
ON THE LIVED EXPERIENCE TOWARDS THE END OF LIFE

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Summary

The hidden nature of death in contemporary biomedicine is well documented in the current literature and experienced by many people towards the end of their lives. In contemporary ideology, the notion of living a long life is paramount, however, the quality of a longer life comes into question with the advancement of modern medicine. This study included eight people who shared their lived experience via social media and who are confronting their mortality. Employing van Manen's (2014) hermeneutic phenomenology, the data was centred on the life world existential themes of corporeality, temporality, relationality, spatiality, and materiality. This enabled a deep exploration on the issues that are pertinent to people who are experiencing the end of their lives. Two overarching themes were drawn from the data; these being the crucial point of diagnosis followed by restoration and transcendence towards the end of life (EoL).

The first major and new finding was that a terminal diagnosis is a catalyst for a conscious awareness towards increasing the quality of life. The second major and new finding was how these people rebuilt their lives in the face of their mortality. Gaining resilience empowered them towards their future as they aimed for an increased quality of life as they neared the EoL. This study also revealed that increasing the quality of life towards the EoL included spirituality concepts with or without religion. As a person proceeds towards the EoL there is a certain acceptance of the eternal nature of the life-death continuum, which is congruent with many Eastern and Indigenous cultures and ancient Anglo-Celtic beliefs. The importance of the need for like-minded people to meet and discuss their psychosocial needs related to dying matters in an open and honest non-confronting way was exposed through this study.

The natural environment offered respite and a sense of a peaceful space in a fast-paced world, enabling transcendence. Reminiscence bought the past into the present, as did the importance of the imagination, to rebuild a new Self. The urgency of time was no longer important. However, the concept of limited time became paramount as people preferred to focus on the quality of life rather than the quantity of life. The arts,

in the form of poetry, song and prose were extremely important towards gaining a deeper insight into the core of the Self and a connection to the ethereal world. The stories voiced, and the subsequent themes described in this thesis, offer new insights with a proposed way to move forward in caring for those who are facing the end of their lives, with the aim of increasing the quality of life towards the EoL.

Statement of Original Authorship

The work contained in this thesis has not been previously submitted to meet requirements for an award at this or any other higher education institution. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made.

Signature: *Signature Redacted*

Date: *January 2019*

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List of Key Words

Ashram - A hermitage, monastic community or other place of religious retreat

Atua - Gods and spirits of the Polynesian peoples

Aura - A human energy field sometimes described as the subtle body, it consists of multiple energy layers called auric fields connecting humans to the outside world

Biofields -The human biofield is an energetic matrix that makes up the human form sometimes referred to as an aura

Biophilia - The innate tendency of human beings to focus on nature and lifelike processes

Buddha - The title of Siddhartha or Gautama, a deified religious teacher of the Buddhists and the founder of Buddhism

Carative Factors – Jean Watson’s Carative Philosophy, caring factors that assist in caring for people to maintain health or die a peaceful death

Celts - A branch of the Indo-European family, including Irish, Scottish, Gaelic, Welsh, Breton, Manx and Cornish, a group of peoples inhabiting Europe and Asia Minor in Pre-Roman times, 5th to 1st Century B C

Chakra - Sanskrit for wheel is a focal point of metaphysical energy in the human subtle body

Chronos - An ancient Greek meaning for the chronological nature of time

Doula - The continuous support of a non-medical person during the stages of birth or death

Ethereal - Extremely delicate and light of another world

Ganesh - An elephant-headed deity, son of Shiva and Parvati also called Ganpati

God - A being conceived of as possessing supernatural power, a deity, an object of worship

Hinduism-Is the principal religion of India that has many Gods (Devas) it teaches that life exists after death in another form

Imagination - The power of the mind to create images from or reproduce an image in the mind, ideally an object of sense previously perceived

Karakia - A traditional Maori prayer or incantation

Kairos - An ancient Greek term meaning the right moment in time, the subjective nature of time

Mana - Maori word meaning spiritual power, and authority

Medicalisation - Aspects of human life that come to be considered a medical problem

Metaphysical - without material form or substance

Phenomenology - A philosophical doctrine purposed by Husserl based on the study of human experience.

Quantum Field Theory - A branch of physics that applies quantum mechanics to physical systems described as electromagnetic fields

Resilience - The capacity to recover quickly from difficulties, toughness.

Self – A persons essential being that makes them unique

Shakti - The female principle of divine energy, when personified as the supreme deity

Soul -The principle of life, feelings and thought in humans, said to be separate from the body

Spirituality- To experience and integrate meaning and purpose in life through a person's connectedness with self, others, art, music, literature, nature, or a power greater than oneself, while at the same time, differentiating spirituality from religiosity but allowing inclusion of religiosity as an integral piece of an individual's spirituality (NANDA-1, 2005)

Survey Monkey- Online survey development that is cloud based, it provides free customised surveys

Therapeutic Touch - Is a holistic, evidence-based therapy that incorporates the intentional and compassionate use of universal energy to promote balance and well-being in all aspects of the individual: body, mind and spirit (<http://therapeutictouch.org/>).

Wairua - Maori word for spirit or the soul

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Nature of Candidate's Contribution, including percentage of total

The opportunity arose from a conference presentation relating to the candidate's personal experience and the thesis topic. It is inspired by the thesis work and relates to the topic, however also expands on ideas of sacred spaces and nursing practice contexts of care. The contribution by the first author is approximately 75%.

Nature of all Co-Authors' Contributions, including percentage of total

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Has this paper been submitted for an award by another research degree candidate (Co-Author), either at CQUniversity or elsewhere? (if yes, give full details)

No

Candidate's Declaration

I declare that the publication above meets the requirements to be included in the thesis as outlined in the Research Higher Degree Theses Policy and Procedure

Jennifer Carter

.....

Date:26/08/2018

List of Abbreviations

CINAHL - Cumulative Index to Nursing and Allied Health Literature

EoL - End of Life

HEF - Human Energy Field

HR - Health Realisation

LED - Lived Experience Description

NDE - Near Death Experience

OBE - Out of body experience

PI - Personal Intelligence

QoL - Quality of Life

UEF - Universal Energy Field

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Date 26/08/2018

Chapter I: Introduction to the Study



Researcher reflections 1: Making the invisible visible.
Photo Credit: Pixabay.com

The effulgence of the Self,
Is not perceived by all.
But it is always blazing.
Though there is no wick,
There is a flame.
Though there is no oil,
That flame never goes out.
It never falls asleep, nor is it awake,
It is there -
Like lightning, like thunder...
(Kabir - in Chidvilasananda, 1992, p. 122)

1.1 INTRODUCTION

Chapter one of this thesis discusses the impetus for this research, ‘On the Lived Experience Towards the End of Life (EoL)’. The lens of this research is focused on the lived experience of a conscious awareness of imminent mortality. The chosen research method, hermeneutic phenomenology, allows for inclusiveness of phenomenological imagination where stories are situated within place and are inclusive of a discourse of history and culture (van Manen, 2014; Denzin, 2014). There is an abundance of material available on the importance of physical care needs at the EoL. However, there is very little research enquiring into the emotionally charged, physically challenging lived experience towards the EoL.

This thesis is distinctive from most other research projects in the health sciences, in that it seeks to enquire on the lived experience towards the EoL from participants who have shared their emotive, real-life experiences, via social media. People who are diagnosed with a terminal illness have the ability through social media to share their lived experience. Contemporary society has witnessed a burgeoning explosion of shared stories via the Internet and it is through this medium that this thesis is focused.

The following section begins with the background story, an anecdote that propelled this thesis into life. It explores the context that began the incubation of thoughts and insights surrounding EoL issues and introduces the methodology that will serve as the backbone of the thesis. Thus, it enables a strong format that will allow an insightful exploration into the lived experience towards the EoL. It will highlight the research problem and clearly identify the research aims and objectives. A brief outline of the thesis is also included within this chapter.

1.2 BACKGROUND

This section begins with a personal story that initiated a deep reflection and further questions regarding the lived experience towards the EoL. Nearing the end of my mother’s life my family and I became her carers. This was a difficult time for everyone, not at least my mother. It meant juggling careers, family needs and being on watch, as she required frequent assistance with daily activities. I was given her diagnosis of dementia hand written and passed under the doctor’s desk, so as not to offend her. She was sitting close by my side to ensure that I did not tell any out of

place stories about her health. She denied that she had any issues with her memory, and she would become upset if it was mentioned.

As the dementia progressed, it became increasingly difficult to care for my mother at home. Witnessing the slow demise of a close relative or loved one such as a mother, father, sibling or friend is something that most of us must face at some point in our lives. Even when emotionally prepared for death it can be disturbing to witness carers who are unable to recognise the metaphysical energy that surrounds individuals during such times. Metaphysical energy, for this study, can be thought of as that which transcends the physical known world (Whitehead, 2003). Metaphysical concepts are often described as having a link to religion and spirituality, and when approaching death, human emotions become extremely sensitive, raw and complex (Feldstein, Grudzen, Johnson & Le Baron 2008; Puchalski et al., 2014).

The following anecdote explains the personal situation that sparked a deep yearning or 'wonder' (van Manen, 2014, *The Wonder*, para. 1), within me to ask further questions surrounding the EoL experience. This experience took place between me and my mother and her carers in a local nursing home:

She bursts into tears as I walk into her room. She looks alone, slightly confused as she searches through her cupboard for the missing 'thing.'
'Don't cry', I say, as she looks me straight in the eye with tears running down her cheeks. Sadness etched in her being. Her bony face softened by the whiteness of her hair.

She looks lost, frail and frightened hunched up in the corner.
'She won't know you', they (the nurses) repeat as I walk towards her.
Very, slowly and deliberately so as not to mix her words she says softly,
'I just feel so much better when you are here'.

I know, I feel it too, before she speaks. I know she knows me. She may not recognise my name, face, body, time or space but we ‘know’ each other.

Researcher reflections 2: She Knows Me

I knew she knew me in a nonverbal-metaphysical-6th sense way of knowing. I knew instantly why the tears, I knew without being able to verbally explain to anyone observing the scene. I wanted to scream out to the nurses “of course we know each other...it doesn't matter if she doesn't know the external me!” But I didn't, resisting the urge I silently walked into the space that engulfed us as if we were in a bubble of unspoken love. We were connecting on a level that we had been connecting since her illness. Without the need for forgotten words, emotionally connecting through a sense of knowing, that metaphysical, unseen, part of us that remains intact when the physical side of our bodies and organs disintegrate with time. I must add that my mother and I did not always have a physical connection. Our relationship was estranged during my adolescent and young adult years. Nevertheless, this rupture within the family did not negate the bond that existed between the two of us in the later years of our lives.

When communication became difficult, due to dementia, the only way to understand my mother's emotions was to look closely and watch her body language and to pause and reflect on her needs. Although nursing and caring staff are well educated on how to care for people living with dementia, they did not appear to understand the importance of interpreting her body language and that was the moment that the seed of this thesis was planted. I was astonished to see that although I had been teaching EoL care to nurses for some time, the concept of a connection between two people that could go beyond the physical to a metaphysical connection was missing. Their only concern was in telling me that she would not know (the physical embodied) me. Their knowledge of her holding a deeper metaphysical connection was not apparent. In fact, my mother died shortly after the scenario in this thesis.

Dementia affects the intricate connections deep inside the brain and therefore, it cannot be physically seen. Dementia is an umbrella term that describes a wide range of symptoms with differentiating devastating brain injury. This injury causes memory loss and a decline in cognitive skills that eventually leaves the individual unable to

carry out usual activities of daily living (alz.org, 2017). The average survival time for someone who is living with dementia is about four to five years. Research shows that if a person is diagnosed before seventy years, they typically live for up to ten years longer (Xie, 2008; Downs, 2005). It takes a long time to die, as each bodily organ shuts down. When major physical symptoms of the illness appear, such as memory loss, fatigue and confusion, the limitations and frustrations of the person living with dementia can be witnessed (alz.org, 2017).

