isolation and silencing are needed. It is hoped that the ambivalence of this critical silencing creates a space for compassion, a platform for words and stories to be told and heard – a personal and collective space advocating compassion and (self)care.

Autoimmune invisible chronic illnesses – The erased self

Invisible... visible…
the self and chronic autoimmune invisible illness
(lying) in the liminality – the in between of
experiencing messiness, chaos, and confusion,
whilst aspiring to find positive meanings,
...a ray of hope… you are you, you, and you.
Actively revealing, voicing, striving to be seen or
concealing the self, hiding in the shadows
unheard…. unvalidated … silent[ced]

The voice of medicine,
cultural and patriarchal overtones,
power and privilege,
condition behaviour, language and thinking.
Patients labelled, named by their condition
rather than for their self and personhood,
considered deviant if they do not collude.

The dichotomy of mind and body,
chronic illness and wellness,
The body: A site of fear, uncertainty,
vulnerability and resilience,
pain and fatigue.

Body self-erased, replaced by
medical terminology
whilst the self, strives to be seen, acknowledged,
embraces agency and self-respect.

Identity – the (multiple)self(ves)

According to Gergen (1991, as cited in Miller, 1974), "[p]ersonal identity cannot seem to be fixed… the person experiences himself as many selves, each of which is felt to have a life of its own" (p. 249).

> *Similarly, in 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.*

Short (2010) claimed that self, multiple selves, and identity formation are socially constructed, created through relationships and interactions.

> *Some questions that I commonly asked were:*
>
> *How does one choose which self/identity to bring forth into the picture?*
>
> *How do I balance the nurse/the counsellor?*
>
> *How do we satisfy our own personal and professional integrity?*

In writing this thesis, the expectation to conform was challenging. As a doctoral student I conformed with the requirements set by the University of Malta up to a certain point. However, whilst remaining rational, coherent and transparent in presenting my work, I felt that I did not conform to the traditional way of doing research. Furthermore, as a person, I was constantly shifting through the different selves, most especially, the nurse/the counsellor, the mother/the daughter.

> *Since I was adamant that I did not want to pathologise or medicalise, I was very cautious in keeping the nurse's voice at bay. However, although I was looking at the geography of emotions, I still did not inhabit fully the counsellor role. In hindsight, I realise that I continued to project the same ambivalence I spoke about earlier. 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, in between, no man's land. I sounded different voices that were elicited from a multitude of experiences. These voices merged with other women's voices. Although I was writing mystory and representing other women's stories, it is not always clear whose voice I was sounding, because after all, it could have been a composite voice. Furthermore, whilst reading through the thesis, the reader might recognise their own*

> *voice, or a close family member or friends voice echoing through the pages (Short, 2010).*

What else is there to say? Where do we as women stand?

Bruner (1986b) expressed that narratives change, all stories are partial, all meanings incomplete. There is no fixed meaning in the past, for with each new telling the context varies, the audience differs, the story is modified (p. 153). When telling life stories, the first purpose was not to describe the past as it was experienced, but to understand the affect the meanings had on the experience and the person.

The past is not frozen in the moment of experience. In presenting illness stories, the goal was to invite the reader and the audience into the emotional space to participate in the evocative "joint production of meaning" (Pollock, 1998 p. 8) of the story being told. The intention was to show ambivalences and contradictions that occurred along the way rather than to romanticize, elicit or declare a conclusive outcome or a theory. Therefore, by sharing *my*story, alongside other women weaving through and around the interplay of ideas, stories, patterns and making them accessible to others, the demarcation line between the private and public life became blurred (Ellis & Bochner, 1992). It is through the writing of the stories that readers are invited to connect engage and to "experience the experience" (Ellis & Bochner, 1992, p. 98).

The heart of autoethnography is connection (Bochner, 2017 p. 70). Ironically, on a macro and micro level, I believe that there is no better time than now to speak of connection or the lack of it. During the COVID pandemic we have experienced social isolation, a lack of communication (especially face-to-face) and a lack of compassion. This was most especially experienced by persons living with autoimmune chronic illness who have been enduring suffering, experiencing similar situation and living with this reality ever since they were diagnosed and *not* because of COVID.

> *Like Alice, 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. My mature age and my personal and professional experience in the field have outgrown the unprejudiced and innocent child. 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 mystory, 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’.*

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Appendix A (English version)

Information letter for participants

Dear Participant,

I am currently embarking on a research project as part of the Degree of Doctor in Philosophy currently pursued at the University of Malta, Faculty of Social Wellbeing.

