An exploration of the trajectory of being a breast cancer patient through collaborative writing in imaginal dialogue

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By: Sui-ping CHAN

S1734096

Doctor of Psychotherapy and Counselling

University of Edinburgh

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Abstract

This study aims to examine my personal lived experience, as a breast cancer patient, in navigating the liminality in the trajectory of illness. It focuses on developing understanding of the complexity in the thoughts, feelings and behaviours related to the (traumatic) cancer- related events that I have encountered over the past three years since diagnosis. The methodology is collaborative writing through imaginal dialogue (CW-ID) with Arthur Frank, the author of the books "*At the Will of the Body*" (2002 [1991]) and "*The Wounded Storyteller*" (2013 [1995]). It opens a creative and safe space for me to make sense of the life-threatening process. I discover that CW-ID, as a research methodology, supports me, as a researcher and cancer patient, in researching how the existential vulnerability of human beings is encountered and negotiated in the trajectory of illness. Surprisingly, CW-ID also manifests itself as therapeutic by making it possible for me to bring the overwhelming emotions in navigating the liminal spaces in the trajectory of illness to my supervisor. He bears witness to this creative-relational relationship which evolved over time between me, Frank, and others in both imaginal and real encounters in my trajectory of illness. The contribution of this study is that it offers an alternative to an autoethnographic approach in researching the deep, personal experience of health conditions that are biographically disruptive. It also opens an invitation to others who are interested in expanding the boundary of working collaboratively through imaginal dialogue with me and others. This can contribute to the knowledge creation of how human beings with medical conditions can develop a renewed sense of self in the process of navigating the liminal spaces in the trajectory of illness.

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I am grateful to my family who rendered me unconditional support and understanding while I could not be by their side when they experienced great difficulty in our hometown under the Covid attack.

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Chapter 1

Introduction

Three years ago, when I had just embarked on my doctoral study, I was diagnosed with breast cancer. Being an international mature student who had no knowledge of the medical system in a foreign country, I was confronted with the dilemma of making a critical decision as to whether I should terminate my study and return home for medical treatment for the sake of my health. After overcoming some internal struggles, I chose to stay in a foreign land to complete my medical treatment and to continue my study while my family members were in our hometown.

This study aims to answer the research question "What is the experience of being a breast cancer patient in navigating the liminality in the trajectory of illness?" Cancer diagnosis and treatment are highly stressful for both the patient and their loved ones. However, there is a common misconception that Post-traumatic Stress Disorder (PTSD) is only relevant in circumstances of acute, physical trauma (Leano, et al. 2019). In 2000, the diagnostic criteria for PTSD were adjusted to include diagnosis and treatment of a life-threatening illness, such as cancer (American Psychiatric Association, 2000). However, PTSD was adjusted in DSM-V, which states that, "a life-threatening illness or debilitating medical condition is not necessarily considered a traumatic event (American Psychiatric Association, 2013). Some see cancer experience as traumatic, but others do not. What makes one experience cancer as traumatic or not? I wonder how I, as a breast cancer patient, experience (traumatic) cancer-related events myself and in relation to others in the trajectory of the illness. Trajectory, in this study, refers to the process in navigating the liminal spaces in living with medical conditions. As

Bondi and Fewell (2016) state, we need examples of practice to add strength to experience-near research.

This study focuses on developing understanding of the complexity in thoughts, feelings, behaviours towards (traumatic) cancer-related events that patients can experience, and it is done through collaborative writing in imaginal dialogue. It aims to explore how a single in-depth insider narrative can contribute to our knowledge of the broader human predicament.

I take my personal experience over the past three years since diagnosis as the subject of study. The methodology that I adopt is collaborative writing through imaginal dialogue with Arthur Frank, the author of the books "*At the Will of the Body*" (2002 [1991]) and "*The Wounded Storyteller*" (2013 [1995]) to open the creative space of making sense of the life-threatening process.

Collaborative writing through imaginal dialogue is a creative means that enables me to claim my voice when developing my own quest narrative. As Frank argues (2013 [1995], 2001, 2002), quest narrative involves reflexivity by the patient, who has self-consciously transformed themselves and has gained some insight from the experience that they feel obliged to pass on to others. This aligns with the ontological and epistemological principles of Creative-Relational Inquiry in researching how I, as a cancer patient, proclaim my new identity and voice through self-narrative inquiry into the renewal process along the illness journey.

In Chapter 2, I delineate the complexity of holding multiple roles as a cancer patient, wounded researcher, and wounded counsellor in conducting the review of the literature. I consider that writing a literature review is a developmental process that does not have a clear beginning and ending. It mirrors the state of my being in the middle of experiencing illness in the trajectory. Being a cancer patient, I evaluate what is known and what is not known to me and what is of help and what is not. I also review through the lens of a wounded researcher and wounded counsellor. I conclude that some may consider cancer, a life-threatening illness, to be not necessarily a traumatic event, but I argue against this. We need to have more experience-near examples to illuminate how cancer patients navigate the trauma-related events in the trajectory of illness. And such a process of inquiry cannot be done by others but can only be done by the patients themselves so that their subjective experiences, be they traumatic or not, recognised and respected.

Chapter 3 presents the Methodology that I adopt in conducting this study. I present my ontological and epistemological position as a social constructivist in researching into the experience of illness. I reflect critically on the benefits and risks of using autoethnography in researching subjective illness experiences of those who live with critical illness and are in trauma. I argue for adopting collaborative writing through imaginal dialogue as a method of inquiry in researching how I experienced the transformed state of well-being impacted by cancer. I provide illustrations of how my attempt in engaging in imaginal dialogue with Arthur Frank enabled me to oscillate between the identity of victim-survivor of illness, and surprisingly, an insider psychotherapist who supports me to reflect on the suffering experiences with some peace of mind. I argue that collaborative writing through imaginal dialogue offers an alternative to autoethnography for generating experience-near examples of how to create an imaginary narrative space which is safe for self-exploration.

Chapter 4 presents the data created from the imaginal dialogue with Frank in making sense of my trajectory of illness over the past three years since the diagnosis of cancer. The data, as presented in the form of a playscript, illustrate how making meaning of illness is derived through narrating in the presence of the imaginary figure who plays the role of imaginary confidant. The dialogical approach is used to discuss, reflect, and examine the unpredictable disruption brought about by cancer with others who have shared experiences of illness. This opened up the creative space for me to narrate the traumatic experiences that enabled me to process and integrate them in memory.

Chapter 5 presents the insight I gained about cancer-related trauma in the illness trajectory. As a cancer patient, I realise the importance of being the witness of my own troubled psyche through the imaginal dialogue and the collaborative act of writing with Frank, as my imaginal confidant and others, both imaginal and real. I highlight the power of witnessing as evidenced in the co-created space of witnessing with my first supervisor the imaginal dialogue and collaborative writing with Frank. I contend that that co-witnessing enabled me to take on another critical role in this research process, not as a cancer patient, but as a wounded researcher. In this role I worked collaboratively with my research supervisor in co-witnessing how I navigate the in-betweenness of both having cancer and not having, of being both fearful and fearless of its recurrence, and being visible and invisible at the same time. It reflects the paradox of living with medical conditions in the state of navigating the liminal space through imaginal dialogue with Frank. It helps me develop a reflective gaze into my illness. This helps cancer-related experiences become speakable, which offers the chance for integrating trauma memory and preventing developing PTSD.

In Chapter 6, I draw implications from the study and suggest that collaborative writing through imaginal dialogue with witnessing in the presence of others offers an alternative to researching subjective experience of illness and it is not only a method of inquiry but also a therapeutic process for trauma-related illness experiences. It is a means of supporting those experiencing cancer-related trauma in life, regardless of the stages they are at as this is the process of proclaiming one’s own voice even under the brutal biographical disruption brought about by the illness.

The contribution of this study to the field of counselling and psychotherapy is that it gives an experience-near example that illuminates the power of witnessing in both the imaginal and real contexts. I propose that when patients/ clients are supported in navigating the liminal spaces in the trajectory of illness through collaborative writing in imaginal dialogue with the presence of witnessing, the experiences can be therapeutic. Unlike the disease trajectory, grounded in the biomedical model, that is predictable, reductive, and quantifiable, my example illustrates that each person’s illness trajectory is unique and unpredictable, but what matters is that it is full of possibilities for us, as patients, to make sense of what it means to ourselves and in relation with others.

As a counsellor and a practitioner researcher, I advocate that an engagement in researching personal illness experience helps to develop knowledge combined with practical wisdom, as the process helps to cultivate holistic, intuitive, and embodied ways of learning and knowing. This is the process of creating a personal quest narrative and testimony, an outcome of witnessing, one that is therapeutic in surfing the hurricane of illness - an idiosyncratic, subjective, and unique trajectory of illness.

Chapter Two

Literature Review

Introduction

As a breast cancer patient, reading literature about illness in general and breast cancer in particular becomes an integral part of the illness trajectory in my life. Ilness refers to the experience of living through the disease. Trajectory, in this study, refers to the process in navigating the liminal spaces in living with medical conditions. Instead of adopting the biomedical perspective of seeing illness as disease, as a biofact with a fixed, linearity and predictable course of development, I am interested in researching patient experiences in navigating their own trajectory.

Once I decided to research my illness experience, reading the literature through a researcher's lens adds an additional layer of complexity in understanding what is related and relevant to this research topic "What is my trajectory of illness like?". Being a counsellor, still finding my footing in the field of psychotherapy, I have another expectation on reading with the hope I can be my own psychotherapist. I am aware of the challenge in positioning myself in doing the literature review. As Etherington (2001) states, there are multiple roles to navigate and selves to gather. I wonder which lens I should adopt in reviewing literature and for whom and what purpose in the context of conducting this research. The more I have engaged in the process of writing the literature review to contextualise my study over these past three years, the more I find myself having multiple voices coming from my multiple roles of being a cancer patient, a wounded researcher, and a wounded counsellor. I wonder how to respond to those voices to ensure that my literature review remains relevant and valid to the topic of investigation. Over time, I realise that my multiple roles form an integral part of personhood. Hence, it may be more valid to welcome the three roles to inform my understanding of the current literature in illness. This reflects the singularity of the individual that shapes their way of perceiving illness experiences (Charon, 2006). Etherington (2001) notices the parts of herself that she has gathered together in doing her qualitative research. I adopt her stance and so allow different voices of selves, being the victim of illness, my observer-participant self as a researcher, my therapeutic self as a counsellor and other selves (in the background) in orchestrating the process of reading, reflecting, engaging, and sharing to identify gaps in the literature for further exploration.

Another challenge is that writing a literature review is a developmental process that does not have a clear beginning and ending, it is always in the middle which mirrors what I am experiencing in the trajectory of illness Hence, what I can present in this chapter is better understood as a developing understanding of the latest research that is related and relevant to my topic of study on the trajectory of being a breast cancer patient. It reflects, to the best of my knowledge, what I am aware of in understanding what has been researched in this area and how I respond to those understandings which have been generated from the studies from the perspective of a cancer patient, a wounded researcher, and a wounded counsellor.

Another question to address in writing this literature review is who the audience of this thesis could be. My assumption is that the potential audience may find the topic of the research “The trajectory of being a breast cancer patient” relevant to their personal or professional role or responsibility. There may be academics with an interest in knowing how a patient gives an account of their illness experiences and professionals in the helping position who are interested in devising support and care to those who are sick with a critical illness. I can see the multiplicities in the potential readers who have different motivations in reading this study. I will adopt a nomadic attitude in reading the literature and reflecting on illness experiences with openness to whatever emerges in the literature of illness and that of the trajectory of a cancer patient in particular.

To begin with, I will review the literature from the perspective of being a cancer patient who engages in reading the literature about illness. I will then evaluate what is known and what is not known to me and what is of help and of what is not. Then, I will bring in a patient-researcher-counsellor perspective to identify any gap in the field that justifies this research through the lens of a cancer patient, a wounded researcher, and a wounded counsellor (Creswell & Poth, 2018).

Illness

Illness is part of life which is indispensable in life history. Illness brings interruptions to our experiences of life before illness and compels us to live with the illness as part of our self, especially when it is chronic and serious.

In the research of illness, grounded in the biomedical model, quantitative studies on the trajectory of illness focus on large scale comparisons across populations and are measurement-driven to examine the incidence rate, efficacy of treatment and analysis of patterns of development and adjustment to cancer. In examining disease trajectories among patients, studies focus on the time-related decline and recovery of functional status across a spectrum of illnesses (Hassett et al. 2006; Lee et al. 2006; Higginson & Costantini. 2008; Wernli et al. 2011; Edwards et al. 2014; Lash et al. 2014; Jensen, et al. 2014; Brand et al. 2016; DeSanitis, et al. 2016; Yang et al. 2017; Lee et al. 2019; Yang et al. 2019). The focus of these studies is on the functional trajectories including incidence rates, rate of hospitalisation, risk and survival rate, prognosis, effects of treatment and therapy, comorbidity and death causes, illness perception and wellbeing. Lynn (2005) identifies three types of disease trajectories of fatal chronic illness, namely cancer, organ system failure and dementia/frailty and suggests how a society can build care around those three patterns and develop the mass customization approach for these groups. These studies dominate in the illness literature and attract most of the research funding, which aims to generate knowledge or truths about illness for the purpose of diagnosis and treatment that can be generalised and applied to the majority suffering the “same” illness.

While these studies might serve the purpose of giving some sense of certainty in diagnosis, prognosis and interventions through quantitative measures, there is also debate about the meaning of numerical information in the communication of illness to the patients. This calls for more qualitative approaches in investigating the power of numbers that shape one’s cancer experience. For instance, in a systematic review of the literature on communicating prognosis in cancer care, Hargerty et al. (2005) find that most of the published research was conducted in the early-stage cancer setting that offers mostly descriptive evidence, with little evidence of the best method of communicating the prognosis or of the impact of prognostic information on patient outcomes. Most patients with early-stage cancer want detailed prognostic information, presented in an open and honest manner and they want to get involved in the prognostic discussion. Similarly, Thorne et al. (2006) drew on an extensive data set derived from interviews with 200 cancer patients. They found that patients expect to have a delicate balance between population-based accuracy regarding the average disease course and individual respect to their unique situation. Hence, the perspective of patients contributes one important dimension to the ongoing understanding of the intricate challenge in communicating cancer diagnosis, prognosis, treatment decision making and trajectory.

Attending to Patients’ Illness Experience

The lived experience of illness represents a disturbance and a feeling of disorder in the life of a human being (Öhman et al. 2003). Living with chronic illness involves an impact on and alteration in the lives of people, as widely documented in the literature. This has attracted a lot of studies which attempt to examine the lived experiences of patients with chronic illness over the past four decades. For instance, Bury (1982) considers the biographical disruption of chronic illness which negatively impacts on patients. Charmaz (1983, 1987) identifies the neglected aspect of suffering - the loss of self - as experienced by chronically ill patients. More studies investigate the meanings of suffering, loss, and stigma in the studies of the experience of illness and some authors find that it is how one interprets their experiences that matters (Frank, 1995; Schroevers, Kraaij and Garnefski, 2011). Sacks et al. (2016,730) point out the importance of “allowing the patient to recount their illness narratives instead of simply asking the professional a series of questions about the course of their illness” that helps improve the empathy between patients and professionals.

Living with uncertainty and fear of the recurrence and of the unknown are common universal experiences while receiving diagnosis, treatment and (non) recovery (Yang et al. 2019). Breast cancer patients (or survivors) have an increased risk of recurrences, early side effects, higher rates of emotional distress, and lower physical and psychological QoL (quality of life) (Amir & Ramati, 2002). They also have increasing survival rates and late adverse health effects related to both the disease and therapy (Kornblith et al. 2003; Higginson and Costantini, 2008; Yang et al. 2019).

As an Asian mature female adult who came to study abroad alone, it was unclear how I would adapt to the unfamiliar Scottish culture and present myself as a cancer patient in a totally unfamiliar medical system during diagnosis and medical treatment. The feelings of alienation, foreignness and loss of identity are not uncommon in the literature. How should I communicate my illness to the medical professionals and how I can speak for my body and psychological needs to those who offer me treatment? Is it good enough to follow the treatment of the protocol as carefully designed for the patients who are categorised under the same umbrella term "Breast cancer patient in Stage X"? This touches on the issues of intersectionality and subjectivity that makes each patient unique in experiencing their illness.

There are increased attempts at looking at the lived experience of living, surviving and suffering with critical illness, the needs of patients, the socio-ecological contexts of survivorship, the meaning of quality of life and the communication of illness through qualitative research by medical professionals and providers of care such as nurses, counsellors or psychotherapists, social workers and others concerned with cancer care (Frank, 2001; Frank, 2002; Wright et al. 2004; Luoma and Hakamies-Blomqvist, 2004; Thewes et al. 2004). Some even add to the sparse literature concerning the psychosocial sequelae of breast cancer among women of color. For instance, Audre Lorde, making her identity as a Black Lesbian poet known, argued in her work "*The Cancer Journal*" (1980) against the dominant culture of making the post-mastectomy breast cancer women wear prostheses or have breast reconstruction as the standard for returning to normalcy - keeping both breasts as the identity of a female. The impact of culture and the socio-ecological contexts of survivorship play an influential role in shaping the life of breast cancer women. In their study on the experience of breast cancer patients of women across different ethnic groups, Ashing-Giwa et al (2004, 412) find that body image and sexual concerns were common issues for women across all ethnic groups. Regarding body image and sexual health concerns, a number of women expressed trauma, loss of body esteem and were vulnerable to experiencing a sense of damaged womanhood (426).

Illness as Biographical Disruption

Critical illness is an embodied phenomenon from which only the people who experience it can make meaning of the trajectory of their illness. Trajectory, in a narrow sense, refers to a path or line of development in one's life. From a biomedical perspective, the trajectory of a patient's illness is presented as disease trajectory that is predictable and quantifiable.

In his classic paper in the study of chronic illness, Bury (1982) describes critical illness as a biographical disruption- an event that brings disruption to the structures of everyday life and the forms of knowledge which underpin them. It is also critical by nature as it makes us recognise and experience the worlds of pain and suffering with even the threat of death which had previously been felt as a distant possibility or the plight of others (Gaydos, 2005, Sakalys, 2003, cited in Bruce et al. 2014). The "not-yet-me" mindset is shaken. Bury (1982) argues that since many chronic illnesses are insidious by nature, it is difficult for us as human being to recognise and legitimate the feelings until diagnosed. Hence, patients are left in the state of shock of disbelief, anxious and disoriented. He contends that there is rarely anything in our biography that provides an immediate basis for recognition of the illness as illness (171). Illness forces people to re-examine their expectations and plans that they hold for the future. Bury concludes that chronic and critical illness compels patients to confront disruptions in directions that can be broadly classified in three areas. These are the disruption of their common-sense boundaries (i.e., taken-for-granted assumptions and behaviours of our way of living); profound disruptions in explanatory systems normally used by people, such that they are made to re-think their biography and self-concept; their response to disruption that involves the mobilisation of resources to face the altered situation (170).

Tembo (2019) conducted research on patients in an Intensive Care Unit (ICU). She further elaborates the biographical disruption by looking at the phenomenological aspects of disruption from bodily and mind perspectives. In studying the disrupted experiences of her ICU patients, their lived experiences unfolded the complexity and significant biographical disruption in their lives. As chronic illness survivors many of them, even after discharge from ICU, are still plagued with the sequelae of disease and the need to reunite themselves to their old self, their family, and the community at large. She gives a detailed account of the biographical disruption that critical illnesses can bring about among patients in the trajectory of illness experience and that emphasises that recovery is complex and not a simple return to before.

Tembo (2019) finds that the experience of critical illness throws people into the state of uncertainty, suspended between life and death. Floating, as a state of being between consciousness and unconsciousness, perpetuates a sense of being in limbo, and thus uncertainty about the future. It is a sudden traumatising experience that affects the objective (outward/external) and subjective (inward/internal) way of being in the world (5). Her study reveals that living through illness brings the mortal nature of life into consciousness. The trajectory of receiving treatment, depending on the intensity of the illness, is characterised by the experience of receiving invasive and painful procedures such as surgery, radiotherapy, or chemotherapy, rendering patients dependent totally on medical professionals and close family members (6). Elliott et al. (2011) claim that even after success in managing critical medical conditions, patients may still live with anxiety, depression, or post-traumatic stress disorder (PTSD) that affects their quality of life. The treatment experiences can be strange, noisy, restrictive, and persecutory. For instance, patients' fear and anxiety are associated with the use of technology that gives them hope and a sense of security and yet dependence on it for their existence. Tembo (2019) finds that patients' embodied experiences of technology evoked feelings of objectification and alienation that further compounds the experiences of being critically ill. Almerud-Osterberg (2010) examines critically the presence of technology in high-tech wards and argues against caretakers' technical closeness to patients with a spectator's vision. She contends that connectedness is obtained by close physical and emotional proximity, not close monitoring with high technology and that "technology is co-creating the way we interpret ourselves and conceptually depict the world" (5). Wang et al. (2008) conducted a study of patients' experience in surviving mechanical ventilation in an intensive care unit. Their study reveals an overwhelming feeling of passivity and helplessness to their physical suffering and experience psychological suffering, like hallucinations, nightmares, and fluctuating levels of consciousness. Objectification, being a subjective experience of disappearance and invisibility, can evoke feelings of loneliness and fear, of being an inanimate object. The literature reveals that while medical examination and treatment bring hope of recovery, they can also be the source of pain and discomfort, such as the penetration of technological devices into the patient’s body, intubation, blood sampling and suctioning. As Tembo (2019) finds, at the objective level technology, in the form of invasive and non-invasive lines, can be experienced as therapeutic, yet at the subjective level, a patient’s tension and discomfort is associated with the presence and foreignness of intravenous and other lines that require patients to lie motionless.

Apart from feeling persecuted or objectified with physical pain, disturbances in cognitive functioning in terms of consciousness such as non-recall, delusions, hallucinations, and dreams are not uncommon experiences reported by patients living with critical illnesses. It has been extensively documented that memory loss of events is not uncommon. For instance, Adamson et al (2004) examined the lived experience and memories of critically ill ICU survivors six months after ICU discharge. They found that some patients had no memory at all of their critical illness. They argued that this might be attributed to the timing of the interview and that six months might be long enough for some patients to have lost memories. However, there are arguments that depressive and disruptive states lead to the fading of both pleasant and unpleasant memories (Walkeret al. 2003, cited in Tembo 2019). Some studies argue that non-recall can be associated with violation of personal space and integrity (Granberg et al. 1999). Some do not wish to know what happened to them while they were unconscious. Avoidance of discussing unpleasant ICU memories (or what I would call them, traumatic experiences) is common in patients who experienced delusional memories during their critical illness in ICU.

However, patients in many studies have reported various reasons for avoiding talking about memories (or lack of them). These can be a means of self-preservation from trauma. The notion of amnesia as a form of self-preservation to protect patients from developing PTSD is supported by Weinert and Sprinkle (2008). They reported that the avoidance tendency was due to embarrassment, particularly in patients with delusional memories. Jones et al (2001), on the other hand, argue that some memory, albeit unpleasant, could offer protection from anxiety (cited in Weinert and Sprinkle, 2008). Dreams are also a feature of the disturbance of consciousness. In fact, memories are a fundamental ingredient of continued existence. The loss of memories can be transformative to one’s continued existence. Mental health problems as manifested by PTSD-related symptoms such as depression, nightmares and delusional memories are commonly reported (Tembo, 2019).

As van Manen (2018 [1990]) notes, human existence comprises four fundamental thematic structures, namely spatiality, corporeality, temporality, and relationality (cited in Tembo, 2019). To understand the lived experience in the illness trajectory and the meaning attached to it, we need to understand the four aspects in their stories, namely their lived space (spatiality), lived body (corporeality), lived time (temporality), lived other (relationality).

The literature seems to suggest that the trajectory of patients with critical illness looks gloomy and scary. I remember that at the time of diagnosis, I wondered if I, as a cancer patient, would have the same destiny of living with diminished personhood, being objectified and succumbing to be a victim of cancer? I frantically grabbed ten small booklets for breast cancer patients published by NHS. They documented neatly the predictable path of treatment and recovery tips that seemed to offer hope and reassurance. However, as time passed by, the more I read the booklets, the more I wondered if my trajectory would be similar or different from those as described in the booklets? It seems I lost the sense of self in the booklets. My wounded researcher voice asked questions.

Cancer, Trauma and PTSD

The conflict between the will to deny horrible events and the will to proclaim them aloud is the central dialectic of psychological trauma.

- Judith Lewis Herman, Trauma and Recovery (cited in Schmidt, 2018, 41)

According to Caruth (1995, 2016 [1996]), trauma refers to sudden or catastrophic events which are characterised by responses to events that are often delayed, uncontrolled and repetitive hallucinations and other intrusive phenomena, overwhelming in nature. It challenges the unprepared victim. The delayed response with accompanying symptoms is central as this response constitutes the actual trauma. Caruth states that the notion of belatedness is derived from findings in psychology and neuroscience and was observed by the French psychologist Pierre Janet and his contemporary Sigmund Freud. Janet and Freud borrowed the term "latency" from medical discourse on infectious diseases in relation to the incubation time until trauma manifested itself in symptoms. It is found that those who suffer from the pathology of trauma do not assimilate or experience the event fully at the time, but only belatedly, in its repeated possession by an image or event (Caruth, 1995, 8-9). How can we address this belated nature of responses to trauma? How likely is the trajectory of illness to be changed if lack of awareness of trauma is brought to consciousness, to the forefront? Is it beneficial or harmful to be aware of being in trauma with the associated biographical disruption? The voice of my wounded-self, wounded- researcher self and wounded-counsellor self emerges like surround sound.

To be traumatised is precisely to be possessed, completely controlled by an image or event. Caruth (2016 [1996]) argues that because of its belatedness, trauma is fully evident only in connection with another place, and in another time and hence not locatable, appearing “outside the boundaries of any single place or time”. This implies that the temporality (the lived time) and spatiality (the lived space) of human existence are impacted. During involuntary sensory flashbacks and nightmares, patients experience memories, sensations, and emotions from the traumatic event as if it were happening again in present time (American Psychiatric Association, 2013). Re-experiencing the trauma may include physiological responses and sensations associated with the trauma, such as heart palpitations, shortness of breath, pain in a mastectomy scar or chemotherapy-related nausea (Leano et al. 2019).

Cancer as Traumatic Event or Traumatic Experience

Unlike single traumatic events that induce PTSD, cancer usually behaves as a chronic and ongoing stressor (Cordova, Riba and Spiegel,2017). Cordova and Andrykowski (2003) find that continuous monitoring and routine follow-up appointments can trigger trauma among cancer survivors by acting as fresh reminders of their cancer. In their critical review on the empirical literature on PTSD following cancer, Kangas, Henry and Bryant (2002) find relatively high incidence of both intrusive and avoidance symptoms related to experience with cancer across studies. PTSD symptoms seem to fluctuate over the course of an individual's experience with cancer.

Caruso et al. (2017) find that cancer and cancer treatment can cause declines in overall functioning, including poor concentration and memory impairment, which can impact normal daily activities. A highly independent individual may have trouble taking on the more dependent role of 'the patient' and experience elevated distress and discomfort by relying on others to take care of them. They may perceive medical testing and treatment as threatening stimuli and feel isolated. These, and other side effects of cancer and cancer treatment, can significantly influence a patient's psychological state, potentially causing a patient to be more susceptible to developing PTSD during a traumatic event in the diagnosis, treatment, or survival.

In their review of literature on PTSD in patients with cancer, Leano et al. (2019) find that cancer is so powerful and daunting that some individuals are even afraid to say 'the C word', and that many aspects of cancer diagnosis and treatment can act as traumatic events, leading to cancer-related PTSD. They comment that there is a common misconception that Post-traumatic StressDisorder (PTSD) is only relevant in circumstances of acute, physical trauma and opine that cancer-related Post-traumatic Stress Disorder (PTSD) is missing in the cancer literature. They note that just a decade after PTSD was described, PTSD was adjusted in DSM (DSM-V) (2013), which states that, "a life-threatening illness or debilitating medical condition is not necessarily considered a traumatic event". It seems that cancer is regarded as an event, implying that it is one-off incident.

However, cancer is unquestionably chronic by nature. Ghazali et al. (2013) find that even patients in remission can have heightened anxiety due to fear of recurrence. Fear in cancer survivors can be triggered by follow-up scans and oncology visits, physical symptoms (i.e., pain), or death of a public figure due to cancer. Studies show that trauma is incomprehensible but demands a listener and a reader (Caruth, 2016 [1996]; Charon, 2006; Charion, 2008; Muller, 2018). Cancer as trauma touches on the four aspects of fundamental structures of human existence as identified by van Mannen (2018 [1990]). To reiterate, they are corporeality (the lived body), spatiality (the lived space), temporality (the lived temporal) and relationality (the lived other).

The review of the literature on the relationship between cancer and PTSD triggered my curiosity about how I would respond to cancer-related events. As a wounded researcher, I wondered how I, as a patient, would recognise that I myself was being traumatised especially in the state of biographical disruption? Due to the belated nature of trauma, how could I tell if I were traumatised? How could I know and recognise how and when those aspects, namely, corporeality, temporality, spatiality, and relationality, were impacted by cancer and in what ways? Who would judge if I were traumatised - myself or the medical professionals with reference to the DSM-V or others who I am in associated with? The aspect of relationality comes in. If, as DSM-V states, life-threatening illness or debilitating condition is not necessarily considered a traumatic event (American Psychiatric Association, 2013), it seems that the meticulous description and identification of the symptoms of PTSD as the manifestation of trauma serves the purpose of classifying or categorising people. It has this function more than helping us understand how and why PSTD is manifested in some but not other patients with critical illness.

Meaning in the Disrupted Life

Conducting a literature review on the biographical disruption brought about by critical illness brings into focus the “potential impacts” of illness on my life. It reminds me of the experience of radiotherapy and mammogram. Having to stay alert to remain immobilised (lying flat and fully awake), but subject to foreign control (by machine) can be experienced as a threat to existence. As Tembo (2019) states, the presence of advanced technology in assessment and treatment can transform an individual’s existence by obliterating the gap between them and technology, making them inseparably one. The experience of technology heightens emotional chaos for the recipient and leads to anxiety and fear. The important revelation is that a patient’s right to survive is surrendered to the equipment. As Bury (1982, 171) describes, this is a shift “towards a fundamentally abnormal and inwardly damaging state, with the relationship between internal and external reality upset.”

I wonder how a patient, like me, sits with this biographical shift when the clock is ticking. According to Bury (1982, 172), this involves uncertain knowledge of the impact and course of the condition and of appropriate behaviour in the face of its effects. As a patient, I fall into a world of confusion: identity loss, recovery with recurrence, vulnerability, risk, and other feelings that I cannot identify until time unfolds them. Studies report that uncertainty in the experience of illness is common (Bury, 1982; Kleinman, 1988; Charon, 2006; Bruce et al. 2014; Tembo, 2019). This involves uncertain knowledge about the impact and course of the condition and of appropriate behaviour in the face of its effects and places us in the state of liminality - the experience of in-between and uncertainty of fear (less-ness), being alive but not living, the (in)visibility of disease and knowing and not knowing (Bruce et al. 2014).

Liminality is used to identify the qualities of transitioning or a state of being in-between and in the context of life-threatening illness, liminality is used to describe "a psychosocial space for people living with critical illness such as end-stage renal disease, HIV-AIDS, and cancer" (Bruce et al. 2014, 36). These uncertain ambiguous experiences are often difficult to talk about and point to an unsayable aspect of liminal experience (Rogers et al. 1999).

Out of good will in the medical world these uncertainties are given certainty, with clear instructions on what to do and what not to do, by producing information booklets for patients with different medical conditions. Access to medical knowledge, as Bury (1982) states, may offer an opportunity to conceptualise the disease as separate from the individual's self, but such a perspective is also under criticism. Bury further elaborates that while it is natural for us, being victims of illness, to attempt to strike a balance between seeing the condition (of chronic & critical illness) as an outside force (*that can be grasped*, *described*, and *made sense of)* it does invade all aspects of life (*that makes it more difficult to understand from within)*. What can be made "concrete" in medical terms could not be synchronised in the inner state.

As a reader of all these research reports on patients' illness experiences, categorised systematically, I feel more discomfort and confusion than before. This is despite these reports being produced to help medical professionals or caretakers to have better understanding of the needs of the patients living with critical illness.