My mother's story is only one of thousands, and her experience is shared by many of her contemporaries. Dementia is the second leading cause of death in Australia and there is no cure. There are more than 425,416 Australians living with dementia, with one diagnosed person every six minutes, making 1,800 new cases per week in Australia. Currently 250 people are diagnosed each day with dementia in Australia. This number is expected to rise to 536,164 by 2025 (Alzheimer's Australia, dementia.org 2018). There is certain blindness in health professionals about the terminal nature of dementia and other chronic diseases (Gawande, 2014; Koenig, 2013). The inability to recognise a cohort of dying people has never been more overtly demonstrated than in a recent survey. One hundred and seventy-four staff and one hundred and ten family members in an Australian nursing home were surveyed. The results found that sixty-per-cent of family carers and approximately fifty-percent of staff members (including Registered Nurses and care workers) did not recognise dementia as a terminal illness (Robinson et al., 2014).

The pattern of not recognising the EoL is not restricted to Australia. When data was collated from three nursing care homes in Canada, results found that despite the awareness that death will eventually occur, it was not acknowledged until the final hours of death (Cable-Williams & Wilson, 2014). Due to injury to the brain, this large cohort of people is dying, silently, unable to give voice to their experience, except for a few who are fervently telling their stories before they can no longer share the lived experience (Bryden, 2015; Bute, 2017; Swaffer, 2016; Taylor, 2007). Having also worked as a registered nurse in palliative care for other conditions like cancer, it became obvious to me that there was a gap within our nursing practices that there is a

need to care for people who are facing their imminent death, which is just as urgent as the care required on the verge of death.

It is said that the spiritual horizon is one of the most difficult to comprehend. That the closer you get to the verge, the harder it is to capture or to articulate, that language becomes ‘redundant’ (Stanworth, 2006, pp. 28-34). The idea of a spiritual disconnection within the health sciences conforms to the biomedical scientific ideology that if a phenomenon cannot be measured or codified then it does not exist (van Manen, 2014). Therefore, it can be surmised that in our modern world, a decline of physicality, including memory, also dictates a decline in a metaphysical context. This previous statement could not appear more truthful than in the scenario between my mother and I. Van Manen (2014) reiterates the importance of inclusiveness of spiritual connections when he states:

The health care profession is acutely aware of the modern complaint that some physicians, medical technicians, and even nursing staff suffer from a dichotomizing Cartesian blindness. They sometimes forget that, in a manner of speaking, there is a person attached to the body. After separating the body from the mind, they only have an eye for the body.

(van Manen, 2014, *The Body of self*, para. 7)

I had to ask myself how we as researchers can begin to acknowledge the voices of those people who are living in this present moment, knowing that they are close to the EoL. It was then that it dawned on me that metaphysical energy is no different to new science theories. These theories are exploring Nanotechnology from the cosmic macroscopic reality to the microscopic unseen Quantum physics (van Manen, 2014, *Reality of the Real*, para.1). From this new science emerges the understanding that matter is a mere vibration of subatomic particles. Further, that this computer on which I am typing, is an energetic mass of vibrations. These vibrations remain unseen and unfelt and just as hidden as the nanoparticles of metaphysical energy. Due to the historic foundations of our current biomedical health system, new age Western

scientific concepts are difficult to convey to some health professionals (Kellehear, 2014; van Manen, 2014).

This notion of ‘denying death’ in our modern society leads to further questions. If people who are diagnosed with a terminal illness are not accepted as dying, then who is? Moreover, how does not acknowledging the EoL affect those who are living, knowing their mortality is close? Why is acknowledging death and dying difficult in this modern age for individuals and between health professionals (Kellehear, 2007)? All these questions drove me to think further about people who are dying and to ask further questions on the subject, such as: what is the lived experience of facing mortality? Furthermore, what is important in their lives as they face their mortality? Therefore, as the focus of my research, I set out to examine further the lived experience towards the EoL.

1.3 CONTEXT

This thesis is situated within the context of contemporary healthcare. As a member of the nursing profession and a carer for people experiencing EoL, I did not enter this research process being distant from the experience. Through my position as a Registered Nurse, tutor, palliative care nurse and recently the care of my mother in her last years of life, I have been embedded within the culture of the experience. By positioning myself as the enquirer, I intend on engaging a wider audience into a discourse of the lived experience towards the EoL. On deeper reflection about the scenario that occurred between my mother, myself and her carers, I have come to understand that there is an assumption in contemporary biomedical medicine that once memory fades, or a person is beginning to lose cognitive abilities, then all knowledge of an inner wisdom or Self-identity is gone.

It is argued that a metaphysical connection between all living creatures does exist; the piece of us, that is unspoken, invisible but felt by the senses. The metaphysical connection is the unexplainable piece of us that is usually left out of the biomedical model of health science (Gawande, 2014; Holloway, 2007; Kellehear, 2007; Wynne, 2013). This metaphysical connection was ignored in the previous scenario. I was left shocked and bewildered by my mother’s carers. If the metaphysical

spiritual energy was largely ignored in my own scenario, how then does this missing human link in our caring affect others who are living towards the EoL? This question is especially important to nurses who provide most the care at the EoL (Kellehear, 2007).

1.4 THE RESEARCH PROBLEM

The research problem is twofold, firstly, Western biomedicine has a history of been driven by the separation of the mind and body, known as Cartesian Dualism, a separation of matter and energy. It has a strong focus on the human body as a well-oiled machine. That if all parts are in good working order, then the body will be able to perform its bodily functions with ease. This concept is well understood in current scientific terms (Koopsen & Young, 2009; Rubik, 2015; Whitehead, 2003). Discarding all notions of a vital force or unseen energy, this prevailing ideology of Western medicine leads to a disconnection of the metaphysical, unseen healing energies from the health care paradigm (Kellehear, 2007). This then elicits further questions, within the history of nursing and other health professionals. Have health care professions always negated the metaphysically, spiritual caring for a person towards the EoL? Further, just how important is this metaphysical energy to a person when they face their mortality?

The second reason for this quandary is contemporary society's alienation of death and dying in Western society. That dying does not come into a collective contemporary conscious awareness until we are literally on our deathbeds (Gawande, 2014; Kaminsky, 2016; Reinhart & Koenig, 2013; Robinson et al., 2014). The art of dying and death is closely linked to spirituality, therefore, the divorce of the spiritual body from the physical body is also confounding the problem (Koenig, 2013). The inadequacy in understanding a deep spirituality and EoL experience was the source of my initial reflexive thoughts regarding the conversations that took place between myself and others in the scenario above. Somehow, health professionals including the nursing profession have become separated from the spiritual nature of being human. There is neglect of the spiritual aspects that make up our known world (van Manen, 2014). We live in a "spiritually bankrupt age," which means that dying is harder than it ought to be. There is a neglect of spirituality and the sacred is given the last priority in our modern times (Warner, 2011, p.65)

This last statement holds true for my original instinctive thoughts that began the initial insights into this research. After many years as a health educator, I was dismayed by the neglect of spiritual care that was given by the nursing staff, it was obvious that there was a piece missing in the EoL care. Spiritual concepts are taught in schools of nursing; however, a gap does occur in the practice of care for an individual as I had witnessed. When trying to understand this phenomenon I found that most nursing textbooks include very little insight into spirituality concepts and there is a stronger focus towards the physical needs of the dying, this notion is supported by other authors (Kazer et al., 2008; Meyer, 2003; Pesut, 2003). Nursing texts related to the transcultural and fundamentals of nursing practice contain slightly more core spirituality concepts. These practices are concerned with the ‘other’ and therefore are made visible, unlike our own cultural and ethnic practices (McEwen, 2004). Further questions arise then from the scenario between my mother and her carers. If spiritual psychosocial concepts were of equal importance as the physical needs towards the EoL for my mother, how important is spirituality to others as they face their mortality?

Questions regarding spirituality and faith in contemporary Australian society are important to ask as the Australian population has moved away from mainstream religious practices. According to the Australian Bureau of Statistics (ABS, 2014) it was identified that the largest growth of response in the religious statistics was ‘no religion’, which increased by 29.4% from the statistics in 2006. In 2011, Hinduism showed the second largest growth, which increased by 84%. This response to the question of religion by the Australian population prompted the ABS to add a list of seven new categories of religious and non-religious practices in 2016 to the Australian census collection.

1.5 AIM OF THE STUDY

The aim of this study is to explore the phenomena of the lived experience towards the EoL, using publicly available stories that are accessible through social media platforms. The arts, in the form of poetry, painting, singing and writing are an imperative part of inclusion as a method of data collection. This inclusion ensures to elicit the emotive voice of those who are living with a terminal illness. Van Manen’s (2014) hermeneutical phenomenology enables the voice of the participant to be seen

through language and the arts and guides the methodological framework that guides this inquiry. This study asks the following central research question:

How do people who are diagnosed with a terminal illness experience living towards the EoL in our contemporary society?

1.6 SIGNIFICANCE AND SCOPE

This research confronts the sequestering face of death and dying in our contemporary society. It explores the voices of people who are experiencing their imminent mortality. The focus of this inquiry is on the lived experience towards the EoL. Death is inevitable and something that we will all experience. It is embedded deep within cultural, societal, spiritual and personal values.

The importance of understanding people's needs towards the EoL cannot be underestimated, given that 74% of the Australian population will die due to a chronic illness as opposed to a sudden death (AIHW, 2014b). In Australia, chronic health conditions account for nine out of every ten deaths (ABS, 2016). Of these deaths, (20%) of people who die will also have five or more comorbidities (AIHW, 2014b). The highest of these comorbidities are coronary heart disease and dementia (ABS, 2016). However, just who is at the EoL is difficult to know, as medical advancements can mean that a person may live a long-protracted life with a severe illness (Gawande, 2014; Kaminsky, 2016). Most people who have a terminal diagnosis are not referred to palliative care services until death is close. The reality of this outcome is that this essential service is missed by those who urgently require it and by people who are not consciously aware that they are dying (Melvin, 2009).

This research process will add to the already existing but extremely limited body of knowledge pertaining to what is known about the lived experience towards the EoL. The findings of this research will add valuable insights into the contemporary EoL lived experience. Currently, most EoL care is informed by the publications of Elizabeth Kubler-Ross (1969), who wrote about the stages of dying. She writes that what started as an experiment turned out to be meaningful for her patients. Her work was to “refocus the patient as a human being, and to include him in all dialogues, to learn from his strengths and weaknesses of our hospital management of the patient” (p.11). It can be seen through her writings that the practice of the medicalisation of dying people has increased. In 1969, when Kubler-Ross presented her first account on

death and dying, she writes that for the dying patient the experience is lonely and impersonal because the patient is frequently rushed into hospital just before death (p.21).

This thesis is concerned with a conscious awareness of impending mortality, and how people choose to live their lives until their death. The central premise of this thesis is to understand the experience of the EoL from the person's perspective, therefore the scope of this thesis is inclusive of spirituality concepts. Many authors (Dobratz, 2013; Dose et al., 2014; Koenig, 2013; Kruse, 2007; Neimeyer et al., 2011; Wynne, 2013) agree that the inclusion of spiritual perspectives at the EoL is extremely important and yet very few studies have been undertaken describing the lived experience of the EoL, to support this statement or to identify what other phenomena may be important to those living at the EoL (Dose et al., 2014; Wynne, 2013).

Spiritual issues surface when people are facing their mortality. Spirituality is indeed one of the most important issues that must be confronted by nurses and is included within their Code of Ethics (Nursing & Midwifery Board Australia [NMBA], 2008a) and the Professional Code of Conduct for Nurses (NMBA, 2008b), yet it is also one of the least-discussed issues in patient care (Feldstein et al., 2008; Kruse, 2007; Koenig, 2013). The profession of nursing understands spirituality as being innate to the human being and of great diversity within cultures, therefore it is of universal significance (Reinert & Koenig, 2013). As this research examines living until the EoL and is situated within the context of the profession of nursing, it is inevitable that spirituality concepts will arise. Therefore, I will proceed to give a clear definition of how the person and the spirit are understood within a nursing context.