Title of the proposed research project: Chronicity: The lived experience of women in Malta

The term "chronic illness" carries several meanings and inexact definitions. Both the World Health Organization (WHO) and the European Union (EU) acknowledge that chronic conditions impose an enormous burden on the daily lives of patients and their relatives andon a society. I am interested in exploring the lived experience of women which includes the perceptions of and beliefs about the condition, their responses to the illness, physically, psychologically, socially, and emotionally. The proposed study aims to look beyond the “medicalization” and pathology of chronic conditions. It will seek to provide thetime and space to listen to illness narrative.

Participants’ selection criteria:

- Sample of 8-10 young to middle aged women 25 years – 55 years,
- Women who have been suffering from an invisible*, unseen, chronic illness for at least 2years
- Women, who do not suffer from any clinically diagnosed acute or chronic psychiatric illnesses/ disabilities

- Women who have not been clinically diagnosed to be suffering from any neurological illnesses that is known to affect cognitive or learning processes
- Women who have not been diagnosed to be terminally ill,
- Women who are able to speak English and / or Maltese fluently

**Invisible or unseen illnesses are disabling conditions that are not immediately apparent.Ex multiple sclerosis, chronic fatigue syndrome.*
***Psychiatric disabilities include major depression, bipolar disorders, anxiety disorders, schizophrenia, personality disabilities, the long-term consequences of physical, psychological, or sexual abuse of children and adults (e.g., Post-Traumatic Stress Disorder).*

The proposed research study seeks to contribute towards a better understanding of the impact and meaning of chronicity, to acknowledge the stories told, to create awareness andeducation, to identify and promote any possible action elicited to embetter the lives of women in the illness trajectory.

I would like to assure you that all necessary ethical and legal measures shall be taken when carrying out this study. Moreover, the identity and anonymity of all participants will be protected throughout the whole research process. Please be assured that internal confidentiality will be maintained through the whole research study and all reporting of the study will ensure that the identification of the participants is fully protected. I would also like to inform you that all participants reserve the right to withdraw from this research study at any stage of the project.

Yours sincerely,
The researcher

Persons interested in participating in this study are kindly asked to contact

Intermediary Person

Intermediary contact details

Appendix A (Maltese version)

Ittra ta’ Informazzjoni għall-parteċipanti

Għażiż partiċipant,

Bħalissa bdejt proġett ta’ riċerka bħala parti mid-dottorat tal-Filosofija fl-Universita ta’Malta fil-Fakulta’ tas- Social Wellbeing.

Titlu tal-proġett : L-istat kroniku: Esperjenzi attwali tan-Nisa` f’Malta

It-termini “mard kroniku” tinkludi tifsiriet diversi u definizzjonijiet skorretti. Kemm l-Organizzazzjoni Dinjija tas-Saħħa (WHO) u l-Unjoni Ewropea (EU) jirrikonoxxu l-fatt li kondizjonijiet kroniki jimponu piż enormi fuq il-ħajja ta’ kuljum tal-pazjenti u l-familjari tagħom kif ukoll fuq is-soċjeta’ in ġenerali.

Jinteressani ħafna nesplora l-ħajja mgħixa min-nisa, il-fehmiet u opinjonijiet dwar il-kondizzjoni tagħhom, kif qed jirreaġixxu għall-mard, fiżikament, psikoloġikament soċjalment u emozzjonalment. Fl-istudju li qed nagħmel qed inħares lil hinn mid-dijagnożi medika, patoloġija ta’ kundizzjonijiet kroniċi. Fiha se niddedika ħin u spazju biex nisma’ l-istorja tiegħek.

Kriterji għall-għażla tal-Partiċipanti:

- Grupp ta’ 8-10 nisa ta’ bejn il-25-55 sena’,
- Nisa li jkunu ilhom ibatu minn marda kronika li ma tidhirx minn ta’ lanqas għal sentejn.
- Nisa li ma jbatux minn xi marda klinikament magħrufa, akuta jew xi mard kroniku psikjatriku/ diżabbilta’.

- Nisa li klinikament ma għandhomx dijanjożi ta' mard newroloġiku li seta' ħalla fuqhom effett fuq il-proċess ta' tagħrif u tagħlim.
- Nisa li ma m'għandhomx dijanjożi ta' mard terminali.
- Nisa li kapaċi jitkellmu bil-Malti u bl-Ingliż tajjeb.