The realisation that medical knowledge is incomplete compels me to search for a more comprehensive level of explanation. As well as coping with the trajectory of illness, other kinds of uncertainty cannot be registered. These include how tolerant others are of my illness, my vulnerability, and my feeling that I am a victim of illness? This aspect of relationality cannot be easily expressed and researched as trauma usually silences the victim.

In searching for meaning in an illness event, Bury (1982) refers to the search for the causation of illness, that is ‘why me?’, ‘why this time?’. There is an underlying assumption that we can trace the cause by presumed knowledge of the disease’s causation. This touches on the “why”- leading to the moral question of familial transmission. This can pass from generation to generation, aggravating the experiences of illness – the feeling of “having done something wrong” to bring about this illness. It operates on the assumption that we could have prevented it from happening if we had behaved well. The mindset of “If we had been…we would have been able to…”, may make the patient feel either the victim or the prisoner of their own wrongdoings. There is a moral judgement here in the meaning-making process. The meaning of the event can also be interpreted in terms of “an analogous shock to life” (Bury, 1982, 175), questioning the issue of fairness, upsetting the way in which an already hard-fought life manages different kinds of life difficulties. The illness event can also be taken as a disruption of existing relationships, or material and practical affairs. Withdrawal from social relationships and growing social isolation are major features of chronic illness. While others are willing to offer support in different ways to help one normalise in the face of disruption, the progression in the disease might make the maintenance of such social relationships vulnerable for different reasons. This really touches on the aspect of lived other (relationality) as one of the fundamental thematic structures of human existence in their living stories. What will happen to me as I am studying abroad and facing the illness alone? How does the issue of relationality, in relation to self and others in a foreign land, manifest itself especially when under the pandemic Covid attack with a national lockdown at the time of the research? These questions open the space in researching the aspect of relationality in the trajectory of illness.

Studies show that most survivors experience transformative or life changing physical and psychological sequelae that continue to afflict them. Some patients continue to experience delusional memories, anxiety, decreased mobility including symptoms of post-traumatic stress disorder which compound decreased HRQoL (Elliott et al. 2011, Skinner, et al. 2011; Tembo, 2019). For instance, Elliott et al conducted a RCT study to assess the efficacy of 8-week graded, individualised, endurance and strength training intervention to adult intensive care patients recruited from 12 Australian hospitals. They conclude that from a practice perspective, it is uncertain whether the access to a systematic and equitable access to post-ICU rehabilitation services can facilitate the recovery of survivors to their optimal physical, psychological, and social function. Tembo (2019, 13) points out that the sequelae are mostly related to delusional memories, depression and anxiety and critical illness and ICU hospitalisation (or other forms of medical treatment) transform perceptions of the world. Increasing survivorship from critical illness places a burden on patients long after hospitalisation. Tembo opines that very few models of care exist that address follow up care for ICU survivors or those who live with chronic critical illness. This points to the need for research into the needs of patients with critical illness as they are the only people who really know what it means to them to suffer from illness and what types of support are valid and relevant to them.

Navigating Liminality in the Trajectory of Illness

As discussed above, when diagnosed with a potentially fatal disease, patients with cancer may experience a loss of certainty and change in perspective about their futures (Grassi et al. 2017). This state of uncertainty is better understood from the concept of liminality that describes the experience of in-between and uncertainty that has been widely studied in different disciplines (Bruce, et al. 2014). Bruce et al. (2014) used liminality as an analytic concept for understanding the grey area of living with life-threatening illness through researching patients' stories. They identify four narratives of pervasive liminality (a) storying into fear (less-ness), (b) being alive but not living, (c) the (in)visibility of disease and (d) knowing and not knowing. They used the term pervasive liminality to differentiate experiences (i.e., fear, living, visibility of disease, knowing) from the commonly used notion of liminality as an in-between phase in a multistage process, like pre-diagnosis, diagnosis, postdiagnosis (Blows et al. 2012, cited in Bruce et al. 2014, 38). In pervasive liminality, the stories convey being amid what might otherwise be seen as discrete experiences that overlap and fluctuate over time, like living a double existence, such as "I do have cancer and I don't" in the state of remission (Bruce, et al. 38). Pervasive liminality points to this "overlap" - the in-between experience of both having and not having cancer. These in-between experiences pose challenges when trying to clearly describe experience. Bruce et al. (2014, 38) uses parenthesis (such as fear(lessness) and (in)visibility to capture the paradoxical experiences where there is an "in-between" at play. Such experiences go beyond polarities to create overlapping spaces of being both fearful and fearless or being visible and invisible at the same time (Meyers, 2008).

As a patient under the biographical disruption impacted by cancer, how would I live with the liminal experiences that are ambiguous, uncertain which are usually unsayable? As wounded-researcher, how could I research into the lived experience of liminality - in-between and uncertainty? This implies the importance of going deeper and nearer to the patient's experience by entering the liminal space. But how?

Call for Narratives of Illness

Critical illness is an embodied phenomenon from which only the people who experience it can make meaning of their trajectory of their illness. That is why there is interest in the narrative inquiry into the lived experiences of patients living with critical, chronic, life-limiting illnesses. It is contended that narratives of illness provide the lens through which such embodied phenomena can be understood.

Frank (2005) argues for the dialogical approach to research in illness. Being influenced by Bakhtin's dialogical ideal, Frank proposes that both the researcher and the researched continue to form themselves as they continue to become who they may yet be (Frank, 2005, 967). Narrative research, whether in storytelling through formal interview or observations, shapes the future that is open to the claim of unfinalisability and the claim of freedom. According to Mikhail Bakhtin's concept of dialogue, unfinalisability refers to the idea that we help create events and concepts that happen in the world. Frank (2013 [1995]) develops narrative structures of restitution, chaos, and quest to understand the pedagogy of suffering. "Pedagogy of suffering means that one who suffers has something to teach" (150). Restitution is based on the assumptions that medicine has the power to cure and that patients yearn to recover. Chaos narrative portrays life that can never get better with a lack of coherence in illness experiences. The patients externalise their disease with reference to “it”. The quest narrative shows a different story. It involves reflexivity by the patient, who has self-consciously transformed themselves and has gained some insight from the experience that they feel obliged to pass on to others. Frank’s narrative structures have been used by others to investigate the lived experiences of patients living with life limiting experiences. For instance, Roultson et al. (2018) used Frank’s (2013 [1995]) narrative structures of restitution, chaos, and quest to analyse and gain insights into the narration of the ‘suffering’ over time by twelve adult patients in Northern Ireland diagnosed with advanced lung cancer.

While it sounds appealing to be able to end up with a quest narrative that is therapeutic and transformative in nature, I feel puzzled how patients navigate their trajectory in ways that help them to live beyond the biographical disruption impacted on them by the illness. At first reading, I found Frank’s notion of narrative inquiry with the use of narrative structures to understand patients’ experiences limited as the structures are used as a tool to locate the type of narrative of illness they belong to. How is this different from the medicalisation of the patients’ illness experiences by attaching medical labels to them? I wonder how a patient can engage in dialoguing with the illness and navigating the trajectory to see how it evolves.

Charon (2006, 45) contends that what distinguishes narrative knowledge from universal or scientific knowledge is “its ability to capture the singular, irreplicable, or incommensurable”. Narrative knowledge provides one person with a rich, resonant grasp of another’s situation as it unfolds in time, whether in such texts as novels, newspaper stories, movies or in such life settings as illnesses, battlefields, or marriages

(9). Unlike scientific knowledge or epidemiological knowledge, which tries to discover things about the natural world that are universally true or at least appear true to any observer, narrative knowledge enables one individual to understand particular events befalling another individual not as an instance of something that is universally true, but as a singular and meaningful situation. She further argues that nonnarrative knowledge attempts to illuminate the universal by transcending the particular; narrative knowledge, by looking closely at individual human beings grappling with the conditions of life, attempts to illuminate the universals of the human condition by revealing the particular (9). She suggests developing narrative medicine as part of the regime of communication with patients. Launer (2018) contends that witnessing narratives can invite change through conversations.

Meaning Making Makes a Difference

Bondi and Fewell (2016, 6) remind us that while the value of objective, experience-forms of knowledge may be useful in some circumstances such as for instrumental purposes, it is "the sensitivity to the very particular context of each therapeutic relationships" that matters most. This points to the question of how the sensitivity to the very particular context that the patient is facing on their own and/or with others is cultivated?

Through a systematic literature review, Higginson and Costantini (2008) found that in Mount's study (1983) some patients rate their quality of life very highly during advanced cancer, even higher than before they were ill. Nakashima and Canada (2005) suggest that paying attention to spiritual and psychological wellbeing and creating meaningful narratives of living and dying promote resilience. Studies show that programmes preparing patients for a narrative account of their lives and goal re-engagement as a coping strategy help improve dignity and psychological well-being. (Chochinov et al. 2005; Schroevers et al. 2011). Lee et al. (2006) highlights the importance of incorporating meaning making intervention in exploring the meaning of the emotional responses and cognitive appraisals of each individual's cancer experiences within the context of past life events and future goals. This has the aim of improving self-esteem, optimism, and self-efficacy (through 4 sessions of intervention). They indicate the efficacy of meaning making in addressing mortality.

In the review of literature on the autobiographies by women living with breast cancer for the past century, Thatcher (2003) documented how breast cancer has been regarded as a taboo that silenced women, their families, and the general public. Women with breast cancer felt ashamed, embarrassed, and de-sexed after radical mastectomy. The feeling of shame silenced most, if not all, women with breast cancer in the public discourse. There was, however, a shift in addressing breast cancer as part of the public fight against cancer in 1970s and 1980s, with prominent advocates like Audre Lorde and Susan Sontag and others who wrote about their cancer autobiographies in a variety of contexts, such as self-published "web diaries". Their proactive acts made breast cancer visible in the public discourse. However, there was still very limited and biased representation of breast cancer, with the focus on helping breast cancer survivors to be seen as "normal" by having models to represent the "official models' body". This concealed a more realistic picture of cancer patients whose breasts are unreconstructed. There is an attempt in the medical world to helping breast cancer survivors rush to normalcy with a preference for the magic creation of reconstructed or prosthetic breasts. As Thatcher (2003, 664) finds, much of the medical-produced postmastectomy literature urges women to reconstruct their breasts or use prosthetic breasts immediately following mastectomy operations. It seems the prosthetic breast is the way to enforce a normalcy that is far from the truth. The renowned advocate, Audre Lorde (1978, 35) declares that "I knew sure hell I'd know the difference", the difference between before and after breast cancer. The autobiographies by Audre Lorde, the author of "*Cancer Journals*" (1980), and many others who wrote their stories of breast cancer stretch the parameters of the female body image and contribute to the need to change the current cultural and medical discourse on breast cancer which is primarily fixated on the concept that having two breasts as the only representation of a normal female (Couser, 1997). It seems that there is weakness in supporting breast cancer patients.

I have traced the lineage of the research that dominates the medical literature in examining the trajectory of illness as linear, standardised, and quantifiable. Currently, however, there is a shift to researching illness from the perspective of patients. This leads to an increase in writing about personal illness in general and cancer in particular in different forms e.g., autobiographies with a common theme of living with illness in one's own way. These include Anatole Broyard (1992), the author of "*Intoxicated by my Illness*", and Ruth Picardie (1998), the victim breast cancer, who wrote the book "*Before I Say Goodbye*" a collection of emails that describe the progress of her illness with friends. Engelberg (2006) uses cancer comics to add humour to her cancer experiences as trauma. Jane Speedy (2015), in her book "*Staring at the Park*", documented her stroke experiences to illustrate how she navigated different plateaus in her trajectory. She expressed her disappointment with the stroke survivor narratives she came across. They were represented with "the neatness of the endings and coherence of stories" (13). For her, it was another conceit that masked confusion and incoherence in experiencing illness (14). Moore et al. (2019) present the bodies of truth that matter to authors with terminal illnesses in their collection. They show the unique illness experiences that cannot be domesticated, privatized, or individualized as if all have the same disease trajectory, which is the predominant narrative in the medical world.

Samuel Sanes (1979), a physician who wrote about his own cancer experience, reflected how much he would like to change the nature of communication between patients and doctors. He wrote,

> "If I live long enough, and if my physical condition permits, I shall write about the "how" of communication during this apparent terminal episode, of course based on my wife's observation and experience" (201)

What is my style in experiencing my cancer illness then? As Thatcher (2003, 666-667) states, our predecessors have created works of art that tell stories of breast cancer without attempting to represent every story of breast cancer. There is no single trajectory or destiny; acceptance and transformation are not necessarily everyone's experience, but what is important is not to domesticate, privatise, or individualise disease, but to transform the culture of assuming the homogeneity of cancer patients. What is needed is to recognize patients' experiences and respect what matters to them most.

What I gained from reading others' writing of their illness experiences are consoling, and their writings shape mine, but I did not know how to get started writing mine. This motivated me to engage in researching the illness through writing about it. Their writings tell me that in the trajectory of illness, the experiences can be this, can be that, can mean this, can mean that. The purpose is not to find a uniform or safe straitjacket to put on. It is to tailor make my own new uniform or straitjacket that suits me in immersing myself in the trajectory.

According to Vygotsky's constructivist principles of learning, it takes place through cultural input and social interaction with other people and the world around us (Vygotsky, 1968; Wilkinson and Hanna, 2016). With the aid of scaffolding, learners are supported to develop new understanding when they are in their zone of proximal development (Vygotsky, 1968; White, 2007; Gremillion, Cheshire and Lewis, 2012). Based on Bruner's theory of the human mind, modes of thought are all narrative, and they are shaped by social interaction and culture. The idea of human agency is central (Takaya, 2015). This motivates me to adopt a narrative approach in conducting this inquiry, to uphold an idea of human agency that is in alignment with a person-centred approach to counselling and psychotherapy. It also reflects the consoling and containing function of developing illness narratives that are healing and transformative. As Frank (2002 [1991]) states, human suffering becomes bearable when we share it. It is the power of recognition that helps reduce suffering that cannot be explained, though it seems fundamental to humanity. Frank (2003 [1995]) further argues that suffering needs stories and we, human beings, are unprepared for becoming wounded. We need a guidebook for the day when we become wounded storytellers.

In the review of literature, I have identified studies that examine the biographical disruption that critical and chronic illness bring about in people's lives before and after diagnosis and treatment. However, among those who put under the category of critical and chronic illness, each patient has their singularity (Charon 2006). So, we need research which studies how a patient can give responses to their experiences of illness through writing them as a process of inquiry.

Dialogue, Writing, Creating as a Process of Inquiry

As Bondi and Fewell (2016) state, we need examples of practice to add strength to experience-near research. Storying is a creative means of claiming one’s own voice. Frank (2000, 2005, 2010) argues for the dialogical approach to research in illness that enables both the researcher and the researched to continue to form themselves in the process of becoming who they may yet be. I contend that collaborative writing in imaginal dialogue creates a new space for cultivating the new sense of self when developing one’s own quest narrative, if we wish to do so. The notion of quest narrative is taken from Frank’s work (2013 [1995]). He finds that in those quest stories, interruption to life by illness is reframed as a challenge that offers an opening to personal growth. The quest narrative affords the ill their most distinctive voice “in searching for alternative ways of being ill” (117). Through reflection and recollection, the storytellers in the quest narrative develop the communicative body that has “the ability to grasp itself reflectively as a communicative body: to *be* associated with itself, open to contingency, dyadic towards others, and desiring for itself in relation to others” (127). This touches on the aspect of relationality.

As a patient with critical illness, the notion of developing a quest narrative is motivating and inspirational. I believe that instead of allowing others to be the expert in researching our lives, I argue for proclaiming one’s new identity and voice through self-narrative inquiry into a self (non-) transformational process in the illness journey. It is a new approach engaging in the quest of illness experiences that affords the opportunity of navigating the path of mortality in the liminal space - the in-between in the present and the future. Quest in living with uncertainty in the liminality of illness offers space for defining a transformed self. This also challenges the current concept of recovery or cure that is rooted in the biomedical model that fails to address the fundamental existential human condition of mortality.

Qualitative approaches in researching patients' narrative experiences through interviewing patients and then identify the themes is common research practice (Öhman, Söderberg and Lundman (2003); Sacks et al. 2016). The duration of interviews can range from one hour (or even less) to three hours. The interviews aim to identify new understandings of the phenomenon with themes or categories which emerge from the interview data. These include experiences in communication during the oncology care process or the lived experience of illness in relation to body, sense of loneliness and struggles for normalcy. When I read those research reports and findings through the lens of wounded researcher (my identity), I find they are experience-far despite the adoption of qualitative approaches to researching the lived experiences. For instance, Öhman, Söderberg and Lundman (2003) aimed to study the illness experiences of patients through a phenomenological hermeneutic method. They interviewed five women and five men with different kinds of serious illness. They interpreted the transcribed interviews that ranged from about 40 minutes to 60 minutes. Three major themes in their lived experience of illness were identified, namely experiencing the body as a hindrance, being alone in illness, and struggling for normalcy. Their study suggested that their subjects seemed to hover between an escape from the emotional suffering, pain of illness and the emotionless state of enduring. They concluded that a comprehensive understanding showed that living with a serious chronic illness means living a life that is hovering between enduring and suffering but also includes the process of reformulation of the self. While the study highlighted the phenomenon of hovering between states of emotional reactions, I am left with the mystery of the reformulating of self in the context of illness.

In another study, Sacks et al. (2016) conducted a qualitative study of cancer patients' experiences of communication during the oncology care process. They held interviews with the patients, ranging between one and three hours. Like other qualitative research which adopts a phenomenological hermeneutic method, the understanding of patients' experiences in communication during the oncology care process is generated through the process of reducing the patients' experiences to categories. This is based on the belief that such categories can represent the holistic understanding of patients' lived experiences which are context-situated and unique. For instance, they identified two themes which affect patients' perception of illness experience, namely an appropriate care process and inadequate information. They highlighted the components of desirable health care in terms of manner with respect, ways of transmitting the information about the disease and a care process with scientific rigour guaranteeing trust and security. Inadequate information about the diagnostic process, and the risks and benefits of the different treatments made the illness experience stressful. While the findings might give health professionals some advice on doctor-patient communication, I question the extent to which those categories are of use in understanding the intricacy of communicating numerical information which is significant to diagnosis, treatment and prognosis grounded in a biomedical model in the medical discipline.

Interestingly, those studies usually point to suggest the use of more investigations that allow patients to recount their illness narrative instead of simply asking a series of questions about the course of their illness. They suggest that this helps not only to improve the quality of the information provided but also the empathy between patients and professionals (Sacks, et al. 2016)

In response to this type of study, as a chronically ill patient and a wounded researcher (dual identity), part of me feels as if I were the subject being "dissected" to be understood in a compartmentalised way. Such emotional reactions to those types of qualitative study remind me of how cancer impacted the normality of my life. I sensed the visceral feelings of discomfort, with body and emotions dissected for study. Even more irritatingly, I could not feel how the life of the subject(s) was reformulated as reported in their study. I feel the research is experience far instead of experience near. There is an increased sense of my frustration or even anger when the lived experience of illness is studied through the interpretation by others, rather than being made sense of by the subjects themselves. I feel an increasing desire from within and an inner voice asking me how my illness experience can contribute to knowledge in the field of illness narratives. I think I can conduct research on the trajectory of my illness and reflect critically through the lens of being a patient, a wounded researcher, and a wounded counsellor. This may contribute to the literature of "thickly descriptive studies that help us understand human sufferings, human conditions, and humanity" (Dunne, 2005, cited in Bondi and Fewell, 2016).

With my tri-role as a cancer patient, a wounded researcher and a wounded counsellor, the focus is not solely on disease trajectories as seen from my perspective as a patient. It is also important to look from a wider and more holistic perspective, experiencing the wholeness of such an illness beyond these disease trajectories from the medical lens of diagnosis, incidence rate, comorbidity, sequential patterns of disease trajectories (disease trajectories) as described in quantitative terms.

To conclude, I propose to shift from research of illness as a bio fact or treatment to research of the patient experiences of illness, offering a more experience-near example of cancer patients' illness experiences. I argue for moving away from the biomedical perspective of prescribing the disease trajectory that is seen as universal and prescriptive in the course of a cure. I argue for research into how individual cancer patients position and experience themselves in surfing the hurricanes of illness – a trajectory that is subjective, unpredictable, and non-linear and needs to be recognised, understood, and respected. The literature review on illness in general and cancer and cancer-related experiences in particular points to gaps in knowledge about how to research one's own trajectory of illness in the liminal space as a process of inquiry and therapy.

Chapter 3

Methodology

Introduction

My motivation to conduct this research is to understand the process of the illness trajectory and to witness how I was and, most important of all, am being impacted by the breast cancer, and how I will be, if at all, transformed in navigating the trajectory. By transformation, I mean a renewed sense of self in living with medical conditions. My purpose of this study is two-fold: (1) to re-establish my subjectivity in the face of objectifying treatment through self- exploration; and (2) to allow others who are in a similar condition to witness my experience of reconstructing and reconceptualising my own' illness trajectory. As Frank (2013 [1995]) advocates, I hope we can create our own illness narratives and share them to contribute to the understanding of how cancer patients make sense of their illness in the trajectory.

In this chapter, I present my ontological and epistemological position as a social constructivist in researching the experience of illness. I reflect critically on the benefits and risks of using autoethnography in researching subjective illness experiences of those who live with critical illness and are in trauma. I will explain why collaborative writing through imaginal dialogue as a method of inquiry serves the purpose of researching the experiences of navigating the liminal spaces in the trajectory of illness.

My Ontological and Epistemological Position in Understanding Illness

In my previous training in the fields of education and medicine, I found my ontological and epistemological stance continually challenged. When I was trained as a teacher, I was impressed by the social-constructivist perspective in knowledge building and construction in conducting educational research. However, when I embarked on my study in psychiatry, I was “trained” to adopt empiricism (positivism) in conducting scientific research which is the characteristic of the natural sciences. It contests that true knowledge needs to be backed up by an objective “evidence base” which is predominantly numerical or quantitative and often statistical (Bondi and Fewell 2016, 5). The process of inquiry is value-free and objective (Flick, 2015). It assumes a unity of scientific methods that are applicable to all fields of knowledge (McLeod, 2013). Positivists seek to make scientific statements explaining phenomena in terms of “cause-and-effect’ (such as X leads to Y) with the aim of making predictions and exerting control over future events. At an ontological level, it seems that there is only a single objectively provable answer to any question, through measurement and experimentation (McLeod 2013, 40-41). The central epistemological question is to ascertain if an explanation (hypothesis or theory) is correct or not through the process of falsification. All statements need to be subject to rigorous empirical tests in a variety of situations and only those meaningful hypotheses that have withstood the attempts of falsification are kept. Knowledge is seen as tentative, and it is derived through quantitative research. However, as Bondi and Fewell (2016, 6) argue, “when evidence is presented as thing-like, it keeps researchers at a distance from the feelings and subjective states of the subject”.

The adoption of a positivist approach in understanding my illness from the perspective of “Cause-effect” made me feel judged especially when I was diagnosed with cancer. I was shown biopsy test results, blood tests which presented the hard statistical evidence that I had cancer. The process of being asked about my family history, my daily life habits such as drinking, or smoking made me feel that they could be the cause of my illness. I felt as if I must have been doing things that led to cancer. This punitive sense of wrongdoing from the cause-effect perspective did not help me to understand how I could make sense of the complicated emotional reactions to the illness experience and how the moral dimension of illness evolved and was constructed. Such moral judgments prevented me, as a patient, from processing the underlying frustration, “What have I done to deserve this?” or “How can this be happening to me?”. Because I felt I was morally judged, I was silenced.

As Bondi and Fewell (2016) state, an approach to medical science emphasising objectivity and technical mastery is “experience far” and is, therefore, remote from the messy, imprecise, difficult to articulate quality of much of the work that happens in therapeutic practice. Being a patient-researcher-counsellor, I need alternative perspectives to understand the nature of the phenomenon or social world that might tell radically different stories (Mason, 2018). As argued by some therapy practitioners, there are important dimensions of human experience that cannot be measured (McLeod, 2013). I am interested in researching the deep, personal lived experience of having medical conditions that are biographically disruptive and the subjective experiences in navigating the liminal spaces in the trajectory of illness which could not be captured from the perspective of disease trajectory. My ontological and epistemological position lies in the social constructivism. I believe that we are part of the world and are socially and historically shaped. As Creswell and Poth (2018, 24) state, our understanding of a phenomenon is a basic structure of our experience of life and our act of interpreting the phenomenon (taking something as something) is subjective and socially co-created. We, as social human beings, seek understanding of the world in which we live and work. We develop the subjective meanings of our experiences that direct us towards certain objects or things. I believe that such subjective meanings are negotiated socially and historically and are formed through interaction with others. Hence, our sociohistorical inherited bias or prejudice needs not be abandoned in order to come to a “clear” understanding of the phenomenon (Schwandt, 2000).

Strictly speaking, there may be many local truths but perhaps not universal truth (Flick, 2015). As McLeod (2013) states, we cannot treat human beings as objects that are subject to experimental manipulation as are physical entities. To carry out systematic research inquiry from a constructivist perspective, interpretive or hermeneutic approaches to inquiry are adopted to allow the researcher to interpret the meanings that are expressed in a research “text” generated in the form of a transcript of a therapy session, or an interview or a client’s personal diary (Taylor, 1979; Flicks, 2015). As a constructivist researcher in this study, I attend to the “process” of interaction of self in relation with others to make sense of the deep personal experiences in the trajectory of illness.

This brings up the question of which methodology matches my ontological and epistemological positions in developing the understanding of my lived experiences in illness in relation to the socio-cultural context in which I am situated. One obvious possibility is the adoption of autoethnography as a method of inquiry. According to Ellis et al. (2011, 273), autoethnography is an approach “to research and writing that seeks to describe and systematically analyse (graphy) personal experience (auto) in order to understand cultural experience (ethno)”. This approach acknowledges that stories of personal lived experiences are complex, constitutive, meaningful phenomena that teach morals and ethics. These personal stories help us make sense of ourselves and others. Autoethnography is one of the approaches that acknowledges and accommodates subjectivity, emotionality, and respects the relational ties to the cultural members in research. It utilises data about self and context to gain understanding of the connectivity between self and others within the same context (Ngunjiri, Hernande and Chang, 2010). There is a sample size of one but arguably it is one in relation to many and, through sharing one’s particular experience, it can speak to the experience of many (Prior, 2021, personal communication). All interchanges and interrelations, including notes on power relations, are performed through the eyes of the researcher (Adams, Jones, and Ellis, 2015).

There are different ways of conducting autoethnography as a process of inquiry in researching subjective illness experiences through writing privately in the form of diary, journal writing or memoirs that engage in a rigorous process of reflection (Ettorre, 2006; Faust, 2017). There are some who confront their personal illness publicly through online publishing of blogs which engage in dialogue with readers or audience in real time (see Herrndorf, 2018 and Schlingensief, 2018, cited in Schmidt, 2018). The benefits of autoethnography in understanding one’s lived experience in illness are well documented in the literature, especially the healing effect in the process of writing (see Richards, 2016; Lapadat, 2017, to quote a few). However, there are also risks in conducting autoethnography. For instance, there are risks in relying on memory in traumatic state, as noted by Tembo (2019) who found the avoidance of discussing unpleasant traumatic experiences common in patients who experienced delusional memories during their critical illness. There are also risks in writing of the feelings of intense vulnerability that can become overwhelming and create ethical anxiety (see Richards, 2016; Lapadat, 2017; McMahon, 2020). Some researchers may have to give up using autoethnography in researching their own lived experience in trauma and adopt another method by collecting the stories of others who have “successfully” gone through similar lived experiences in suffering (see Teague, 2018). As Chatham-Carpenter states (2010), when writing about personal experiences that are so tied to our life course, autoethnographers have to be in a certain space to feel comfortable to write and are willing to engage in the process of writing that brings you in touch with the deep and repressed pain. However, I wonder how an autoethnographer can sustain and endure the process of writing about their pain and suffering especially when the wounds are still raw. As Teague (2018) states, as her traumatic experience happened only a year and a half before, it was too risky to adopt autoethnography as a method of inquiry in her context. The ethical guidelines for autoethnographic research require student researchers to maintain the critical distance required for research and hence it is not advisable for student researchers to undertake autoethnographic research on a topic they are processing emotionally for the first time (The University of Edinburgh, 2017). Does it imply that I should drop the idea of doing autoethnography or writing about my own cancer illness experiences that happened only three years ago while I am still living with it with uncertainty? How raw or not raw are the experiences of suffering that can be subject to investigation and reflection to generate knowledge of illness experiences that has no time boundary?

In most cases, as Couser (1997, 40), states, an autoethnographic approach to one’s illness experiences is retrospective by nature. Some authoethnographers conduct the research through retrospection of their life path impacted by illness only when they feel they are in recovery from the illness. However, for this type of research, the narrative closure is out of date and the condition of the author, who usually recovers at the end of the story, is usually known to him at the time of writing (62). As studies show, breast cancer is rarely considered cured because it is always susceptible to recurrence. There is no guarantee of a positive resolution and both myself and those who read my work will be led to a continuing state of uncertainty, unlike retrospective inquiry in which the writer knows the ending of the story (Couser, 1997).

For the purpose of coming close to the “truths” of the illness experiences, I think my study needs to be concurrent so that it captures the ongoing, moment by moment knowledge construction and creation in the process of developing one’s subjective meaning of the cancer experiences that are fraught with anxiety. The benefits of this type of research have the potential to focus on the fragile process of human vulnerability and mortality that might help process traumatic experiences. This adds value to the field of researching subjective illness experiences that are concurrent, not retrospective, in navigating the liminal spaces in the trajectory of illness.

To borrow Deleuze’s and Guattari’s (1980/1987) concept of rhizomes that have no beginnings or ends but are always in the middle (cited in St Pierre, 1997a, 187), this reflects the state of my illness condition. The image of the rhizome describes “a kind of adventitious multiplicity that is not rooted as are the roots of trees, but which produces stems and filaments… that penetrates what is rooted and put it to “strange new uses” (Deleuze and Guattari,1980/1987,15, cited in St Pierre, 1997a). I contend that the trajectory of illness is adventitious and has no predictable course of development. I am in no position to know how the cancer cells work inside my body. I suppose that how I experience cancer illness is relational, subject to people and events that I encounter in both the clinical and non-clinical contexts.

The notion of middle-ness and in-between-ness matches the current state of my medical condition in the illness trajectory. I need to find another methodology that can generate knowledge of how to live with illness that is ongoing, unpredictable, fluid, messy, chaotic, and that has no trace of absolute beginnings and no ends. This is different from the biomedical perspective of disease that has the beginning point neatly marked by the date of diagnosis and the ending by the date of treatment completion or ending of life. I want to develop a third kind of knowledge, not only beyond "knowing how" and "knowing that" but "knowing what it is like" (Goodall, 2008, cited in Richards, 2016, 164). This leads to the current inquiry and the research question "What is the trajectory of illness like?".

Towards a Methodology of Collaborative Writing through Imaginal Dialogue

In terms of epistemology, I believe that knowledge is co-created and co-constructed in the process of interactions with self and others.

> "Human beings are social creatures. We are social not in the trivial sense that we like company, and not just in the obvious sense that we each depend on others. We are social in an elemental way: simply to exist as a normal human being requires interaction with other people." (Atul Gawande, 2014, cited in McMahon, 2020)

Collaborative research offers multiple possibilities in opening a new arena in inquiry. Traditionally, inquiry is recognised as being solitary in process and product and as individual academic achievement even though collaborations are encouraged (Wyatt and Gale, 2012). Over the past decades there has been an increasing challenge to these orthodoxies. Wyatt and Gale (2012, 345), in their preface to a special issue on collaborative writing, state that collaborative writing is conceptualised as "fluid and contradictory" and "entanglements of matter and meaning". It highlights the other side of the academic world, one that is loving, intimate, embodied, and messy and deconstructs the binary between single- and co-authoring. For instance, Speedy (2012, 355) defines collaborative writing as an engagement with the "highly subversive activity, much neglected amongst scholars, of building *loving* communities within and across groups of writers, across disciplines and themes, and across continents". There are different forms of collaboration, broadly defined by Speedy (350-351) as "co-authored emotionally with and by… I had audience of my fellow collaborative writers… Each writing space, so-called "sole-authored" … was in fact co-peopled to the gunnels". Collaborative writing offers the space for writers to write themselves into each other's lives and open the imaginative spaces for readers and listeners to bring their lives into this collaborative writing (352). I was attracted by the open invitation to write my life into the lives of others and invite others to write theirs into mine.