1.7 DEFINING THE PERSON AND THE SPIRIT

The historical foundations of theoretical nursing arose from the United Kingdom and were inclusive of religious practices, therefore questions surrounding the importance of spirituality concepts are integral to the profession (Koenig, 2014). Yet many authors (Dose et al., 2014; Gijssberts et al., 2011; Wynne, 2013) confirm that the concept of spirituality in nursing practice today is very complex and difficult to define or capture as a single entity. However, nursing theorist Jean Watson (1988) in her

definition of the person clearly indicates that a person is both a physical and spiritual being:

A person is both a physical being and a spiritual being, with an individual experience and existence. The person and the self are the same when the person is congruent with the real self. That occurs when there is harmony in mind body and soul of the person. (Watson, 1988, p. 5)

Watson (2018) refers to the Self as being the person's essential being that is unique and requires introspection as it is the "real self". The major elements of Watson's theory are carative (relating to care) factors (developed in 1979) and the transpersonal caring relationship. The nurse's authentic self and consciousness of caring is said to hold a higher frequency of energy than non-caring awareness of caring. This higher frequency is said to open the channels of consciousness to the universal field and access an inner healing and caring quality (Watson, 2018, para.2). Caring-healing modalities are non-invasive and are a natural human energetic field of awareness. Transpersonal human caring can be defined as:

A concern for the inner life world and subjective meaning of another who is fully embodied but transpersonal who also goes beyond the ego-self and beyond the given moment, reaching to the deeper connections with the spirit and broader universe. (Watson, 2018, para. 4)

Evidence in the literature confirms that there are many new definitions of spirituality. Many of these definitions describe spirituality as being separate from but intertwined with religion. Most authors (Candy et al., 2012; Krampl, 2007; Lepherd, 2013; Sessanna, Finnell, & Jezewski, 2007; Sinclair, Periera, & Raffin, 2006;) agree that spirituality is metaphysical or a transcendental phenomenon. The genesis of the English meaning of the word 'spirit' derives from the Middle English, word 'spiritus'

meaning breath spirit, from spirare-breath or to breathe (Oxford dictionary online, 2014). Other words synonymous with spirit are linked to our emotions, such as energy, sparkle, vigour and happiness. Therefore, the metaphysical part of the person, is the 'seat' of emotions, is as far-reaching and as individual as the human being and not bound to a doctrine of religiosity. For this study, the North American Nursing Diagnostic Association definition will be used as it is inclusive of spirituality concepts:

To experience and integrate meaning and purpose in life through a person's connectedness with Self, others, art, music, literature, nature, or a power greater than oneself, while at the same time, differentiating spirituality from religiosity but allowing inclusion of religiosity as an integral piece of an individual's spirituality. (NANDA-1, 2005 in Sessanna et al., 2007, p. 258)

It is important to capture each person's individual cultural interpretation of spirituality in clinical practice. Therefore, a broad definition of spirituality was used in this thesis (Koenig, 2008). Spiritual concepts are integral to caring for the whole person towards the end of life. Therefore, it is important that a clear and succinct definition of spirituality is included within this thesis. This will assist in dispelling any confusion between religiosity and spirituality that may remain from past experiences (Dobratz, 2013; Dose et al., 2014; Koenig, 2013; Kruse, 2007; Neimeyer, et al., 2011; Wynne, 2013).

1.8 RESEARCH METHODOLOGY

This research is guided by van Manen's (2014) theoretical interpretation of hermeneutic phenomenology. The main principle underlying phenomenology is a search for the meaning within a lived experience. It begins with a wonderment of an event or an insight to a happening. Phenomenology then aims to grasp an understanding of the essence under focus, or the phenomena using language. The

Greek word phenomenon can be read as “that which shows itself in itself” (van Manen 1990, p. 762). Hermeneutics is the “art of interpretation”, the origin of the word arriving from the Greek God Hermes who is a Divine messenger (Kokkori, 2009, p. 22). Interpretation is the key difference between phenomenology and hermeneutic phenomenology. I chose this methodological approach as it was essential that the choice methodology could uncover the essence of the lived experience. Hermeneutic phenomenology can align with the human sciences and enable interpretation of the lived experience (van Manen, 2014). It is emerging as a strong theoretical framework in the health sciences (Dose et al., 2014; Farcus, 2012; Hemsley, 2003; Jackson, 2012; Krampfl, 1994; Peacock, Duggleby & Koop, 2014).

The strength of using hermeneutic phenomenology resides in the ability of hermeneutics to be interpretive, as it allows for the researcher’s interpretations to be included (van Manen, 2014). This was extremely important to me, as being the researcher who has had years of experience as a nurse, and a personal experience of caring for a relative, I would not be able to completely distance myself from being the researcher undertaking this enquiry. Nor could my years of nursing practice be negated or detached from the research journey. It was also important that I found a theory which would honestly and evocatively interpret the EoL experience from personal stories. Whilst phenomenology asks the questions and elicits the response, it is the hermeneutic method of interpreting the data by writing, and rewriting the data, which enables the data to bring to life the lived experience (van Manen, 2014).

This research also aims to be inclusive of the arts by exploring deeply into the lived experience towards the EoL. The arts include activities like singing, painting, poetry and prose and have a way of knowing that is intuitive and connected to the unconscious part of our minds. Intuitive knowing is understood as being a creative intelligence that is linked with our ability to be imaginative. The arts can create an alternative way of being that can generate imaginative insights, therefore, honouring the Divine Intelligence that is created through an inner spiritual connection (Painter, 2007; van Manen, 2014).

1.9 METHOD OF RECRUITMENT

Finding participants was not a difficult task; however, it did require careful ethical consideration, which is discussed further in chapter three in this thesis.

Through my nursing experience, I had become aware that once a person is diagnosed with a terminal illness and following their initial treatment, there is very little prospect of receiving further medical care until they are dying. However, people who have received a terminal diagnosis continue to live towards the EoL and are living longer with illness than the final stage of dying (Gawande, 2014; Hillman, 2017; Kaminsky, 2016; Koenig, 2013). I was also aware that stories existed online from people who were publicly sharing their lived experience towards the EoL. ‘Towards’, is the key word in this thesis, indicating that the focus is not about dying but rather the focus of this thesis is exploring the essence of living towards dying.

Many people gather in groups through cyberspace and social media platforms with a shared life experience, where they feel safe to discuss their emotions and vulnerabilities. Most of these people use the arts, song, dance or poetry as a method of disseminating their emotionally-laden experiences. Therefore, social media was an obvious method for data collection. I sought ethical advice about finding participants and data collection using social media and it was deemed appropriate, as many personal stories are widely available to the public. The participants, through their personal stories, state explicitly that their intention was to share their stories with a wider audience. Therefore, some time was dedicated to researching evidence on the use of social media as a method of data collection. The concepts of using social media as a method of data collection is examined further in chapters two and three.

1.10 THESIS OUTLINE

1.10.1 Chapter 2: Literature Review

Chapter two focuses on concepts that are closely related to living and dying in the Western and Indigenous nations. Spiritual needs at the time of dying are extremely important, therefore chapter two discusses issues that enhance the sacredness inherent within dying in all cultures. It introduces the concept of biofields, which are well known to all cultures including Western, in different forms. It provides a review of current literature of what is already known in EoL and spirituality towards the EoL. Finally, chapter two reviews current trends in social media, with a focus on the blogosphere and the importance placed on including social media within current research methodologies.

1.10.2 Chapter 3: Methodology and Methods

Chapter three introduces the methodological framework that guides this thesis. The principles of van Manen's (2014) hermeneutic phenomenology related to the interpretation of the lived experience towards the EoL are explored. My preconceptions regarding the research are identified. Ethical guidelines and rigour pertaining to this thesis are discussed. Chapter three contains a synopsis into the gathering of participants' stories that inform the reader about how the Internet and social media were searched for gathering of empirical data. The inclusion and exclusion criteria are discussed along with an introduction on the depth of courage required for blogging stories. Importantly, each storyteller is introduced. This chapter also outlines the importance of self-care that both the researcher and supervisors who are involved with sensitive research must undertake.

1.10.3 Chapter 4: Findings Following the Diagnosis

Chapter four commences the data collection with narratives that are told by each person as they experience the news of facing their mortality. The diagnosis is the pivotal point that changes the trajectory of lives. This is the first part towards their EoL story. Under each existential theme, pertinent anecdotes are written, and the most salient words are then rewritten. Heartbreaking stories are shared, and lives are changed forever with a new awareness. This chapter then provides a summary of the main underlying themes.

1.10.4 Chapter 5 Findings Towards Restoration

Chapter five is the second chapter on the data analysis section of this thesis. It focuses on the participants' narratives as they move forward towards the EoL. Anecdotes are positioned under their existential themes and salient insights are highlighted. We follow the people in this thesis as they restore the meaning of their lives while living towards the EoL, regaining their sense of purpose and agency towards the EoL.

1.10.5 Chapter 6: Discussion using Insight Cultivators

Chapter six synthesizes the previous two chapters towards the EoL stories. It further examines how each person has moved forward, discovering their strengths towards living a full life until the end. Subthemes are identified and explored within the existential themes. Contemporary literature is used to gain insights and further

examine the participant's stories and look for insightful interpretations to guide practice.

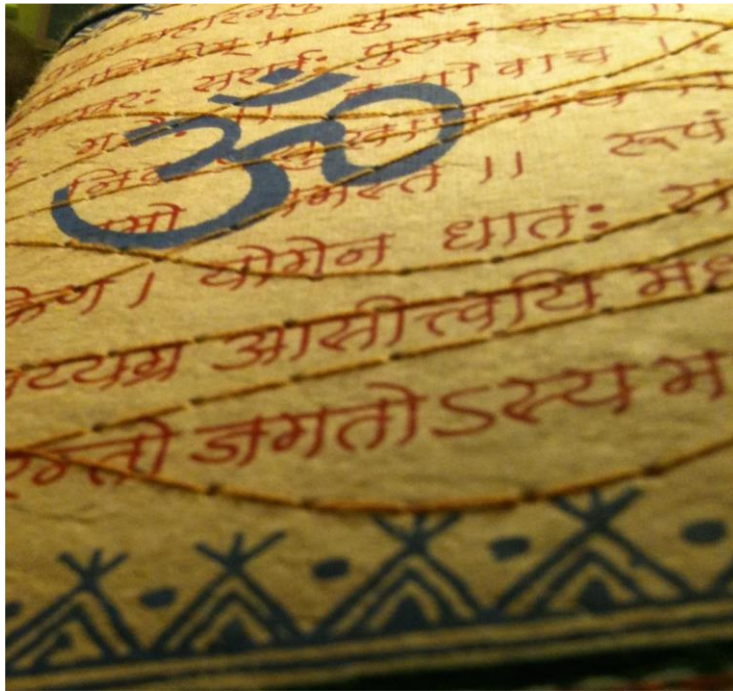
1.10.6 Chapter 7: Conclusion: Demystifying dying

The final chapter of thesis recapitulates the aims of this thesis and provides a summary of insights that have shown themselves through the emotive EoL stories. Intentions for guiding future practice are shared and the limitations found on completing this thesis are discussed. Some models to guide future patient-centred practices are presented.

1.11 SUMMARY

Chapter one of this thesis has introduced the phenomena under research; the lived experience towards the EoL. It has further discussed a personal scenario that was the impetus for this research. It was through the personal experience of witnessing the care of a family member that raised many concerns regarding the human caring needs that are required towards the EoL. Due to this experience I was left wondering if research had enquired into the lived experience towards dying, and just what is required for people who are facing their mortality? The aim of this thesis was identified, and a gap has been highlighted between the theoretical knowledge and therefore the practice of the holistic nursing care required towards the EoL. The identification of the research problem was introduced as being related to Cartesian Dualism and the hidden role that dying plays in contemporary Western societies. For this thesis the concepts of the person and spirituality have been succinctly defined. A brief synopsis of the research methodology; hermeneutic phenomenology has been outlined. The importance that these research findings have for the nursing profession has been discussed and the participant group, the method of data collection has been introduced. Lastly, this chapter has outlined a brief structure that will guide this thesis.

Chapter 2: Literature Review



Researcher reflections 3: Autobiographical texts hold the key for future generations.

Photo credit: J. Carter

The sages in the past always invoked the grace of the supreme Spirit.

These days we feel we do everything.

In ancient times, it was everyone's firm experience that it is the supreme Spirit that makes everyone move, makes everyone think, makes every-one feel, makes everyone act. Therefore, they performed any action, they always asked for the grace of the supreme Spirit.

They prayed, "Come to me, be with me always."