**Diżabbilta' psikjatrika tinkludi dipressjoni qawwija, diżordni 'bipolar', ansjeta', skizofernja, disabbilta' fil-personalita', kif ukoll konsegwenzi ta' tul ta' żmien minħabba abbużi fiżikali, psikoloġiċi u sesswali fuq tfal u adulti (Ez: Post Traumatic Stress Disorder, PTSD).*

Għal din ir-raġuni, qegħda nitlob permess biex nibgħat ittra ta' tagħrif fid-Dipartiment …………………………………… biex nagħżel il-parteċipanti.

Dan l-istudju ta' riċerka hu biex nistgħu nifhmu aħjar l-impatt u t-tifsira ta' stat ta' saħħa kronika, li tiddixxerna dak li tisma', li tiffaċilita' t-tagħlim billi tqajjem kuxjenza dwar dak li għandu jsir ħalli nisa li jbatu b'mard kroniku jkunu jistgħu jiġu megħjuna aħjar. Nassigurakhom li kull miżura etika u legali se tittieħed meta nkun qed nagħmel dan l-istudju. Barra minn hekk, l-anonimita' u identita' tal-parteċipanti tkun protetta tul ir-riċerka kollha. Nixtieq nassigurakom li konfidenzjalita interna tinżamm tul ir-riċerka dwar l-identita' tal-parteċipanti u li dawn jistgħu fi kwalunkwe ħin jirtiraw mir-riċerka u minn dan il-proġett.

Dejjem tiegħek,

Persuni interessati li jipartecipaw f'din ir-ricerka huma ġentilment mitluba jikkuntattjaw lil persuna intermedjarja

Dettalji tal-persuna intermedjarja:

Appendix B (English Version)

Consent Form

You have been selected to participate in this research study, in which data willbe collected from one-to-one interviews. By sharing your knowledge and experience through your participation in this research study, you will be contributing towards creating a better awareness and understanding of women's lived experiences of chronicity.

Title of Project: Chronicity: The lived experience of women in Malta

It is envisaged that there will be 3 face- to-face interviews. The duration of eachinterview shall last approximately one and a half hours.

A) The first interview will serve as the primary data collection method.

B) The second interview would be a semi-structured interview. Questions for second interview would be elicited from first interview narrative.to clarify,

C) The third interview, the researcher would carry out member validation interview to check meaningfulness and validity of information elicited from first and second interviews.

The interviews will be held at a date, time and place that is convenient for you. The sessions will be recorded and transcribed and later analysed by myself. You will be presented with a copy of the findings on completion of the research study. Please be assured that internal confidentiality will be maintained throughout the whole research study and all reporting of the study will ensure that the identification of the participants is fully protected.

Should you accept this invitation to participate in this research study, please be informed that you are free to withdraw from participating in this research at any moment you decide to. No explanations will be expected. In the meantime, please take your time to read and complete this form. I would be very happy to discuss any queriesyou may have.

Please initial each box if you agree

1. I confirm that I have read and understood the information sheet dated_____for the above study. I have had the opportunity to consider the information, ask questions and have had any questions answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw atany time, without giving any reason, without any of my rights being effected. ☐
3. I am aware that confidentiality will be respected throughout the research and that internal confidentiality is being assured. ☐
   I am aware that recordings will be destroyed on completion of the research study
4. I agree to take part in the above study. ☐

Name of Participant Date Signature

Name of Researcher Date Signature

Name of Supervisor Date Signature

<u>Researcher personal details</u>

Appendix B (Maltese version)

Ittra ta' Kunsens

Int ġejt magħżul/a sabiex tipparteċipa fi studju ta' riċerka fejn l-informazzjoni ser tkun miġbura minn tlett interviews ma kull individwu. Il-parteċipazzjoni f'din ir-riċerka, bil-kontribut u l-esperjenzi tiegħek fuq dan is-suġġett, jista' jikkontribwixxi sabiex nifhmu aħjar l-esperjenzi tan-nisa kif jgħixu il-mard kroniku.

Titlu tal-proġett: L-istat kroniku: Esperjenzi attwali tan-nisa f'Malta

Qiegħed jiġi stmat li kull interview għandu jdum madwar siegħa u nofs.

A) L-ewwel interview ser iservi biex tinġabar informazzjoni primarja fuq is-suġġett.