Diversity in collaborative writing practices and modes has emerged over recent years. These practices include collective biography, nomadic inquiry and other emergent collaborative genres and approaches such as duoethnography, collaborative autoethnography and community autoethnography. Multiplicities in modes of collaborative writing arise organically to suit the context and the purpose of collaborative writing that allow fluidity in the process of inquiry (Wyatt et al. 2018). The familiar modes are "discuss®write"[1], "data®write[2], "the concept challenge"[3] and other forms such as "separate-together". These involve writing separately and then

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[1] discuss ®write: fertile discussions about the topic to hand are followed by one person writing the paper or book (Harre &Secord, 1972)

[2] data®write: collaboration begins with data that are generated by one author and written about by the other (Rosser & Harre, 1976)

[3] The concept challenge": the two or more authors engage in rigorous discussion back and forth about a concept to explore positioning

piecing the work together, allowing the creative flow among the collaborators. It appears that whoever collaborates in the writing, two or more “real persons” agree to work collaboratively over the agreed period to engage in the inquiry. Is there a mode that suits my purpose of inquiry into the process of experiencing illness?

Collaborative Writing through Imaginal Dialogue

The conceptual framework of the inquiry is built upon the belief that the experiencing persons can only validly portray their experience through a rigorous process of self-dialogue, tacit knowing and intuition, indwelling, focusing, and drawing on their internal frame of reference (Moustakas, 1990). Our most significant awareness is developed from our own internal searches and from our attunement to and empathic understandings of others. Through heuristic inquiry, I could move between my internal world and the external world that I inhabit. The process of self-dialogue could enable me to develop a deeper understanding of my own experience and this personal appreciation helps me to be more empathetic to the experiences of others. However, I was not ready to open my own vulnerability to work with others due to that the fact that I was still emotionally vulnerable and wounded. How could I conduct this study ethically then?

I needed a method that was “safe” for me to engage in the deep exploration of my emotional pain and transformation. As Fang (2020) asks, how can we narrate trauma when the intensity of emotional registers has disrupted the ordinary capacity to make sense of the experience. She experienced the power of imaginary dialogue that enabled her to search for voices in Virginia Woolf’s fiction and through which she could situate herself in a relational home where she could meaningfully engage with parts of self that bore reminders of grievous experiences. As Fang (2020, 18) argues, ”the emergence of emotional responses ignited by relational engagement with the voices mobilised a self-reflexive inquiry surrounding their historical origins and their relation to the continuous now”. Pineau’s *“Haunted by Ghosts*” (2012) and Tamas’s “*Life after Leaving: The Remains of Spousal Abuse”* (2016) present the power of collaborating with absent others (ghostly partners, internalised others, even others long dead and reincarnated in the narrative journey) that still allows the “solitary” practice of critically conscious autoethnography (Pineau, 2012, 460).

I felt the need for an imaginary space which is safe for self-exploration and yet in collaboration with others. Hence, I think engaging in imaginal dialogue as a mode of collaborative writing seems to suit my purpose of engaging in the inquiry into illness. I, as a psychotherapy practitioner, and Frank, as a sociologist, alter the academic spaces we inhabit and the ethical know-how that we come by as human beings confronting our existential human condition of mortality. I think by inviting Frank to be my imaginary collaborator, I/We can begin to rework and expand the social imagination (of illness) (Speedy, 2012). This collaboration in the form of imaginary dialogue is an explication of performative autoethnography that addresses those risks and concerns raised in the conventional autoethnographic approach to illness inquiry.

At the beginning of my research into the trajectory of being a chronically ill patient myself, I had not thought of collaborative writing. I was introduced to it by my supervisor who is one of the guest editors of this collection on the special issue: Collaborative writing as a method of inquiry (Wyatt and Gale, 2012). I remember that when I first read this collection in 2019, I felt alienated as this is not an approach that I had thought of. I had not thought of adopting this approach as I could not think of who I could collaborate with in exploring my own trajectory of being a chronically ill patient and a researcher of my own experience. I think this illness experience is so personal, so private, that I am the “only” one who knows what happens. I have such a “restrictive” or even “protective” sense of my vulnerability that I think it may be more appropriate to follow the norm of taking an autoethnographic approach in my inquiry.

When I started to engage in my “dialogue” with the author of the books “*At the Will of the Illness*” and “*The Wounded Healer*”, I felt set free from my repressed feelings of being vulnerable in exploring the lived experience of being chronically ill. I found that once I engaged in the open and genuine dialogue of Frank’s illness experience and mine. I found I could let those repressed negative feelings of fear, shame and frustration emerge and be responded to as if I had “my own psychotherapy”- a talking cure process which was non-judgmental and non-directive while being listened to. And such an open dialogue with the other who shares a similar trajectory enabled me not only to listen to my own, but also helped me co-construct a new understanding of our lived experiences in the illness world. When I shared this experience with a former classmate, she said that it seemed that I was having an empty-chair dialogue with Frank. Empty chair dialogue is a Gestalt intervention technique that is used in the therapeutic context that assists the client to engage in an imaginary dialogue with the significant other. This aims to help the client access restricted feelings, allow the feelings to run their course and be restructured a safe therapy environment (Paivio and Greenberg, 1995). I responded that this was the best description of my experience. I felt the profound effect of the empty chair dialogue with Frank.

I feel the shift in my way of researching the lived experience of illness. I think I have found the need to have narrative space to engage in discourse about “self”, through engaging in the discourse with the “Other”- a significant other who plays an important role in my trajectory. I cannot engage in my own without the presence of the Other. As the classic statement by Mikhail Bakhtin (1984 [1921], 252) puts it,

> “To portray the inner man... was possible only by portraying his communion with another. Only in communion, in the interactions of one person with another, can the “man in man” be revealed, for others as for oneself” (cited in Frank, 2002, 115)

I started to look for stories of illness with the hope that I could find the “right” way of telling my story of illness. After reading some life stories, I came across Frank’s story “*At the Will of the Body: Reflections on Illness*” (2002 [1991]) last July in 2019, the first anniversary of the completion of my radiotherapy. I was deeply influenced by Frank’s reflections on being a cancer patient. I had the impulse to write frantically on the margin of each page in response to Frank’s experiences that triggered my reflections. Gradually the book was filled with my words that represented my long-repressed feelings of fear, frustration, helplessness, and lack of direction. I felt emotionally overwhelmed. While I felt vulnerable, I felt as if Frank were listening to me, holding me and gradually the imaginal dialogue with him became so natural that I started writing dialogue with my imaginal friend, Frank, on my illness experiences. While I kept writing, I felt happy but also anxious about whether this could be a method of inquiry into my illness and could be an acceptable approach to research. But what I am sure is that, as St Pierre (1997b) states, writing generated a lot of transgressive data which are emotional, sensual and dream-like that might have escaped entirely if I were not engaging in nomadic writing practices. I felt as if I were in nomadic inquiry, that is characterised by the exchanges of thoughts and feelings through writing between authors to discover what is possible to become in the particular co-created space of inquiry (Wyatt et al. 2018). My supervisor encouraged me to keep writing and to allow the writing to lead me to wherever it will take me. Hence, I am also writing as if I were nomadic in collaboration with Frank and others, though not necessarily in turn (Wyatt et al. 2018, 742).

After a couple of months of engaging in this imaginal dialogue (Fang, 2020), a form of a dialogical interaction with Frank as my imaginary peer with life-threatening illness, I gradually found my voice, my sense of being. I told my supervisor that this methodological approach by engaging in an imaginal dialogue through collaborative writing with Frank helped me emerge from my deeply repressed sense of self as a cancer patient, which I had denied as a new identity since diagnosis. Through this process I realised that I had created critical psychic distance to reflect on my subjectivity in this new identity as a cancer patient (Wyatt, 2006).

I think that my dialogue with Frank about his illness experience enables me to have narrative space for my own illness experience. I think such a dialogue is not an ordinary dialogue, such as everyday conversation with friends, family members or colleagues. I find it is similar to “dialogue” described by Paulo Freire, the author of “*Pedagogy of the Oppressed”*,

> “Dialogue is the encounter between two men, mediated by the world, in order to name the world…it requires the two parties to reclaim their primordial right to speak their world…in speaking their word that people, by naming the world, transform it, dialogue imposes itself as the way by which they achieve significance as human beings. Dialogue is thus an existential necessity.” (Paulo Freire, Pedagogy of the Oppressed, 2011 [1970], 88)” (cited in Moreira and Diversi, 2014, 301)

I can decide what to bring to the dialogue and what not as Frank and I have reclaimed our own voice to name our experience, to make sense of our lived illness experience and its trajectory. The absence of “dehumanizing aggression” (Freire, 2011 [1970]) with someone who wants to overpower me allows me to understand myself and the world of illness I am in without taking in blindly the “script” that is written by medical professionals and the culture that I am in. I think the relationship that I have built with Frank through dialogue first and then collaborative writing is “betweeners” - the existence of those experiencing life more often “between” clear categories of identity than within them (Wyatt et al. 2018).

Since my research is about the experience of navigating the trajectory of being chronically ill, if I position myself as a lone expert in researching “the Other’, I am afraid that I will fall into the trap of seeing myself as having an innate right to observe the other, to put the other as an object to be interpreted and represented to claim my expertise of knowing them. And studying other does not mean that I understand my own world of illness.

As I come from Asia and I am foreign to the local culture, medical culture, and medical language, it is unbelievably stressful to adapt to the language used in the medical field and to be constantly reminded of self-care as a student here. I feel “oppressed” and even though my experiences throughout the treatment have been very positive, subjectively, I feel I do not belong here. I work hard to adhere closely to my treatment regime as if I were a kindergarten child. I feel scared by not knowing how to ask, what language or words to use, to convey my experience of being a patient. However, when I engaged in dialogue with Frank, I realized that it is not only me who has such experiences of feeling “alien” or “foreign” when communicating our thoughts or feelings even though he is receiving treatment in his home country. While we have some divergent visceral experiences of oppression, we do share some similar visceral experiences of oppression from being a patient. I find that by having a dialogue with Frank and turning the dialogue into a collaborative writing process with him, I feel I am no longer lonely. The initial attempt at engaging in the imaginal dialogue and documenting this as a process of collaborative writing helps me make the distortions of my illness experiences more bearable and meaningfully shaped. As Moreira and Diversi (2014, 300) argue, “writing together gives us more insights about the system of oppression and subjugation of the Other than writing alone.”

Probably the experience in navigating the trajectory of illness can better be understood through collaborative writing which includes at least one participant who has been and is still in that trajectory of finding the meaning of the lived experience of being chronically ill. As Diversi and Moreira (2009,13) state,

> “We can’t press the keys at the same time, but this introduction and the entire book are ours. Equally ours.”

Frank wrote his experiences of illness long before I experienced my chronic illness. However, through holding a dialogue between our illness experiences and turning it into a form of playscript that captured the imaginal dialogue, I engaged with Frank as a new form of collaborative writing of my autoethnography. This enriches and extends my understanding of the trajectory. Probably, dialogue and collaborative writing with many others going through the trajectory of being chronically ill can enrich our lived experiences and cross the boundary of time.

Collaborative Writing through Imaginal Dialogue as a form of Performative Auto-ethnography

Without knowing when and how, I gradually settle myself into autoethnography that I have once doubted I can and will be able to do. To be more accurate, I am doing and performing autoethnography, "performative autoethnography" (Spry 2001, 706). When concentrating on the body as the site from which the story is generated, and *performing* autoethnography, Spry conceptualises it as beginning the methodological praxis of integrating body and mind through dialogically looking back upon self as other and, generating critical agency in the stories of her life. She finds her authorial voice in her continuing process of integrating the *doing* of autoethnography, through poetic writing, with critical reflection upon autoethnography as a methodological praxis. It allows her to position herself as an active agent with narrative authority over many hegemonizing dominant cultural myths that restrict her own social freedom and personal development, as well as the social freedom and personal development of others (711). As Spry claims, it is through calling on the body as a site of scholarly awareness and corporeal literacy and through autoethnographic performance that we can become acutely aware of how we "I-witness" (ibid., 713) our own reality construction. However, being a convincing "I-witness", it is not simply about literary self-exposure, but must be emotionally and critically engaging and able to take us somewhere we could not otherwise get to.

In the context of this thesis, I am doing and performing autoethnography of my illness experiences in the form of collaborative writing through imaginal dialogue (Spry, 2001). Collaborative writing broadens our horizon in looking at the system of oppression and subjugation of the other better than writing alone. I feel energy that encourages me to be more creative, free-flowing, risk taking and articulate about my subjective lived experiences. The "let go" feeling is emancipatory if I am writing collaboratively. I feel emancipated in referring to my collaborative writing experiences and less subject to a research authority in justifying my choice of an inquiry method. I feel I am invited into collaborative writing instead of me being told to use it.

Through engaging in an imaginary dialogue with Frank, I find a secure base from which to unfold my fears, anger, and helplessness, as well as humour and resilience. The process of collaborative writing becomes a tool for researching the trajectory of my illness. According to Watkins (1986), imaginal dialogue as a dialogical interaction, can take different forms, between the self and an imaginal other, between aspects of self, or between imaginal others with self being the audience or witness (Watkins, 1986). I think this method aligns with the ontological perspective of self that the nature of self is fundamentally dialogical. Our sense of identity arises from narratively construed "wholeness", and we cannot be dialogical in the absence of any objects for relatedness (Sabrin, 2017; Fang, 2020). Relationships, ultimately, become "the very way of knowing, the locus of knowledge creation" (Diversi and Moreira, 2009, 20). As Wegener (2014, 355) states, critical self-reflection in ethnography has led researchers to speak about the "truth" of the research subject as an outcome of interaction, or even collaboration between research subjects and researchers. Shaping perceptions of our lived experiences occurs unconsciously. We can also seek it intentionally by seeking inspiration, as for instance, the fictional Phineas in Wegener's experience, Virginia Woolf in Fang's, and Frank in my experience. It is an indispensable process right at the beginning to make sense of my lived experiences. It is an important relational process in discovering my trajectory through engaging dialogues with the Other, including fictional Others. However, using imaginal dialogue as a method of narrative inquiry remains much under-researched and conceptualised (Fang, 2020).

When I started to enter a deeper layer of performance, from imaginal dialogue to the collaborative writing of a playscript, it is a further embodied, interactive and critical performative act of reflective writing that affords me to (re)enter the uninhabitable corporeal terrain of my cancer body and to problematise the context in which my cancer is experienced and embodied culturally. As Spry states (2001), theory helps to name the experiences interred in the body, whereas performance helps her reinhabit her body, immersing herself into those scary spaces, and through the semantic expression of autoethnographic practice it reflects the somatic experience of the sociocultural body. Such dialogical performance embodies an intimate understanding of self's engagement with another within a specific sociocultural context. Dialogical performance is a way of understanding the intersections of self, other, and context passionately and reflexively. This resonates what I experienced in my initial attempt to engage in the imaginal dialogue with Frank.

To enable that I have developed an informed consent from myself to engaging in narration of my illness experiences through imaginal dialogue and collaborative writing as a method of inquiry. I “played around” with this novel experience to get a taste of how bearable and containable such a research process is for me with the resources available (e.g., supervision, self-care mechanisms).

When re-reading my initial attempt at engaging in the imaginal dialogue with Frank, I experienced the back and forth in our exchanges. Such exchanges enabled me to oscillate between the identity of victim-survivor of illness and, surprisingly, an insider psychotherapist who supports me to reflect on the suffering experiences with some peace of mind. This initial attempt gave me a snapshot of how the engagement in an imaginary dialogue through collaborative writing could bring my embodied experiences of illness alive to create a new set of data for narrative inquiry and analysis of the illness trajectory.

Collaborative writing through imaginal dialogue illustrates that the performance of autoethnography corporeally manifests the dialogical praxis of critical theory and the performing body offers the performative turn in resisting bodiless voices in ethnographic writing. The voiceless bodies are empowered to resist the colonizing powers of the dominant hegemonic discourse (Langellier, 1999, cited in Spry, 2001, 718). The notion of “performativity” is central in performing autoethnography that aims to identify and critique the power relations rooted in the sociohistorical contexts of discourse that are occurring in the act of performing social stories (718).

To conclude, this thesis attempts to offer a reflective explication of collaborative writing through imaginal dialogue as a form of performative auto-ethnography. It explicates “the personal/professional/political emancipatory potential of autoethnographic performance as a method of inquiry” (Spry, 2001,706). Through reading Frank’s works, his narration of his illness story resonated with my illness experiences. Being a reader and audience of his story, I could empathise with his suffering and identify mine with his and subsequently the narrator part of mine is opened. This performative act of holding imaginal dialogue with Frank as if he were my confidant created the open space for me to navigate the liminal space through collaborative writing with him and others, and generating the multi-authored “playscript” in this thesis as the praxis of performing autoethnography in developing the third kind of knowledge of “What is the trajectory of illness like?”. This form of performative autoethnography opens an arena for emancipating the “Scholarly Voice”

(Spry, 2001, 720) that allows the wounded body and mind to be heard, felt and understood. In the form of playscript, this performative autoethnography turns the internally somatic (of all kinds of vulnerabilities) into the externally semantic and thus become “the tool for reflexive knowledge” (721) that moves beyond self- exposure. As Spry states (1998), the published version of this collaborative writing through imaginal dialogue in the form of playscript, reflects the critical agency of the corporeal agent, the living body in performance. This body, this cancer body, becomes a communicative body that bears “I-witness” in witnessing the trajectory of illness in the presence of Others.

Data Creation and Reflexivity: Oscillating between the Imaginal and Real Dialogues with Self and Others

In accordance with the ontological and epistemological positions adopted in this research, the methodological approach to the research was through engaging in an in-depth imaginal dialogue with Frank through reading his books about his own illness experiences. Reading was the medium that allowed me to enter Frank’s lived experience of suffering and he reciprocally entered mine. Reader Response Theory reminds me that we, as readers, are active agents who impart "real existence" to the work and complete its meaning through interpretation. It is the reader who makes meaning. As a reader responding to Frank’s work, I documented my emotional responses to his experiences that emerged from the process of reading. I noted down all possible thoughts and feelings evoked when reading his works in relation to cancer-related events and situations. However, while I was a reader, I was also an active listener or audience who could empathise with Franks’ experiences and offer back my feelings and thoughts reciprocally. Then, I sat with those emotions evoked and entered the imaginal exchanges with Frank, consciously and unconsciously, to capture the stream of consciousness that was unfolding naturally. I kept a dialogical diary to capture our imaginal exchanges which contained emotional, sensuous, dream data as well as the ethical responses evoked (St Pierre, 1997a). The constant crafting and recrafting of the imaginal dialogues between me and Frank produced a rich set of data that gradually took shape in the form of the playscript. It was the outcome of the performative act of creating an imaginal space of writing collaboratively with Frank as if I were responding to his Frank's invitation to engage in the dialogue with him about illness experiences which he initiated in his work in 1992.

While my illness experience was unfolded through reading and writing in an imaginal context, my illness experience was also unfolded through direct interaction with medical professionals in attending the clinical examinations and treatments as well as my reflective dialogue with my supervisor as an integral part of the research process. Hence, I had another role as observer participant to take field notes of how I engaged in the dialogues with medical professionals that form the data for sharing with Frank as my imaginal confidant. I documented the field notes of clinical experiences in the illness diary which formed the input data for reflection in collaboration with Frank as my imaginary confidant. The third set of data that helped me develop insight from the imaginal dialogue was generated from the reflective dialogue with my supervisor who was also the witness of my dialogical approach with Frank in developing my knowledge of the subjective experience of illness. As Charmaz (1999, 372) claims, it makes a great difference whether people endorse the story of suffering themselves instead of having it enforced by others. And the acceptance and understanding of the story by a confidante makes a significant difference too.

By adopting a reflexive gaze on different sets of data created in the research journey, I studied the imaginal dialogues between me and Frank in the form of collaborative writing in supervision. I reflected on how I felt about this imagined collaborative writing process and how it made me develop an understanding of my illness trajectory. By engaging in an iterative process in imaginal dialogue and the collaborative writing process with witnessing from supervision, the trajectory of illness was unfolded in the presence of Others.

Data analysis and interpretation involved the process of data review and theme search individually that offered insights into the trajectory of being a breast cancer patient. I drew upon the notion of reflexivity in qualitative research to enable me to perform my role as a researcher while I was also the researched. How could I navigate, oscillate between the imaginal and real dialogues with Self and Others as a researcher of self in relation to Others in developing my understanding of the illness trajectory? Guillemin and Gillan (2004, 274) state that reflexivity is a process of critical reflection “both on the kind of knowledge produced from research and how that knowledge is generated”. Drawing from the post-modern relational constructionist premises which my research is situated in, and the dialogical approach adopted for this study, I consider that ongoing dialoguing, a less articulated and less commonly practiced form of reflexivity, relevant to my research (Hosking and Plutt, 2010). As Hosking and Plutt state, the understanding of the reality (ontology) is relational and the local realities are constantly in the process of making, breaking, and reconstructing. It is “the ontology of becoming” instead of “the ontology of being” (Chia, 1995; 1996, cited in Hosking and Plutt, 2010, 60). Hence, reflexivity is continuous with the researcher attending to the relational process with the view that inquiry is intervention and intervention is transformation (63). So, unlike other forms of reflexivity which are situated in the domain of positive science that aim either to minimise bias or make bias visible, I adopt the stance that reflexivity is an ongoing dialoguing that is reflexive. In other words, I would take all those invited (consciously or unconsciously) to my research to play the part in constructing and reconstructing our local knowledges, identities, and relations in my researching on the trajectory of illness. Be they imaginal or real participants in my research process, our reflexive dialogues will heighten the possibility that multiple local realities will be unveiled and offer possible ways of radically reconstructing reflexive practices (71).

As Speedy (2008, 31) states, reflexivities represent the relationships between researchers and researched (here, it is me as both the researcher and the researched), between the researcher and texts (here, my relation to Frank's work who is an imaginal confidant), as well as the stuff of my research (i.e., the collaborative writing in the form of playscript in my study). "Everything we write is part of the reflexive cycle of meaning-making".

By adopting discursive positioning, we experience ourselves 'like being held in a hall of "mirrors" (Davies et al. 2004, 386). I adopted Speedy's ways of positioning self as a researcher by taking the following strategies in keeping intertextual account book that kept a record of my thoughts, feelings, and behaviours in engaging dialogues with self and others. I kept a notebook of my imaginal dialogue with Frank, a reflective research journal of my dialogue with my supervisor and a notebook of recording the field notes of my clinical experiences. All these "data" shed light on the illness trajectory I experienced. They enabled me to see how my sense of self was constituted through dialoguing and writing with self, with others and between self and others. I share with Speedy that reflexivities are invitations towards liminality and towards constructing identities not as fixed, but "as discursive process that may lead us into creative (messier) research conversations" (Speedy, 2008, 42). This reminds me of Rowe (2003, 198) who contends that researchers, as storyteller and performer, must trust the research process and “resist the temptation to force meaning but instead allow it to emerge from a deep immersion in the material and the experience of the research field”.

I have engaged in a rigorous and discursive process of data creation through the following stages:

- engaging in in-depth imaginal dialogue with Frank through reading his books about his own illness experiences;
- documenting my responses to his experiences;
- taking down all the thoughts and feelings that are evoked in the process of reading his works and sharing those that I also experienced in cancer-related events and situations;
- turning those imaginal exchanges into dialogues in written form and developing these into an extensive form of collaborative writing to capture the stream of consciousness that unfolds naturally;
- bringing those dialogues to supervision in the form of collaborative writing;
- reflecting on how I feel about this collaborative writing process and how it has developed my understanding of my own illness trajectory;
- engaging in an iterative process in imaginal dialogue and collaborative writing, with witnessing from supervision, to unfold the repressed sense of self as a cancer patient.

This is inquiry as research and as therapy that assists self-healing and becoming.

Ethical Considerations

In conducting this study, I was aware of the ethical issues that might arise. Guillemin and Gillam (2004) identified three kinds of ethics in research. They are procedural ethics, relational ethics (ethics of care) and ethics in practice (situational ethics). In upholding the procedural ethics, although my family have no direct presence in my story, they are still there in the background. I shared with them the intention of writing about my illness experiences with an explicit focus on myself as the subject in the story. I kept them informed of the self-care strategies that I adopted to protect myself in their physical absence from me as I was studying abroad. For confidentiality and rights to privacy, places and people related to my cancer-related events (like medical examinations) were kept anonymous. As I am the only subject of the research, the privacy of my own illness and relationships with others will be guarded under the principle of no harm to self and others. I stayed cautious throughout the writing the process by not revealing any personal details that might bring harm or distress by disclosure. I maintained constant consultation with my supervisor lest any disclosures might bring harm to self and others, for instance, my medical history and treatment. All data were stored securely in the one-drive of the University for the purpose of this research.

In terms of relational ethics or ethics of care, I am aware the importance of “Do no harm” to self and others. Would the research on my own illness bring potential harm, in whatever degree and manner, for myself and others due to the act of self-disclosure in a self-exploratory process? I stayed aware of the potential risks that I was facing. These include the recall of some unpleasant illness experiences that could trigger emotional pain. Hence, under the supervision of my supervisor, over the past year, I tried to test if I could manage the emotional challenge of engaging in a deep exploration of the trajectory of my illness, containing sensitive information, by means of imaginal dialogue with Frank's illness experiences as documented in his works. I put myself at the centre of the analysis (Fang, 2016).

How could I manage when I felt overwhelmed by repressed emotions? I had personal therapy for two and a half years with the same psychotherapist who had given me tremendous support in self-care. I have also undertaken mindfulness practice on a regular basis since I took a summer course at the University of Oxford two years ago. I continued to seek professional advice and guidance from my supervisor to ensure that I adhered closely to ethics of care as being an ethical practitioner and researcher.

Since I have created space to explore my resilience in engaging in deep exploration of my illness experiences under the supervision of my supervisor, I have not suffered from emotional distress that might compromise my safety. I followed all the ethics of care to self and significant others by utilizing the network of support from my supervisor, research group, classmates, family, and friends.

As my family members may be the potential readers of my work, they are indirectly associated with the research. Although my family have no direct presence in my story, they are still there in the background. I am aware of the negative reactions that reading the account might evoke, for instance, when reading the disclosure of my feeling of loneliness in undergoing treatment and fear of death etc. Hence, I have kept them informed of what I would be writing about, and enquired if they feel safe to engage in a dialogue with my writing experiences. I offered to share with them what I had written at an appropriate time before publication. My family are well-informed of my intention to write about my illness experiences, but they were not involved in this research. If they were mentioned, I was mindful of any emotions that might be evoked if they would happen to read my experiences in my thesis after completion or publication in journals. As it is not possible to predict and forewarn in advance during the research process, I will find ways to engage in genuine and honest dialogue with the family members and other significant others to address the potential tensions the research may generate (Wyatt, 2006).

Guillemin and Gillam (2004) also highlight ethics in practice which refer to situational ethics that are unpredictable, often subtle, yet ethically important moments in the research process. As I am researching my illness trajectory, there might be unpredictable but yet ethically important moments that I needed to be alert to and resolve ethically. For instance, I might feel emotionally vulnerable in recounting a particular aspect of illness experience but might feel the inner urge to reflect on it. I was aware that this might present ethical dilemmas in terms of doing no harm to self. Being reflexive in engaging in a continuous process of critical scrutiny and interpretation of the research experience in constant consultation with my supervisor is paramount. I kept my reflective journal and brought ethical dilemmas to supervision on a regular basis.

To conclude, there are very few studies examining how patients experience the process of navigating the trajectory of critical and chronic illness (Frank, 2002; Wade, 2003; Roulston, et al. 2018; Schmidt, 2018). For this study, I adopted collaborative writing as the process of inquiry with my imaginary friend, Arthur Frank, the author of the books "*At the Will of the Body*" and "*The Wounded Storyteller*" (Frank, 2002 [1991]; Frank, 2013[1995]). I believe that such knowledge of illness experiences is value-laden and socially co-constructed, subject to our own personal experience in the past and present as well as being influenced by the general social perspective held by the society that we live in. Frank is a sociologist, and I am a psychotherapy practitioner, and both of us have the shared experiences of illness. I think the collaborative writing process with an imaginary figure created space for me to rework and expand the social imagination (Tamas, 2011; Pineau, 2012; Speedy, 2012; Wyatt, et al. 2018).

Chapter 4

Imaginal Dialogue with Frank: Collaborative Exploration of the Shared Illness Experiences

In this chapter, I will present the research outcomes in the form of a playscript which was derived from collaborative writing in imaginal dialogue. The playscript evolved over the past three years as I engaged in dialogue and writing collaboratively with Frank, who is my imaginary partner with multiple roles (teacher, confidant, witness, and psychotherapist). This playscript is an assemblage of multi-layered threads of conversations between me and Frank, starting from the randomness of my reader response to Frank's work and then talking back and forth with Frank about my cancer-related experiences and with many others in the real world.

Frank's illness experiences were deeply embodied in my own illness experience. Themes of existential human conditions in the context of illness were triggered and brought to the fore for reflection. I documented those random thoughts, feelings and common themes emerged over time. I captured them in the margins of Frank's books, content pages, chapter pages, and wherever I could to keep the footprints of reflection. It is by this nature of nomadic inquiry and responding that I find many landmarks - existential themes in my trajectory that bear meaning. They brought me back to the past, the present and the future. These multi-layered threads of thoughts and feelings gradually took shape and were assembled and presented chronologically to reflect how I navigated the liminal spaces in the trajectory of illness. The numerical references I make in the playscript represent the subthemes that emerged in Frank's and others' works that had resonance for me and we both engaged in deep dialogue concerning their underlying meaning. The playscript shows how I finally came to the stage of holding an honest dialogue with my disease directly, not through Frank or others, that was healing. This chapter illustrates how my illness experience has been negotiated and processed.

The Trajectory of Illness

Act I Cancer Experiences

Scene 1 Frank and I

July 2019

It is a year since the completion of the radiotherapy. I am on my way back home for the summer vacation. During nearly 18 hours of flight back home I keep wondering if I can write about the trajectory of my illness as a cancer patient for my thesis. Can I really engage in the dialogue with my illness? It sounds scary to speak to this “sick-me”. How can I get started? Who can I talk to? I take out a book from my backpack, a thin one of 160 pages, handy, readable, and the title “*At the Will of the Body*” [i] resonates so deeply with what I am experiencing. Yes, talk to Arthur …

Me (M)
A (Arthur Frank)

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M: Hi Professor Frank, I want to write about my illness experiences, but I am so scared to start a dialogue with my illness. I am impressed by the courage you show in opening up yourself and putting your experiences into words. I want to talk with you about our illness experiences so that I can talk with my illness. You advocate a dialogical approach[ii] to illness and I want to use this as a mean to access my feelings and make sense of the meaning of illness… I am really scared, not knowing to get started.

Arthur: Sure. As I did not write my experiences of illness as any kind of expert but presented myself only as a fellow sufferer, trying to make sense of my own illness, I
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would like you to call me “Arthur”. I think talking back is how we find our experiences in a story someone else has written.[iii]

M: Thanks, Arthur. How did you get the strength to “engage with” your illness without being drawn into the state of feeling ill?

A: I think it is the purpose of writing. I hope my reflections on my illness enable me and those relevant to my illnesses to have a different way of looking at their own illnesses and those of others in whatever capacity and roles they are in. With hindsight, illness is a “dangerous opportunity”.[iv] I realized that my cancer is not curable but only in remission; I had no interest in living the same way as I had before. Such suffering and the process of remission granted me a costly opportunity to rethink the renewal of my life, not just recovery in a physical sense.

M: But who can you talk to about your illness? (feeling puzzled)

A: My wife, relatives, friends, and I keep talking about “our” experiences of illness. It is not just “my” experience, it is our experiences, experiencing together and witnessing it together. I emphasise experiencing and witnessing together because in the process of treatment, I find I did not meet others (e.g., medical staff) who were ready or willing to “witness” my experience.

M: Witnessing with and by others? (feeling discomfort). No, I don’t want to inform anyone of my treatment. I prefer going alone… witnessing the process myself. I can’t imagine getting my close one(s) to go through the horrifying process with me… what a burden, a torture, not only for me, but also for the one who cares for me, to have so much to worry about.

A: I can feel your fear… the challenge of being a caretaker[v], but at this moment, I think I want to focus more on the needs of being a patient. What touches me is when I receive letters from people who are willing to become involved in my experience, offering their experiences to me. Talking back seems to be a process that helps me find my experience in relation to others. I am not sure why you prefer to keep your own experiences to yourself and don't want to share them with others. I find too many ill people are deprived of conversation. Even if they are asked about their illnesses, they will simply repeat the "medical report" from doctors – telling us the "facts" of blood tests, x-rays, and scanning results; whether these are normal or abnormal or whether further tests are needed. It seems I have lost myself - my words, my language, my feelings… feeling alien, not only to others, but to myself.