(Sw. Chidvilasananda, 1995, Dec.)

2.1 INTRODUCTION

Chapter two commences with exploring the Western origins of contemporary medical science, which are firmly rooted in the Enlightenment age of rational reasoning. This thesis is focused on living until dying within modern society, therefore it is important to understand how and why contemporary thought has arrived at the exclusion of metaphysical concepts in contemporary medical science. A brief discussion on the philosophy of Indigenous health is undertaken, which serves to demonstrate the inclusivity of spiritual health within Indigenous cultures. The concept of an energy field (biofield) existing in health care was introduced in chapter one. Metaphysical energy fields are threaded deeply throughout Western, Eastern and Indigenous cultural history, therefore, require further consideration.

This chapter presents a literature review of research articles concerning people who are consciously aware of their imminent mortality, highlighting the gap in current knowledge. This research is unique amongst the health sciences, as it draws from personal experiences through the medium of social media and the arts. Therefore, the last section of this chapter includes a discussion of the literature that has been undertaken employing social media as a source of data collection. An examination of Internet blogs, where people find refuge to share their deepest inner emotional thoughts, is undertaken. An introduction to the following chapter is given.

2.2 HISTORICAL ORIGINS OF MEDICALISATION IN WESTERN CULTURE

The modern medical paradigm has arisen from the landscape of the earlier Enlightenment age (1685- 1730), which observed the rise of rational reasoning and informed the current trend in Western health practices (Bristow, 2011). This landscape has set the scene for contemporary medical thought and is woven throughout the fabric of biomedical history (Bristow, 2011; Kellehear, 2007; Koopsen & Young, 2009). The idea of living towards the EoL cannot be considered without an analysis into what constitutes our contemporary idea of ‘living.’ How we live, think and be in this

contemporary world is a sum of all our past experiences and scientific knowledge (Frank, 2013).

Medical dominance is described as the authority given to the medical profession and scientific inquiry in terms of control over health resources and health policies. It originates from the total control of health that is given to doctors from diagnosis to treatment, and according to Germov (2014) is less than a century old. The rise of medical dominance in Western medicine has also witnessed the segregation of complementary and traditional methods from modern health practices (Chary & Sargent, 2016). Western allopathic medicine dominates throughout most of the contemporary Western world with very few physicians endorsing alternate methods of health care (Chary & Sargent, 2016). Through this segregation, Western medicine has also experienced a disconnection with its spiritual roots. In principle, this disconnect can be traced through the philosophical writings of the present age (Gawande, 2014; Germov, 2014; Kellehear, 2007; Silf, 2014).

Western philosophical writings on the spirit can be traced back to the historical writings of Socrates (470-399 BC), Plato (428-348 BC) and his student Aristotle (384-322 BC) (Garvey & Stangroom, 2012). Socrates believed that the real world was not the physical world, as we know it but the spiritual world (Garvey & Stangroom, 2012). Plato followed in the footsteps of Socrates by describing the spirit as consisting of everything perfect in their physical forms, including that human souls exist before they enter the body, possessing all knowledge, which returns during a person's lifetime. Plato postulated that there is a conflict that exists within humans and that the soul is a captive in the body. He postulated that there are three parts or conflicts to the human soul within the body: the upper part that controls our thoughts and emotions; the middle part, which is the spirit; and the lower part that is our appetite for material needs. Plato goes further to suggest that we will not find harmony within ourselves if the energies are not aligned (Page, 2003).

Rene Descartes (1596-1650), a French philosopher, was often referred to as the founder of the Enlightenment period, where scientific reasoning ruled over empiricism (Bristow, 2011). Descartes rejected Aristotle's metaphysical writings arguing that there is a definite distinction between the mind and the body. Descartes postulated that sensations were separate from the body. In 'The Treatise on Man', Descartes (1664) outlines his argument for his dualistic metaphysical perspective of the human being.

He invites us to imagine the human body as a machine, working the same way as a clock.

Descartes writes that items of knowledge are two different identities - one caused by the spirit and the other by the body. He proposed that our Will causes us to 'imagine' an action, but it is passive in that action until our perception of the action causes volition or action. Furthermore, Descartes suggests that these imaginings do not arise from the Will and therefore do not count as actions of the soul but as agitated spirits. In his thesis 'Passions of the Soul' Descartes suggests that passion (animal spirits) can attack the soul, which lies within the pineal gland of the body. The passions then, through the soul, force the body to commit inappropriate actions (Descartes translated by Bennett, 2015). Descartes strongly believed that the body should belong to scientific inquiry and the mind and spirit should remain in the realm of the Church (Rakel & Weil, 2007).

This notion of Descartes', of the separation between the mind and the body in scientific terms, is further translated into current Western philosophy through the works of Foucault (1963-2003, para. 2), who described the "clinical gaze" as a physician's view, intoxicated by the patient's body, rather than the emotions or personality. This was the new direction for medicine, a shift towards a focus on the mechanics of the body. The introduction of modern technology coupled with the knowledge gained through the availability of powerful diagnostic tools has witnessed the increase of medical dominance in Western societies. The profession of nursing has followed the scientific paradigm of medical dominance, with a strong focus towards the physical health needs of the body. This is in direct contrast to the roots of the nursing profession that are strongly grounded in religious orders and the metaphysical concepts of spirituality (Germov, 2014; Koenig, 2013).

The contemporary interpretation of a separation of the mind and body (known as the biomedical model) of health in allopathic medicine is incongruent with many other traditions of health. In fact, the biomedical model is a relatively new concept within Western Celtic heritage (Gawande, 2014; Germov, 2014; Kellehear, 2007). The Celts of the past never doubted the notion of the existence of two worlds: the material and the spiritual. The visible and invisible realities were interwoven into daily life

(Silf, 2014). While the biomedical model of health and illness has slowly eroded the metaphysical concepts that blur the lines between the worlds of both the tangible and intangible, this is not the case for Indigenous people of many nations, who have kept their strong ties to spiritual metaphysical concepts within their health paradigms (Germov, 2014; Koopsen & Young, 2009; Lindquist & Snyder, 2006). An example of the inclusive nature that the spiritual world plays within the totality of a health paradigm is that of the Māori peoples of Aotearoa.

2.3 INDIGENOUS PHILOSOPHY ON LIVING AND DYING

I am of Celtic-Māori heritage; therefore, I include here a brief synopsis of Māori philosophy on wellbeing in New Zealand (Aotearoa). This discussion will serve to demonstrate the cyclic nature of living and dying that remains within Indigenous cultures. As in most other Indigenous cultures, the conversion to Christianity has left its mark on the spirituality of the Māori people. Some Indigenous people believe that this was akin to an “assault on the Indigenous Soul” (Mikaere, 2011, p. 218). The spiritual life of Aotearoa’s Indigenous peoples is linked to the earth, animals and oceans. Māori legend asserts that in the beginning, God ‘*Tane*’ offered mankind three baskets of knowledge. These baskets held the stories of creation. The baskets contained all knowledge of peace, love, warfare, agriculture and philosophies (Karetu, 2008).

A theme that emerges from Māori creation stories is the concept of balance and reciprocity. A state of balance must be found and maintained between all living creatures. The coexistence of the physical and spiritual realms and the significance of time are also important. Ancestors are remembered daily, and their presence is acknowledged. All animate and inanimate objects contain Mana, or a life force, a supernatural force (*Atua*) that can be associated with an ancestor (Mikaere, 2011).

Māori models of health are represented by an image. One of these is a house, or the *Whare Tapa Whā* (Durie in Irwin, 1982) (Figure, 1 below). It compares the state of health to the four walls of a house: the family, spiritual health, physical health and the mind, including thoughts and feelings. Another model of health is depicted as an Octopus, or *Te Wheke* (Pere, in Moeke-Maxwell, 2014). The *Te Wheke* model identifies spirituality, the mind, physical wellbeing and family as important to Māori health. This was a seamless link before the introduction of Western Medicine (Moeke-Maxwell, 2014). The following section introduces the concept of the biofield or the

energy field that surrounds all animate and inanimate objects and discusses the role that energy fields play within contemporary health practices.

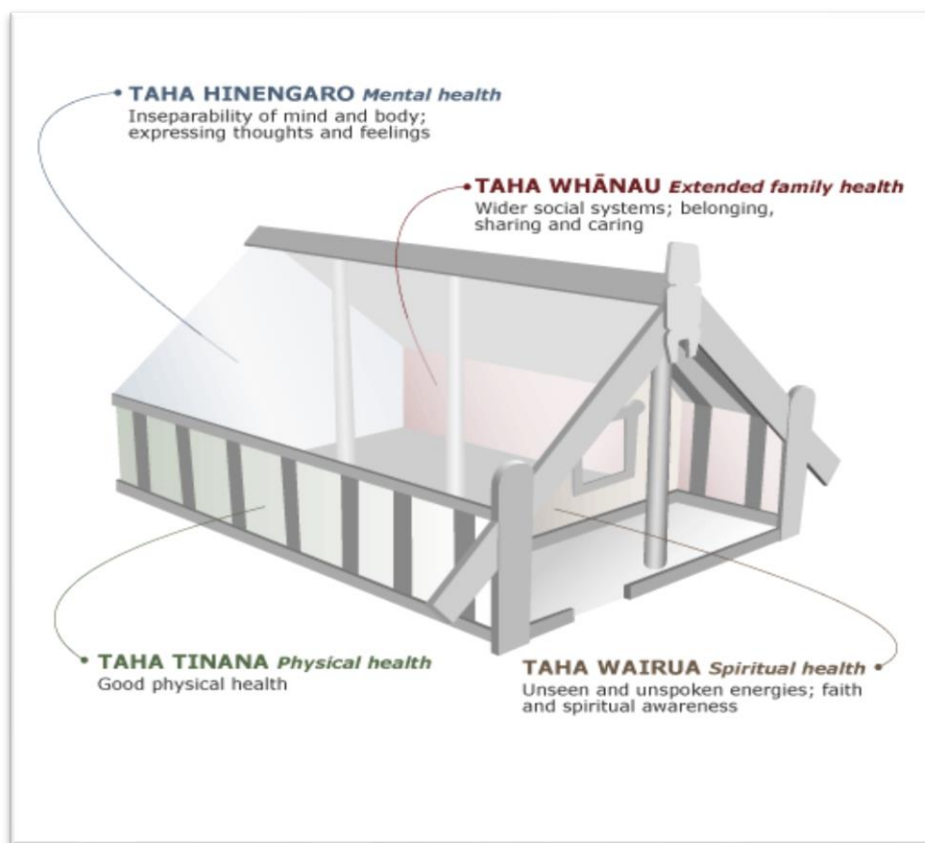


Figure 1: Māori health expert Professor Sir Mason Durie developed the whare tapa Whā model of health (in Irwin, 1982)

Image Credit: Pixabay.com

2.4 HISTORICAL ORIGINS OF THE BIOFIELD IN WESTERN MEDICINE

Chapter one introduced the impetus for this study through a scenario between my mother and myself. There was a felt reverence within an energy field between us that was not perceived by others observing the scene. Therefore, it is important that this thesis examines the metaphysical nature of the energy field, or biofield, as discussed recently by scientists (Kafatos et al, 2015). The biofield is described as “a field of energy and information, both putative and subtle, that regulates the

haemodynamic function of living organisms that may play a substantial role in understanding and guiding health processors” (Jain et al., 2015, p.16-24). Although the term biofield is a recent addition to the health sciences (Rubik, 2015), the concept of a universal energy field (UEF) had been discussed in Aristotle’s understanding of the soul and has always existed in Western medicine. It was however, designated to the realms of the Church in preference to the Cartesian model of biomedicine (Koopsen & Young, 2009; Rubik, 2015).

Biofields can be described as existing in two forms, these being veritable and putative (Koopsen & Young, 2009). Veritable biofields can be measured, such as vibrations/sound, light/laser beams, or other energies from the electromagnetic spectrum. Endogenous human electromagnetic energies allow the recording of an electrocardiography, which records the human electrical activity of the heart (Kafatos et al., 2015). Putative energies are subtle energies that are difficult to measure (Koopsen & Young, 2009; Rubik, 2015). The introduction of Kirlian cameras has recently allowed the photography of subtle biofields to be made visible. The image below (Figure, 2) is a Kirlian photograph of a coleus leaf. It depicts rays or aura of light that surrounds the leaf. This aura is said to be faintly noticeable as the leaf is torn apart and dies (Pederson, 2016; Ciesielska, 2009).