B) It-tieni interview ser jkun gwidat b' domandi speċifiċi sabiex jiġu kkajarifikati ċertu affarijiet li ħarġu mill-ewwel interview.

C) Fit-Tielet interview, ir-riċerkatur jippreżenta l-informazzjoni lura lil partiċipantisabiex jassiguraw it-tifsira u l-validita tal-informazzjoni mill-ewwel u t-tieni interviews.

L-interviews ser jigu organizzati f'data, f'ħin u f'post li hu konvenjenti għalik.

L- interviews ser jiġu rrekordjati, transkritti u analizzati minni iżjed il-quddiem.

L-identita' u l-parteċipazzjoni tagħkom se tkun protetta u ser tinżamm mistura.

Qegħda tiġi assikurata l-kunfidenzjalita sabiex tipproteġi l-identita' tagħkom minn persuni oħra li ma pparteċipawx fir-riċerka.

Għandek tkun taf li għandek kull dritt li tiddeċidi li ma tipparteċipax iżjed meta trid int, mingħajr il-bżonn li tagħti l-ebda spejġazzjoni.

Iffirma l-inizjali tiegħek fil-kaxex jekk taqbel ma li hemm miktub.

1. Nikkonferma li qrajt u fhimt l-informazzjoni li ntbagħtet lili dwar din ir-riċerka. Kelli l-ħin naħseb fuqha u nistaqsi l-mistoqsijiet li kelli bżonn nagħmel u ħadt ir-risposti li xtaqt.	
2. Nifhem li qiegħed nipparteċipa b'mod volontarju u nista' nagħzel li nwaqqaf il-parteċipazzjoni tiegħi meta rrid mingħajr ma nagħti l-ebdaspejgazzjoni u mingħajr li d-drittijiet tiegħi ma jiġu mgħedda.	
3. Nifhem li l-informazzjoni li se tiġi miġbura waqt dan l-istudju tista' tigi studjata minn individwi u awtoritajiet fl-Universita' ta' Malta. Nagħti l-permess tiegħi lil dawn il-persuni biex jaraw din l-informazzjoni	
4. Gejt infurmat li se nibqa' anomimu f'din ir-riċerka.	
5. Naqbel li nipparteċipa f'din ir-riċerka.	

Isem tal-parteċipant Data Firma

Isem ir-riċerkatur Data Firma

Isem is-supervisor Data Firma

Researcher personal details

Appendix C (English version)

Single Interview question

I am interested in listening to people’s experiences and meaning of living with a chronic illness as part of my research project. Could you please tell your story, the events, experiences that have been important to you up till now and that left an impact on you as a person.

Appendix C (Maltese version)

Domanda għall-ewwel Interview

Jien interessata li nisma l-esperjenzi u s-significat tan-nies li jgħixu b'marda kronika bħala parti mir-riċerka tiegħi. Tista' gentilment tgħidli l-istorja u l-esperjenzi tiegħek, xi ġrajjiet li huma importanti ghalik s'issa u li ħallew impatt fuqek bħala persuna.

Appendix D (English version)

Permission letter

The Director xxxxxxxxxxxxxxxxxxxxxx

Dear

I am currently embarking on a research project as part of the Degree of Doctor in Philosophy currently pursued at the University of Malta, Faculty of Social Wellbeing.

Title of research project is Chronicity: The lived experience of women in Malta.

The term "chronic illness" carries several meanings and inexact definitions. Both the World Health Organization (WHO) and the European Union (EU) acknowledge that chronic conditions impose an enormous burden on the daily lives of patients and their relatives andon a society as a whole. I am interested in exploring the lived experience of women which includes the perceptions of and beliefs about the condition, their responses to the illness, physically, psychologically, socially, and emotionally. The proposed study aims to look beyond the “medicalization” and pathology of chronic conditions. It will seek to provide the time and space to listen to illness narrative. It aims to analyse: the attributes (characteristics), the antecedents (background); and the consequences of chronicity resultant from invisible illnesses on the identity of the woman as a whole person.