M: Exactly. (feeling the resonance inside). When I was suspected of having breast cancer and was informed that I needed to go through a series of tests and examinations, I was given a very detailed booklet on "Breast cancer" which explains all the possibilities. While I appreciated the details given in advance which helped me to prepare myself for the process of investigation and treatment, I felt daunted. I spent a significant time understanding the special terms, the abbreviations used, the stages of cancer, the samples of images of stages of cancer. I found myself drawn to the "medical" stream to identify "a category" that I fall into. My focus is the "category" I belong to. I am afraid that I could not understand the terms they used to describe me. I suddenly found that I needed to learn a new language to get to know myself. I felt I had lost my original name and my identity as a person but had a new identity encoded with a patient number and the category of cancer. The course of my life seemed to be pre-determined and followed a fixed pattern. I would not say it is not "good". I think it is a very professional way of handling an illness, which has been well researched and is evidence-based. What I feel is that I was reduced to one of the millions who belongs to the same category, receiving a standardised treatment. I felt the loss of my own uniqueness as there are many other aspects of me that make me unique as a human being.

A: I think we are very used to the current medical model of talking about our disease, not about our illness. In other words, whenever we engage in a dialogue with medical professionals, the focus is on our disease, with a focus on the measures of our body[vi]. There is little, perhaps no, talk on what my feelings are towards my body, which is breaking down. This is "disease talk" that medical professionals are well trained for, while "illness talk" is minimal and if there is any, we do not know how to talk about it. We may even wonder if we could talk about it, about how we feel. We lack the language, the experience to talk about the loss, the fears, the hopes, the pains. These seem to be difficult issues to touch on by ill people and those around them. To quote from my book, what I want to talk about is "What's happening to *me?* Not *it [the body],* but *me [as a human being]. [my addition]*[vii]

M: If I understand it correctly, you feel that as a patient, you do not just want to have talk that is linear and one-directional; you do not want to be talked *to*. You want to be in a mutual and respectful situation in which you could explore what it means to you and to your life. You want to have your experiences of pain, suffering and learning to be voiced and heard, not as a prescribed "script" imposed onto the patients in mechanical, directive medical terms.

A: Absolutely, imagine how you feel when you were just addressed by the abbreviation of your illness with a number such "c.a.- number 12345'. [viii]

M: We are turned into objects… (feeling lost, feeling sad)

A: When in pain, I lose the words to describe that specific pain… burning… sharp, just beyond words… feeling lonely… isolated while others do share the experience of my pain. Such incoherence in feelings of physical pain could not be shared with anyone who is not in pain. [ix]

M: You have spoken for me… Frank… that's it… It is so disruptive… How on earth do you live with such incoherence?

A: (sigh) Hmmm… I have learnt that I must find a way to communicate that experience of pain… I composed a haiku (poem) one night… This helped me express myself in the absence of others and I was back in connection with them [x]… I was alone but my words put me in the presence of those others through my haiku… sharing the humanity again… creating coherence…[xi]

M: Here I hear you that telling me that illness separates you from others, but through making your poem, you connect yourself with them and you find your place in the world again. Is that what you have experienced?

A: I think I care for, not only my pain, but care for my loved ones. Instead of looking at the loss of my coherence in terms of suffering from pain resulting from my illness, I turn to look for another coherence in which to live. As I have shared in my book, I realized that I pay less attention to the bodily pain, but care for more to protect the sleep of my loved one, and to what I saw in the window, which gave me the sense of coherence that I needed to care for myself.

M: Being a cancer patient is a life-threatening experience. It is not only a matter of life and death. It is a threat of the loss of everything you have, all the attachments you make with others. I remember when I was in the process of cancer diagnosis, I already had a great fear of losing my life, my connections with family, my place in the world, my study, everything that I had. Such a fear made me disoriented. I started thinking of how to disconnect from others gradually to make the total loss bearable for me and them. For instance, I started to write my will, allocating those material things that I have, thinking of what memories (in pictures, in electronic or paper formats, documents) that need to be deleted, what I did not want to be discovered. I seem to be preparing to count-down to the end stage of my life – preparing for the farewell. I must confess that I was aware of the vulnerability of life, but I was just not prepared for it to come without warning.

A: Yes, a danger… just coming

Silence

Scene 2 Mourning the Loss

July 2019

Back home… a long journey. I get settled. It is midnight, everyone has gone to sleep. I open Frank's book, we talk…

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M: Arthur, I am thinking of loss. I am feeling the loss… My family has gone to sleep… I feel I am losing them… It's a dreadfully lonely feeling. Can you tell me how you experienced the loss; in whatever aspects you can think of? I want to hear…

A: I could still feel the powerful impact of loss. I could no longer trust my body to function as normal and do I what I usually want to do. The loss of ability is the beginning of the loss of belonging[xii]. The treatment made me lose weight, hair, energy, appetite. I also lost friendships, the ability to work, status, my roles. Things are simply out of place. I could see that I would no longer grow old with my family members. The loss of the chance of being with, being for and even being in them did scare me[xiii]. It is no longer only the physical pain that goes with cancer, it is the pain of death - loss of the future and the past. I think this is what you have mentioned, about facing the truth of saying farewell to the past, the present and the future.

M: death… loss of the future… no longer… loss of ability (*these words hammering in my head*)

A: Before my operation… I looked at my body. I understood that I was no longer the same. Surgery, chemo all these would irrevocably break my body's continuity with its healthy past, the place I have been in. It is goodbye to how I have lived. I have also
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experienced the loss of friends in different ways, some appeared to be more distant than before. I have a loss of certainty; I am amid unpredictability with myself and my loved ones about the future.

M: loss of certainty… *(head feeling heavy)* ... You make me think of mourning… thinking of my clients coming for counselling after bereavement. They find it difficult to mourn the loss… they feel depressed and stuck. I feel like them… I could feel the fear viscerally… (*shivering*)

A: It is important to have time and space to mourn for our own loss and that of others.

M: No... no… no… mourn with others… definitely not for me…

A: Why not?

M: I wonder if it is a cultural difference, or more a personal issue. But, in my Asian culture, we tend to keep our pain inside and repress it. We do not mourn publicly, we do it quietly… it is important to fight the disease, not to waste time mourning for the loss… a sign of weakness... (*murmur)*

A: There seems to be external pressure for people to get mourning over…[xiv] I doubt if mourning is thought to slow down the treatment of the sick and remind others of their own mortality… We need to mourn our loss fully and in its own time [xv].

M: Mourning… (murmur)… I have never allowed myself to mourn for the death of my father… not able to accept the loss of him… getting stuck with that unresolved business of loss in that relationship for years... It has taken me decades to work through the long-delayed grief and I paid a great price for this. I dare not say that I have allowed myself to go through the full process of grief or mourning for the loss of my health. I feel deep inside that if I admit that I have lost my health, it will be as though I have lost the battle and I will really lose my health. For instance, when I knew that I had to have surgery on my breast and that it would change the shape of it. After radiotherapy, I knew I would experience the side effect of losing my energy and strength that allowed me to work normally for some period. I would also lose my identity as a "healthy" person and would have a label attached to my medical record permanently as a cancer patient. I knew I would not be able to get medical insurance at a normal rate, with a risk of not being accepted at all. I also lost the ownership of my body as I had "chips" newly installed onto the cancerous part that enabled easy tracking of changes in the annual mammogram check-up. What I want to say is that such a loss, for me, was a gateway to "survival" or "re-birth" (possible gains) after surgery and treatment. I wonder if I should mourn or if I should celebrate the loss. There is an overwhelming feeling of ambivalence.

A: If we deprive ourselves of time and opportunity to mourn for the loss, we fail to affirm the life that has been led and it might devalue who or what has been lost.[xvi] Only through mourning can we begin to live again…

M: (*in tears*)

Silence

Scene 3: Me, Body, Identity

Mid-August 2019

It is my birthday month. I am different, not the same now. What do I celebrate for? A birthday cake, sharing with my family. They are singing the birthday song… Why on earth am I not feeling happy? What do I celebrate on my birthday? I need to talk…

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M: Arthur, I want to grieve (*feeling angry, anxious, frustrated*)

A: For what, for whom? (*sounding curious*)

M: For me, for my body… I have something installed in my body as a marker to facilitate the annual check-up on my cancer condition. I feel that I am "different". The "chip-markers" have significant symbolic meanings to me representing who I am - A Cancer Patient. Each time I experience irregular and sudden pain around the site of my surgery I wonder if the chip markers are sending me the message that I am in trouble. I have got "police" inside me, policing my body. I have a "new" neighbour inside my body. I am not sure how to make friends with it. Sometimes I told myself that I was "pregnant" again. This little baby "the chip-marker" will send messages to let me know whether my body is well or sick. When I feel intense sensations, I think I am being warned that I needed to attend to it by going to bed early, not overloading myself. And sometimes, I may ask if I should take myself to my GP to check if something has really gone wrong with the "chip-marker" as it is made of "special metal". I wonder if it will go rusty inside, just like my body got rusted by cancer. It seems that I have lost the ability to use my own feelings to ascertain my health. Hence, when you talk about the
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body as territory and as wonder, I have a lot of mixed thoughts and feelings about my relationship with my body that I had never thought I could have.

A: Yes, a life-threatening illness puts us in the hands of doctors who claim control of our body through medication, surgery and a series of investigations and tests. We are no longer the "master" of our body. I do feel that my body is "colonized" and has become a passive object, subject to examination and investigation by unknown others and that this has occupied such an "active" and "dominant" position in my daily life… Yes, we need to renegotiate our relationship with our body and to cede our body to medical professionals…

M: I sense the dilemma in our relationship with medical professionals.

A: My body and myself are in an intimate relationship with the medical professionals but we rarely get intimate in a real sense. There is "medical intimacy", serving the purpose of categorizing my illness, but I have experienced a lack of emotional intensity in the care most of the time [xvii]. I need to adapt to my emotional vulnerability. It was no small thing to discover that I had changed[xviii]…

M: Change (murmur)… I could not help expressing my full agreement with your feelings that it was "no small thing" to adapt to this change process. What is daunting is that the process of change is subtle, unknown, and unexpected! For me, while I was reassured that I was "cured" and what I needed was to have an annual medical check-up, I still feared its recurrence without warning. I still needed to pay heed to irregular sensations of "pain" at the site of my surgery. At times, I experienced breathing difficulty and chest pain and was referred to emergency for other tests to rule out any possibilities of the side effects of radiotherapy. It seems the illness and the treatment have left footprints in my body and my body has embodied the experiences of all sorts of feelings throughout the process of diagnosis and treatment and the never-ending "worries" of family members about my health status. It is no small thing but when I attempt to express these fears, I feel I have to silence myself as my GP will only focus on my "symptoms". It is difficult to get these feelings across to loved ones as they do not know how to embrace this uncertainty as they are vulnerable too. The only channel is to share with my personal therapist. So, again, I have to invite another "stranger" to witness my bodily changes and my feelings of being a cancer patient. I get lost and wonder who is at centre stage of my life drama.

A: I think we have hit on one critical experience that we both share. That is, we are in the continuing battle of trying to reclaim our body as our own territory while we still need to allow others to play a dominant part in our health that affects our life.[xix]

M: Yes, a battle… a power struggle... not an easy battle indeed. I feel myself reduced in front of the medical professionals. As a foreign language speaker, it is more difficult for me as I need to make sense of those medical terms. I need to be vigilant, be competent enough to let another language speak to me about my body. I see myself not only alien to my illness, but also alien to the medical professionals and to myself who just feels dumb at times. The feelings of belittling are overwhelming. The pressure of gaining my own voice back and the need to allow the voice of others into my drama is unbelievably stressful. When could I speak? When could I allow myself to listen to them? There are lots of internal negotiations that are unspoken. I am afraid that if I ask too much, I am too "bossy". Yet, if I do not ask or express my concerns, I feel guilty that I have not taken responsibility for my health.

A: You touch on guilt and responsibility. Let me say a bit more about that. My experience was that when the body goes out of control, the patient is treated as if he has lost control. The focus is on the medical professionals taking control. But what I have learnt is that feeling the wonder of my body helps. [xx]

M: Feeling wonder? (*feeling puzzled)*

A: Yes, wondering at the body means trusting our body rather than trying to control it. It is an attitude… I regained my connection to my body by not worrying endlessly about what I was going to do… I stopped evaluating my body… started exercising, running, experiencing the strength I still have… I experienced coherence by having wonder at the body by opening it up to all kinds of possibilities, like listening to music…[xxi]

M: Your sharing makes me feel that I need to respect the potential of my body. I have always separated my body from the mind. My experience has been of using it as a "tool" to fulfil my wishes. When it feels sick, I hate it and feel that it misbehaves. Probably I have always found that my body brings me a great many inconveniences in life. I was a premature baby weighing under 2 kg, causing my family a great deal of anxiety about my survival. I have suffered from asthma and eczema since I was very small. I was considered a burden to my family, both financially and psychologically as compared to my other siblings. I heard a lot of complaints about my body, my health, and my feelings of hatred towards it. Hence, I think I have disconnected myself from my body as if it is "an alien" part of me that I could not make sense of or be in control of. I think I attempted to get a bit more in touch with "it" when I needed to undergo surgery to remove part of the breast as the treatment of cancer. I started to realise that I had never felt this "body". I felt sad for the loss of it. I started to talk to it while I was taking a bath. I told the body that I cared for it. I missed it. I hoped I could keep it with me and be its companion. Through this dialogue, I felt the realness of my body, the sadness towards my breast for leaving me. I feel the wonder of “feeling it” now. Since then, after surgery and during a series of my radiotherapy sessions, I started talking to my body, appreciating its strength in recovering from the radiotherapy, from losing colour and then to regaining its colour and texture. Though it is no longer the same as before, it was re-born as my new self. I think that is what you mean when you talk about “feeling the wonder of the strength of the body and trusting the body”.

A: Yes, yes… I could not think of any words to show how it feels to be able to reclaim our voice on behalf of our body or even who we are... so important to the person we still are, even as medicine or treatment tries to colonize our body. My belief is that disease cannot be separated from other parts of a person’s identity and life. [xxii]

M: I feel energy inside (*feeling the warmth*).

Silence

Scene 4: Witnessing as Recovery, as Care

Last week in August 2019

Time to fly back to Edinburgh to continue my study. Everything is packed. Frank's book is still in my backpack. All body examinations are done. "You are fine, no worries.", my gynaecologist tells me after telling him about my cancer. He joked, "You have been rewarded after doing annual body check-ups for a decade". I smiled bitterly but he is right. I am lucky to have spotted the cancer at the early stage. Flight sets off… Bye, my dear family members…

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M: Arthur, it is me again.

A: Welcome back.

M: I stopped reading at page 57… (*feeling low*) … difficult to continue…

A: Why?

M: Don't feel good about your mentioning of death.

A: Did I? … When? Can you remind me of what I wrote… nearly a quarter of a decade ago? (*looks curious*)?

M: You said you had learnt that the changes in life begin, and illness would not end even when the treatment ends…[xxiii]

A: …. (*in deliberation*) … Ah… yes… that's so true…What hit you?
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M: You said you need to deal with the consequences of what has not been recognized in the medical treatment.

A: What has not been recognised … (*murmur*)… yeah yeah… If I die, my family must deal with all that was not said, handling the unfinished business of a life closed out… no more a continuity of experience…[xxiv]

M: It's so hard to leave those matters… (*feeling the deeper sense of anxiety beneath*) … the aftermath of death if treatment fails.

A: But even if we recover, we need to recover not only from the disease but from being a patient.

M: Recover from being a patient as our new identity? (*feeling irritated*)

A: I have learnt that recovery will proceed far more smoothly if the person within the patient has been recognized throughout the period of illness and recovery. [xxv]

M: (*murmur*)…Recognising the person within the patient (*in rising tone*) … That sounds fascinating to me (*suddenly feeling awake*). Let me guess what you mean… Do you mean that recovery… not only the recovery from the disease as if it were an "object", most importantly of all, such recovery is subject to our recognition of "the person" within the patient… the person… the vulnerable me in illness…?

A: Yeah... it is the process of continuing to recognize myself as the person undergoing the illness, reclaiming my body as my territory in a setting which was medically dominated… it is certainly not easy [xxvi].

M: But medicine is helping us… shouldn’t it be medically dominated? We need those cancer treatments… (*feeling confused*)

A: As a sociologist, I find that society is obsessed by the thought that the body can and ought to be controlled. Losing control means to fail socially and morally… being ill... not only a sign of moral failure, but also a reflection on me as being irresponsible. My experience of illness makes me challenge that societal assumption… the idea that we need to control the body… is wrong in the first place [xxvii].

M: If I get it correct, it seems you have suffered from a feeling of being blamed for not taking good control of your body and hence suffering from illness… feeling judged and criticised for failing to fulfil your moral responsibility of caring for your body.

A: Control, at least management, becomes a medical ideal. And it is justifiable for physicians to fulfil their duty to restore the control that the sick person is believed to have lost. And the power rests with the physician and I, as a patient, am reduced to a subordinate state, as I lost the control of self since I allowed the disease to happen to me [xxviii].

M: It sounds very difficult to accept this view of one’s moral failure and responsibility when suffering from disease. Our dialogue makes me recall my first response to the diagnosis of cancer. I immediately wondered what I had done wrong - I questioned whether I had put myself under too much stress in the past, if I had followed a bad diet… I kept questioning myself for my failure to take control of my fitness. It has been a punitive process. Even after the treatment, when I decided to tell my siblings that I had cancer, they responded by asking me not to stress myself, not to... I took it as if I have not done well and I need to do things right now… This made me silence myself on many occasions as I didn't want to be judged for my moral failure of not looking after my body. This makes me think more of what you shared. I wonder if you are struggling to learn how to how to not only recognize but also hold (or contain) the person inside the patient self.

A: Yes, whose body, who has the say on my body and me, whose illness, or whose illness experiences… in the sick room… I hear and receive a lot of encouragement and praise… "courageous, optimistic, cheerful" …[xxix] … I wonder if we all could only embrace the outcome of recovery, but not failure… it seems it has taken me as well as other sick people a lot of effort to make others feel good… A lot of emotional work is needed to work with the emotions of fear, frustration, and loss and to find the coherence about what it means to be ill… what a challenge … to keep being seen as "normal" as if I were not sick. It is hard work[xxx].

M: (*sigh*)… What hard work… to be seen as "normal" and to convince others that I am "normal" in the course of treatment… checking if I have lost hair… making myself look different… changing the bras that support my body shape… disposing of those I used to wear… saying "goodbye" to my previous self and yet on the outside, I need to be seen as the "same old me"… This incoherent sense of self makes it difficult for me to go through the transition of becoming a cancer patient who is no longer the same old me. What is to be kept? What is to be disposed of? What is to be left to be seen? What is supposed to be seen as a new self? … All these seem to be out of place in finding my footing in the recovery stage. Sometimes, I struggled to understand if I should "change" when the radiotherapy sessions were all completed. Yet, I feel such a change has started, probably well before the cancer cells developed… there is no clear stage of transition in this illness process. I don’t know where and when to begin, to trespass, to come to a safe landing as my permanent identity as a cancer patient (*feeling lost*).

A: It is sad indeed… when we could only have space for positive emotions… be they disguised or real… expressed or not … I have never heard an ill person praised for how well she expressed fear or grief or was openly sad… When they do so, they usually apologise if they show any emotions other than laughter. [xxxi]

M: I can see myself there… I keep apologizing for crying in the large study group when I am asked about my health, or if I express my fear… When my classmates offer the space to listen to me in our study group, I keep apologizing for using up their time, making them put up with my tears… I simply feel my fear was far too much for their empathy. I just feel my emotions “contaminate” the atmosphere.

A: Tears are categorized as temporary outbursts… not being understood as part of an ongoing emotion… It seems as if sustained “negative” emotions are out of place… if too much sadness is shown… it could be seen as “depression” … a treatable medical disease… I wonder if medical staff, family, or friends are willing to accept that depression could be the ill person’s most appropriate response to the situation… I wonder… at some moments even fairly deep depression must be accepted as part of the experience of illness... [xxxii]

M: I do feel myself struggling with the way self and others experience the negative emotions presented by the patient... On one hand, I feel it is legitimate to accept that being in depressive state is a form of response to the situation but who decides how long we “stay on” or are allowed “to sustain” that negative emotion. DMS-V states that if someone presents the symptoms of depression for more than two weeks, they may benefit from treatment for depression. It seems that we could "quantify" scientifically if someone is pathologically healthy or not. What if we do not have such a "scientific perspective" of the sustained negative emotions? Could the person who is ill tell if they need more time to retain those negative emotions as a normal response or if they need to seek professional help. This reminds me of those who suffer from bereavement. While there is no magic formula to say how long a grief process is needed, normally the referral for counselling is 6 months after the death of loved ones…

Again, my question is, who can validate my need for "feeling negative emotions"? To share with you in person, being trained in the field of psychiatry, I am quite wary of my emotional state when it goes beyond "two weeks" … I will feel more anxious. The more there is transparency of the diagnostic criteria in DSM-V or in the social media, the more it appears that people get the "magic formula" to determine how long they could be allowed to remain in the state of misery… I sound self-defeating... On one hand, I like having clarity in making a diagnosis, and yet I have my sense of "rebellion" inside by saying that I am fine, I just need more time and space to recognize "self or the person" inside the patient-self.

A: I feel our attempt to recognize ourselves in the illness process.

M: Do you think we both want to tell the world that we want to "protect" our negative emotions from being judged or diagnosed? (*feeling the anger of not being fairly understood by others*)

A: I wonder if there is someone in the sick room willing to witness our experience… I wonder what the cost of sustaining our "happy" image is while we are really suffering... to sustain a cheerful and tidy image costs me "energy", which was already scarce. It also costs me opportunities to express what was happening in my life and the chance to understand that life… it also diminishes my relationships with others by preventing them from sharing my experience… the cost of the denial of having death at the end and putting on a “positive image” on… it costs far more we can think [xxxiii]

M: (*interrupting*)… This deprives us of the opportunity to engage in the grief process… ah, but there is another school of thought, positive psychology, which advocates being positive in adversity…

A: As a patient… I want to focus on what and how I feel and want... not what others tell me to do, as if I need another kind of “medication” to treat my “feelings” which are part of self, inside the patient-me.[xxxiv]

M: Yes, I experience your feeling of frustration here. I feel reassured when the illness is witnessed, and my sense of ambivalence is recognised and held. I remember the moment when the cancer was confirmed by the biopsy test, I felt really my sense of existence was denied by my disease. I sensed that “death’ was right in front of me. I went to see the nursing specialist to understand the whole process of treatment that I would undergo, and she explained in detail the procedures. I had no problem understanding the logistics of the treatment. I felt disoriented not by the procedures of the treatment, as they were clearly laid out in a booklet and the appointment letter but by the loss of my health which made me dependent on others to tell me what to do and when to do it. I become a follower, not a pilot in my life. I remember when I left the nursing room, I felt so disoriented that I did not know where the exit was. The nurse was probably very professional in discerning my disorientation. She comforted me that she was a breast cancer survivor herself. She could feel how I felt. She led me down to the main entrance of the hospital and checked if I knew where the bus stop was. At that moment, I experienced the power of someone witnessing my experience, and such witnessing was humanely communicated. I felt firmly held and found my footing again after my disorientation. She made me feel that even though we were “strangers” to each other, in the context of “cancer”, we were brought together by witnessing the experience of cancer, me as a new member in the cancer family, and she, the “experienced” member in this family. This experiencing of “being with” others gave me a sense of “existence” in this new family. The process of wiring the markers onto my breast was an art experience, with me on one hand staring at the pictures on the wall, and me as the statue for the specialist to perform the art of wiring on my body… To be honest, I did not feel much pain at that moment; I felt physical discomfort, but I had more sense of appreciation of self as a “model” and as artwork observer. I think this experience of witnessing was a very powerful source of energy to help me stay hopeful.

However, I also felt disappointed when my illness was not “witnessed” or “recognized” when I shared my experience with my personal therapist who I had been with for consultation for about 3 months. I remember that after just a month of personal therapy I was diagnosed with cancer. This became one topic we explored in the counselling room. However, I felt my experience was not strongly recognised… (*struggle if I should say more*) … On one occasion we talked about the surgery. I told her my experience of how I dissociated myself from my body when I underwent the minor procedure of inserting the “wire” onto my breast as a marker of the site of cancer. The surgery was done while I was awake, and I could see and witness the process of inserting the wire onto my breast. I dissociated myself from the process by looking at the pictures hanging on the x-ray room. All along, I stayed quiet, stopped feeling whatever effect it was having on me, not allowing myself to feel anything, be it pain, numbness or whatever. I shut down all my senses to get myself through this process. I witnessed not only myself in this process as a patient, but I also witnessed the professionalism of the specialist in twisting her body to an angle that enabled her to insert the needle into my breast to insert the wire. It is a very delicate, gentle, and highly skilled process. I felt the "witnessing" of the experience, not my own witnessing, but that of others who were invited to centre stage of the treatment drama. I felt immense gratitude, appreciation, and respect for my body and for me as a human being. I think the witnessing was not about me but about the collaborative effort and mutual trust and respect we grant to each other - this shared process of witnessing was so empowering that I had great trust in the medical professionals playing their parts in my drama of cancer treatment. I would like to say that without that "witnessing", I think I might have felt ambivalent about my treatment as I am a "foreigner" in this country.

A: Illness is a shared experience and process… witnessing the particulars of that experience, and recognizing all its differences, is care. My wife has been with me in the process of witnessing. [xxxv]

M: However, when I broke the silence about my illness … I received mixed responses or silence… I don't want to share much… but my feeling is that it is better not to make the illness known… You mentioned that some used "blame" as comfort but actually it is "accuser" ... hence I silenced myself… In a therapy session with my personal therapist, when she asked about my surgery, I asked if I could show her the photo of the site of my surgery… I don't know why I wanted to show it to her, but she responded with hesitancy and gently "rejected" the suggestion… I felt abandoned, unwelcome as if something was too disgusting to share… It made me feel puzzled and confused as to what could be witnessed and what could not be… It seems people are happy to witness how I manage physical pain but not emotional pain. I have learnt the process of "splitting" self in encountering others in the process of witnessing…

A: I think the "damaged body" resulting from all kinds of cancer treatment - chemotherapy… surgery… cancer is stigma… I could hide my heart attack, which was invisible, whereas the spoiled body could not be hidden. I feel marginalized, stigmatized when "betrayed" by the visible mutilations of my body. I experienced the visible signs of cancer as defects not just in my appearance, but in myself… cancer made baldness into a stigma …Baldness, for me, was a process of reduction to the passivity of a victim, a patient, or a sufferer. [xxxvi]

M: Being ill is indeed a process of reduction to passivity. It is a public announcement that I am "no longer the same me" … I am afraid of being seen as a "victim" as it deprives me of the right to be a warrior in my life as I was used to… since diagnosis, I was constantly reminded to slow down, to take care of myself, to stop if I needed to. The "pause" button seemed to be pressed immediately by others who care for me as well those who worried if they would be affected by my illness in many ways, spoken and unspoken. This makes me distance myself from others… just wanting to be on my own… (*feeling frustrated*)

A: As a cancer patient, I felt the need to hide the disease, to be invisible as my experience of society towards cancer is that they use cancer as a metaphor for all the worst that can happen. The ill person becomes the bearer of these horrors. Resisting stigmatisation requires more than individual will [xxxvii]. I feel stigmatization will be overcome only when we learn to witness the experience of cancer not to hide it. Every concealment will only reconfirm that the stigma is real and deserved… We need to break the cycle of stigma.[xxxviii]

M: Can you say a bit more about the experiencing of others when you were ill?

A: I experienced a swing from closeness to distancing, with a greater feeling that both giving and receiving responses were being exaggerated. Even the strongest relationship was under stress with subtle denials and strained affirmations. [xxxix]

M: What are the subtle denials and strained affirmations you experienced? Could you enlighten me about this?

A: For instance, when a nurse expressed empathy with the death of my wife's mother, she said "Oh, your mother died of c.a. too" [xl]. I felt it was another refusal to say the dreaded c-word. I wondered if her use of "c.a" was a denial? While I was waiting for the examination with the fear of recurrence of cancer, the nurse's refusal to say the word "cancer" made me feel that what might be happening to my body was too awful to be called by its proper name.

M: So, the use of abbreviation "c.a" was an attempt or even a denial… to reduce the "awful impact" that it might have on you as a patient. You think the nurse's act was denying the tragedy on your behalf?

A: I think the nurse's refusal to say the word made me feel ashamed of what might be wrong with me.

M: Why ashamed?

A: I don't know. But in silencing the word "cancer", I, as a person with cancer was also silenced.

M: I do not feel ashamed of telling medical professionals that I am a cancer patient when I need a medical consultation. I find that they are more “sensitive” and “compassionate”, and I feel I am “visibly important” as a chronic patient. I don’t feel ashamed. But I do find that others will try to shift the topic if I want to share a bit more about my cancer… it seems it is unbearable for others. I need to fill the dead silence… (*feeling sad*)

A: I find that medical professionals are good at cueing patients to express the emotions that they think it is appropriate to express. For instance, nurses and physicians cue patients to deny their own experience when they compare one patient’s suffering to that of someone who is “much worse off”. For me, comparisons deny the uniqueness of each individual’s experience. As losses, disfigurements and pains are compared and each suffering can be measured, I feel my suffering is devalued when it is compared to other “worst cases”. It seems that only that “designated complainer” would have any right to express discomfort, unhappiness, fear, or any other “negative” emotion. [xli]

M: Oh, I have not thought in this way. I am brought up in a culture in which there is a golden saying: “Never complain as there are many others who are much worse off than you.” Hence, when I was told that my cancer is at a very early stage and only partial surgery and radiotherapy is needed, I told myself automatically that I should not complain about any physical discomfort since it is the most modest treatment. Instead, I should feel grateful and not complain too much. Hence, I do put on a “positive outlook” to say “I am fine. I am okay.” though there are times that I am really not okay.

A: I think ill persons deserve better. I believe that my suffering cannot be compared to yours or to anyone else’s. It can only be witnessed for what it is. I think we need to respect each other’s experiences. Having cancer is no small thing.

M: So, why do people like to make comparisons?

A: I guess medical staff who make comparisons are trapped by a belief that unless they can do something to reduce the bodily suffering, they have failed as professionals. In fact, continuing suffering threatens them, so they deny it exists. I guess what they could not treat, the patient is not allowed to experience. I want to state that when treatment runs out, there can still be care. [xlii]

M: I feel really touched when you mention the sense of "self-worth" in your book. I think it is particularly shaken when one loses the ability to "prove" their self-worth through productivity when they struggle with illness. Illness just deprives the individual of their ability to be productive. It takes away not only their health, but also their sense of worth. [xliii]

A: It is sad that the ill person ends up feeling guilty for having the disease, the suffering, or the low productivity[xliv].

M: Can't agree more. Probably I am afraid of losing my sense of worth and hence I make sure that I am as productive as before or even more productive than before to prove that I am ill, but I am not sick, and I am still productive… (*ironic laughter*) … I feel really anxious when you mention ultimate denial…[xlv]

A: In disappearing, it may take different forms. They deny that anything special is happening or, alternatively, that the ill person exists at all.

M: Do you mean that other people find it difficult to accept that they have to face a life of drastic change because of the impact of the illness not only on the patient but also on them? And it can also be a defence that they cannot accept that the "normal" part of that friend or loved one is lost and that they are no longer “the same”. Also, there is a new relationship with this “old” friend or family member, and it is an unfamiliar one. You are pointing at the “strangeness” that the illness has brought into their relationship.

A:(*laughter*) …Let me share my own experience of this distancing or even “strangeness” which is your word. Some friends or relatives send excuses for disappearing from my life and my wife’s by saying that “they cared silently at a distance”. [xlvi]

M: Do you feel “distancing” is also a form of care?

A: Cancer is hard for people to confront. But from the perspective of the ill person and caregivers, “caring silently” seem to me as “distancing” and such distance looks like another denial of the illness. [xlvii]

M: Have you experienced care from those who really know how to care for you?

A: I find those who have been through critical illness themselves are able to accept what they see… they rarely try to cheer me up, but their presence does cheer me up. I feel human suffering becomes bearable when we share it. It is the power of recognition that helps reduce suffering that cannot be explained, but it seems fundamental to humanity. [xlviii]

M: You have mentioned witnessing and recognition as significant in experiencing care that is what you need. Could you tell me more?