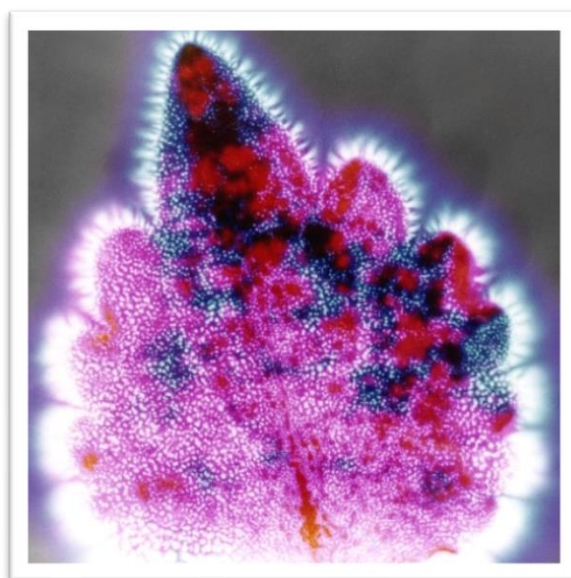


Figure 2: A Kirlian photograph depicting the aura of a leaf
Image credit: Creative-Commons

Universal energy also known as a life force or energy field is always flowing through and around the human body (Brennan, 2017; Koopsen & Young, 2009; Pederson, 2016; Rubik, 2015; Whitfield, 2009). Traditional healers from all cultures and continents have practiced methods of energy healing for centuries in the form of both hands-on and hands-off therapies, such as Reiki, Therapeutic Touch, and Acupuncture. Therapies involving veritable and putative energies are used in all cultures, and are known as Chi in traditional Chinese medicine, Ki in Japanese Kampo system, Doshas in Ayurvedic medicine and prana, mana, and orgone in other cultures. It is the belief in these cultures, that sickness arises from imbalances in the body's vital energy (Rubik, 2015). Therefore, modalities of healing are employed to correct the imbalance, such as Tai Chi and Qigong (Koopsen & Young, 2009, p.63).

An aura is the life force that emanates from all objects in nature. The words aura and energy field can be interchanged. The structure of the human energy field (HEF) consists of seven auric layers. The seven layers are thought of as the 'energy' body, which has many different frequencies and colours. The levels within the HEF correspond to having a human conscious awareness. Levels one to three are related to three-dimensional reality, level four is the link between the physical and metaphysical dimensions of reality. Level five to seven are connected to the spiritual world (Brennan, 2017). It is through these layers that the connection to the human consciousness occurs. These energy levels are associated with human reasoning, our will and emotions. The notion of 'Time' within the HEF is not linear. Rather it is a conscious experience in that it is not limited to the present time and space (Brennan, 2017).

The HEF is absorbed within the body through seven chakras (Sanskrit for wheel), also known as human energy centres (Brennan, 2017; Gerber, 2000). Chakras are situated at different levels, which are seated close to the spine throughout the body and are said to look like a lotus flower with many petals. The chakras "vitalise" and "control various organs and nerves throughout the body" (Kripananda, 1995, p. 82). The chakras belong to the subtle body and therefore they cannot be seen by the naked eye and are dismissed in biomedical science (Figure 3). The main role of the chakras is to receive energy from the UEF and to be the sensory organs. This is where messages

are received, like hunches, ideas, and feelings such as a sense of dread. The final role of the chakras is that of governance, to control the energy on each level within the body (Brennan, 2017).

As this thesis is on the lived experience *towards* the EoL, the energy that surrounds the living until their final moments is worth exploring. This living energy, or vital force, is the connection to the spirit that waxes and wanes until it leaves the body through the breath on death (Kripananda, 1995). Since this understanding, exploration of how energy fields can be explained has led to the science of quantum physics.

Quantum physics describes the biofield as a connection that belongs to the whole organism (Kafatos et al., 2015). This would be in direct opposition to the reductionist technique of molecular biology that reduces cells to microscopic cellular processes (Kafatos et al., 2015). Biofields have been further defined in health as being the diagnostic and a therapeutic use of energy that stimulates the repair of tissues (Oschman, 2000). There is a noticeable emergence of health science scholars who have written on their direct practical application and experience with human biofields and energy healing, especially in the form of therapeutic touch (Dose, et al., 2014; Hemsley, 2003; Jackson, 2012; Watson & Smith, 2002; Whitfield, 2009).



Figure 3: The Chakras (energy centres) within the body
Image credit: Pixabay.com

The next section moves from this foundational discussion of what is being uncovered in the literature about Indigenous and historical understandings, to what is known about the lived experience towards the EoL. Therefore, the next section of this thesis discusses the findings of the review of this literature.

2.5 LITERATURE REVIEW ON THE LIVED EXPERIENCE TOWARDS EOL

To explore what is already known about the lived experience towards the EoL, I instigated a search of the literature by using the key words ‘lived experience’ and ‘end of life’ and knowing how intrinsically linked the concepts of spirituality and dying were, I also included the word ‘spirituality’ (Kellehear, 2007; Koenig, 2007; Puchalski, et al., 2014; Silf, 2014). I began with a search of the Cochrane library (systematic reviews), which revealed thousands (8,682) of articles related to the physicality of dying. Without a doubt, physical needs, especially regarding pain management, dominated the literature. However, physical pain is a subjective, lived experience and is unique to each individual person (van Manen, 2014). A person’s human emotional experience, including those linked to spirituality, influences how the physical experience is interpreted, known and manifested (Kaminsky, 2016; Koenig, 2007; Wynne, 2013). Therefore, spiritual concepts must be an inclusion within the EoL story. The inclusion and exclusion criteria required for this study are listed in Table 1, below.

Table 1: Inclusion and exclusion criteria of the literature review

Inclusion criteria	Exclusion criteria
Must be the written personal account of LED towards dying	Must not be written by others for the participant
Open year	No date limit
A documented experience of a person over 18 years of age for at least 6 months	Articles included by those under the age of 18 years not considered due to ethical considerations
Must include the voice of the participant in the data collection	Questionnaires must not be the only method of data collection

The key words ‘patient’s experience’ were included to narrow down the literature in a meaningful manner, and to ensure that all articles related to the patient’s lived experience were included. This action retrieved a further sixty-five articles. To elicit articles that may contain metaphysical concepts, the words ‘metaphysical’ and ‘transcendence’ were added to ‘lived experience’ and ‘EoL’ using the search engine Medline and CINAHL, which retrieved a further 400 articles. After refining the literature search using the words, ‘transcendence’ and ‘end of life’, a further six articles were retrieved. Most of the articles returned following the use of all the key words (9,082), were related to pain management. Following a scan of the titles and abstracts, most of these were excluded (8,682) as they did not satisfy the inclusion criteria for this study. A further 465 articles were excluded following an examination of abstracts. The final review included an in-depth examination of the remaining six articles, which revealed that the single case study did not contain any of the original thoughts or experiences of the participant and was therefore excluded from the final review (see Figure, 4)

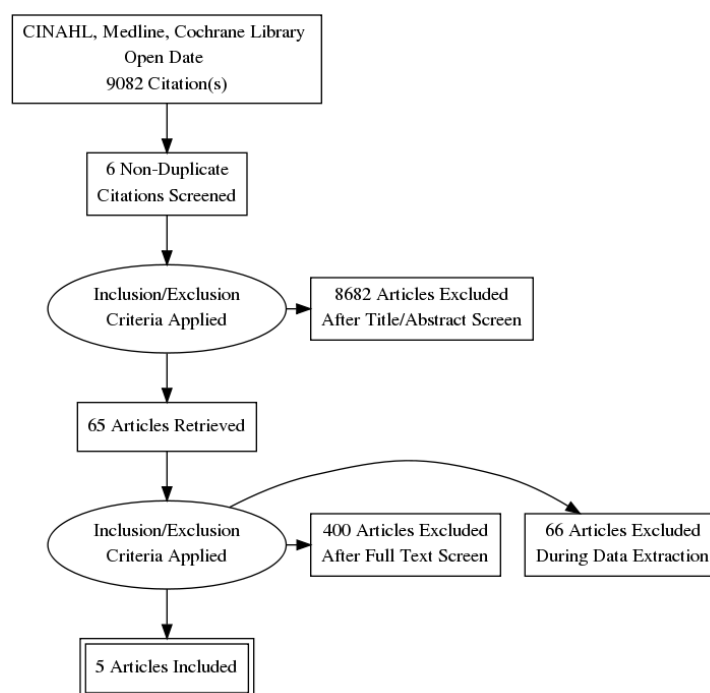


Figure 4: The literature review selection process following the PRISMA flow chart format for clarity (Moher et al. 2009)

2.6 FINDINGS FOLLOWING THE LITERATURE REVIEW

In this section, I review each of the final five articles from the literature search and follow with a summary of the findings (see, Table 3), beginning with the article by Dobratz (2013), who undertook a secondary content analysis on the importance of spirituality at the EoL. There were ninety-seven participants living in a USA hospice centre who were included in this study. The inclusion criteria included participants with six months to live, over the age of thirty years, who were English speaking and had an intact cognitive functioning level. Forty-four participants (mean age = 66.1 years) with the majority being Caucasian (38%) who referred to the concepts of spirituality ninety-one times. Three separate themes arose, religious beliefs systems, non-religious belief systems and life purpose. The most participant responses (30.8%) were related to religious beliefs; the second highest participant response was non-religious beliefs (11%) and life meaning/purpose was the third highest participant response (8.8%). Life meaning responses included some aspects of the natural environment. Having a connection to family and friends was also noted in the response (4.4%) and participants felt that they could not survive without their family's love and support. Only two responses referred to the concept of transcendence (2.2%), they referred to the ability to find peace within to fight the physical limitations of their illness. This response was directly opposed to three participants who found peace in handing over their illness to a Higher Power in religious transcendence (3.3%).

The findings related to transcendence need to be considered carefully as the concept of transcendence could lie embedded in other multifaceted constructs of spirituality (Puchalski et al., 2003). The author referred to Sessanna et al. (2007) concept of transcendence as being "transcending or rising above life in an abstract sense" (p.257). The difficulty lies in interpreting the participants' understanding of the word transcendence. The lines not only blur between transcendence and connectedness to self or others in the Dobratz (2013) study, they also blur between the concept of life purpose and non-religious spirituality. Spiritual concepts may also include finding a purpose for life and achieving that purpose before death (Vachon et al., 2009).

A phenomenological qualitative study undertaken by Dose et al. (2014) included eleven English speaking, cognitively competent participants, who were recruited from

two hospice programs in the United States of America (USA). Participants (7 females & 4 males, mean age = 84) were asked to think about and document their spiritual lifelines before they were interviewed. The participants (5 Christians, 4 Catholics, & 2 non-denominational) were given some guidelines on the concept of spirituality by the authors. Spiritual concepts were described as: relationship with self and others; God or a Higher Power; connectedness with nature; meaning and purpose of life, 6 participants completed their lifelines, 5 did not.

Participants in the Dose et al. (2014) study were asked to reflect on their spiritual life line during a series of unstructured interviews (3 to 4 interviews of each participant, lasting 45 minutes). Due to inability of the participants to read the instructions and to describe the concept of spirituality (despite being given the definitions) and to complete their lifelines, weekly interviews ceased after one month. Final themes that were identified following a review of the transcripts were: connectedness with subthemes of family, God and clergy; and Spiritual Life Moments, which encompassed moments in time that were connected to either states of happiness or sadness. Pick up the Pieces and move on, was the third theme identified, referring to the tough times that the participants or their family had to traverse. The final theme identified was related to religious matters. In this final theme, spiritual concepts were reflected through religious notions of the church. Participants shared that religious concepts mattered when it came to be prepared for death and the funeral.