Participants’ selection criteria:

- Sample of 8-10 young to middle aged women 25 years – 55 years,

- Women who have been suffering from an invisible*, unseen, chronic illness for atleast 2 years
- Women, who do not suffer from any clinically diagnosed acute or chronicpsychiatric illnesses/ disabilities
- Women who have not been clinically diagnosed to be suffering from any neurological illnesses that is known to affect cognitive or learning processes
- Women who have not been diagnosed to be terminally ill,
- Women who are able to speak English and / or Maltese fluently

**Invisible or unseen illnesses are disabling conditions that are not immediately apparent. Ex multiple sclerosis, chronic fatigue syndrome.*
***Psychiatric disabilities include major depression, bipolar disorders, anxiety disorders, schizophrenia, personality disabilities, the long-term consequences of physical, psychological or sexual abuse of children and adults (e.g., Post-Traumatic Stress Disorder).*

For this reason, I am requesting your permission to distribute an information letter in the ………………… department for the recruitment of participants.

The proposed research study seeks to contribute towards a better understanding of the impact and meaning of chronicity, to acknowledge the stories told, to facilitate educationthrough consciousness raising and identify any possible action to be taken in order to address women's lived experience with chronicity more effectively.

I would like to assure you that all necessary ethical and legal measures shall be taken when carrying out this study. Moreover, the identity and anonymity of all participants will be protected throughout the whole research process. Please be assured that internal confidentiality will be maintained through the whole research study and all reporting of the study will ensure that the identification of the participants is fully protected**.** I would also like to inform you that all participants reserve the right to withdraw from this research study at any stage of the project.

Yours sincerely,

Appendix E (English version)

Data protection permission

Data protection officer:

I am currently embarking on a research project as part of the Degree of Doctor in Philosophy currently pursued at the University of Malta. The title of the proposed research project is:

Title of project: Chronicity: The lived experience of women in Malta.

The term "chronic illness" carries several meanings and inexact definitions. Both the World Health Organization (WHO) and the European Union (EU) acknowledge that chronic conditions impose an enormous burden on the daily lives of patients and their relatives andon a society as a whole. I am interested in exploring the lived experience of women which includes the perceptions of and beliefs about the condition, their responses to the illness, physically, psychologically, socially, and emotionally. The proposed study aims to look beyond the "medicalization" and pathology of chronic conditions. It will seek to provide the time and space to listen to illness narrative. It aims to analyse: the attributes (characteristics), the antecedents (background); and the consequences of chronicity resultant from invisible illnesses on the identity of the woman as a whole person.

Participants' selection criteria:

- Sample of 8-10 young to middle aged women 25 years – 55 years,
- Women who have been suffering from an invisible*, chronic illness, for at least 2 years

- Women, who do not suffer from any clinically diagnosed acute or chronic psychiatric illnesses/ disabilities
- Women who have not been clinically diagnosed to be suffering from any neurological illnesses that are known to affect cognitive or learning processes
- Women who have not been diagnosed to be terminally ill,
- Women who are able to speak English and / or Maltese fluently

**Invisible or unseen illnesses are disabling conditions that are not immediately apparent. Ex multiple sclerosis, chronic fatigue syndrome.*
***Psychiatric disabilities include major depression, bipolar disorders, anxiety disorders, schizophrenia, personality disabilities, the long-term consequences of physical, psychological or sexual abuse of children and adults (e.g., Post-Traumatic Stress Disorder).*

The proposed research study seeks to contribute towards a better understanding of the impact and meaning of chronicity, to acknowledge the stories told, to create awareness andeducation, to identify and promote any possible action elicited to enhance the lives of women in the illness trajectory.

I would like to assure you that all necessary ethical and legal measures shall be taken when carrying out this study. Moreover, the identity and anonymity of all participants will be protected throughout the whole research process. Please be assured that internal confidentiality will be maintained through the whole research study and all reporting of the study will ensure that the identification of the participants is fully protected**.** I would also like to inform you that all participants reserve the right to withdraw from this research study at any stage of the project.

Yours sincerely,

Appendix F (English version)

Applicant's email: sharon.martinelli@um.edu.mt

Index No:

We have examined the above proposal and advise

[✓ Acceptance] Refusal Conditional Acceptance

For the following reason/s:

Signature:

Date: 27/7/2017

To be completed by University Research Ethics Committee

We have examined the above proposal and advise

[✓ Acceptance] Refusal Conditional Acceptance

For the following reason/s:

2/10/2017

Signature:

Date:

Appendix G

Francesca’ story: “Everything happens for a reason…it’s true”