A: We need friends who call, bring food, send cards, and take my wife out. They affirm that they we are still there and have needs. I say “we” because in many of these affirmations, as in many denials, an action toward me or toward my wife affects the other one equally… illness is an experience that a couple has together, each differently, but one no less than the other... [xlix]

M: So, it is not only the loss experienced directly by the one who is ill. It is a multiple loss for the one who is ill and their caregivers: the loss in relation to self and self in relation to others. As a patient, we lose our health and what we possess in terms of career, relationships, and status whereas those who care for us suffer a similar or even greater loss in terms of their life, relationship with us, with friends, with other family members and so on… (*feeling scared*)

Silence

Scene 5: What an illness is Worth

One night in August 2019

Sitting with a critical illness application form given me by my insurance agent with a pile of medical documents to be submitted for application… What a chore! When I read the section on the nature of the illness, all the shocked experiences of diagnosis, surgery and treatment and re-assessment come back to me, I feel frozen, and I cannot move on to fill the form. I need to scream… to talk… The chapter "Valuing Illness" in "At the will of the body" catches my sight… the book is by the bedside.

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M: Arthur, I feel sick with the chore of completing the critical illness form … What trouble it is to be ill… to be critically ill… *(feeling frustrated*) …

A: Society needs to learn to value illness, to recognize the suffering of the ill as a common condition of humanity.

M: value illness? (*feeling puzzled*)

A: What I mean is to accept the inevitability of illness… each of us will die… with deaths being preceded by a long or a short illness… but what I find hard or even cruel is to be forced to make my own treatment decisions based on cost…[1]

M: So true… (*feeling glad I have taken out critical illness insurance a long time ago because of the fear of the high cost of medical treatment*)
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A: I would feel really stressed to decide how frequently to flush an intravenous line with saline solution if it were based on a budget… the illness experience makes me engage in a dialogue about the value of illness...

M: Like we are doing here…

A: Several years after chemotherapy, I start to question myself as to whether what I'm doing is so terribly important that I should allow it to crowd out all else. I think it is better not to set the healthy and the ill apart. I have started to think about the rights of living.

M: The rights of living? (*feeling puzzled*)

A: we are so rushed from moment to moment… not able to reflect on what we are becoming… so used to using our bodies as instruments of production... yet, we know very little of what it means to be productive ***of*** ourselves … our basic human right[li].

M: Your view on the rights of living touches me... Probably I would use the term "meaning of living" rather than rights of living. I can't agree more that the ultimate value of illness is that it teaches us the value of being alive. As you shared, "death is no enemy of life; it restores the sense of the value of living" [lii].

A: Yes, illness restores the sense of proportion that is lost when we take life for granted… we look like a flicker of light… what counts is to keep it burning... To be ill, to share in the suffering of being human, is to know your place in that whole, to know your connection with others [liii].

M: So… we should not make our body simply an instrument of being productive... It is using our “self”, our body and mind to connect, not only to self who is suffering, but also to others who are suffering.

A: I have a basic question in mind: “What is the core experience that binds us together as human?” For me, if the answer includes suffering, do we have the strength to recognize our own place in that suffering? If we recognize it, how do we honour it?

M: How? (*feeling curious*)

A: To begin by witnessing the suffering of illness, sharing it, and allowing ourselves to live in the light of what that sharing teaches us we can be [liv].

M: Wow, we seem to come to a philosophical and existential search for the meaning of life in the experiencing of illness and suffering. I have been told that my cancer is curable and what I need is to have an annual mammogram for monitoring. It seems that I have a green light to live on. I do ask how I am going to make good use of the time granted to me. I start to grant myself permission to say “yes” only to those things that have meaning for me, and “absolutely no” to those people and tasks that might take away the limited time left in my life. I seem to gain back my own voice in my life. This makes me think of “healing”. How do you feel about healing now?

A: I think the healing of the body can bring a healing of the mind. In the case of my cancer, the healing of body means the healing of mind [lv].

M: But for me, it is the illness of the body that brings me the hope of healing the mind by reconnecting myself to the body that I have abandoned for a long time. It is the discovery that I have abandoned my body through realising the imminent loss of the body. Such realisation of the loss made me love and care for the body. It helps to both recovery in mind and body (*feeling enlightened, spirit lifted*) … Suddenly it seems that we are all in the drama of illness, taking up roles of different characters, willingly or unconsciously, being cared for and caring for others. Sadly, all these experiences are raw without rehearsal. We act and react clumsily, regardless of our experiences, age, gender, roles, or status (*murmur*).

A: I think it is the responsibility of the ill to witness their own suffering and to express this experience so that the rest of us can learn from it. It is a reciprocal process and a relationship between the ill and others in the society. I find how people tell their stories reflects their history of relationships with other people and hence produces different behaviours.[lvi].

M: Yes, when I tell my story of illness to you, I see how I relate to others in the past and the present…

A: Whatever causes the disease, the response to it is learned…[lvii]

M: Our response to illness is a learned behaviour... (*murmur…feeling puzzled*)

A: Some are open to talking about their illness because they feel valued regardless of being ill… Some withdraw when they experience others not feeling comfortable with what they represent… there might not be explicit expressions, but they could sense from others' expressions. [lviii]

M: I don't know how to respond. I could feel my heart aching when hearing that we need to choose how to respond not to our feelings but more to how much others can contain or accept them. But it is bitterly true in many ways in reality. Probably I am withdrawn when responding to my own cancer. I am afraid of being a troublemaker again for not being able to take care of my own health. I am afraid of being judged and feel guilty for choosing to study abroad at a late stage of life. I even blame myself for being so naïve at spending so much money on studying abroad. I feel scared of draining my family's time and financial resources. Hence, I choose to "silence" myself and stay withdrawn but seen to be "healthy". The sense of guilt and regret could be so powerful as to prevent me from telling the true story of my own illness experience. As you said, I am making the best deal in communicating what I could communicate to others to ensure that they could contain me and my suffering. There is a lot of checking, calculating to adjust to my changing health condition. I think engaging in the dialogue with you, with the understanding that you know what it means to be listened to, is the only time that I could be so open about my story of illness.

A: Yes, Whose story? Story for whom? Who tells? Who listens? When we discuss withdrawal as "psychologically damaging" and openness as being "better adjusted" … I am worried… such psychological language can turn the reality of the ill person inward… hand over the whole thing to medicine [lix].

M: Oh, what a painful truth if that is the case. There is no doubt I am a withdrawn child… I have learnt, since birth, that my body is just a burden to others in terms of the time and money that it costs…

A: That may not be shared by others, but I advocate that the responsibility of the ill is not to get well but to express their illness well [lx].

M: What? The responsibility of the ill is not to get well, but to express their illness?

A: I believe that those who express their illness will have a greater chance of recovery and of living fully to the end of the illness [lxi]… the responsibility of the rest of us is to see and hear what illness is, and ultimately that means seeing and hearing what life is.

M: It sounds so wonderful…

A: Being alive is a dual responsibility: to our shared frailty, on one hand, and to all we can create, on the other… the paradox is that illness must remain painful… and the most painful sight to confront is that we yield to impermanence... When our children become critically ill, it reveals their frail impermanence that leads us to withdraw into an illusion of permanence. Sadly, that illusion is another sleight of hand in which life, that creative frailty and the frail creativity, disappears [lxii].

M: We touch on the impermanence of human life. At the beginning of our conversation, you said that illness is a "dangerous opportunity". Suffering from life threatening illness twice made you realise that cancer is not curable but is only in remission. Such suffering and the process of remission grants you a costly opportunity to rethink the renewal of your life, not just recovery in a physical sense. Before we explore further what renewal of life means, I am curious to know how you live with incurable cancer, with the understanding that it is only in remission and will come back one day without knowing when. How do you live with recovery and in uncertainty?

A: You know, many aboriginal peoples have re-entry rituals during which a person who has been stigmatized is purified. These rituals are a rebirth… each of my critical illnesses ended with a medical event that could have been given a ritual value. However, the physicians allowed themselves to be reduced to mere medical technicians and we, both patients and physician are thus deprived of the spiritual experience of illness. Since ritual self-awareness is excluded from the system, it takes longer to work out one's own terms of re-entry. [lxiii]

M: Excuse me, I am not clear what spiritual experience of illness you refer to here. What is ritual self-awareness and how important it is for one to re-enter the community they belong to?

A: Okay, for me, the angiogram showed that my heart problems were over, it bears ritual potential… but the angiogram only signalled the end of a breakdown not an occasion for rebirth… it marked the beginning of a life that was now different… The experience of cancer is even worse... cancer never disappears... Cancer creates the disturbing image of the body as a time bomb, genetically programmed to explode at some future time…

M: Exactly, a time bomb… (*in affirmative tone*)

A: We are never cured of cancer… we can only live in remission… life remains a remission [lxiv]… the completion of chemotherapy marked the end of the treatment... moving to the stage of remission... marked the beginning of life after cancer... medical staff may see suffering as a problem of managing illness… they focus on the surface of bodies... but for me and my wife, all that preparation for tests and treatment drained our resources - physical and emotional reserves... the experience of illness is a crisis of spirit… I hope we do not miss the ritual… a passage through real and symbolic dangers in preparation for the opportunity of a life enhanced by that passage[lxv].

M: It is a journey of dangers that paves the way for a new opportunity. It is the journey that matters… not the hair growth on the body as a symbol of recovery… It seems I start to understand what you mean by the spiritual experience of illness and the importance of ritual self-awareness, which you refer to now as ceremonies of recovery. Taking my own illness experience, I have gone through different ceremonial stages to mark the progress of recovery. The first surgery left me with a long scar and part of the breast removed and this was the ritual of being able to survive for another opportunity of treatment - radiotherapy. The insertion of chips into the breast to mark the precise location of the cancer was a ritual of "scarification", that is the rite of going through the next stage of recovery by radiotherapy. The 25 sessions of radiotherapy left a massive sunburn mark on my body, which marked the completion of the ritual of re-entry to the healthy community, or strictly speaking, a community of remission. So, the treatment gives me a different body, with cancer cells supposedly "killed", silenced, to sleep without knowing when they might wake up. As you shared, the process of re-entry to the "healthy community" is not easy. My body and mind have gone through different rituals in the path of recovery. The experience of illness does make me think of how I want to live my life now as it is a new life. There is a deeper level of search for the value of my life. I do sense the recovery in spirit, not only the body and mind. I could feel the "endless energy" inside me as if I were an active volcano. You have made me aware of the importance of ritual self- awareness and the spiritual experience of illness. Although I have no religion, as a human being, I could sense the spiritual part of me that I was not aware of until I had a life-threatening illness. I think this revelation echoes what you quoted in the book - the Chinese character for "crisis" - which combines the characters for danger and opportunity. As a Chinese, I embrace the Chinese meaning of crisis that sends you hope and danger brings opportunity. And yet, unless we survive the danger with courage, opportunity cannot be grasped. It makes me think of another Chinese proverb - Conquer the fear of death and we will come out alive.

A: Yes, this is a matter of choice. The only difference between people is not health or illness but the way each holds onto a sense of value in life. [lxvi]… health and illness, wellness, and sickness perpetually alternate as a foreground and background... So, in health, there can only be fear of illness, and in illness, there is only discontent at not being healthy... In recovery, I seek not health but a word that has no opposite, a word that just is, in itself. When I seek the meaning of my recovery- the "opportunity" of illness, I call it "gravy" [lxvii]

M: (*sensing tingling pain at the site of my surgery*) … (*voice in my mind… what my body wants to tell me… still in danger… not yet fully heading towards an opportunity state*)

A: Unexpected… probably all happened unexpectedly... I would rather think disease just happened and happened differently to each of us… the strangeness of contingency… neither my body nor my mind knows why these things happened as they did. It just happened as it happens.

M: Out of our control (*feeling powerless*) … So, how does the role of "choice" fit in in your illness experience?

A: I think choice becomes possible when we shift the perspective from the disease to the illness … a matter of choice on how to experience illness… yet ... choices are limited, and we can choose only what is available… So, the idea of choice is another half-truth. The trick is to hold onto the half that is true[lxviii].

(We both laugh)

M: You made me think of the choice I made for my cancer treatment here. I remember when I had just started my second semester in the first year of study here, I was diagnosed with cancer. I had two choices. One was to end the study and fly back home for treatment in the company of family there. Yet, this would certainly have marked the end of my study. Another choice was to stay here for treatment without family support. At that moment, a queer thought popped in. It said,

"You have chosen to study counselling and psychotherapy here. Probably, it is your destiny to become ill before you become qualified to help others. Your experience of illness and treatment will be the opportunity to learn how to help others. The experiences of communicating illness, negotiating the treatment plans, receiving help, juggling with life demands are ingredients for becoming a well-informed patient embodied with illness experiences of pain, suffering, desperation, regret, guilt, shame… Surviving these experiences of illness will inform you how to feel and listen to those who suffer…"

These thoughts kept popping into my dreams and endless moments of self-talk in solitude. They spoke louder and louder day by day. Having the positive experiences of seeking professional advice from the medical staff, tutors, and course-mates, I made the choice to receive treatment here and continue my study. With hindsight, I think it all just happened as it happens, it is more destiny than a deliberate, planned choice. I even made a joke that I had not signed up for the "illness" module of this course, and I was having a bonus of one-to-one, tailor-made medical treatment, free of charge for this experiential learning opportunity – use of self. It is "gravy" as you said.

[We both laugh again.]

M: I am very thankful for this very intimate dialogue about our shared lived experiences of illness. This open dialogue brings me to another stage of reflection on the meaning of my experience which happens by chance, survived by chance and now how I would like to live with the understanding that I am only at the stage of remission with uncertainty and risk of recurrence. Before the danger comes, I think I need to grasp the chance of rebirth at this stage of my recovery. (*feeling energised, spirits lifted*)

A: (smile)

Silence

Act II Liminality

January- March 2020

Scene 1 Paradox of Certainty in the Liminal Space in Illness

January 2020

It is the beginning of the new year of 2020. I will have been in my new identity as a cancer patient for two years by this March. Time flies but I still feel unsure what my identity is. Where is my position in this trajectory of illness?

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M: Happy New Year, Arthur.

A: Happy New Year!

M: I feel rather confused in this festive period. It is another new year. I am going to have been living with this illness for two years by this March… I still feel unsure who I am?

A: Wanna to say a bit more?

M: I hope I can make myself clear… I may be muddling myself. I want to explore how I position myself throughout the illness process… probably making use of the three forms of narratives you identify when making sense of how ill people narrate their illness stories … I think this might help me see where I position myself as a patient in the trajectory of illness.

A: Sure.
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M: Arthur, you have experienced critical illness, and your experience informs your trajectory in embracing that illness. You have taken yourself beyond illness by taking a step further into the exploration of how others tell their narratives, reflecting how their position is defined by self or by the illness.

A: Yes, my intention is to serve that purpose at a personal level, to gain insights and articulations of other ill people to assure myself I wasn't crazy. I need others' thoughts in order to become fully aware of my own[lxix]... Suffering needs stories… people are unprepared for becoming wounded and they need a guidebook for the day when they become wounded storytellers... it is my attempt to provide that guidebook.

M: You explained that how people tell their stories about illness and how people make sense of the story depends on shared ways of narrating illness. I find that you have presented three kinds of narrative in describing one's own experience of illness. You identify three narratives that storytellers and listeners use to structure and interpret stories, namely restitution, chaos, and quest… you think each narrative expresses a moment in your own illness experience.

A: Yes…

M: I wonder if you have experienced these narratives in your own trajectory of illness.

A: Sure. Restitution represents my life as a patient [lxx]. Health-care workers expected any experience to be interpreted within a narrative of movement toward the recovery of health.

M: Do you mean that they focus on the recovery of health instead of the actual narrative that the patient wants to communicate? Or at least that narrative is not fully heard or understood from the patient's perspective... Instead, the patient communicates what the health profesionals want to hear.

A: That is what I experienced in the conversations between me and the health worker… it’s mainly towards the achievable goal of health …. whereas I also need recognition of my suffering at that particular moment… [lxxi]

M: I hear that you feel frustrated about the limited capacity of the restitution narrative of illness to hold your true feelings towards the suffering/experience of your own illness. It seems that the restitution narrative is imposed on you by health workers. You are made to be the object of that protagonist’s heroism, with the physician positioned as the protagonist. While you are certainly part of this restitution story, you mentioned that it could never be truly your story.[lxxii] So, what is not truly represented in this narrative of your illness experience?

A: My own chaos. There is no space for the chaos part of my illnesses - the chaos in misdiagnosis, from injury to the unknown and then to the uncertainty of cancer [lxxiii].

M: So, it is the state of unknown and uncertainty that keeps you in confusion.

A: Yes, chaos was in the disconnection between the increasing pain that was sending my life off the rails and my physician’s frustrated insistence that nothing serious was wrong. It is the state of claustrophobia of confronting others’ inability to see what I so clearly felt [lxxiv]. The diagnostic uncertainty is just so frustrating, and it is a relief to have the illness experience validated. It is a relief when some physician validates how much is actually wrong.

M: I can understand how profoundly you feel the chaos when your experience of something wrong is not recognized or validated by the physician. So, may I say that the wider gap between your feelings of suffering and the recognition by your physician through his clinical diagnosis led to chaos.

A: Not only that, but there are also other misfortunes triggered by disease, such as job loss, housing crisis etc. I have seen many people feel trapped by these. I have experienced how I have been silenced and the desperation that chaos imposes. Those living in chaos are least able to tell a story because they lack any sense of a viable future. Probably, at that moment, life is reduced to a series of present-tense assaults [lxxv].

M: That explains why you say that if a narrative involves temporal progression, chaos is anti-narrative.

A: Now, I have learnt how well I could craft a life, whether I were ill or healthy [lxxvi].

M: It sounds as if you were no longer defined by illness. Is this the attitude that one holds in the quest narrative as you discovered?

A: Absolutely. Illness remains a nightmare in many ways, but it also becomes a possibility, especially for a more intimate level of connection with others.

M: (*interrupting*) Possibility of… sorry, why does it relate to others?... I could not follow.

A: Anatole Broyard’s posthumous collection of writings “Intoxicated by My Illness” presents his illness experience as a problem of style… for him, each person with a serious illness needs to develop a style for his illness. Through storytelling, we discover what that style might be… it is a process of discovery.

M: In other words, you want the patients to have their own voices, their own ways of expressing and exploring their illness experiences.

A: Yes, as Broyard states, physicians are often a part of the problem of diminished lives. They discourage our stories. My wish is that professionals should bring their personal suffering into their work, and ill people should discover forms of testimony in illness. The wounded storyteller becomes the wounded healer who ends silences, speaks the truth, and creates communities[lxxvii].

M: That sounds very meaningful if patients and professionals can come close to experiencing the illness narratives that both share instead of one relating experiences on behalf of others, imposing their stories onto the person who is the “subject” of that story. My immediate reaction to our conversation is that while the medical professionals might possess the knowledge of the disease, they are not the ones who dictate the narratives of the ill persons. It is the ill person who has the right or power to define their illness, live with their illness, relate their own version of illness. Diagnosis and treatment should form a part of the illness experience but not determine that experience of illness; providing treatment should not be equated to offering care.

A: Yes, that’s what I want to advocate. How about your narrative of illness? Wanna share it with me?

M: Sure. I think I would like to start with the experience of a chaos narrative. My lived experience of chaos in receiving the diagnosis of cancer, with hindsight, was not necessarily bad at all. As you remember when I shared the confusion, a loss of direction came after meeting the professional nurse and discussing the series of treatments which are neatly set out in the schedule. The nurse sent me off to the clinic and gave me directions so I could take the bus. While I felt disoriented, I felt I was “opening up” an alternative path that was strange and unfamiliar with an unknown direction. It felt chaotic but at the same time I felt it was well laid out in the treatment schedule. I was sent off to a “wonderland”, which was not fun, but it seemed to promise recovery as there was a treatment plan - symbolically, it was a plan of hope for cure, for recovery, for being okay again, being fine again. The chaos experience created the need for me to find my footing by holding the faith that the neat treatment plan was the map to bring me out from chaos. I felt alien and foreign with all those procedures for treating the wound after surgery, for applying cream after radiotherapy and reading guidelines for the prevention of psoriasis as a side effect of radiotherapy. When my skin turned red and itchy, my nerves were wrecked, and my bodily reactions were messy. You never know how clumsy and fearful it could feel when your skin gets red and itchy with needle pains… I kept feeling as if blisters were developing. I wondered if my daily routine of study and counselling work would be interrupted. I felt as if I was at the lowest point of my life, what you describe as the features of a story of chaos. As you describe, in the chaos narrative speech is neither accessible nor available. For me, my chaos experience (narrative) was the state of silence or tears that couldn’t be articulated in words. It was a state beyond words.

While I am on my own in owning that chaos experience in caring for my body, I feel I was drawn to the clarity of the instructions in the prescribed medication leaflets. I read every single word carefully, repeatedly, checking all the steps by referring to those pictures that illustrated how to deal with the side effects, the symptoms of deterioration or normal reactions. Gradually, I trained myself to become an expert in watching my bodily reactions to surgery and radiotherapy. It is interesting that the body was not so chaotic, my way of communicating to “self” as a nurse of my body was no longer chaotic. I found my voice and sounded like “a professional” as if I were a nurse who could tell “the body” that it was behaving well, it was recovering. I felt more comfortable when I had turned myself into an expert at caring for my “wounded” body and was starting to pick up the “expert voice and tone” to communicate with my nurse and the surgeons during the follow up consultations. I had acquired their medical language and I could make them understand me as if I had become a member of their team. I communicated the recovery of “my body” to the professionals and myself with a great focus on how the scar looked, the skin colour changes… my focus was “my body”, not how I felt, how I experienced the changes in the body with the hope that we could find the signs of recovery. I checked with the nurse whether it was fine, it was normal… all the communication was about the body. There was no “scope” for communicating feelings of disorientation, messiness, fears… no... no… it was not the place to talk about feelings even though deep inside the body there were emotions of confusion, fear, shame, alienness, loneliness…

A: I hear that the communication with the medical professionals seemed to be about “the body”, about how it recovered “from its outlook”, how radiotherapy worked. I hear you both checked for “signs of recovery” or returning to normality.

M: Yes, I was so eager to engage in a dialogue concerning finding signs of becoming normal again. It was so comforting to hear the professionals saying that those complaints of pain, the swollen wound and burnt feelings are normal. My experience was that I wanted to seek comfort and reassurance that my body was under control now, that the cancer cells were killed, and everything was fine again. The need for such reassurance was the most common reason behind questions that I kept asking whenever I had a medical consultation with a radiologist, a specialist nurse, an oncologist and so on… It seemed all their words dictated my sense of being in control of myself, my body, my illness. Probably, I was constructing my restitution narrative that relied on the professionals to be “director” and I performed the medical script that was written for all cancer patients with the hope for recovery. The scripts are there, and I was only one of the many who happened to be on the stage to perform what has been scripted for us - cancer patients. The more I was close to the script, using the same medical language they use, expressing those symptoms that are scripted in the checklist for cancer patients to report… the more competent I felt to go through these acts of reporting. Yet even though I was told I was fine, I still felt unsure whether I was fine. There is a part of me feeling deeply that there is something that I have not revealed but I don’t know what it is. Hence, in terms of prognosis, based on the diagnosis by the professionals, I was told I was fine, but strangely, I do not fully feel I am fine. It is as if there is something missing in my “illness narrative”. I don’t know what is missing, what I am looking for, but it seems I still feel I have lost part of myself since I got a new label as “cancer patient”. I wonder if that is what you describe about a restitution narrative in which we “outdistance mortality by rendering illness transitory”[lxxviii]

A: I hear that the reinstitution narrative co-constructed by you and the medical professionals does not fit your whole experience. There is something unknown hanging there?

M: Yes… I remember in the first year of my study after being diagnosed with cancer, I was advised by tutors and family to take care of myself, not to push myself to continue the study or client work if I needed time to recover. I experienced the pressure of having to make a choice to stay on or to return home for treatment.

A: What a dilemma!

M: In your quest narrative, you state that this narrative affords the ill person a distinct voice as teller of their own story. Unlike the restitution narrative in which the remedy (such as a drug or the physician) plays the active role, it is the teller (here the patient) who has a story to tell. My understanding is that story is not scripted by someone out there. You bring in the concept of a communicative body in relation to illness. Within a quest narrative, illness is seen as a journey in which one searches for alternative ways of being ill. It is a journey in which meaning emerges recursively to discover what sort of journey one has been taking. This is the reflexive quality of journeys. You refer to Campell's hero narrative structure[4]. The hero journey starts with the departure, beginning with a call, usually the call is the symptom to signal that the body is not as it should be. It is responded to with a refusal as the hero has not yet become a hero. Gradually a diagnosis is made, and the patient receives treatment. Once this threshold is crossed, the second stage starts, initiation, the road of trials in which illness brings about various sufferings, not only physical, but also emotional and social. This road may lead through other stages, such as temptation and atonement, until the ending or apotheosis[lxxix] .

As you state, the quest narrative tells self-consciously of being transformed; undergoing transformation is a significant dimension of the storyteller's responsibility. Quest stories of illness imply that the teller has been given something by the experience, usually some insight that must be passed on to others. And the final stage is the "return" - the teller returns as one who is no longer ill but remains marked by illness, being the master of the two worlds. I think the use of Campell's schematic of departure, initiation, surviving the ordeal, and return for the hero's journey might help to capture the

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[4] Campell, J. (1948; 2008) *The hero with a thousand faces.*

narrative structure of quest stories. I was impressed by your statement that “The returns thus set in place the ill person’s responsibility, and problem, of being a witness.” [lxxx]. I like the idea of “return” more than the idea of “recovery”.

Probably I feel I am in the state of embarking on a journey of researching my experience of illness through this collaborative dialogue or writing with you. I hope I have turned my role as a patient into that of a witness of my illness journey that could be shared with others (*feeling spirit lifted*)

A: (listening … nodding… in silence)

Silence

Act III Mortality

Scene 1: Trilogue on Mortality - Hard Conversations

June 2020

Looking at the formal reply from the insurance agency, stating that I need to give clarifications on different sections… and full set of the pathology reports for pre- and post-surgery… What the hell… I have submitted all those provided by NHS… What else you want? … I am still under national lockdown. How long will it take to get those pathology reports? Feeling very exhausted, anxious, and angry… Who can I vent my frustration on in the lockdown?

The book "*Being Mortal: Illness, Medicine, and What Matters in the End*" by Atul Gawande (2015) is just by my side. Having the dialogue with Frank for months has intensified the sense of feeling mortal. Yes, what matters in the end?

Me (M)
A (Arthur)
G (Atul Gawande)

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M: Hi Arthur and Atul, I am glad you both are willing to listen to me. I feel more mortal than before (*feeling irritated*) … You know, it is hard to talk about death and mortality especially with your close ones.

A: Yes, it's not easy to talk about death, as I have experienced before… even the medical professionals, supposed to be trained, still avoid talking about mortality with patients. I want more recognition of my journey as a patient, who is vulnerable, at the edge of my life. [lxxxi]
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G: Mortality is not a topic that is touched on in Medical School, almost nothing on ageing, or frailty or dying. Medical training focuses on teaching how to save lives, not how to tend to their demise. [lxxxii]

M: I feel myself getting more irritated… probably the lockdown… the pressure from the critical illness insurance claim process… feeling mortal… really upset. You know, Arthur… since talking with you about the trajectory of my illness for nearly a year, I can no longer hide my emotional vulnerability… In the past, I was so successful in distracting myself by being task-oriented, but now… I feel the need to let out openly the haunted feeling of being mortal… but it is so difficult to engage in these difficult conversations with others… it is so hard to find someone who can be resilient enough to engage in the dialogue of death (*sigh after a deep breath*).

G: I hear you. This causes most profound pain… when death is not a subject that doctors, friends, or family can countenance. [lxxxiii]

M: This is the unspoken pain of not being able to talk about dying, the thought of dying, the fear of dying that I am experiencing in my personal life especially when I am far away from family. How can I confront my own mortality without suppressing it? The more modern medicine advances, the more difficult it becomes to talk about the thought of dying as there is a lot of "objective assessment" of the stages of cancer that you are in… mine is classified as 0-stage cancer. It is not critical enough to be worried about as many others have more advanced cancer and are fighting for their survival… Whenever I tended to confide my fear to others, responses that I received are "You are fine. It is not cancer at all." … but I had surgery and radiotherapy … (*hearing my inner roar of protest*) … "You are only required to come back for an annual mammogram." … feeling happy but deep inside having a profound feeling of my own mortality... The alarm of being mortal is on… Where can I talk about mortality? Should I talk about my death anxiety… anticipated demise?

G: As a doctor, I encountered patients forced to confront the realities of decline and mortality, and it did not take long to realise how unready I was to help them.[lxxxiv]

M: I think this awareness of not knowing or understanding mortality is so important as a doctor. However, it seems mortality relates mainly to those facing imminent death, the last stage of their life, in months, or weeks or days. I am an outlier... not yet qualified to have a place to talk about my mortality… but I do feel my mortality (*feeling abandoned).*

A: Bauman has talked about the relationship between our body and mortality[lxxxv]. He points out a paradox of body association… body is the enemy of survival… as long as the body is healthy and mortality is beyond the horizon of consciousness, associating the self comes easily. The recognition of mortality complicates this association[lxxxvi]… modern medicine does much to dissociate body from mortality…

G: Yes… advancements in science have turned matters of ageing and dying over to the hands of medical professionals, but alarmingly we are unprepared for it... [lxxxvii] I remember a case… a man aged 60, suffered from incurable cancer… we, medical professionals failed to bring ourselves to discuss the larger truth about his condition or the ultimate limits of our capabilities, let alone what might matter most to him as he neared the end of his life.[lxxxviii]

M: The culture of our modern society has made us distant from ageing and death and we leave them to "others", the medical professionals and those who offer care in hospice or hospitals. In other words, we, human beings, alienate ourselves from experiencing honestly or truthfully the process of our own deaths or those of others… (*feeling more irritated)*

G: I knew theoretically that my patients could die, of course, but every actual instance seemed like a violation, as if rules I thought we were playing to were broken. [lxxxix]

M: It seems the idea of death is there but also not there for you?

G: I know death is normal… it may be the enemy… but it is also the natural order of things… I knew the truth abstractly, but I didn't know it concretely…[xc] Our reluctance to honestly examine the experience of ageing and dying is troubling… causing callousness, inhumanity, and extraordinary suffering…

A: In popular culture, we are obsessed with medical cures… What I observe in restitution narratives is that the preferred narrative… as Bauman argues, exorcises the fear of mortality by breaking down threats…[xci]

M: I need someone to engage in hard conversations about death, not only for those who are medically considered as dying, but also for me even though I'm not yet seen as dying … but my gut feeling is that I am on the path to death… waiting - in-between-ness, in Kellehear's term [xcii] in his book "The Inner Life of the Dying Person", but probably I am seen to be at the far end of the dying queue in that death is not seen as "imminent" and hence my thoughts and feelings seem not to be heard; like a " prisoner with a death sentence" waiting to be executed. (*with a bitter smile*)

A: And you feel the urge to talk about mortality with us as you have nowhere to go to…

M: Yes, I have always been a warrior in my life, as have many patients in your book, and I have longed to be independent, and I have been able to achieve that. However, as many others have experienced, being able to engage in hard conversations about dying and death after being diagnosed with cancer, is rare. I think being able to engage in hard conversations about one's own mortality with others is the path to accepting one's mortality. I deliberately do not choose the expression "curing" or "recovery".

G: Exactly, when I realized my father might not be immortal, our family was embarking on its own confrontation with the reality of mortality… the timer had been started… but we had not even registered that the test had begun.[xciii]

M: Yes, the timer has started for most of us without us consciously or unconsciously being aware of it as patients or as family members of patients.