It does appear in the findings, that all themes were interrelated with religious concepts, with concerns by the participants regarding family members who were not affiliated with a religious practice. The age group of this study (mean age = 84 years) depicts the cultural practice of this generation. Despite the participants in the Dose et al. (2014) study being given a guideline of spiritual concepts, the participants remained vague about the concepts. This is not a surprising outcome, given that many participants aligned with an established religious belief. Although the authors do state that creating a lifeline of spirituality assisted the participants in reflecting on their spiritual journey, the findings did not add strength to the overall understanding of spiritual concepts at the EoL. These findings assisted me to conclude that this study would be better informed if the participants' ages were broader, and the study was recorded over a longer period, which would enable a rich description of real time lived

experience to be explored. I noted these conclusions in my reflective diary for consideration for recruitment.

Gourdji, McVey and Purden (2009) undertook a qualitative descriptive study, which focused on the quality of life (QoL) from the patient's perspective. Ten hospice patients in Montreal, Canada (mean age = 59 years, 5 females & 5 males) participated in semi-structured interviews. The duration of their illness had been from four months to nine years. Most of the audiotaped interviews took place within a week on admission to the palliative care unit. The findings of three distinct aspects of QoL were revealed in the study. These were centred on the meaning of the QoL and how their illness affected their own QoL.

The participants in the Gourdji et al. (2009) study identified that their ideal QoL was themed around being independent, happy, and without pain. Their approach to life was to maintain a positive outlook, spirituality, humour and hope. The participants thought that these aspects allowed them to cope with their illness. The authors state that spirituality concepts included religious faith and existential wellbeing. Evidence of the hope could be seen in the findings, along with the ability to remain independent, to laugh and to make their own choices, clearly demonstrated as important to the participants. Here the authors use the term a 'quality end of life,' which does appear to be an oxymoron; it is however what all people strive to achieve (p. 45).

The Gourdji et al. (2009) study was centred in a hospice where dying people have come to prepare for their death in the final days or weeks. Four participants died during the research. If this study were replicated over a longer period, it would allow further insights into how the participants maintained their QoL throughout their illness. Despite the increasing fragility and declining physicality, this study demonstrates that the QoL can continue to evolve despite impending death. These participants were living in a caring environment at the time of the study and they all found this allowed them to have a QoL, albeit in the context of their illness.

Wrubel, Acree, Goodman and Folkman (2009), using a mixed method of inquiry explored how 88 people experienced living with cancer and autoimmune deficiency syndrome (AIDS) in San Francisco (USA). They had been referred by their physician with a prognosis of 6-12 months to live and were living at home. The quantitative

aspect of the study included three questionnaires: a visual analogue scale that focused on wellbeing; a self-report depression inventory; and a patient health questionnaire. Narrative data was collected from two or more interviews. Thirty-two participants were interviewed monthly until their death.

The results of the Wrubel et al. study found that 57% of the participants maintained a life-world. By life-world the authors referred to achieving goals, engagement in spirituality and spiritual practices. The participants also recorded lower scores on pain, suffering and depression. Although the participants continued to struggle with the physicality of living with an illness, they maintained a positive sense of wellbeing. The authors note that there was a large difference in participants who focused on living, compared with those who focused on death. Those who focused on their death had higher depression scores and reduced life world experiences. I pose the question that perhaps the participants who focused on living had already overcome their fear of death. Enquiring further into the participant's ability to overcome the fear of death would assist in helping others to maintain a QoL in the face of dying.

Neimeyer et al. (2011), in a mixed method study, used questionnaires to elicit responses from hospice patients who were recruited over a two-year period. All the participants (153) were residing in a Methodist hospice in Tennessee (USA). There was a large percentage of African American people (35%) with the majority being Caucasian (65%). The ages of participants were between thirty-nine to ninety-nine years (no mean was given). A Likert Religious Orientation Scale was used to elicit religious information. A Self-Esteem Scale was used to elicit self-esteem responses, a Regret Scale, a QoL scale and a Death Attitude Profile was also undertaken by the participants. Open-ended questions were also asked however they were only included in the final analysis to add further clarification to the responses in the questionnaires. Therefore, no new insights were identified.

Findings from the Neimeyer et al. (2011) study highlighted that participants with an internalised religious worldview reported a greater acceptance of death than those without a religious focus. However, a surprising result also found that those with a religious worldview were less likely to discuss death and some participants experienced a negative religious coping experience view of God, hoping not to displease their God on their death. The quality of a social life was also consistent with predicting an improved QoL. Men reported greater death anxiety than women, and

African American participants exhibited greater death avoidance than Caucasians. The authors found that gender and ethnicity were predictors in death avoidance. There was also a noted correlation of the participants' answers in relation to regret, fear of death and reduced QoL. Participants felt that they lacked time to make up some of their regrets. Given that most of their results were the findings of many questionnaires over, in some cases, two hours to complete, it would be difficult to rely on their findings, although the large number of participants (153) included in their study is worth considering.

2.7 SUMMARY OF THE LITERATURE REVIEWED

In summary, the final studies that were reviewed within in this thesis, added to the knowledge of understanding of the lived experience of dying (Table, 2). The five studies employed different methods, both qualitative (Dose, et al.2014; Gourdji et al., 2009) and mixed methods (Neimeyer et al., 2011; Wrubel et al., 2009) in undertaking their research. Most of the authors state how surprised they were to discover that people living with dying continue to find happiness and peace in their lives. These findings are synonymous with previous findings on the link between spirituality and a peaceful death (Koenig, 2014; Puchalski et al., 2014; Wynne, 2013). This outcome was achieved through maintaining life choices, independence in the face of reducing physicality, and connection to family, friends and spiritual and religious concepts (Dose, et al., 2014; Gourdji et al., 2009; Neimeyer et al., 2011; Wrubel et al., 2009).

While one study (Gourdji et al., 2009) found no issue in accepting spiritual concepts as part of everyday living, others had difficulty in interpreting religious and spiritual connections (Dose et al., 2014). The confusion between the concepts of religion, spirituality and transcendence (Dobratz, 2013) continues to exist and is well documented in the literature (Gijsberts et al., 2011; Kellehear, 2007; Puchalski et al., 2014) therefore inhibiting research on spirituality concepts from moving forward. It would have been ideal if Dose et al.'s (2014) study had delved deeper into the crises (picking up the pieces) of the individual experience of those people living with illness. This task would assist in understanding how to unknot the tangles that make living well achievable in the face of impending death. Drawing conclusions through questionnaires (Neimeyer et al., 2011) at the final stages of living made it difficult for

participants to recall the events as they occurred in real time. Most of the research was undertaken in the final moments preceding death, and none were longitudinal, following people through the years of their illness. As a result, pertinent, rich, real time data was not available (van Manen, 2014).

Table 2: Final five articles included in the literature review

Author	Methodology	Method	Outcomes	Subjects
Gourdji, McVey, & Purden. (2009)	Qualitative	Semi-structured interviews	Focus on QoL the meaning, experience, & factors of QoL	10
Dobratz. (2013)	Content Analysis/Qualitative	Structured interviews	Greater focus towards spirituality concepts needed	44
Dose, McAlpine, Leonard, & Kreitzer (2014)	Qualitative	Structured interviews	Spiritual concepts improved QoL	11
Wrubel, Acree, Goodman and Folkman (2009)	Mixed method	Recorded narrative responses	Spiritual concepts improved QoL, achieving goals	32
Neimeyer, Currier, Coleman, Tomer and Samuel (2011)	Mixed method	Questionnaires & Open-ended questions	Greater focus towards spirituality concepts needed, family important close to death	>150

Retrospectively, considering spiritual concepts (Dose et al., 2014) did not allow the essence of the moments to be captured, leaving gaps in the lived experience recollections. Very little thought was given in the studies regarding the strength that each person must find to maintain their QoL until the EoL. Of importance to note in Gourdji et al.'s study, is the conclusion that, although faith was not important to everyone in the study, existential wellbeing was. There was an acceptance of other means of wellbeing, so there did not seem to a struggle by the authors to segregate spiritual concepts from a health wellbeing perspective (Silf, 2014).

A limitation of Neimeyer et al.'s study was the number of questionnaires that the participants were expected to answer during a difficult time in their lives. The authors state that the interviews took from forty-five minutes up to two hours to complete, with some participants unable to complete all the questions. The exhaustion and the

concentration required to complete these questionnaires would be difficult to maintain for any person. The authors unsurprisingly highlighted that the participants did not have the energy to focus on the concepts in the study, as their focus close to death was centred on personal and family needs. This highlights a greater need to discuss issues around death and dying before the final stages of death.

While Dobratz (2007) concludes that many participants referred to a belief in the “after life” and looking forward to going the “spirit world, and mental discipline,” and “reincarnation” (p.195), these responses also aligned to the concept of transcendence, leaving doubt as to the findings (Silf, 2014; Kellehear, 2007). Kellehear (2007) argues that two early Celtic cultural tasks of transcendence were to acquire skills for “other-world journey” and to believe in life after death (p. 58). Dobratz (2007) concludes that more work needs to be done in researching the existentials to understand the myriad complexities related to spirituality concepts.

It is interesting to note that none of the research identified in the review of the literature included data obtained from Internet sites. Considering the many people who are sharing their real-time lived experience via the World Wide Web (WWW), this is a concerning finding. Therefore, the next section of this thesis introduces social media as a viable source for gathering research data in the health sciences. It describes why the Internet was the chosen method of data collection and explores the blogosphere as a reservoir of rich empirical data of the lived experience in real time (Udtha, Nomie & Sanner, 2015; Walker, 2013).

2.8 SOCIAL MEDIA AND THE RESEARCH PROCESS

In the outset of this thesis, the usual method of collecting data was considered, that is, through participant’s face-to-face interviews. Taking into consideration that I am employed as a nurse in palliative care, this would have been the usual avenue for data collection. However, through my experience with caring for the dying, I was aware that asking questions during the final moments of life is inappropriate. While many people do want to share their lived experience on dying, retrospectively speaking on their experience at the time of death is exhausting for the participants (Dose et al. 2014).

I decided to look on the Internet for people who were openly sharing their experience of dying. While scrolling through the Internet I was surprised by the number of people who were sharing their lived experience towards the EoL. I was drawn into people's lives as one person after another had a story to tell. It dawned on me (another epiphany) that asking people who were dying or at the EoL would be missing the essence of the lived experience towards the EoL story. Therefore, a shift in my awareness was required. This was a very subtle, but an important change and it required a new approach to the research process, although I was not aware of this until I had searched the literature.

In my role as an RN, I have cared for many people as they die, and I implicitly understood that it is the time for dying. The focus on this existing problem, of the inability to recognise the stages towards death, disempowers the dying process, leaving people unprepared for their final ending. The need for a focus on the preparation for death, as people are living longer, is a preferred option. This action would enable people to live fuller lives until their death. This concept is supported by recent authors who write on death and dying (Gawande, 2014; Koenig, 2013; Saul, 2014; Werner, 2014). Therefore, I decided the best choice for this research was to explore the lived experience towards the EoL, through social media platforms. I was nervous at the proposed idea of using social media inquiry for scientific research, due to its pioneering stages in the profession of nursing. Nonetheless, after reading the emotionally charged stories of people who were sharing their stories for the expressed purpose of disseminating their experiences, I realised that it was an important change.

Following my research of the literature, I was surprised to discover that very few nursing scholars are using the Internet for gathering data to undertake qualitative nursing research. The fact that there are minimal qualitative studies in health science utilizing social media as a method of data collection is surprising, given that in 2015, there were 1.96 billion people in the world using the Internet, with the expected number to increase to 2.5 billion by 2018. By 2015, over 70% of people in the United States had a social media profile. WordPress.com (2012), a social media blog site, indicated that 378 million people read blogging websites, leaving 50.7 million recent comments per month. Blog sites appear in many forms over the Internet and many personal blog sites are dedicated to chronic illness.

The number of Australians using the Internet for sharing information publicly is in line with other Western countries. The Australian Bureau of Statistics (2014) reported Internet usage by Australian residents has increased exponentially with the introduction of the Broadband network. Statistics for Australian Internet use show that from 2012-2013, 83% of people within Australia used social media sites. Of those people aged over 65 years, 45% reported using the Internet, this demonstrates the numbers of people who are becoming competent at using the Internet as a means of communication.