THE INTERVIEW	TRANSLATION OF INTERVIEW AND SELECTION OF WORDS	FINAL PRESENTATION OF FOUND POETRY
It all started about 10 /11 years ago, kont Junior College. I had glandular fever which turned out to be carrying on for a period of time … after a year and a half ... I was diagnosed with this thing that was fibromalygia… which at the time no one knew anything about... in the past ten years I have seen the evolution of knowledge of fibromyalgia in Malta. An increase in the number of persons .. nies li jkollhom uġigħ qawwi ..jaqbdu jgħidulhom li għandhom hekk….mingħajr ebda tip ta’ investigation mingħajr edba tip ta’ analiżi tas-sitwazjoni li ilha recurring for a number of months.	all started about 10 /11 years ago, kont Junior College. I had glandular fever which turned out to be carrying on for a period of time … after a year and a half ... I was diagnosed with this thing that was fibromalygia… which at the time no one knew anything about... in the past ten years I have seen the evolution of knowledge offibromyalgia in Malta. An increase in the number of persons…… persons who because they complained of excruciating pain …they are told that they have fibromyalgia….without without adequate investigation or analysis of the situation that had been recurring for a number of months.	Excruciating pain labelled Fibromyalgia, without adequate investigation

Appendix H

Jessica' story: The curtain comes down

THE INTERVIEW	**SELECTION OF WORDS**	**FOUND POETRY (English version)**
Jiena fil-verita ġejt diagnosed with MS a year ago imma kienet ilha ġejja mit 2011 mill-ewwel episodju u wara hafna visiti A&E. We had gone to eat Saturday evening. Meta mort lura d-dar irrealiżajt li ma bdejtx nara kollox ċar u dakinhar naf li ħadt il-limoncello. L-ewwel darba li ħadt il-limoncello…..u malli ħadtu sturdini u mort norqod u l-għada filgħodu qomt inħares lejn l-arloġġ li kien wieqaf hekk fuq il-komodina, u bejt ngħid "Kif mhux qed nara ċar?" Rajt biss ċpar. Bdjet nara n-nofs naqra shady. Għidt naħseb ġejja xi allerġija, mort għand il-mummy, mort għand l- ispiżjar u għedilitha jekk għandix xi ħaga… jew xi allerġija u din taghni l-Optrex.	Ġejt diagnosed MS Sitt snin wara l-ewwel episodju Darba fost l-oħrajn irrealiżajt li ma bdejtx nara ċar Inħares lejn l-arloġġ Li kien wieqaf hekk fuq il-komodina Rajt biss ċpar Ħsibta ġejja xi allerġija	I was diagnosed with Multiple Sclerosis after six years and numerousvisits to A&E first symptom, blurred vision the clock on the bedside table showed hazy, distorted time

Appendix I

Erica’s story: Never give up!

THE INTERVIEW	**FOUND TEXT**
I was 9 years old Helping with home chores was a duty was something I normallywould not have minded so much but….. I remember the days when it was hard getting up in the morning I remember the suffering, finding difficulty to get up on my feet from the floor. Notwithstanding the pain I continued to help, with home chores I continued to go to school However, life seemed to roll on very slowly. I recall there was little awareness of Rheumatoid arthritis (RA)	I was 9 years old Helping with home chores was something I normally would not have minded so much but….. I remember the days when it was hard getting up in the morning I remember the suffering, Notwithstanding the pain I continued to help, I continued to go to school. Life seemed to roll on very slowly I recall there was little awareness of Rheumatoid arthritis (RA)

Appendix J

Jasmine’ story: “IT doesn't define me, IT's just a part of me"

THE INTERVIEW	**SELECTION OF WORDS**	**FOUND POETRY**
Let me start from the very beginning. So, in my late teens I had issues with my bowels, I would visit the bathroom multiple times…. there was blood!! Before I found blood, I thought it was a virus I thought “uwija issa jghadili ….wara gimgha” (It will pass…. in a week’s time) …..or whatever…..however, it didn’t get any better… blood persisted… I started to find blood consistently and realized that there is an issue here	Let me start from the very beginning. In my late teens, I had issues with my bowels, I visited the bathroom multiple times…. and…there was blood!! Before the blood, I thought it was a virus I thought “uwija issa jghadili” (Now it will pass) or whatever… however, it didn’t get any better…blood persisted…	Let me start from the very beginning. In my late teens, I had issues with my bowels, Ivisited the bathroom multiple times… and…there was blood!! Before the blood, I thought it was a virus I thought “uwija issa jghadili” (Now it will pass) …. or whatever……. however, it didn’t get any better…blood persisted… it didn’t get any better…blood persisted…