G: I still remember the time when my father and I spoke to two surgeons to decide which treatment option to go for. One doctor focused mainly on talking about the operation and its risks, mainly concerned with the tumor, by citing a lot of facts… my father coped with the uncertainties of fear by asking a lot of questions about how exactly the operation would be done… and this was not welcomed…[xciv]

M: It seems to be a kind of "restitution" narrative…

A: This seems to be so…

M: I hear the authoritative voice about the chance of "being cured/ treated" and the patient is either left in the chaotic state to make their own choice or just follows faithfully the doctor's advice … no space to engage in the quest dialogue, in a reciprocal manner…

G: My father decided not to have this doctor as his surgeon... we got another surgeon who could identify that my father's questions came from fear. He took time to answer them, even annoying ones… [xcv]

M: I really feel how touching the moment was when your dad's fear, which was disguised as questions, was interpreted by the previous doctor as being annoying… Your father's experience makes me think of a doctor who keeps typing things in the computer when diagnosing the client and then after a couple minutes without a single glance at the patient and then prints out the prescription as if she's done a good job. Again, how much I want the medical professionals and close family to able to engage in hard conversations about what the needs and wants of sick people are and to hold these conversations earlier rather than later in their trajectory of illness… you know… how much I want people to ask me, as you suggest, "What is most important to you? What are your worries?" These conversations help the patient make choices that matter to them most and even challenge them to re-think ill-considered priorities and beliefs…[xcvi]

M: Arthur, I think this is the quest narrative that enables patients to open up possibilities to explore, stay curious and be brave to engage in the difficult conversations.

A: Yes, this is the quest process that heals…

M: For me, holding hard conversations should have started right at the beginning of the diagnosis instead of being kept under the carpet until it's time to sweep up the mess… It is an ethical act to begin hard conversations, including addressing mortality, which open the space and time for the patient to make sense of their medical conditions.

G: Yes, only now did I begin to recognize how understanding the finiteness of one's time could be a gift… the sudden knowledge of the fragility of one's life narrows one's focus and alters one's desires[xcvii]…I witnessed an unexpected transformation in my father who kept redefining his lifelong identity…[xcviii].

M: That's autonomy… as you suggested; we may not control life's circumstances but taking authorship of our life means acquiring control of what we do with them[xcix]

A (murmur): Control… fighting... accepting… a matter of a choice… choice becomes possible when we shift the perspective from the disease to the illness… we can choose how we experience illness… turn the worst of circumstances into an experience of value …[c]

M: I really feel grateful to you both for letting me talk about my mortality and the frustration of not being able to talk to others… I can appreciate now that it is a very frightening task to engage in hard conversations with self or others about our mortality and fragility… it requires great courage to put our fears, needs and wants to the forefront when health deteriorates… yet… it is also an indispensable part of the quest process that helps me to make peace with my mortality and fragility in the anticipated demise of self, free from the grips of anxiety and fear… (*feeling relief*)

Act IV Living with Cancer under Covid 19

Scene 1: Uncovering the Richness in the "Lost" Trajectory (or Territory?)

August 2020 -Phase 3 Lockdown

It is my fourth year of doctorate study, the final year for my thesis. This is really an unprecedented experience, not only for me, but for all the people in the world. We are still in Phase 3 lockdown. It is still a near empty hostel without new hostel mates moving in for a new academic year. The world is experiencing a substantial degree of separation and loss under the Covid-19 attack. Looking at my diary, I wrote,

"Starting from January, my hometown was under lockdown with a surge of cases in hospitals. My countrymen queued overnight to purchase facial masks, as shown on my laptop. They are so far away from me, but I feel so close to their desperation. The 19th of March marks the start of the first national lockdown here. It is lifted gradually in June/July. The flatmates in my hostel on the same corridor moved out in a night or two... leaving only a couple of us to take up all the cleaning work as all hostel staff have gone under lockdown. No cleaning, no garbage collection, no parcel delivery… all a sudden, we become aliens to each other with masks on. We live in deadly silence, without greeting one another, because of the fear of spreading the deadly virus to others or fear of being infected ourselves. The deadly silence in the corridor, the pantry, and the reception area make the accommodation seem a haunted place to stay. This is shared on FB by those of us who are left alone, with strict restrictions about meeting. We are totally abandoned. My experience of biographical disruption brought on by my cancer is now shared by my family and all the people in the world as a result of Covid-

19. How can I survive with my illness under Covid-19? Looking back… what a miracle!"

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M: Hi Arthur (*feeling excited*)

A: Hi Shirley

M: I feel excited meeting you. You know... it is our first time to meet via Zoom. What an unprecedented moment.

A: Yes, really unprecedented… We all keep ourselves distanced even from our loved ones.

M: Exactly, it is horrific, not knowing if I am a threat to others or they are threats to me. Suddenly, there is total loss of the trust that we assume is there. We cannot know if we pose a threat to others or vice versa. We are left in the state of not knowing. The pandemic brings disruption to the relationships we have with ourselves and others and the world outside. I wonder if it is a kind of biographical disruption caused by the pandemic that makes people confused.

A: It sounds to me and you as if the whole world is receiving a diagnosis of a life-threatening illness that make us feel as if we are experiencing our mortality.

M: Exactly. (*in affirmative tone*)

A: I feel curious about how you're managing your life as you live alone in the university hostel. Are you still far away from your family?
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M: Yes, we are far apart and could only maintain contact by phone. I found the whole transition to the lockdown phase abrupt and disruptive to many others but, honestly, not so much to me as I might have thought.

A: That sounds interesting. Can you say a bit more?

M: First, I have experienced that biographical disruption brought on by cancer for more than two years. It has caused me to live with confusion, fear, and withdrawal from others… Probably I have developed coping strategies to deal with the fear of the unknown at the present moment, not to say the future. Having experienced the power of Covid-19 since November or December last year when it first caused disruption in my hometown, I know what to prepare for self- protection. I kept ordering masks in early January for my family in my hometown when they were running out. I kept posting those masks well before local people here realized the need for them a couple of months after. I developed plans for how to protect myself in a pandemic by purchasing protective masks and hand sanitisers. I also had procedures for keeping a distance from others. This was developed when my hometown was first brutally hit by SARS in 2003 with the deaths of 8 healthcare workers and a whole block of estate residents being sent to an isolated camp just in one night. All these recent and past experiences of social distancing and staying in isolation are well stored in my mind as a plan for survival in the face of biographical disruption.

A: In other words, even if others here did not know what was happening, you knew what to do and how to protect yourself when your life was under threat?

M: Yes. The SARS experience 17 years ago was a rehearsal for today’s experience of having life disrupted in all respects - social life, economic life, health wise and so on.

It seems the response to Covid 19 here was abrupt and confusing with lots of chaotic messages being sent out… I feel as if the whole country is in chaos. Although there is a hotline to answer queries about when to get help if affected by Covid 19, my experience of that hotline just made me laugh out loud. *(in mocking smile)*

A: Did you try the hotline?

M: Yes, I kept following the guidelines about who should self-isolate as we were told in the media that there were certain types of people who need to do this for twelve weeks. When I called and checked if I belonged to that category, the hotline staff sounded very hesitant and said that I needed to check with my GP. When I called my GP, the GP on duty listened to my medical history and said that I belonged to that group, and I needed to be in social isolation for twelve weeks. Then, he said if I wanted to know more about Covid 19, he could not give me further information, I needed to call the hotline again. When I called the hotline for further information, the hotline staff just read out the information on the official website that was open to the public. Whenever I asked more information about my personal situation, he reverted to telling me to contact my GP. What I want to share is that it was just a vicious circle. It was unlike my experience with the cancer diagnosis, where there is a script that has been clearly written down on what to do when the patient is at a particular stage. The pathway is clearly laid out from a medical perspective, though the emotional reactions of an individual patient are unique. I find I can transfer the coping skills or wisdom in managing my cancer to manage the anxiety of living in the turmoil of Covid 19. I have my script for crisis management and consciously, yes, consciously I played that script again at this chaotic time.

A: So, I hear that you did not suffer psychologically from the shutdown.

M: I think I did suffer but more from inconvenience. For instance, I cancelled appointments scheduled in late February about two weeks before the actual lock-down. … I decided to cancel though the lockdown was not imposed until March as I really sensed the “deadly, highly infectious” virus (it was invisible, but the visceral visibility was strongly felt). I called and postponed the appointments… I didn’t want to get infected. I imposed my “bodily” lockdown or shutdown far earlier than when it was officially announced. Why? Because of my “lay” knowledge and wisdom that I gained from what happened in my hometown over the past few months and the traumatic SARS lived experience that killed 276 people in Hong Kong 17 years ago. I have the embodied experience and feelings of how “frightening” those days were. I was not sure whether I would be infected, whether my family members would be infected… the experience of not knowing is so familiar that I activated my protective mechanism of shut-down or lock-down with masks and gloves on… I couldn’t trust the professional knowledge of this Covid situation as they were still unsure what medical script they needed to write for the general public. On the other hand, I had my lay knowledge that was informed by my lived experience.

Biologically and socially, I shut down myself in self-isolation… I got all the basic stuff needed and stored it in my hostel room to get prepared for not being able to go out at all or even get sick.

A: I hear that you feel proud of yourself for being able to live with uncertainty even when you are in self-isolation with the risk of getting a deadly infectious disease.

M: Yes, I feel myself behaving normally, without falling apart, as compared to other normal people who felt agitated, frustrated or even rebellious about the mandatory lockdown.

A: It’s great to hear that you found strength and a way of managing uncertainty without falling into the chaos narrative.

M: I think the narrative is chaos indeed, but bearable. Since the medical professionals were also in chaos when encountering this unprecedented threat, I was not drawn to the restitution narrative of finding answers or certainty. I did not feel the need for clarity about the path ahead for healing or recovery, which is normally prescriptive in nature.

A: If I hear you correctly, you found a way of writing your script that was informed by your lived experiences in the past and the present.

M: Yes, exactly. Unbelievably, this enabled me not to focus on my thirst for clarity as others were also in the dark. This lack of knowledge on the part of other people somehow empowered me to search from within (my inner self) what resources I had, what I have known… Over the past few months, I spent more time in self- reflection, recalling my past life and my fears; I read more books about mortality and the inner life of dying people. (*feeling excited with a rising tone*)

A: What insights you have gained? You sound excited about what you have been doing (*a gentle smile*)

M: Yeah, if you are interested to hear… I want to carry on describing the experiences of bodily shut-down and how I managed to “recover” from it without dying.

A: That sounds horrifying. I can sense impending death when you said bodily shut down.

M: The experience of immediate bodily shut-down in the form of being unable to breathe is not a new experience. I reckon that impending death is not an unknown experience. Probably a decade ago, when I was on my way home, in the middle of a subway, I suddenly lost the ability to breathe. I felt no air coming in; however hard I tried to breathe through my nose, through my wide open mouth, no air came in… the more, the harder I tried, the more I sensed the intense shutdown of my ways of breathing: my nose, my mouth… I searched my purse for the inhaler (the medicine for an asthma attack) … I had no energy to search even though it was just inside. I couldn’t hear people close to me. I could see they were talking and were eager to help but I couldn’t hear what they were saying. I couldn’t speak, I lost control of my body, which shut down automatically. I know I needed to surrender, need not fight, need not respond to the external world… I stopped fighting for the air that was keeping me alive. The more I needed that air, the more I gave up the will to survive as my body just shut down faster… Consciously… yes, consciously, I stopped reacting to the external world of noises (whatever those noises were…), I allowed myself not to breathe, not to react, not to fight. … This was surrender in the sense of stillness, just being, not doing; my inner voice told me just not to respond, not to react. Gradually I felt my body loosen, then I sensed something. I felt the air again, something cold, fresh... I heard something; someone saying something… My senses came back… I could breathe… I was back again… in this world… (*murmur*).

I learnt from that experience of bodily shut down that brought me near death. I realized that in experiencing impending death, the best resolution is to let go when the conscious mind is still functioning. It is best not to allow panic to stop myself being able to turn to stillness for rest, for recovery…

A: I can feel the inner power or resources that you have stored to confront the near-death threat.

M: Yes, it seems this experience has helped me live with the sudden lockdown here without connecting with the outside, staying isolated, completely on my own and not being able to go out for fear of losing my life if I get close to people… If social connections are an important aspect of living, isolation is another form of cutting off oxygen, which is so vital for survival.

A: So, how do you fight with this disconnection, isolation, separation?

M: As I have already said, I have had the experience of conserving energy and effort by not fighting; remaining still to conserve my energy while being unable to breathe in that life and death moment… I learnt that the more I can stay still (not frozen), the more I can embrace the silence, the calmness, the unknown, and the more I have my serenity and gain my equanimity…

A: How long were you in self-isolation?

M: I was in self-isolation from the start of the lock-down in March, just staying in the hostel room and going to the nearby pantry, about 10 steps walk, for almost 12 weeks till mid-June when there was a gradual relaxation of the restrictions… However, as I was a person with underlying medical conditions, I took on this "label" of being vulnerable, more susceptible to death than any other "normal" people. I still maintain a stringent discipline of distancing myself… This somehow makes me anxious but at the same time excited when I tried to eat outside. I still keep to myself but feel that I connect to the outside world physically yet also disconnected socially. For me, it seems that I belong to this existential world, and don't belong… Oh, when I speak about it, it seems I have assigned myself a "physical presence" but "spiritual and psychological absence or non-existence" in this world… That sounds "weird" as if I describe myself as a “spirit” or “ghost” … It seems I am waiting for permission to rejoin this community of “normal” beings. Oh, this makes me connect with your experience of having to get a passport to be in the remission community, but this is temporary… it can be ended at any time, and I may need to re-apply…

A: Yes, I can absolutely empathise your experience in self isolation during the Covid-19 lockdown with the threat of your medical condition…

M: Probably the cumulative threats in whatever forms do help to cultivate or nurture some form of resilience embodied in mind and body. Cumulative threats might also mean cumulative dosages of booster to mobilise my inner resources (psychological, spiritual, physical energy) to balance against the threats…

For instance, being in self isolation for more than 12 weeks gave me time and space to connect to my vulnerable part as well as the part with strength that was built over my life in the past. I gained the insight that being on my own is not so horrifying. Probably this can be traced back to my childhood when six family members lived in a tiny village house which was filled with bags of plastic flowers everywhere as making plastic flowers was a means to earn our living. In my childhood I had not a single corner that belonged to me. The bed was my place for sleep, for work, for fun, for studying… That compares with my present university hostel room, of roughly 90 sq feet; I felt in luxury when I sat in the corner and felt like the little girl I used to be. Over the past three years here I have created my personal space for multiple purposes: bed for rest, for daydreaming and for dialogue with self; floor with yoga mat for exercise; desk for study; an entertainment corner; piles of books for spiritual input… This room is spacious enough to hold me but with a great sense of familiarity of being alone (emotionally and physically) as in childhood and a sense of gratitude for being able to own a much larger space now in this hostel room …

A: I can feel how you explore and experience the process of finding how you gain strength in self isolation under this horrifying situation.

M: Thank you so much for listening to me … without the on-going dialogue with you, I wonder if I can really be brave enough to go deep into the dark side of my fear but at the same time recognise the inner strength in the other part of myself.

F: You are welcome. Take care and see you again next time.

M: You too, take care (*taking a deep breath and breathing out slowly*).

(Pressing the exit button… silence)

Scene 2: Emergent Sense of Impending Doom

September 2020

August is just chaos… being called back to do the mammogram again as the result was unclear. Feeling depressed with the fear that I am going to leave the remission community and return to the treatment queue. So frustrated, I cancelled the monthly supervision with my supervisor as I had enough on my plate. I have produced nothing of value to show to my supervisor… but once the email was sent, I felt so guilty…

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M: Hi Arthur, nice to meet again.

A: Yes, great to meet again though it is still via zoom. How are you getting on?

M: Since our last meeting, I have experienced a roller-coaster of emotions... *(sad and trembling*). While I feel at ease with myself about the lockdown, it seems the physical sense of uneasiness does irritate me. In February, I received the blood test results, indicating something abnormal. I did not mention it last time when we met because I was not sure whether it was an issue or not.

A: You sound worried.

M: Yes, the blood test result in February indicated that they found the presence of anti-nuclear antibodies with a nuclear dots pattern that may be associated with overlap syndromes with Primary Billary Cholangitis and Primary Sjorgen's Syndrome. ANAs may also be seen following infection, in some normal individuals and in other
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autoimmune/inflammatory conditions… Again, all these medical terms are alien to me and make me feel alienated from my body again. My body seems to not belong to me again.

A: I am sorry to hear that... It is as if you experience splitting yourself in two.

M: Yes, all along I have tried to bring my mind, body, and soul together again. Now, it seems that the body wants to run away from my mind and soul. It seems it does not like me. (*sobbing*)... I consulted the GP, who said she was not sure and needed to check further with a colleague when I saw her for the results. She comforted me by saying that it should be okay, and I didn't need to worry. A regular blood test would be arranged later… Then lockdown came in March, nothing moved… No access to the Heath Centre, to my GP…

With an increased sense of tightness on the surgery site, I keep feeling increased physical discomfort. This was quite annoying as the annual mammogram was supposed to be in April to confirm there was no recurrence of cancer. As time passed by, month after month, my body seemed to expect me to tell "her" that she is fine.

A: Her?

M: (in heavy tone) Yes, her, I didn't want to have any relationship with "this body" …

A: This body?

M: Yes, this body.

A: Not your body?

M: No no... not my body... it has been derailed and wants me to tell her that she is okay… *(sounds frustrated*). In June, I called NHS and they said that I need to wait as they are still under lockdown with a long waiting list… Another two months; in August, I called again and was told that they could not find the record of arranging my mammogram. In other words, no arrangement is scheduled at all. That came as a shock. "You can't find my record? There is no record of the arrangement for my mammogram?" I could sense my anxiety to be told that I am okay so that I can move on. Without this annual confirmation, I feel my anxiety growing… getting increasingly hungry to receive confirmation. I was lost again… how long do I need to wait for the mammogram? I feel irritated and the nurse probably sensed my anxiety. She asked me if I wanted to meet their breast specialist.

A: I feel you experienced a similar sense of frustration to me of having to get a permit back to the remission community, no matter how temporary it is.

M: Exactly. I hate to be called back to be certified that I am okay though rationally I do need this confirmation biologically. I feel I lose my autonomy, no matter how hard I try to educate myself to live with uncertainty. It is so irritating that the feeling of being okay is subject to all forms of medical assessments… this is definitely a loss of personhood. I feel a powerful sense of objectification - as if I were reduced to an object to be examined. I am angry about all these advanced medical treatments and assessments. I am angry to witness myself going down the route of objectification, no matter how much I try to protect my subjective sense of being an individual with "autonomy".

At one point, I told myself, even if the mammogram turns out to be normal, it does not mean that the next moment is okay as cancer cells are inside. They may only be “suppressed” or “made quiet/dormant” for the time being; once they gain strength, they could return to re-occupy their territory”. Surprisingly, once I allow myself the thought of their presence inside my body there is a qualitative shift… at least at that moment… towards accepting them as being part of me. I had a thought that I didn’t need to rely on being told I am okay... I have the power to tell myself I am okay and to live my life as much as I can. Then, the sense of equanimity returns temporarily… That gives me at least some brief period of calmness.

However, on the day I consulted the nurse in late August, which was specially arranged, the tide of disruption returns… The nurse gave me a careful body check to see if any lumps were apparent. She kindly immediately arranged the mammogram for me on the same day without me having to wait for another couple of weeks since the department had forgotten to reserve a date for my annual check-up. The physical check-up seemed to go smoothly. Only the mammogram results remained to confirm that there was no recurrence of cancer. It would take at least two weeks to receive the results.

On returning home, I marked on the desk-top diary the possible date I might get the mammogram result by post if there was nothing special found. Or I may receive a phone call to go back for a re-assessment if there was anything suspicious. The two weeks of waiting for the results were irritating as the chances of the report being okay or not okay seemed to me to be 50:50. I used to consider the chance of recurrence as 50% though the “statistics” show that there is a high chance of a cure. Those medical statistics couldn’t convince me as I have held a rather “pessimistic” perspective of myself as being unlucky. You know what happens in the clinical room…

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That day, the horrifying call came… Ring… ring… ring… the NHS breast unit popped up… I held the phone up... I took a deep breath…

M: Hello

Female voice: Hello, this is a call from the Breast Unit… (I can’t take it in anymore… her voice became inaudible … I felt as if I was shutting myself down…)

M: It’s me.

Female voice: On 27th August, you had a mammogram. We’ve got the results and the doctor would like you to come back … there is nothing to worry about… we just want to clarify …

M: What’s wrong with the image? Can you tell me more?

Female: The doctor will explain it to you. I can’t tell you the details.

Me: But please, I am really anxious about it. Can you tell me what’s wrong? … (probably the lady heard my anxiety and could not reject my request to know more…)

Female: What I could say is that we see some density in the image. We want to check if it is the scar tissue that makes the mammogram unclear …

The word “density” occupies my mind. I had become so acquainted with the terminology they use in describing breast cancer… I knew “density” represents something suspicious, not normal… I held my breath - a form of freezing myself to calm myself down that I do when I am scared.

Female: Can we check if you can come on Monday afternoon, 3:10 p.m.?

M: Monday afternoon, 3:10 p.m. Yes, yes (in a sinking tone).

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M: Arthur, you know, after I hung the phone up, I sat with my mind empty… just leaving the functional part of the brain recording the time of the medical assessment on Monday… When I looked at the calendar, it would be the second medical appointment after another one scheduled at 1:30 p.m. In my I diary wrote,

Good, let me know straightway that I am not okay, then I can stop doing anything, stop living, just retreat home to live the rest of my life... (feeling frustrated, betrayed, angry… as if what I have done to live on, to carry on with my study will turn out to be futile…)

It is enough, more than enough. Over the past two weeks at the beginning of September, I was already fighting another health battle that attacked a member of my family. Now, without allowing me any peace in mind, this comes to attack me… To fight back against the feeling of being betrayed by the health monster in both me and my family member, I sent an email to my supervisor to cancel the upcoming supervision session. It was enough… I totally surrendered.

A: (listening, in silence)

M: You know what happened when I came for the re-assessment? (in a challenging tone)

A: I’d like to know if you feel comfortable (*in a soft tone*)

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At the Clinical room: To Quit or to Live On?

I was in the hospital on Monday afternoon, after the medical consultation with another specialist at 1:45 p.m. I had another hour before meeting my breast nursing specialist to do the re-assessment. It was still too early for my 3:10 p.m. appointment. Where could I go to ease the anxiety? I wandered mindlessly to the oncology unit where there was a café corner. It was so quiet, just a man sitting in a corner. I found a seat, carefully wiped the desk and chair with my hand sanitizer. I wiped my hand with sanitizer, carefully got a tissue to wrap my mask in, all these had become a routine for making myself "safe" to eat or drink outside. I sipped the coffee and then decided to finish it quickly as I couldn't sit too long… The longer I exposed myself to the public area, especially in the hospital, the more the chance I might be infected. The agitated feeling was unbearable, and I decided to throw away my half-finished coffee.

Walking back, not knowing where the mammogram unit was as I had taken the wrong route, I was lost, feeling directionless. It is probably the actual state I was in – being directionless, re-experiencing the feeling of biographical disruption…

Finally, I was at the reception of the mammogram unit. I told the nursing staff that my appointment was 3:10 p.m. She said I was too early. I could go outside for a walk or rest before coming back. I said I had nowhere to go. I had been outside. I just wanted to be in. I could sense my helplessness and loneliness. Luckily, she let me stay in the waiting room.

Nurse (N): I will check if we can get you to meet our specialist. Please wait.

Me (M): Thank you very much.

N: Oh, sorry, our specialists are doing a biopsy now. I am afraid you need to wait till your actual appointment time.

M: It’s fine. Thank you. (But it is not fine. When I heard that the previous patient was having a biopsy, I immediately thought that I was going to have one too… we were back doing a biopsy to confirm that we were in trouble…)

(My heart sank, it was no longer 50:50, it was 100%... I was in trouble… I was certain that I was in trouble.)

N: Hi Sui. (someone called my name)

M: Yes (*a nurse holding a file*).

N, Hi, this way please…

(*I followed the nurse… the place is familiar … I was here just two weeks ago…*)

N: Please get your top off and lie down. We want to give you a further examination.

M: I am scared. Am I okay? (*How silly I am by asking this question? I know they can’t tell until the examination is done… I want reassurance, not an answer*!)

N: No worries… We are trying to see if it is your scar tissue that makes the mammogram unclear. I can’t tell you more. I will get another nurse to do the examination and she can tell you more.

M: (*lying down, surrender to my body, not feeling, not thinking, just lying still…)*

Nurse (2): Hi, I am Rita (pseudonym). We want to check if it is the scar tissue that makes the mammogram image unclear… I will apply the gel onto your breast. It is a bit cold…

M: Yes, thanks… (*I felt humble and vulnerable… I knew I needed to surrender, not to ask, not to feel, to wait for the verdict from the specialist nurse.*)

My ears were getting very sensitive, I heard the clicking sound whenever the nurse touched a particular part of my breast, with a circular motion, pause and click, move on, pause, and click. Move on… this was a journey to my "scary" body through the ultra-sound scanning device… I heard "click" "click" "click" … nearly 10 clicks with images captured. My nerves were sensitively activated by each click. It seemed each click meant a problem found, ten or more than ten clicks meant more than ten spots in trouble… this was the "verdict" I gave myself. While I was still busy counting the click sounds and interpreting them…

Nurse (2): It is okay. You can put on your clothes.

Me: (My mind was still not back…) After a while, with my clothes on (probably the nurse saw me ready)

Nurse (2): It is okay. Everything is okay.

Me: (Not believing what I heard) (*responding in high pitch*) Everything is okay?

Nurse (2): Yes (*with a gentle smile even though the room is dark*)

Me: Oh, you are **my angels. Thank you, thank you (***with emphasis***).** (*I looked at the two nurses in the room gratefully with tears) (I started to sob) (all my stress and anxiety* *were released… like a balloon just pricked*) … I can tell my supervisor… I can carry on my study. (*I opened up my private life to them as if they were my good friends*)

Nurse (1): That’s great… what are you studying?

Me: I study psychotherapy. (*once I mentioned this, I felt ashamed. How come a psychotherapist behaves like a kid? I said to myself*)

Nurse (2): That’s lovely to hear… See you next year.

Me: Yes, see you next year…

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M: Arthur, do you know why I call the two nurses my angels?

A: Why? (*looking amused*)

M: I could feel that their examination, their expertise, or their wisdom, when they called me back for the re-assessment brought me alive again when I had surrendered myself to the path towards death. I was saved from the edge of dying and granted a permit to live on. When I left the examination room, I felt revived, I had been rescued… I could live on... I had the permit to live on. I rejoiced though I knew I would go through similar “traumas” of checking and getting or not getting a permit… But at least I could move on at this moment. Arthur, you know… when I looked at the sky after leaving the hospital?

A: *(looking curious)*

M: I looked at the sky and said "Arthur, I have a passport… I am back now, back in the remission community."

A: Welcome back… (*smiling*)

M: Arthur, my spirit was uplifted… My fourth year of study started. Unlike other "normal students" who are only required to attend the induction programme, meeting their personal tutor for matriculation of study, I have extra requirements – my body allows me to carry on without any indications of recurrence and no infection by covid-19… More importantly, the richness in experiencing the evolutionary nature of the trajectory somehow gives me some knowledge and wisdom (formula: i+1), borrowing from the theory of comprehensible input by Stephen Krashen, in helping me realise that this life (i+1) is not completely incomprehensible. I regained my sovereignty (*emphasis)…* I am living with whatever conditions I have… whether dying… with life-limiting illness or critical illness… being mortal…whatever adjectives should be used to describe my condition… (*in affirmative tone*)

F: (*silence, holding this moment of silence*)

M: *(taking a deep breath, feeling the peace*) … thank you, Arthur, for listening…

Silence

Scene 3: At the Will of my Consciousness

October 2020

A month later, having a physical examination for another health problem… It is always scary to go for a check-up during lockdown…

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M: Hi Arthur, we are on Zoom again…I can't help telling you something (*taking a breath*) … something exciting I experienced this month. (*sounds light-hearted*)

A: You sound excited. (*looking curious*)

Me: Last Monday, 19th, I had another physical examination on another part of my body.

A: Again?

M: Yes, again. If you remember, I told you last month that I just had a re-assessment of my breast.

A: Yes, I still remember how worried you were and that you felt a great relief at being told that there was no sign of recurrence.

M: Yes. I think I gained peace again. However, just a week after our conversation, I received a call from another department of the hospital, telling me that they have arranged a colonoscopy appointment for me, as advised by another specialist who I consulted on the same day as the re-assessment of the breast.

A: (*silence with a frown*) (*looking worried*)

M: You know, I know how frustrated you felt when you were called back for other assessments. I can tell you can feel how I felt… (*silence*)… This time it was for a colon examination to rule out any potential cancer cells there as I had been suffering from bowel bleeding... (couldn't hold back the tears… sobbing) … My daily routine was disrupted again… (*feeling frustrated*) to get myself ready psychologically and physically for the examination. You know, I felt grateful that because of the Covid situation I could still get a medical assessment so quickly. Yet, I did feel anxious. I told you last time I felt I had the permit back to the remission community… and now… again… they had to check if cancer was in another part of my body. I had just managed to recover from the "panic" of the re-assessment last month.

A: *(silence, frowning)*

M: Not fair… really not fair... why can't it let me have a break… (*suddenly, starting giggling*) … you know, what was challenging was that if I had the colonoscopy with sedation, I needed to have someone who could pick me up after the examination from the hospital and accompany me for another 24 hours. Under this Covid situation, how could I be so selfish to ask for someone to pick me up from the hospital and accompany me? I decided not to bother anyone as I did not want them to get infected. Ten years ago, I underwent a colonoscopy with sedation. I had no memory of what happened throughout the course of the examination. I felt safe. Now, it was done without sedation. I kept struggling, unsure if I could manage to witness the process of the examination. What would happen if I could not stand the pain…? What would happen if I got infected with Covid? … A lot of "What happens if…?" questions kept flowing through my mind…

A: Oh… that's really disruptive and intrusive…

M: Yes, those very disruptive and intrusive thoughts and fears violated my daily routine…

A: I can fully empathise with your struggle…

M: Yes, it was a real struggle… how much I wanted to be under sedation, just to be unconscious and then be told the result. I did not want to know the process…

A: The process?

M: The process of examination… I just wanted to be told…

A: You are afraid of seeing it, feeling yourself…

M: Absolutely… we all know that the process of experiencing is more cruel than the result itself.

A: The process of experiencing is more cruel… (*repeating what I said*)

M: Yes, I was fed up with the process of waiting, sitting in-between the state of not knowing… what a torture…

A: Yes, a torture… I'm feeling impatient or, to put it more correctly, I am curious as to how you went through the state of staying conscious in the colonoscopy… I remember when we started our conversations at the beginning, you sounded "excited" about your experience.

M: Ha ha… you are motivated to know how I sat with the torture of the in-betweenness…

A: Yes… it seems you are going to tell me something surprising…

M: Are you sure you want to know the process… the process of colonoscopy?

A: Yes, if you feel comfortable to share…

M: It is absolutely fine to share with you… it is not an experience I feel embarrassed about…

A: Thank you for the trust in me.

M: I warn you in advance that you must bear with my openness about the details… If you feel you can't bear to hear it, you must let me know and I can stop… not everyone can bear to hear this … definitely not my family…

A: Why not…

M: No no… I can't tell how they would respond… I wouldn't be able to deal with the emotions that would be stirred by their possible responses … (feeling *the fear)*

A: I see… I fully understand.

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At the hospital it was 1 p.m. In the waiting area there were six patients waiting for their appointments. We sat 2 metres apart. We waited silently for our turn. When nurse came close to the patient sitting opposite me, I overheard the patient say she used to be accompanied with family member for consultation. Now, under Covid, she had to come on her own. The nurse comforted her by saying that it would be fine. When the examination was completed, they would call her family member to pick her up. I kept playing with my mobile, though I had brought a book with me, thinking that I could kill time by reading. In the end, I read nothing, just browsing the news on the mobile… without taking in any information.

Nurse (N): Are you Sui? (*a nurse came close to me and asked my name*)

Me (M): Yes, I am Sui.

N: I'm Rachel (pseudonym). What would you like us to call you?

M: Sui is fine. Thank you, Rachel.

N: I'll check your temperature and take your blood pressure. After that, I will take you to the ward inside.

M: Yes. Thank you.

(while waiting… I was sensing, feeling, observing…) I didn't have to wait long. *I was led into the ward. There were about eight cubicles separated with screens. The nursing station was in the middle of the ward. There were many patients, about eight, waiting for their turn for examination. Some seemed to have finished, with staff bring them hot drinks and biscuits. I saw the warm smiles, heard some laughter, busy explanations of the procedures to patients… I could feel the warmth here with the nurses telling us their first names whenever they came to do the routine checking with us. Why did I feel the warmth here? It was the staff smiles, the care in talking through the procedures, their personal touch in inviting us to use their first names. It was different from what I experienced in my hometown. In my hometown, it was more businesslike with the services delivered very efficiently with staff speaking quickly, in loud voices due to the crowded environment, with hospital beds and wards full of patients. All the checking*

needed to be done very quickly. So, there was very little of the human or personal touch that I experienced here.