A search of the literature via CQU search engine, using key terms ‘lived experience, social media and health’, revealed that most studies undertaken on health using social media platforms, thus far focus on web-based data collated via questionnaires (8 studies) (Edwards & James, 2008; Hunter et al., 2012; Huntington et al., 2008; Jones, Murphy,; Kimberly et al., 2011; Mrayyan, 2004; Strickland et al. 2003). The ease and speed of the Internet to contact many potential participants, is one reason given for the popularity of using the Internet for survey-based research (Eastham, 2011; James, 2016; Mrayyan, 2004; Udtha, Nomie & Sanner, 2015; Walker, 2013).

There was one retrieved qualitative article which was related to health care (Davis, 2014). Transabled.org is an online community, which attracts people who openly share their experiences of living with an illness. The data was collated from three sites on the website, triangulating information received from bloggers’ first posts and subsequent posts and conversations between public statements entered on the blog site. Introduction statements on the website contained sensitive material and were coded into themes. The methodology used in this study was Geertzian interpretative perspective, or a Grounded Theory approach.

Gustafson and Woodworth (2014) undertook a meta-analysis of six quantitative studies using social media as a data source for exploring public awareness of Papillomaviruses (HPV) and HPV vaccination. Their findings should be considered with caution as they do state that most of the studies did not apply for ethical clearance and that only one study used two-way communication on social media sites. The requirement for two-way conversations was most likely not the intention of the article

under review, nor is it a requirement of research processes related to social media. In fact, some blogs sites do not allow for chat sessions and participants must be invited to join the site. The studies that undertook questionnaires via the Internet found that it was worthwhile, especially the ability to contact many participants through emails, but issues arose with Internet access and participants' ability to use the computer. However, with the significant increase in use of the Internet, this is not likely to continue to be a problem. For the benefit of this study, the use of the internet as a source of data was considered pertinent. I extended my search of the Internet and related literature, focusing on the use of the internet.

2.9 IMPLICATIONS OF BLOGS FOR RESEARCH PURPOSES

A blog is frequently modified web pages and is an amalgam of journaling, diaries and online communities (Jones & Alony, 2008). The word 'blog' began as a Web-Log, which in turn became shortened to blog. Researchers are only just beginning to realise the value that social media presents as a source of data for research. The first blogs started to appear in 1999, when it was noted that there were 23 blogs on the Internet (Blood in Jones & Alony, 2008). Since then, there are over 30 million blogs and a new blog appears every second (Embrey, 2002; Jones & Alony, 2008).

The number of blogs over the Internet increased to 90 million in 2007 and is doubling every six months (Jones & Alony, 2008). An example of a successful blog for academics is that of Saunders and Janiszewski. The authors commenced an online blog after discovering that their Ph.D. research results were largely being hidden amongst journals with very few reviewers. They also felt that the public were being bombarded with misinformation, so they were invited to join an online site called Obesity Panacea, a website that included evidence based medical information. Since then, they have noticed an increase in their cited publications. Now their scientific information is reaching thousands of people in just one day (this can be traced by online software). Since 2008, they have created the blogs: Science of Blogging and Research Blogging.com and they have appeared many times on radio and television discussing their research findings.

The image (Figure, 5) depicted below demonstrates the myriad Internet connections that are continuously being made throughout the world. Originally collated in England (2005), each line is connecting computer addresses between each

node, the different connections are colour coded. Yellow indicates connections from Government networks, black from unknown sites, green from organisations and educational sites are depicted in blue. Pink sites are traced from the USA and Canada.

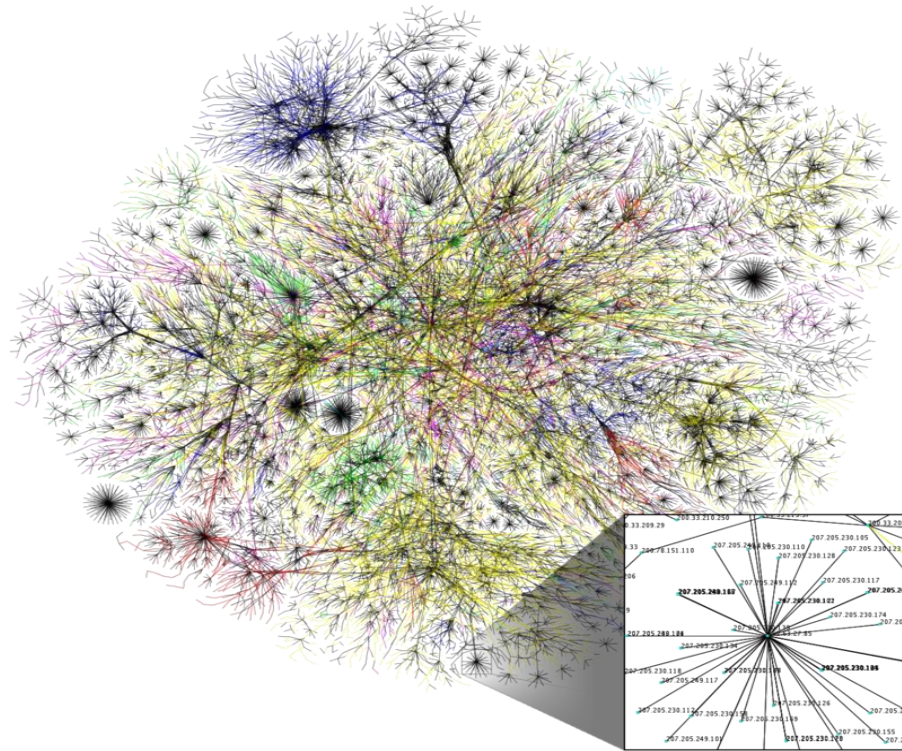


Figure 5: The image depicts millions of Internet connections
Image credit: <https://commons.wikimedia.org/w/index.php?curid=2569871>

There are many reasons why the Internet has proven to be a valuable method for data collection. Gathering data via online sources is economical, there is no travelling involved, limited or no direct contact with the participants thereby reducing bias. It is also very fast, enabling immediate email contact with participants through generic online questionnaires like Survey Monkey (Eastham, 2011; James, 2016; Mrayyan, 2004; Udtha, Nomie & Sanner, 2015; Walker, 2012). The online storage system known

as the Cloud, enables secure storage and retrieval for longitudinal data, enabling data to be downloaded from a variety of secured computer sources (Jones and Alony, 2008; Udtha, Nomie, Yu, & Sanner, 2015). Authors of blogs are articulate and record their reflections contemporaneously. They also record their insights over many years and therefore are an excellent source for qualitative longitudinal data, as is the case for this thesis (Hunter, et al., 2012; Udtha, Nomie & Sanner, 2015; Walker, 2013). Inger Mewburn writes a well-known blog titled 'The Thesis Whisperer' (WordPress.com). It is recommended by many Australian Universities as an adjunct to their curriculum. Inger subsequently published an eBook that included her blog posts for fear that her original blog posts would become lost amongst archived material.

Internet blogs have an underestimated influential power. It was a blog known as Wiki Leaks that first alerted the world to the abuse of prisoners held in Cuba. Blogs are considered a source of rich codified data as they are written succinctly, and most bloggers list different subjects under headings. Stories can be collected from alternate using alternating media sites, such as eBooks and YouTube (Jones & Alony, 2008; Walker, 2013). Many of the authors of blogs have a high community profile and have been interviewed by reporters for television, radio and newspapers. Using open questions, the interviewers explore the essence of the person's lived experience as can be seen in this thesis. These media sources add a further layer of rich data, which endorses the individual's original blog entries, where they share their personal insights (van Manen, 2014).

2.10 CHAPTER SUMMARY

Chapter two explored the rise of the medicalisation of allopathic medicine through the dominant thought in Western philosophies. Highlighting the attention that has been given to the physicality of the body, led to the separation of the spiritual essence of the person in care. This chapter also discussed the vital link between biofields that are required for spiritual inclusivity in all cultures, and that exists in all living things. Current literature pertaining to the lived experience towards the EoL was reviewed, establishing the shortfall of current research on this phenomenon.

Research of the literature found numerous articles related to the physicality of dying and most were focused on the care of the dying person. Of the five articles on the personal lived experience of dying that were reviewed, there was a deficit in

longitudinal studies with a focus on living well towards death. This chapter also explored the strengths and weakness of the Internet for research purposes, and further discussed the Internet as a source of data collection, in the health sciences. It was concluded that the use of the Internet is underutilised in research, considering the myriad of Internet sites available for research purposes in contemporary society. It was also concluded as a suitable avenue from which to collect data.

The next chapter introduces the methodological framework underpinning this thesis, hermeneutic phenomenology. It also introduces the methods used to explore the power of the anecdote to inspire evocative writing. It further takes the reader on a journey through the Internet and demonstrates the innovative techniques that have driven the methods of data collection to provide evocative real-life longitudinal experiences of the lived experience. This will enable the development of new understandings of the topic, including the real time highs and lows that encompass the experience of dying.

Chapter 3 Research Approach: Methodology



Researcher reflections 4: Reflections of light are caught on the surface illuminating and recreating the scene.

Photo credit: J. Carter

Not unlike the poet, the phenomenologist directs the gaze toward the regions where meaning originates, wells up, percolates through the porous membranes of past sedimentations—and then infuses us, permeates us, infects us, touches us, stirs us, exercises a formative affect. (van Manen, 2007, p. 12)

3.1 INTRODUCTION

Chapter three of this thesis introduces phenomenology, the chosen methodological framework that underpins the research process. Just as an artist uses paints and brushes to create an image, words in the same way are crafted to show imaginative images. Hermeneutic Phenomenology allows for the creative inclusion of the imagined, which is important for this thesis, it is both descriptive and interpretive. I chose this methodological approach as it was essential that the choice of methodology could show the essence of the lived experience towards the EoL. The voice of the participants can be seen through the emotional personal and insightful descriptions of living with a terminal illness, provided in depth in chapter 4 and 5 within this thesis. Interpretation of the participant's voice then follows in chapter 6, which unpacks the lived experience enabling the essence of the lived experience to show itself.

It is postulated that the horizon of the spirit is perhaps the hardest to capture and language alone cannot interpret its meaning. For this reason, the inclusion of the arts, in the form of prose and poetry are included within hermeneutic phenomenology. The founding ontological and epistemological understandings are discussed further in this chapter along with the basic philosophical principles that guide phenomenology. The underlining principles of van Manen's (2014) interpretation of hermeneutic phenomenology is introduced, along with an exploration of existential theme analysis. The research approach is also described, followed by insights that form my own personal preconceptions. Lastly, this chapter clearly defines and elaborates further on the data collection procedure, analysis, ethical clearance and rigour.

3.2 PHENOMENOLOGY

The aim of this study is to explore the phenomena of the lived experience towards the EoL, using social media and the arts. Max van Manen's interpretation of hermeneutic phenomenology will be the theoretical framework. Firstly, it is important to differentiate between phenomenology and hermeneutics. Phenomenology aims to grasp an understanding of the essence under focus, or the lived experience, as it exists in the pre-reflective life of everyday existence, and to understand the ontological way of 'being' in the world and the epistemology of to 'know' the lived experience (van

Manen, 2014). Hermeneutic phenomenology is known as interpretive descriptive phenomenology and is a method for approaching a phenomenon. Hermeneutics then relies heavily on descriptive language to sensitively interpret the lived experience (van Manen, 2014).

The Greek word phenomenon can be read as “that which shows its self in its self” (van Manen 1990, p. 762). Therefore, phenomenology aims at making explicit the universal meaning of the lived experience. Van Manen states that phenomenology is “more a method of questioning than answering” (p.746). Edmund Husserl, per van Manen (2014) is widely regarded as the intellectual founder of phenomenological philosophy. Husserl’s ontological understanding of the ‘thing’ is that it comes into being from a stream of consciousness and causes us then, to wonder upon its being. Van Manen (2014, *Transcendental Phenomenology*, para. 4) states that: “Husserl defines phenomenology as a descriptive philosophy of the essences of pure experiences. He aims to capture experience in its primordial origin or essence, without interpreting, explaining, or theorizing (sic).”