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Arthur (A): I feel you were sensitive to the physical environment… to the staff there… and these were important to make you feel safe.

M: Yes, I felt I was making use of all my senses as if I were a frightened animal who needed to feel safe in the forest… My nerves were heightened… I listened actively and attentively to ensure that I got things right and I would not get lost.

A: Forest? I can feel the heightened alertness.

M: Absolutely, heightened alertness… in the forest… that's exactly where I was. I was in… in fighting mode… I felt as if I were a wounded animal that was trapped… I needed to find a way to hold myself… to embrace myself…

A: How did you manage to create your safe feeling?

M: I browsed the news on my mobile phone, took photos of myself inside the cubicle while waiting… when I saw that my look on the photo seemed anxious, I deleted it… and took it again…

A: why… why did you delete it? …

M: I didn't like to look anxious, I wanted to feel relaxed… I tried to put on a smile even though I was wearing a mask… there was no way to see my smile… so I also relaxed my eyebrows… it was fun to keep seeing how relaxed I looked… this really helped to pass the time while waiting… (*giggles*)

A (giggles): You were finding ways of holding yourself…

M: Yes, I think I had learnt to be more creative in sitting with the anxiety in the betweenness of waiting… I wanted to capture my presence in witnessing the in-betweenness… between the fighting and stillness, the not knowing to knowing…

A: Yeah, taking photos of your presence in the in-betweenness enabled you to ground yourself.

M: Yes, it helped a lot and I felt I have shifted my state from passive being to active being…

A: Can you say a bit more about this shift?

M: As an anxious patient, I felt passive and had to wait aimlessly… I was not in control of my state… but when I changed my state to being the photographer of myself, I was the one to witness, to document, to capture my presence - my outlook, my position, what should be included in my photos … oh… don’t worry, I was mindful of the ethics … I did not take photos of anyone or anything beyond the boundary of my space… I just took photos within my boundary - inside the cubicle I was left in… this was my space…

A: I hear that being the witness of your experience was important for you…

M: I think so… I felt that when I made myself not limit my state to that of an anxious patient waiting passively inside the cubicle and kept exploring my mood, my state, my role, the environment, I felt I was an explorer … an explorer of my illness experience… feeling the unfamiliarity but with a sense of curiosity… I felt my sense of self had expanded gradually day by day from the beginning of the diagnosis nearly two and a half years before.

A: The word “expansive-self” pops into my mind.

M: I felt I set myself spiritually free from the passivity of the patient role… this gave me strength in re-orienting myself as an observer of my experience… I regained my intellectual strength in selecting what to see, how to feel, what to record on my mobile… You know, when I took photos, starting with the journey from home to the hospital, from the taxi to the waiting room, from the waiting room to the ward… I documented this journey, the trajectory of going through the unknown… I was making the invisible visible…

A: The invisible visible… (*in rising tone*) (*expressing curiosity*)

M: Yeah, the invisible visible… unfolding what I been afraid of, what I was going to go through, to witnessing what I actually was going through here and now, at this moment, this present moment… it is no longer mysterious to me… no more myth…

A: And…

M: And this unfolding of the mysterious process to actually seeing it, feeling it… gave me peace again… I was feeling myself moving away from the state of in-betweenness… I remember I read about the anxiety of in-betweenness… like in-between life and death especially when we confront our mortality…

A: (*in silence*) (*in deep thought*)

M: (*feeling tears in eyes*) … I took a deep breath to give myself energy to … unleash the pain of sitting with the in-betweenness... Arthur, you know… the pain is beyond words… there is no way to express such pain so openly and honestly without worrying if the listener can bear my yearning to be heard…

A: I feel you…

M: I sound courageous when I hear what I share with you, but I was wounded, hurt, scared… timid… (*in tears*)

A: (*in silence*) (*nodding head*)

M: (*taking a deep breath again*) … Frank, when it came to my turn to go to the real destination for the appointment - the examination room, I returned to the passive state… lying on the bed, feeling myself being pulled through one door after another, door after door, I stared at the ceiling... feeling the staff walking past… I felt I lost my reality again… moving to a new reality…

Arthur: Moving to a new reality…(*murmur*)

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(Transition to the scene)

In the examination room for colonoscopy, I saw two nurses…

Nurse (1): Hi, Sui. This is Rose (pseudonym), my colleague.

Nurse (2): Hi Sui.

Me (M): Hi Rose... thank you to you both for helping me, Nurse Rose: How are you feeling? (*in gentle voice*)

M: Anxious (*in a bitter smile*)

Nurse (1): It will be fine. As you chose to do the examination without sedation, let me show you how to use this breathing tube to help you when you feel discomfort during the examination…

M: (*listening attentively*)

Nurse (1): When you breathe in, you will get the painkillers from the tube that will help to reduce the pain… just breathe in when you feel discomfort… when you breathe deeply, you may feel dizzy…

M: (*trying to hold the tube and breathe through the tube*)

Nurse (1): Yes, like this... you're doing it right… Have you used this before?

M: Yes… (*in bitter smile*) …when I gave birth my baby… but I found it not helpful at all… the delivery process was just so painful that I threw it away… (*burst out laughing*)

Nurse (1) & (2): (*laughing too*)

M: I will try to behave this time… I don't want to make a mess here... (*I felt the nurse pat my shoulder*) … (*I heard myself sound like a good girl*) … I'll start practising breathing in and out…

Nurse (1): Yes, that's it… (*soft and encouraging tone*) …

Hi Sui, this is Dr XXX. She will conduct the examination…

M: Hi, Doctor *(I can't remember her surname*) …

Doctor: Hi, Sui. Would you like me to explain the procedure to you again?

Me: No, thanks. It is very clear to me *(I had really studied the pamphlet so well that I knew what the procedures will be*).

Doctor: Good. (*pointing to the overhead screen on the left side of the bed*) You can see the whole process clearly…

M: (*turning my head to the left and looking at the screen*) (*feeling that it was very unlikely that I would have the capacity and courage to look at the screen when the examination was in progress*) … Thanks, Doctor.

The examination procedure started… I could feel something being inserted and gradually going deeper and deeper into my colon… I started to reach out for the breathing tube… I breathed in and out… breathed in and out… I lost track of the time and only felt increased pain at some point and heard the nurse telling me that I was doing well… hearing a lot of praise from the nurse while feeling the loss of self in responding… I heard them talking about something casual... gradually, lost the sense of time… I felt I gradually lost consciousness… I just focused on breathing in and out… I could vaguely feel and hear, just sense that the doctor was working hard to go through the journey of examining my colon… I felt I was losing touch with reality… I felt my sensitivity reduced… I wanted to sleep… I heard the nurse say that it was going to finish soon… I felt I was going to get back my sense of self soon… (I felt safe to sleep) …

:

Doctor: What is this? (*sounding a bit serious*)

Nurse (1): (*breathing deeply*)

Doctor: Give me the forceps…

Nurse: the forceps… in the top drawer (telling another nurse)

Doctor: What’s that? …

M: (*waking up … regaining consciousness… feeling curious and anxious, I looked at the screen… I could see something red and swollen on my colon*)

Doctor: Closer, closer…

M: (*seeing the image of the red object bigger and clearer*) …

Nurse: It is like metal…

M: (*metallic…? How can I have metal inside...?)*

A nurse voice: Get it out to see…?

Doctor: It’s stuck there…

M: (*feeling that something was touched and pulled from my colon*)

Doctor: It’s stuck…

Nurse: She is feeling the pain.

M: (*I heard the nurse telling the doctor the expression she saw on my face. I felt desperate, wondering what I could do… kept thinking what was wrong… what was* *that metallic thing inside… My mind kept searching for what I had done that could have left things in my colon… travelling between semi-consciousness and being half awake, I felt I was in control of what was happening… my mind was telling me to surrender… let it be… leave it to the doctor and nurses to decide what is the best for me… I was not in control of my body… at the will of the body… I stopped guessing what the red metallic thing was … not bothered what the problem was… I surrendered… this surrender … in a positive sense… not giving in … but more in terms of trusting the doctor and nurses to decide… I think this surrender was to accept my state, regardless of what it was… unlike what I felt last time, when the re-assessment of the breast was done, when I kept thinking negatively how much worse the situation could be.). … Not knowing how long I was negotiating with myself… my conscious state was fading… I felt my spirit was set free, I experienced peace and equanimity again… I was conscious, not anxious… I felt tranquil…*

Doctor: Let me try to get it out…

Nurses: (*helping to adjust my position*)

Doctor: Yes, closer… coming closer… let's see if a biopsy is needed…

M: (*biopsy… my consciousness was revived… biopsy… eyes open… I looked at the screen again… suddenly…)* … I remember a long time ago… about a decade ago… I had an operation... is it likely that it is the legacy of the operation before?... (*it seemed I offered something important and useful to the doctor and the nurses) I could feel their excitement…*) … I had frequent bleeding before, and my doctor did some surgery there… though I don't know if this red part is related to where I had the operation before…

Doctor: That makes sense… (*sounding relieved*)

M: (*feeling great that my information had helped to address the puzzle… The room returned to the relaxed atmosphere… the examination continued… I did not feel any anxiety or pain… I felt we were going to come to the end of the journey… out of the forest…*)

Doctor: It is fine. Everything is fine.

M: No biopsy is needed?

Doctor: No. It is fine. (*in a comforting tone*)

M: (*feeling so proud of myself for witnessing this process of exploration... offering useful information to the doctor, being the spokesperson of my body… I felt I had regained my strength, my knowledge of my body, my sense of self, my power. I was not alienated from the process, not objectified… feeling great that I had participated in the process of exploration… I had contributed to this process…*)

Doctor: (*finished filling in the form*), coming close to me … can you remember what the operation was last time…?

M: … (*giving her more details of what I could recall…*)

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Arthur (A): Wow… (*expressing exclamation*) …

Me (M): I think I was very courageous. I had never thought that without sedation, I could act so bravely... I felt so glad that I was the spokesperson of my body… I was not abandoning my body… I put forward my best knowledge of my body (*in a tone of excitement*)

A: I can feel your great sense of fulfilment.

M: You know… being able to witness the process, being responsible in the process… of course, it was great to know that everything was normal… no biopsy was needed… what mattered even more is that I engaged in the quest process with the medical professionals in understanding my body… I had not imagined that I could speak for my body…

A: Exactly, I feel you were in the quest process though you were in state of not knowing, feeling panicky and anxious, timid, and vulnerable…

M: It is so great that I had my voice … and the voice was the voice of understanding myself… (*feeling tears in my eyes*) … I can't express my overwhelming sense of feeling my love for myself… (*sobbing*)… I wanted to rescue my body. I wanted my body to be understood…

A: So, you joined in to change the dialogue from restitution to a quest dialogue…

M: Yes, I am happy to feel that I am not in a restitution mode of communication, surrendering my body… instead, I feel I can offer myself in this journey of exploration… this quest… Although I did write down the medical history of when I had the operation before, that information was not noticed or thought to be directly relevant to what the doctor saw in the examination… The doctor focused on here and how, on what she saw in front of her… while I was the one who offered my historical medical information, bridging the past and the present, to make sense of what the problem was… I was helping to bridge the gap between the past and the present…

A: That sounds fantastic.

M: This is really something unexpected… I was the witness in the colonoscopy.

A: Being the witness gave you strength (*in a gentle smile*)

M: Yes, I felt my strength, my power …

A: I feel happy to hear your experience of witnessing in the trajectory of illness.

M: I do feel grateful to you for listening to me… for hearing me… for giving me the space to listen to myself… Under this disruption brought about by the illness, it is really very easy to lose my sense of orientation and ownership, my territory, my sense of self, my selfhood… It is so great that I have not given up my body, I have cared for my body tenderly as if I were the mother of my body, myself… I am nurturing and reconnecting myself to my body… I have not abandoned my body…I speak for my body when it cannot speak for itself (*like a baby who has not developed language*) … I remember all the battle marks the body carries in my life journey… Arthur, I remember your book “At the Will of the Body” … I think I would prefer to say “At the will of my consciousness and self- awareness or awakening…” … I have experienced the power of being conscious, being self-aware…

A: That sounds great.

M: I am going to share more with you about the power of our dialogues in my quest trajectory of illness… I have read your paper on “Dialogue as narrative de-stabilization” …

A: Brilliant…

M: Thank you, Arthur. See you next time.

Act V Dialogue with Disease : Breast Cancer

In two weeks' time it will be the third anniversary of my surgery for the treatment of cancer. When reading my illness diary, interestingly, I discovered that I had never used the medical term "lumpectomy", the breast-conserving surgery. I still sense my resistance to letting it be heard. Why? In February, I shared with my supervisor a draft chapter about the role of writing in my illness trajectory. I wrote,

> *"Writing, done collaboratively, whether imaginal or real, is an emancipatory process… When I engaged in a dialogue with the illness through dialoguing in an imaginal context, my troubled psyche was opening up to be felt, be heard and be visible…"*
>
> *My supervisor asked, "What would happen if you did directly write a dialogue with your illness?". My immediate response was, "I did not expect you to have spotted this (that I did not engage in a direct dialogue with my illness), and I have only managed to do it indirectly. I said, "If you had not spotted that (the use of indirect means to get close to my illness), I would have left it as it is. But since you spotted it, I could tell you I am very afraid. I am scared. I can't talk directly with my illness. I need to protect myself…" (Reflective Journal, dated 11 February 2021)*

This conversation was held two months ago. I am still sitting with the question "What would happen if I directly had a dialogue with my illness?"

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Scene 1 Breast Cancer and I

4 April (Easter Day)

Without Arthur Frank, without anyone around, I am alone. In the student hostel, a bright morning, wind outside. Music on… Now typing out the dialogue I had with my disease, yes, disease, cancer is a disease caused when cells divide uncontrollably and spread into surrounding tissues. There are many types of cancer, and I am dialoguing with the one called "breast cancer".

Me (M)
Breast cancer (BC)

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M: (*Looking at BC represented by figures and images in the form of blood test reports, biopsy, and mammogram reports*) (*spreading all the reports received over the past three years*) … (*taking a deep breath*) … I know you a little more now… my supervisor asked me how it would be if I talked to you directly… I can tell you that I don't like talking to you. I don't like your invisibility, aggressiveness, sudden attack, fast growth, and your licence to kill. I can feel my hatred for you. I hate you… hate your immortality… transcending generations. It is you … you … who has taken away the life of my grandmother, and your relative in the cancer family killed my dad… What a bad spell you have put on my family members…

BC: (*sitting quietly inside the forms*)

M: The first time I heard of you was decades ago when you took away my grandmother's life and that was followed by the death of my father a year later. You
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and your relative killed my two family members over two years. You are so powerful that you could take away my two family members' lives just in two years. You are my enemy… your invisible presence in my family has haunted me… you are invisible, but you are here… (*feeling sad and helpless*) … you never let us talk on equal terms….

BC: (*still in silence*)

M: Now, you catch me as your prey… you have never changed your role as a predator. Each time you presented yourself in the form of medical reports, I found you nasty and arrogant. You have successfully invaded my body and my life as you invaded the bodies of my ancestors before. How dare you have such power to deprive us of our autonomy. I hate you... (*taking a deep breath*) … You never talk to me directly. Your invasion is silent, invisible. You announce your presence through strangers… the medical professionals… I am made to listen to your commands through the mouths of the medical professionals… (*feeling fed up*) … Your brutality can only be stopped by another form of brutality - surgery and radiation. I am objectified by you... How can I talk to you, the invader of my life… my life trajectory is disrupted by you… (*feeling my anger*) …

BC: (*still in silence*)

M: Your silence silenced me… but over the past three years, I kept talking about you, reading about you in the reports… in the literature[ci]… it seems I am not as scared of you as before. I am still angry with you… but I am no longer running away from you… I know the more I try to run away… the more I give you the power to captivate me…

the more I make you visible, if I un-silence myself, the more energy I gain to tame you, yes… to tame you… you know ... I have learnt to read you in the reports… you are numbers, figures, images… but you are also caught by advanced technology… you can be immortal, and I am mortal… and so what? … I know now that I am a mortal being… you can remain a silent predator, but I have chosen not to be silenced by you… I have a choice… I choose to talk about you, talk directly to you… you can still scare me … haunt me… but I will learn to live with your aggression…

BC*: (being put back to the medical folder… invisible and silent again)*

M: (*feeling calm and contented*) I have finally talked directly to the disease - the predator, the enemy - without fear. Hurray.

Chapter 5

Discussion

(Re)visioning Cancer-related Trauma in the Illness Trajectory and the Power of Witnessing

The engagement in my cancer trajectory through collaborative writing in an imaginal dialogue with Frank and Gawande and the actual conversations with my supervisor and medical professionals opened up a new arena for me within which to make sense of the threat to my life. A major discovery in this quest process was that from the medical perspective, my cancer was curable, with a good prognosis. This seemed not to justify my feeling vulnerable as compared with many others who are medically far worse in their diagnosis. Under the current biomedical stages of cancer, it seems that any cancer related traumatic reactions were unwarranted and they were not in proportion to the stage of cancer that I was in. Ultimately, I felt my grief in the loss of health but the grief that silenced me was disenfranchised.

In this chapter, I will discuss how my awareness of cancer-related trauma was discerned and realized through collaborative writing in imaginal dialogue. I highlight the importance of being the witness of my own troubled psyche and the power of witnessing the emergence of a renewed sense of self, as evidenced in the created space of co-witnessing with my first supervisor.

Awareness of Cancer-related Trauma in the Trajectory

The quest process reveals the brutality of cancer that brings biographical disruption to my life in many respects. The process makes me aware of my lived illness as traumatic, which is not to be determined by the external standard of medical classification of the stage of my cancer but by myself who is the witness of my own suffering. Cancer diagnosis and treatment are highly stressful for both the patient and their loved ones. However, there is a common misconception that PTSD is only relevant in circumstances of acute, physical trauma (Leano, et al. 2019). It was not until the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) that the diagnostic criteria for PTSD were adjusted to include diagnosis and treatment of a life-threatening illness, such as cancer. This was not properly recognised as a traumatic stressor that can induce PTSD (American Psychiatric Association, 2000). Yet, just a decade after, PTSD was adjusted in DSM-V, which states that, "a life-threatening illness or debilitating medical condition is not necessarily considered a traumatic event. Medical incidents that qualify as traumatic events involve events that are experienced as sudden and catastrophic" (American Psychiatric Association, 2013). The DSM-V argues that this does not mean that patients cannot suffer from cancer-related PTSD; it means that patients must experience a traumatic, catastrophic event during their diagnosis or treatment of cancer to meet DSM-V criteria for PTSD (Leano, et al. 2019).

As a cancer patient, having gone through the process of diagnosis and treatment over the past three years, I would argue against this definition. This revised statement seems to underestimate the complexity of the trauma of biographical disruption that cancer, regardless of the stage as defined by oncology, has on the patient. To borrow Caruth's (2006 [1996]) term, "Unclaimed experience" is exactly what cancer patients face in a state of passivity, with their illness defined by others but not themselves. As revealed in the literature, many aspects of cancer diagnosis and treatment can act as traumatic events that can lead to cancer-related PTSD (Wess, 2007; Cordova et al. 2017). For instance, follow-up scans and oncology visits or physical symptoms can trigger fear of recurrence amongst patients in remission (Ghazali et al. 2013). This is exactly how I experienced when I received notifications of follow-up scans or re-examinations when the results were suspicious. These trauma-related reactions are cumulative, incomprehensible and could only be discerned through the interaction with an empathic listener or reader (Caruth, 1996; Charon, 2006; Muller, 2018). Cancer can indeed embody PTSD lived experiences, regardless of the stages of cancer one is in. However, cancer-related Post-traumatic Stress Disorder (PTSD) is reported to be missing in the cancer literature (Leano, et al. 2019).

Collaborative Writing through Imaginal Dialogue as Inquiry and Therapy: Witnessing the Troubled Psyche

In the situation of being in a foreign land and mostly in physical isolation under the extended period of national lockdown due to the threat of the Covid-19 pandemic[cii], I realised that this personal isolation did not give me that intense sense of loneliness and depression that I had prepared for. I think this can be attributed mainly to the ongoing collaborative writing through imaginal dialogue together with a regular reality check with my supervisor on a monthly basis over the past two years. They provided me with a safe and secure place in which I could manage the overwhelming anxiety-provoking moments and events that intruded in my life disguised as life-saving gestures in the form of medical assessments and treatments. It is a surprise to notice that my emotional reactions to the traumatic experiences of illness were less catastrophic than I had expected, albeit with occasional ups and downs. Why could my mind stay sane in the light of the biographical disruption in life that cancer, with the fear of its recurrence, brought about over the past three years?

As well documented in the literature, trauma is realised only belatedly, is incomprehensible, yet demands a listener. Its paradoxical nature can dominate a person’s life. When it is there, it presents in the form of flashbacks or nightmares, but its absence is expressed as amnesia or by leaving only a void (Etherington, 2003a, Etherington, 2003b; Schmidt, 2018). My assessment is that the preservation of my sanity can be attributed largely to the containment of my emotional vulnerability through the evolving relationship with Frank as my imaginary confidant. Initially I regarded him as a co-sufferer and was attracted by his openness in the narration of personal illness and vulnerability. Reading his experience gave me consolation and support that helped me shape my perception of illness. As time passed by, through imaginal dialogue, I have created him, unconsciously, as my fictional psychotherapist and collaborative writer with whom I felt safe to confront my fears and anxieties. I could generate an authentic narrative of illness in the form of a playscript that unveils the cancer-related traumatic experiences in navigating the liminal spaces in the trajectory of illness. Although my fears were not suppressed, this helped to prevent the “return of the ghosts”, and even when the return was likely they were addressed, processed, digested, and contained (van der Kolb, 1987; Etherington, 2003a; van der Kolk, 2014; Schmidt, 2018). Hence, I did not experience those uncontrollable, repetitive, and intrusive phenomena which could have driven me to a state of passivity, imprisoned by those traumatic repetitive memories. When the victim fails to fully understand how trauma manifests and is unable to have it processed, trauma memory dominates and distorts the victim’s past and present (van der Kolk, 2014). As Barnett (2002, cited in Etherington, 2003b, 191) states,

> The ‘undigested’ elements of trauma may remain in psyche like ‘foreign bodies’ blocking our normal functioning directly or by taking up psychic space and psychic energy if they are kept repressed and denied or encapsulated - locked away in a corner of our mind.

I contend here that turning the imaginal dialogue with Frank and Gawande into a collaborative writing process, presented as a playscript, created the psychic space, with moments of pauses for reflection and revisiting of the dialogues. It helped me make the trauma experience visible and comprehensible through being listened to; it transformed it into a language of expression. This is an act of sensing, reflecting, naming, witnessing, and reframing creatively, with the trust that whatever emotions were evoked, they could be contained and borne in the creative space I shared with Frank, Gawande and others during our imaginal encounters. This might explain why I did not have those intrusive images or memories in my trajectory, as supposed to be traumatic experiences, with threat of recurrence. I think I was able to stay away from the intrusive fear or images mainly because I had created the “space” for processing those experiences, making them speakable. This created a counterforce against the intensity of biographical disruption which might, like a ghost or spirit, have had such an impact on my mind that it would have become indelible (Schmidt, 2018).

Biographical disruption is a violent process. But the process of collaborative writing through imaginal dialogues weakened the aggression as I had space to find words to describe those traumatic experiences, which are usually unspeakable, and to process and integrate those haunting images and experiences. In my quest process of writing collaboratively with my fictional and real listeners, in both fictional and real contexts, collaborative writing filled the gap in travelling through the liminal space of becoming.

From Imaginal Dialogue to Collaborative Writing: How it Works

Studies show that opening up is a way to recovery and growth (Muller, 2018). However, it is not uncommon that traumatised patients avoid past, painful feelings and relationships and find their stories too painful to tell. Even though trauma is always the story of a wound that brings us close to the trauma reality, trauma memory cannot actively be retrieved due to the potential re-enactment of images of trauma in the form of flashbacks or nightmares. The victim of trauma may suffer from amnesia - a manifestation of the fact that conscious or active retrieval of the traumatic memory is impossible. Literality of repetition and dissociation of the memory of the event at the root of the trauma form a paradoxical pair (Caruth, 1996). Unlike memories of non-traumatic events, traumatic-related memories are involuntary and usually occur as a whole-body experience with sensory re-experiencing. Undoubtedly, patients with PTSD frequently avoid trauma-related cues or triggers to prevent the aversive re-experiencing of the trauma (Ellis and Zaretsky, 2018; Muller, 2018).

From a physiological perspective, the brain goes into sympathetic overdrive when reacting to a traumatic event; during and after the trauma, the amygdala is in a state of hyper-arousal and the prefrontal salience network loses its capacity to assess cues for danger and thought control, causing non-dangerous cues to be perceived as threatening, especially if associated with the trauma. This constant state of fearful hyper-arousal frequently results in insomnia, irritability, increased tension, and startling, and sometimes aggressive or reckless, behaviours (Ellis & Zaretsky, 2018). Studies show the important role of emotional expression for individuals who confront a cancer diagnosis (Stanton and Burg, 2002; Pennebaker and Smyth, 2016).

How was the avoidance of opening up overcome in the context in which I was situated, that is. living in a foreign land and in isolation under a year-long period of Covid lockdown? Attachment theory in supporting traumatised patients to move from avoidance to recovery and growth, indicates that an honest telling of the lived experience in the presence of a secure attachment relationship is needed. It helps the traumatised patient to engage in the shared talk that can give the promise of recovery and growth (Muller, 2018). Dialogue helped me talk about the unspeakable experiences and connect complex emotional reactions and thoughts which unfolded day by day throughout the course of treatment.

As stated, critical illness is a complex biographical disruption occurring in different forms at different stages of the critical illness trajectory (Tembo, 2019). We need to acknowledge the limitations of modern-day medicine and recognize the value of developing models of narrative inquiry (or narrative as medicine) that facilitate the holistic care of patients throughout their trajectory of illness (Charon, 2006; Charion, 2008; Tembo, 2019).

Navigating Liminality: Shared World of Vulnerability

By re-reading the imaginal dialogues and real-life conversations presented in the form of playscripts, I believe that I have experienced most, if not all, of those stressful, unpredictable cancer-related events that placed me in the state of heightened alertness, anxiety, fear, and doubt that made me crippled and vulnerable, that were initially outside my rim of awareness.

Through reading Frank’s narrative of his cancer illness experiences, I entered his liminal space of fear(lessness), (in)visibility of illness, knowing and not knowing. The reading process made me identify with his experiences and I was then able to empathise through responding to his experiences in the imaginal dialogue. It is as if we were both creating a shared space of experiencing pervasive liminality that bridged the temporal distance between our illness experiences.

As Bruce et al. (2014) state, the uncertainty of not knowing the disease trajectory is difficult for many and sharing can be emotionally charged; it is uncertain how the listener would respond. There is trepidation. It was through the open and genuine dialogues with Frank that I gained courage to explore my fear of life and death by searching books on death. This opened up another imaginal dialogue with Gawande, who wrote about his experiences of witnessing his loved one facing death. My fear of not knowing how my family feel about my illness is unspeakable. Yet, the muted fear needs an avenue by which it can be let out. Imaginal dialogues make invisible visible and unspeakable speakable. I am free to tell what emerged to my consciousness without too much self-censorship. The spontaneity of reflection in the intersubjective space created a third space within which I could be realistic about the cancer-loaded fear, confusion, courage, and disorientation.

I contend that imaginal dialogue breaks the spell of living a pervasive in-between, not seeking to resolve and move on. This relates to Meyers' (2008, 80) conceptualisation of liminality as "resistance to representation and thus frequently elicits paradoxical description: the liminal position is both "this" ***and*** "its other" at the same time it is neither one". Through translating the imaginal dialogues to playscript as a representation of collaborative writing, I could distance myself from the liminal space of in-betweenness to witness how complex the emotional reactions and thoughts were in encountering the traumatic events in the trajectory. This is a process of crystalising the overlapping narratives between opposites (of fear or fearlessness, visible or invisible, living or dying and knowing or not knowing) in the illness trajectory. This helped me not to fall unconsciously into constructing a restitution narrative that began with story of becoming ill, then focused on getting better and eventually becoming healthy again, as expected in the culture in which I live. The restitution narrative is the preferred narrative in my culture; it signifies resilience and independence as valuable attributes to aspire to (Bruce, et al. 2014). Yet, the cost was surrendering my right to speak for my body and mind to those medical professionals who can make decisions about my future as if I were reduced to one of the many millions who are classified in the same stage of cancer. My subjectivity and uniqueness are marginalised.

The dialogical approach in the quest of illness helps to re-centre life amid the shadows of illness. Deep illness, situations where illness is always present and defines one's life, invokes suffering that medicine alone cannot address (Frank, 2013 [1995]; Frank, 1998). To survive this kind of suffering, people narrate stories that allow them take control of their reality through narrating what is meaningful (Janet, 1919-25 cited in Caruth, 1995; Frank, 1998; Kleinman, 1998). Having the courage to acknowledge my vulnerability was therapeutic. Entering the liminal space in the illness trajectory through dialogues about life-threatening experiences afforded me an opportunity to make sense of the ambiguous experiences of wellness within illness and living while dying (Frommer 2005). It is also consistent with a growing interest in aesthetic forms of knowledge and inquiry (Schmidt, 2018).

Frank and Gawande as Empathic Listeners

Frank and Gawande, as my imaginary friends, became my loyal and empathic listeners who offered a secure space to contain my overwhelmingly fearful emotional reactions to the unpredictable and stressful incidents of diagnosis, re-diagnosis, body examinations and thoughts of mortality. Their seemingly authentic and immediate presence in the context of imaginal dialogues broke the spell of the suppression of inner fears, frustrations and hopelessness that might have been detrimental to my mental health and physical wellbeing. Frank and Gawande listened to my attempts to tell a traumatic reality. Through the documentation of our dialogues, they became my collaborative partners in making my traumatic reality available and speakable. This makes me think of Winnicott's classic "Squiggle Game" in which thoughts and feelings are elicited in an unstructured format (Berger 1980). Collaborative writing in the imaginal dialogue shared the unstructured features that allowed the maximal latitude for me to share ideas and thoughts, especially in the state of liminality. This helped me off the hook of "avoidance" that prevented me from processing and integrating traumatic memories and experiences. The literature on trauma state associates failure in processing and integrating trauma memories with PTSD (van der Kolk and Kadish, 1987; van der Kolk and van der Hart; 1995).

Wegener (2014, 358) states that writing with a fictional character who seemed not to be there but who was always present enabled her to find a voice of experience. The presence of the fictional character "served as a lever for alienating herself from the writing process and enabled her to immerse herself into self-conscious writing in innovative ways".

Although Frank and Gawande are real authors and researchers who wrote about their experiences in relation to illness, in my process of inquiry, in this study, I have invited them to be my imaginal and fictional characters to listen to my illness drama. In the process of writing my dialogues with Frank and Gawande, I could feel the trauma surfaced and the need to be heard. The process of dialogical exploration with Frank, Gawande and my supervisor as well as medical professionals generated the strength to externalise fear, the deeply repressed fears (which is my usual coping strategy). Through the space created imaginatively and collaboratively with Others, this facilitated transition between the real and unreal experiences, the in-betweenness in the liminal space of transition from ableism to disablism, from living to living-dying or a dying state (as recorded in my diary, dated 31 December 2020). Being open to all kinds of feelings or responses counteracts the fears inherent in life-threatening illness which cause trauma or traumatic reactions when one is in a vulnerable life and death state. These fears include shame, weakness, fear of becoming nothing, marginalisation in the social culture. As Wegener (2014) contends, fictional genres and co-writing with fictional characters are ways of generating some truths about the field under study.

Relational Depth: Externalising Problems through Dialogical Encounter

As the relationships with Frank deepened, I experienced the shift in the content of my sharing with him. At the initial stage, our dialogues contained more the elements of intellectual exchange about illness and his research on types of illness narratives, with emotional content or feelings being kept at bay. This reflected my strong sense of self-protection, with a hidden fear of getting close to the real reactions to the cancer-related trauma events I experienced. But as time went on, without knowing when, I started to go deeper and deeper, to the extent of sharing very personal feelings and thoughts about illness, as evidenced by the sharing of the actual experience of colonoscopy, for instance. I realised that a secure attachment had been formed. I think this indicated that my imaginal encounter with Frank was working at relational depth. According to Mearns and Cooper (2017), relational depth is a form of encounter in which therapist and client experience profound feelings of contact and engagement with each other, and in which the client has an opportunity to explore whatever is experienced as most fundamental to her or his existence.

Some may wonder if such dialogue was one way, in which I was contributing whereas Frank was not reciprocating. I would argue for an expanded notion of collaborative effort in writing about shared experiences through imaginal dialogue that is beyond time boundary. Frank (2002 [1991], 4) emphasises the power of talking back. He states that the purpose of his writing about his illness was to offer the starting points for talking and thinking about illness. He reminds us that there is no one recipe that fits all, and we have our own way to make sense of our illness experience, but in the process of searching for meaning we need not be alone. I agree with Frank that talk helps to elevate illness beyond pain and loss. He offers an invitation to his readers to talk back through which we find our experiences in a story someone else has written. He invites the readers to add their lives to his and change what he has written to fit their own situation. And he believes that those changes can become a conversation between him and the readers. It is in response to this gesture of invitation that I embarked on my journey of engaging in conversations with Frank in an imagined context. The exchange of feelings and thoughts about our (traumatic) cancer-related experiences became a conversation between us. I feel that I am not talking back to Frank, but rather talking with him in a joint exploration of what it is like to be in the trajectory of illness. This is in alignment with the spirit of collaborative writing.

I contend that collaborative writing through imaginal dialogue with Frank is a performative act that fosters a creative space for imagination of shared illness experiences as well as a research partnership in researching illness experiences. I argue that we "collaborate" to write the conversations but this time it was me who turned our imaginal dialogue into a playscript. This is a form of collaborative writing we co-created by having him start his story and me adding mine to his with him as a co-writer in writing about the illness experiences that we shared. This opens up the parameters in the field of collaborative writing.

This justifies why it is collaborative writing - it is the deal Frank offered me. I agreed to accept this deal with him and extend its boundary by inviting others who will read my thesis to continue writing about their illness experiences and to change "mine" in a way that suits their needs and fits their own situations. This is the performative act of collaborative writing that I invite my readers to continue with me, with Frank and with whoever feels like joining this "form" of collaborative writing in my "physical absence", not bound by temporal boundary.

Frank offers his presence to those who suffer through his book as a partner, and I take up this offer of partnership to embark on the conversation about illness experiences with him as the witness of my experiences in the trajectory of illness. And it is also my intention to uphold Frank's invitation to accept him as my good partner in silent conversation,

> “For those who read this book alone, I hope it will be a good partner in silent conversation … and I hope that for most it will be the beginning of conversations with others.” (Frank, 2002 [1991], 5)

When looking back, the dialogues between me and Frank showed that the narration of the clinical experiences increased in detail over time. This reflected the richness in the emotional memories that captured the thoughts and feelings accompanying my responses to the medical treatment and assessments. It is evident that I did not dissociate myself from cancer-related traumatic experiences and memories. I developed resilience and cultivated a capacity to talk about them and make sense of them. These were positive signs that I was integrating them into existing meaning schemes (van der Kolk and van der Hart, 1995). This protected me from developing PTSD as dissociation or amnesia as a response to trauma.

For instance, the apparently trivial acts, such as taking photos of myself while waiting for my turn to have the colonoscopy (see Act III) took up more space in my illness narrative. I reflected on the underlying meaning of those acts which enabled me to become a witness to my vulnerability, and on my courage in responding to the medical professionals’ query during examination. I became the master of my mind and became less fearful of re-experiencing the trauma. Drawing from Bowlby’s theory of attachment and Bion’s theory of containment, I have conceptualised Frank as my fictional therapist who offered me a secure base from which to explore my lived experience of illness. The introjection of Frank as my secure attachment figure helps to contain my emotions as I feel he could contain his (Bowlby, 2005; Szykierski, 2010).

Being able to engage in a detailed account of illness experience, I felt as if I were rescued in three different respects. Firstly, from being tortured by the immediacy of the overwhelming adjustments to my body; secondly, from the psychological disruption and the aggressive intrusion to the body by surgery and radiotherapy; lastly, the fear of recurrence especially in the state of the nation-wide lockdown under Covid-19 restrictions.

Writing and dialoguing was a calming process that has a lasting healing effect as it brought the fears of the unknown, uncertainties and threats of death to the forefront, allowing me to negotiate with my mortal self, rather than turning away from it (Schmidt, 2018). For instance, when I re-read the part concerning the colonoscopy, the horrifying experience of witnessing how the examination was conducted and how I engaged in the dialogue with the surgeon and nurses to make sense of the suspicious material found in my colon, I realised that I was indeed an expert on my own body that that gave me back the sense of ownership of that could not be taken away even by the medical professionals.

The episode of direct interaction on the topic of my body with the medical professionals could be seen as unbearable by others when the troubled body parts were perceived as a site of abjection that was shameful (Schmidt, 2018). As Schmidt (2018) states, the abject makes its subject aware of its “relation to death, corporeality, animality, materiality” - those relations which consciousness and reason find intolerable (Grosz, 1994 cited in Schmidt, 2018). These reactions were not suppressed in my trajectory while I engaged in the collaborative writing process. On the contrary, they were honestly exposed to self and Others who were invited to play a part in the illness drama I experienced. I have transgressed all boundaries between telling or not telling, exposing, or not exposing my body, filled with feelings of vulnerability and abjection (Kristeva, 2011).

Engaging in imaginal dialogues made cancer-related trauma visible and speakable which allowed me to move away from the repressed unconscious state to awareness of my thoughts and feelings, which is fundamental in processing and integrating memory. This might explain why I did not find the uncertainties of illness fearful (see Act III).

The Power of Witnessing

Narrative writing is about writing lives that expresses concrete lived experiences. It includes forms such as autobiography, diary and autofiction. It has been widely practised and researched in the field of illness and was reported to bear therapeutic value (White and Epston, 1990; Bochner et al. 2016). I have adopted a different path in engaging in ethnographic narrative with a specific focus on how I navigate the liminality in the illness trajectory when I encounter traumatic cancer-related events and experiences.

I am aware that I benefited from collaborative writing through imaginal dialogue. My ability to counter-act the violence and brutality which the unknown and uncertainty impacted on my mind and body was enhanced throughout the illness trajectory and I became aware that I might be experiencing cancer-related PTSD symptoms or traumatic reactions. In addition, the monthly meetings over two years with my first thesis supervisor enabled me to engage in a critical self-reflection about my encounters with the two fictional characters, Frank and Gawande. By turning the imaginal dialogues into a playscript, I reclaimed my agency in validating the trauma experiences.

The multiple layers of dialogue with self and Others were the key to developing the self-reflexivity that prevented me from experiencing cancer-related PTSD, especially under the national lockdown due to the Covid-19 pandemic. This lockdown also formed a barrier to connecting with family and others, physically and psychologically, when we all became vulnerable under Covid-19. I benefited from engaging in this quest collaborative writing process that helped me emerge from the in-betweenness of the cancer trajectory.

Hindsight

Three years ago, on 19th April was the date of the surgery which transformed my life. Surgery is a "ritual" representation of the castration of my normality, giving me a new identity as a cancer patient. Coming to the third anniversary of the surgery and the near completion of the thesis in writing about my illness trajectory, what have I learnt from this trajectory? What have I discovered and what I would like to further discover if I live longer? What have I learnt from the experience of writing and talking collaboratively with Frank, Gawande, my first supervisor, and the medical professionals who have been so active in my trajectory of illness? There is so much to reflect on. Where do I start and how do I start? It is another uncertain trajectory in the spirit of a quest.

Reviewing the research notes that I made after the supervisory meetings, I found my reflection on the second session of supervision (dated April 2019). I wrote,

> "Where is your voice?" my supervisor asked… yes, where is my voice? How do I know? (feeling puzzled) I asked, "how can I research the trajectory as the subject may refer to the experience that is in the past, but it could still be present…?" my supervisor suggested, "You may read the book "Hindsight" by

> Mark Freeman (2010) to see if it helps.” (Research Reflective journal, dated April 4, 2019)

Freeman (2010) suggests that the power of hindsight has to do with the relationship between life as lived, moment to moment, and life as told, in retrospect, from the vantage point of the present. The challenge of writing a memoir (though mine is not a memoir, it bears some similarity in reflecting the past in understanding the present), is to hold in tension both then and now, past, and present, but the primary concern is about the movement of life itself, an ongoing process of living. Freeman puts forward his two-fold thesis, “Self-understanding occurs, in significant part, through narrative reflection, which is itself a product of hindsight” (4) and “hindsight plays an integral role in shaping and deepening moral life” (5).

Hindsight might be regarded as a source of distortion of “what really was”, but what happens in me is that hindsight is an ongoing process of pausing to attend, whether to past or present, by moving from unconsciousness to consciousness, with an attempt to gain greater awareness of what is real and true for me (7). How can this be made possible? I would contend here that it is through the process of co-witnessing in the presence of my first supervisor. He actively challenged me to reflect critically on how the imaginary dialogue with Frank and Gawande and real conversations with Others have evolved in the collaborative writing process that helped me make sense of my illness experiences. This collegial witnessing process helped me bind together the disparate episodes of my illness experiences into plots and characters, with a setting that ultimately became an increasingly coherent discourse of living that made indiscernible parts of illness discernable and insanity, sanity.

Supervisor as Companion-Listener-Witness: Testimony in Trauma

The supervisory relationship and process with my research supervisor over the past two years has been an indispensable and parallel process that has made collaborative writing through imaginal dialogue as a method of inquiry into my illness experience possible and authentic.

In the initial attempt to imaginal dialogue with Frank about his illness and experiences, I kept writing my reactions to his experiences and shared mine. I felt such dialogues so real that it was as if he were just by my side. The vulnerable illness-me wondered if I were insane. When presenting my imaginal encounters with Frank and Gawande, I have always worried that I might sound crazy presenting these imaginal encounters. There were always moments when I doubted if I should present my writing and how genuine and transparent those imaginal materials would appear to my supervisor. I was haunted by self-doubt. As Schmidt (2018) states, even if the author can write detail about their traumatic experiences, they may still not be believable. It is the suspicion of the self that can be an expression of trauma. She quotes her own reflection on her story of trauma.

> “It narrates itself out from inside of me. I cannot rid myself of the feeling that I am lying to everyone in telling this story… I am a fraud. An exhibitionist. With the imaginary story, I simply want to take centre stage, or push myself to the fore, or whatever. (5)

I fully empathise with how this author felt because I felt the same when I wrote about my imaginal encounter with Frank and Gawande. It was my supervisor, as a companion-listener- witness, who made me feel I was neither insane nor a liar. His curiosity about my imaginal encounters made me think critically and adopt a reflective stance by looking at the deep meaning of those encounters. That empathic listening and questioning offered me the space to self-reflect. Trauma demands witness, but at the same time defies such witness. Its paradoxical nature confuses the victim because traumatic testimony is always “enigmatic testimony which resists simple comprehension” (Schmidt, 2018, 45).

What did I really need from my supervisor as a witness in my trauma trajectory and how did it help, if it did? Before addressing this question, I think it helps to delineate the concept of witness and witnessing, using Weingarten’s typology of witnessing. Weingarten (2000, 393) considers witnessing as taking place in spoken and written language and “mirroring the fracturing of language experienced by those whose experience is witnessed”. Weingarten develops a typology of witnessing in describing the witness positions which are shaped by the two constructs, namely awareness and empowerment. Based on these two constructs, she derives four witness positions: namely the states of aware and empowered, unaware and disempowered, unaware but empowered or aware but disempowered. She contends that we are all always witnesses, and our witness positions are dependent upon our role and the relationships with the one whose experience is witnessed.

In my case, as the reader of Frank’s testimony of his illness experiences, I am in a patient yet witness position, probably travelling in the state of awareness but oscillating between disempowered and empowered. I am aware of his illness experiences by his openness in his sharing and I could feel empowered by his ability to transcend from his position as a victim of illness and to give a testimony of his illness that made me, as his reader, empowered. When I engaged in the dialogue with my own illness through Frank, I was the witness of my soul- searching process through Frank as my imaginary witness. This made sense of my illness experiences that oscillated between different states of being aware and unaware of what was to be unfolded in the collaborative dialogical inquiry. I experienced moments of the presence or absence of empowerment throughout the trajectory of illness.

The oscillation between states, in the context of imaginary dialogue, can be confusing and lonely, though productive and illuminating. It is as if I were riding a real, yet invisible horse which seems to know where to take me. It has previous knowledge and experience of a similar journey of darkness and grants me the hope of enlightenment. However, it is still my journey, not anyone's else journey. Hence, while I may trust the guidance of the invisible, yet real horse, I also argue with the horse as I am unsure that I feel as it feels. How can I sustain this navigation in the liminality of illness? For me, the answer is the presence of a third witness – my supervisor - as my co-witness throughout the process of inquiry.

My dialogical experiences with Frank and Others took the forms of multiple shapes and forms of writing, whether random dialogues deriving from my reading responses to Frank's work or my recounts of the lived experience under Covid and my absence from my hometown. When presented with these, my supervisor took up another position - the witness of my journey riding on a horse, beating the path wildly, mindlessly, falling and jumping back on horseback and moving on, without knowing what would happen.

Others might not have seen me riding the horse as it was invisible in a physical sense, but it was real with rich embodied experiences of illness that I was drawn to feel connected with. It was important that someone should lend me their vision and wisdom so that I could feel my experiences were truly witnessed and not judged from the biomedical perspective of illness. Probably I was afraid of a psychiatric diagnosis, that I was delusional because I was engaging in imaginal dialogue and co-writing the trajectory with somebody invisible - someone riding on a real, yet invisible horse?

It was my supervisor. It was the qualities of trust in one's imagination and curiosity through writing as creative-relational inquiry that offered the possibilities of generating another kind of liminal and creative space for reflexivity (Speedy, 2008; Wyatt, 2018). As Wyatt states (2018, 42), writing as a method of inquiry is creative-relational, which is a minor gesture (of love), with "gestural force that opens experience to its potential variation, that takes us towards the place where we do not know, to that which is beyond us". I am reminded of Speedy's work (2008, 31) on exploring liminal and creative spaces which more readily appear when we engage "in the more writerly and fictional accounts" of experiences. It is a daily practice of multiple listening to what is being said, to what is not being said and to what is being referred to that reveals the gaps and cracks that exist between these different stories. It also reveals the liminal spaces that offer the entry to "other" sites and identify performances (32).

In my case, in the context of supervision, my supervisor offered himself as the listener and witness in witnessing my process of developing the "testimony" through imaginal dialogues with Frank and Others that were then represented in the form of a playscript. It was a rigorous process of writing, re-writing, deleting, and expanding thoughts and feelings, enacted messily in the process of discursive positioning. Thoughts and feelings were hopefully distilled, crystalised and reflected upon (Davies and Harré, 1990). I can feel the metaphor "like being held in a hall of mirrors" (Davies et al. 2004, 386). Probably, the presence of my supervisor as a co-witness gave me the strength and courage to stand against the compulsion to lock myself up as a defence against the horror and brutality unfolding as trauma-related events and reactions, since I was still a wounded writer and researcher of my illness experiences (Romanyshyn, 2013).

The following examples illustrate the significance of collegial co-witnessing. Our spoken conversations were recorded with the permission of the supervisor before national lockdown under Covid restrictions. For those sessions that were conducted through video conferencing, I immediately recalled the discussions and transcribed them as written records for reflection on the issues which emerged. There were moments that I could immediately respond to with clarity in thoughts and feelings, and yet there were many moments when I could only sit in silence, finding thoughts and feelings beyond words. At times they were just beyond reach at the edge of consciousness. When I re-read and re-visited those questions that invited focusing, I could feel the delayed nature in response to trauma. When time is ripe, with patience and perseverance on the part of both my supervisor and I, reflections just spoke for themselves. As Laub (2012, 79) states, when working with psychotic patients, "the only way of delimiting psychosis is that of holding and of waiting for the emotional to rebalance themselves – a matter of tolerance and of persistence".

To illustrate, I will quote a few incidents showing how the presence of a co-witness enabled me to reflect. The authentic dialogical approach in real time with my supervisor about my imaginal encounters with Frank and Gawande provided me with a platform on which to integrate both my internal reality and the external reality that finally brought me harmony and peace. I gained the confidence to engage in the imaginal dialogue with Frank and Others (in imaginal contexts) that did not seem to be delusional, though this might be perceived differently from a medical perspective in psychiatry. This allowed me to keep this "space for exploration" in the trajectory of illness as open and authentic as I could.

With hindsight, I find the supervisory relationship between me and my supervisor to be as if we both were the audience of a film. In the film I am both a character and the film producer, working collaboratively with my fictional characters, Frank and Gawande, transcending the darkness with mixed traumatic-related emotions. And while travelling this journey, I have another voice of witness coming from my supervisor who was curious about my journey with my imaginary friends. The open and curious invitation to me, as a narrator, to narrate the scene opened up the creative-relational space in which I tried to give words, expressions and meaning to this seemingly confusing, wild journey.

His presence, as a co-witness, made me adopt a different witness position. I witnessed the journey on which I had embarked, moment by moment, with hindsight, with foresight, but not foreclosure, embracing realness and unreal qualities of what was ahead. Probably this is what he means by "towards creative-relational inquiry", that offers the space for reframing our lived experiences (Wyatt, 2018).

His empathic responses to some evocative parts of the dialogues made me connect to my emotional world that I might otherwise have frozen out to keep myself sane. For instance, his remarks

"It is poignant",

"I, as a reader, I feel…

"I wonder how… "

These genuine responses with expressions of feelings enabled me to get in touch with my emotional pain. They acted as resonances to witnessing what was not visible and confirmed the realness of trauma that reassured me that I was not insane. For instance, my supervisor, as a co-witness, asked if I experienced a shift in my relationship with Frank. His curiosity about my relationship with Frank, whom I had made my fictional confidant and psychotherapist, showed that he was willing to stay in my frame of mind. His acknowledgement of the presence of Frank opened up the creative space for me to explore why there was a subtle change in our relationship in the context of imaginal dialogues that evolved over time. The discernment of this imaginal relationship, as an integral part of collaboratively writing the testimony of illness, made the inquiry sustainable.

In another incident, when my supervisor expressed curiosity about the purpose of making the clinical colonoscopy experience explicit, at first, I felt challenged as if I were acting against the culture I was living in. I wondered if I should delete that experience from the testimony. However, without knowing where I got the courage, I overcame my inner fear and resolved the dilemma as to whether the incident was too demanding for anyone who might read it. I expressed the dilemma I was in. Part of me felt that I was making a taboo film that was culturally classified as “Not suitable for XXX”. On the other hand, another part of me argued that it was my experience and feeling that needed to be honoured and owned. It was not me who decided whether it was suitable for others to read and see. It was for those outside my subjective reality to decide if it was suitable for them or not. It was their choice to decide if they felt connected to my inner world. They had the freedom not to get involved if they could not bear witnessing it. For me, I should protect my right to express my sense of having gone through this unpleasant experience. I no longer felt I needed to hide myself just because others might not be able to bear it.

Once I made my voice and positioning loudly heard, I could feel my agency energised by this co-witnessing of the documentation of my colonoscopy experience. What my supervisor, in this respect of witnessing in the supervisory relationship, offered me is the space to engage in “creative-relational inquiry” (Wyatt, 2018). I was supported to engage in this nomadic process, which was full of tentativeness, fluidity, and intimacy (Deleuze and Guattari, 1988; Wyatt et al. 2018). I suddenly realised that I could connect with my experiences with more tolerance of the unknown and uncertainty. I think this

> was healing, especially when I was exploring my illness experiences concurrently with the illness having an impact on me. As a patient, I had an instinct to seek reassurance, in the form of a restitution narrative, but ultimately, I might have suffered from the false promise of certainty that would take away my agency to understand my own trauma and mortality. Of course, there is no such guarantee in remission as we are all mortal (see Frank, 2002 [1991]; 2013 [1995]).

Laub (2012), informed by his own childhood trauma in the Holocaust and his life-long work in trauma, states that testimony is the process of narrating before a witness and that this lies at the heart of qualitative research and therapy. Testimonial acts may be seen as the engine of personal and social change and can be our primary source of knowledge (Tamas and Wyatt, 2013). Drawing from psychoanalytic theory, Laub (2017) states that testimony is a powerful, libido-driven process of putting fragments together that helps restore the narrative flow and symbolises the concrete so that traumatic experiences can be made communicable to oneself and transmissible to an “other”. The presence of a companion-listener is the indispensable condition for the dialogic process between the internal “I” and the internal “Thou” to occur. While I could reconnect myself through imaginal dialogue with Frank and Gawande, the sense of “self -doubt” still made the connection between “I” and “Thou” vulnerable. The presence of my supervisor, listening to my imaginal encounters, helped me integrate and turn those traumatic memories into real knowledge as a healing process.

Some may wonder how likely it is that the witness can really understand the unimaginable pains and suffering that the subject is experiencing (Agamben, 1999). My experience tells me that the power of witnessing is the offer of the physical presence as companionship until the testimonial journey comes to its end and the witness is willing to say “I’ll be with you in the very process of your losing me. I am your witness” (Laub, 2012, 69).

The presence of my first supervisor, who bore witness to the imaginary encounter at the later stage of my inquiry, represented by the playscript co-created with Frank and Gawande, was another stage of the emancipation of my troubled psyche in the illness trajectory. Unlike other forms of narrative writing of illness, such as diary or autofiction, I had a witness who offered me the lens through which my imaginary dialogues in my quest of illness experiences could be (re)visioned in the context of real human interaction. This authenticated the imaginary dialogue which is so important in the process of exploration.

Chapter 6

Implications and Conclusion

Towards Collaborative Writing through Imaginal Dialogue with Witnessing as Inquiry and Therapy for Trauma-related Illness Experiences

Writing is a process which, done collaboratively, whether imaginal or real, is emancipatory. It is a form of life writing that provides more fluidity than other forms of autobiographical writing. When I present my dialogue with my illness through dialoguing in an imaginal context, my troubled psyche is opened up to feel, to be audible or visible. I can link the events of diagnosis and treatment through reflecting upon their relationships to me as wounded. I have not been able to engage in direct dialogue with my disease until I have gone through an extended period of creative-relational inquiry in the form of collaborative writing through imaginal dialogue with the presence of collegial witnessing of the encounter. I am aware that my fear of cancer seems to be disproportionate to the stage of cancer I am at. This is probably due to my long-repressed fear of such a disease as a muted witness who has viewed its brutality within my family (see Act V: Dialogue with Disease). Such a realization towards the later stages of this inquiry surprised me but also set me free from this state of being a muted witness, which has existed inside me for decades.

This process has enabled me to develop the capacity to counteract the biographical disruption that is brought about by critical illness. I propose that patients experiencing critical illness have the potential and capacity to contain, recognize and acknowledge the presence of cancer-related trauma experiences when they allow themselves to engage in dialogue with their illness through reading the works of others (in the same or a similar illness community). They could also have an imaginal dialogue throughout their trajectory of illness and share that imaginative encounter with Others to bear witness to their suffering.

My trajectory of illness was experienced through an imaginary dialogue which documented the emotions as common symptoms or reactions as presented in sick patients. What enabled me to protect self from the worst effects of biographical disruption is the power of the imaginal and collaborative writing as a performative act to counter-act this force in the presence of a witness.

It is a renewing and transformative process of becoming and developing a new sense of self. Frank (2002 [1991]) points out that paradox of recovery. To understand the reality of illness, we need to understand the brutality that there are people who do not recover. He further challenges that if recovery is taken to be ideal, how is it possible to find value in the experience of illness that either lingers on as chronic or ends in death? I adopt his critical stance that the answer seems to be in focusing less on recovery and more on renewal. Even continuing illness and dying contain opportunities for renewal. Frank does not see his tale as serving the purpose of telling anyone how to cope, but it does bear witness as to what goes into coping and that witness is enough. As Frank states, he presents himself only as fellow sufferer, trying to make sense of his own illness. We can only witness some of the realities of illness. As Kleinman (2004, xii), the author of "*The Illness Narratives*", states

> "It is possible to talk with patients, even those who are most distressed, about the actual experience of illness… Witnessing and helping to order that experience can be of therapeutic value"

I experience the power of writing about personal suffering by taking it as a shared process. I have been able to shift from the focus of recovery to feeling the creativity of self through writing in the imaginal dialogue towards a new sense of self-renewal. It has been less a matter of recovering what I had been than of discovering what else I might be. Instead of looking back at the loss, I am open to seeing what the possibilities are in the future. Writing is part of the discovery.

As Agamben (1999, 39) states, “to bear witness of the presence of something, such as light, it was not light, but was sent to bear witness to the light”. My supervisor offers himself to co-witness with me, witnessing how I navigate my illness trajectory through collaborative writing in a natural flow of imaginal dialogue with Frank and Others. This resembles the emotionally mature parents who bear witness to their child in exploring their life and are ready to stay curious to their child’s process of inquiry. It simply provides a double layer of security for the trauma victim to pick up the pieces of episodes and see beyond the trauma and illness.

The trajectory when navigating the pervasive liminality of fear(less), knowing/not knowing, living/dying, is unlike the biological trajectory graph which starts on a plateau and is followed by an absolute and abrupt ending of life, with the loss of all vital signs as a mean of certification of “death”. I argue that the trajectory of illness is a living-dying spiral mode that encompasses “richness” in all sensations: physical, psychological, and spiritual, that keep life robust even in the critical moments of threat. This sense of “richness” is extremely evident in the context of biographical disruption.

Richness, in this thesis, probably does not carry the connotation of positive or negative. It is more a reflection of the “dynamic” interchange of multiple paradoxical experiences of mortality in human life. These require constant engagement through holding dialogue with the emotions evoked when confronting pain and suffering brought about by cancer-related events. The experience of survival through hardship is cumulative, embodied, shaped and reshaped but those chaotic experiences in the past and the present, whether on the surface or repressed, are sources of knowledge and the understanding of self. They renew me through the process of inquiry in a quest spirit.

It is the process of engaging in the dialogue with self through imaginal dialogue with Others that makes the quest narrative possible for me. It enables me to witness my own process of "transformation" from being normal to being "new-normal" (as currently people say we need to live a 'new-normal' life under Covid-19). This process of inquiry enables me to find personal truth through coming close to "that person" inside my illness me, moving from depersonalisation to reconstructing a new personhood. (Frank, 2013 [1995]). This opens up the opportunity to develop a narrative inquiry that bears no narrative foreclosure, like restitution narrative, which does not offer the prospect of opening up a new chapter, with a certain future (Freeman, 2010; Frank, 2013 [1995]).

The contribution of this study to the field of counselling and psychotherapy is that it gives an experience-near example that illuminates the power of witnessing in both the imaginal and real contexts. I propose that when patients/clients are supported in navigating the liminal spaces in the trajectory of illness through collaborative writing in imaginal dialogue with the presence of witnessing, the experiences can be therapeutic. Unlike the disease trajectory, grounded in the biomedical model, that is predictable, reductive, and quantifiable, my example illustrates that each person's illness trajectory is unique and unpredictable, but what matters is that it is full of possibilities for us, as patients, to make sense of what it means to ourselves and in relation with others.

In addition, collaborative writing through imaginal dialogue with witnessing in the presence of others offers an alternative to researching subjective experience of illness. It is not only a method of inquiry but also a therapeutic process for trauma-related illness experiences. It is a means of supporting those experiencing cancer-related trauma in life, regardless of the stages they are in as this is the process of proclaiming one’s own voice even under the brutal biographical disruption brought about by the illness.

The process of change is gradual, subtle, and non-directive but it will take its course when both the client and the counsellor have a good and trusting therapeutic relationship. As the literature suggests, the main change agent in psychotherapy is the relationship between the counsellor and the client (Howe, 1999; Wilkins, 1999; Kirkwood, 2012). In this study, collaborative writing in imaginal dialogue created a therapeutic space for me, as a wounded-self-researcher- psychotherapist, to engage in nomadic inquiry into illness trajectory in collaboration with others in both imaginary and real contexts. I hope this can offer an alternative to an autoethnographic approach to researching one’s personal and deep experience. I also hope this can be applied in the context of counselling and psychotherapy for those who might not be able to attend regular face-to-face counselling on a weekly basis. Under the Covid attack, many clients are prevented from attending face-to-face therapy sessions. I have experienced the same difficulty. This study enables me to see how counselling can be offered differently, opening up a new possibility by which clients can access their inner world safely in an imaginary context with an experienced empathetic listener. The two can work together as co-witnesses in the process of (re) visioning their subjective experiences of illness.

Conclusion

The research question is "What is the trajectory of being a breast cancer patient like?". It focuses on developing an understanding of the complexity in thoughts, feelings, and aspects of behaviour towards (traumatic) cancer-related events that I have encountered over the past three years since diagnosis. Unlike the disease trajectory, my illness experience presents the unpredictable and idiosyncratic nature of an illness trajectory, which is process-oriented and subject to interaction with self and others in both the imaginary and real worlds.

An illness trajectory can be a transformational process towards accepting a new sense of self with a life-long threatening illness. Collaborative writing through imaginal dialogue creates a space for cultivating the new sense of self while constructing our own quest narrative. This offers an alternative to autoethnography in researching how I, as a cancer patient, proclaim my new identity and voice in this transformational process.

This thesis is the outcome of the ongoing dialogue with self and Others in imaginal and real contexts that finally helps me experience the evolutionary nature of my life script. Instead of seeing this a "playscript", it is an authentic life-script written with many others. These are mainly Frank as my major imaginary confidant and psychotherapist, Gawande, my first supervisor, medical professionals as well as my family members in the background. It is collaborative writing that documents the "richness" of the life trajectory as being a new normal human being *with life-threatening conditions*. The qualifier "with xxx conditions" feels strange to me as this is still a form of segregation. It marginalizes me and places me outside the "normal" territory while I increasingly get confused with the concept of being "normal". Probably the term "being mortal" makes better sense to me. I regain my sense of personhood because I see that we are all normal, regardless of the medical conditions under which we are classified. I will grant myself a new-normal identity for my personhood.

What I proclaim, as a "pause", in writing up this thesis, is that even under such an uncontrollable Covid-19 situation with a record high number of 60,000 daily infected cases on 6 January, I have never felt so tranquil with equanimity and inner peace. I think this is the gift of engaging in the quest process which has led to my finding peace which was lost because of the biographical disruption brought about by cancer. I have made peace with myself through engaging in imaginal dialogue and collaborative writing with Frank as if he is a fictional character. The real conversation with my supervisor about my imaginal encounters with Frank and Gawande and others in the real world takes me to a critical reflective positioning that distances me from the subjective self and views it through a compassionate lens by seeing this "ill" part of me in dialogue with self and others.

The journey back and forth between internal and external reality is a healing process that keeps me sane in mind and body. The writing process allows me to engage in the stream of consciousness that protects me from cancer-related PTSD. I hope my imaginal dialogical approach to collaborative writing can offer an alternative means of supporting those experiencing cancer-related trauma in life, regardless of the stages they are at. I would also argue against the definition of PTSD in DSM-V as this can make cancer-related trauma unclaimed experiences.

I would like to end my nomadic inquiry for this thesis with the following quote taken from Frank (1991/2002, 7).

> "I write to the younger self I was before illness overwhelmed me. I write to a self not so many years younger but a gulf of experience away. In a short story by Jorge

> Luis Borges, the writer, who now is old, is sitting by river. Along comes his young self, out for a walk. They recognize each other and talk. The young man is particularly shocked that the other is almost blind. The older comforts him, telling him the condition is nothing to be feared."

How comforting and healing it is to realise that my journey resonates with his. I would like to keep it as a torch of wisdom to pass on to those who would like to continue the collaborative writing with us, after reading our shared experience. As Frank states, we are entitled to mourn what we can no longer be, but do not let this mourning obscure our sense of what we can become. We are embarking on a dangerous journey.

As a counsellor and a practitioner researcher, I believe that engaging in researching my illness experience helps me to develop knowledge combined with practical wisdom, as the process helps to cultivate my holistic, intuitive, and embodied ways of learning and knowing. This can only be acquired through reflexivity which honours the uniqueness of each human experience as context situated. For three years now, I have been able to manage the study without any interruption in my coursework, practicum, and research. This is the process of creating my quest narrative and testimony, an outcome of witnessing, that is therapeutic in surfing the hurricane of illness - an idiosyncratic, subjective, and unique trajectory of illness.

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[cii] In 2020 March, due to Covid 19 Pandemic, a deadly highly contagious disease, a national lockdown was imposed between March and June, the second between September and December and then the third lockdown in January 2021. It affects the world for more than a year and brings about death toll above 100,000 in UK.