Phenomenology was further advanced by the writings of Merleau-Ponty, Sartre, Hans-Georg Gadamer, de Beauvoir and Ricoeur. These scholars have created and expanded their own insights and understanding of phenomenology (van Manen, 2014, *Meaning and Method*, para. 4). The guiding principles of phenomenology are the epoché (bracketing or suspension of belief) and the reduction (reflection) on the basic structure of the lived experience of human existence. The heuristic, the hermeneutic, the experiential and the methodological reduction of the phenomenon per the writings of van Manen (2014) are the four preparatory elements of the reduction proper, starting with the epoché. It is at this point important to remember that the four elements of the epoché, the heuristic, the hermeneutic, the experiential and the methodological reduction often dance together in concert depending on the experience under consideration. These four elements guide the epoché (opening experience) so that the researcher can approach the phenomena under focus.

The epoché of the event is considered the shattering of a previously taken-for-granted awareness. Van Manen (1990) referred to this as holding presuppositions at bay. This then becomes the wonder, a moment which is not simply a fascination or a curiosity but an enquiry into the essence moment (van Manen, 2014). This is the heuristic moment when we awaken to a different or new awareness. Others may call it

an epiphany or an insight. Van Manen (2014, Heuristic Epoche Reduction, para. 3) says, “momentarily we are speechless as when the mouth hangs open when we are taken in by the wonder of something.” This moment of jaw dropping wonderment is important in heuristic reduction inquiry because it is this moment that compels us to think deeper and reflect on the moment. Hermeneutic epoché reduction is where all is uncovered to reveal the essence of the phenomena and with this reduction, the researcher overcomes their own prejudice, inclinations and expectations to become open to the phenomena under scrutiny, so that it can be understood. To become open is where the researcher must reflect and examine their own understandings, for the real meaning of the phenomena under examination can be revealed rather than being covered with a frame of meaning (Van Manen, 2014).

The experiential epoché reduction aims at bracketing all theory, all belief, in what is real or unreal and aims at a certain kind of concreteness in the understanding of the lived experience. Van Manen (2014, Experimental Epoche Reduction, para. 1) expertly explains this as “the experiential reduction suspends abstractions in favor (sic) of concrete experiential facticities.” Here the experiential meaning is placed into a concreteness of understanding, where and how we are in time and place (corporeality, temporality, spatiality, materiality and relationally). The lived experience is what we are confronted with in each moment in time, yet it is interpreted through our thoughts, images, languages and emotions at that time. The experiential reduction then aims to suspend all judgment, theorizing and generalizations, including a belief in what is real or not. Most important of all, in my understanding is that a person’s dreams can be drawn into the conversation as being included in the lived experience. The importance is per van Manen (2014) the concreteness brought into reality by the experience of the person.

The methodological epoché reduction is indeed a method within a method, explained further by van Manen (2014) as being phenomenology that engages in reflection by including the creativity of the phenomenologist to reinvent the reflective and pre-reflective experience of consciousness under examination. The author of the text needs to be able to recreate the sense of wonder of the lived experience. Then, further create a tension between concreteness and the universality of the phenomena,

drawing a line between subjectivity and objectiveness of the lived experience. It is important to remember that phenomenology is not psychology, rather it is an interpretation of the lived experience. The following table (Table 3 below) discusses the five versions of the reduction proper as interpreted by Max van Manen (2014). They are eidetic, ontological, ethical, radical and originary reduction as they might be found within the literature.

Table 3: Five versions of the reduction proper (van Manen, 2014)

Five Versions of the Reduction Proper -van Manen (2014)	Interpretation
Eidetic	Testing of insight-imagination through comparing examples.
Ontological	Way of Being in the world via arts and emotions - sometimes difficult to interpret due to the saturation of meaning.
Radical	Relies on the Self to reveal itself, the way a phenomenon can show itself.
Originary	Insight, awareness, shock of awakening - the origin of the experience.
Alterality	Ethical, experience, caring responsibly.

3.3 THEMATIC ANALYSIS: HERMENEUTIC EXISTENTIAL GUIDED ENQUIRY

Existential guided inquiry is used in this study as a way of writing and rewriting and aligning the main themes that inhabit everyone's world-view. Van Manen writes that there are five fundamental world themes, which he refers to as existentials, in that they are a part of everyone's lived experience. These are known as: relationality - lived self and other; corporeality - lived body; spatiality - lived space; temporality - lived time; and materiality - lived things (van Manen, 1990). It is these five themes that will underpin the thematic analysis pertaining to this thesis. This theory is depicted in Figure 6, where all five concepts are linked to the lived experience, where one cannot exist without the other. This was the chosen method of analysis as it is everyone's experience of living. As van Manen (2014, p.11093) reiterates phenomenology in its "contemporary manifestations and historical orientation" continues to bring into conscious awareness how our lives are socially and culturally existentially existing.

Phenomenology differs from other methods of qualitative enquiry, in that it cannot be moulded into a set of rules and restrictions, it is described as a human science or the study of the mind (van Manen, 2014, p. 11093).

The existential idea of the Lived body is that without this body we cannot live, and that corporality shows how we live in the world. Corporeality can guide questions on how we experience the body regarding the phenomena under question. The body is what we present to the worldview, however because the mind is often thought to be separate to the body, it is important here to intentionally include the mind. Our minds (consciousness) have a hidden worldview, we can think, create, and imagine other worlds that might not necessarily be known to others. Van Manen (1990, p. 104) explains further that we have an unconscious awareness of our bodies and it is not until we catch someone paying attention to us then we become aware of our differences and alter the lived experience. He refers to Merleau-Ponty (in van Manen, 2014) as the phenomenologist of the body. The body is the keeping place of hidden fears that can, and do, show themselves to others who are aware of the subtle changes that the body cannot hide.

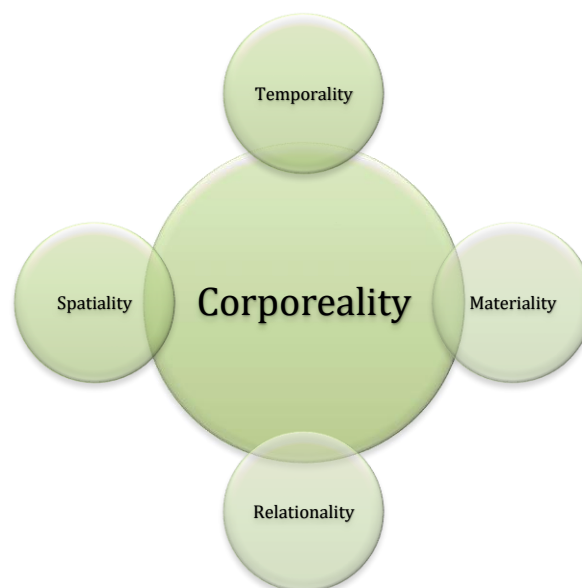


Figure 6: The 5 existentials that relate to the lived experience as interpreted by Van Manen (2014)

The existential concept of Lived time (temporality) is also a subjective experience, an example being that when we are frightened or disturbed in some way, time seems to slow down or the opposite, speed up when we are enjoying ourselves or busy. Therefore, it is important to conclude that time is reflective of our lived experience at any given place in time (van Manen, 2014). Time can continue to cloud our thoughts if we feel under pressure from past events and that this is carried forward to the present time. Van Manen (2014) points to Heidegger as regarding temporality as his fundamental understanding of human phenomena. Our life or identity is often measured in 'stages of time,' such as childhood, adulthood and old age, or marked in life stages of time like the time when we were married, or the time we went to work, or the first time we went to the movies. Of course, our relationship with cyberspace can also be marked in real-time.

The Lived relationship (relationality) or other is the space in which we include all others that we meet. Van Manen (2014) argues that this is the space that allows us to transcend ourselves and look for approval or a life purpose. Relationality can guide the reflection towards asking how people or things connect to the phenomena under consideration. Our family are our relations and how we relate to them informs our own understanding of ourselves. Also, included in relationality are those who we meet who are not related but with whom we have close relations. Van Manen (2014) reiterates that phenomena such as love can be examined for relational qualities, to discover how people are connected and whether it is in real (current) time. Van Manen (2014) refers to the phenomenologist Levinas and the ethical relation of Alterity, the experience of the otherness, when discussing the ethical relationality. This coincides with what nursing therapist, Jean Watson (2001), refers to as the ethical relationality of the first meeting between the nurse and the patient.

The existential concept of Lived space (spatiality) includes the social world (cultural space). Spatiality is experienced differently as is perceived by the person within the space. Van Manen (2014) likens this to the sparseness of a space like a temple, or to the closeness of a space like a prison, and the feeling and messages that this relates to a person. The outside space or the inside space are felt differently, depending on the experience that we are undergoing. An example van Manen (2014) uses is the bedroom when we are well it is our restful room, or when we are feeling sick, it becomes the sick room. There is also the virtual space or the space that we

entertain within, the third space as it is often referred to. van Manen (2014) throws into the mix the idea of cyberspace, and how we also relate to the cyber-world.

Materiality has recently been added to the existential list (van Manen, 2014). It is described as that which further divides our world existence into micro and macro objects such as at the Nano level of particles unseen by the naked eye to the grand level of earthquakes. Van Manen (2014) asserts that we have certain things that become our reality. For example, within the last few years we have created the 'selfie', taking images with our things to ensure that we are who we think we are. We cannot see our face, we can see hands and feet, but our face is not within our view, so selfies become the way we see ourselves. The things around us make up who we are. The things in our lives can be secret things or secret thoughts of things. All objects have a materiality about them, even if they are inanimate, and things can disappoint us and reflect to us and hold memories that elicit strong emotions within our being, the things of the symbolic world in which we surround ourselves.

Lived Cyborg Relations is how van Manen (2014) describes technology and it is said to have agency like humans and therefore exerts a moral influence on our lives. Van Manen (2014) identifies this as experiencing technology ontologically and lists five lived cyborg relations with technology. These include experiencing technology as taken for granted experience and experiencing technology ontologically. The relationship that humans share with technology and the moral implications of this and the aesthetic nature of technology and human relationship. The advancement of technology has changed the lived experience, examples being the technology that is now used in classrooms, such as smart boards in primary school to YouTube and power points. Technology has also changed our medical lived experience, with machines that keep us alive for longer. This has impacted greatly on our moral understanding and interpretation of ethical situations in health science (Germov, 2014).

3.4 THE RECRUITMENT PROCESS: IDENTIFYING SUITABLE PARTICIPANTS

This thesis explores the lived experience towards the EoL using social media and the arts. Therefore, the data consist of the lived experience as recorded by people who have been given a terminal diagnosis and experiencing an awareness of their

approaching the EoL. There is a changed perception when we become ill: our once taken-for-granted body becomes the focus of our attention. Van Manen reflects on the work of John Paul Sartre (in van Manen, 2014, para.1) to guide his understandings of body awareness or “what is passed over in silence” identifying this as pre-reflective consciousness. This is the underlying consciousness of everyday awareness, where we are mostly preoccupied with our surroundings. Van Manen (2014) explains this further, reiterating that serious illness can change the relationship that we have with the lived experience, our sense of time and our priorities change. The relationship that we share with others also changes as does our sense of Self. It is as if discovering that the body at the time of illness is being discovered, that it is usually taken for granted.

There are eight stories on the lived experience towards the EoL included within this thesis, that enable the eidetic of the experience to show itself through the number of narratives. The original number of chosen narratives was ten, however, this provided an overwhelming amount of data. In hermeneutic phenomenology, too many transcripts can be over-reducing the richness of the available data through time constraints (Steeves, 2000; van Manen, 2014). Recall that in hermeneutic writing, it is not the number of participants that counts within the research, but the accuracy and the voice of the description and interpretation. As van Manen states:

The aim is to construct an animating evocative description (text) of human actions, behaviors (sic), intentions and experiences as we meet them in the life-world. To this purpose, the human scientist likes to make use of the works of poets, authors, and artists, cinematographers - because it is in this material that the human being can be found in condensed and transcended form. (van Manen, 1990, p.19)

Theme analysis in this thesis is interpreted using van Manen’s (2014) hermeneutic phenomenological approach to writing. This style incorporates reading the text, then reading selectively, enquiring further into the essential components of what is being experienced, followed by a detailed reading to find thematic phrases or

understandings (Figure, 7). In hermeneutical phenomenology, it is important to find meanings of the story structures of the experience, as themes are identified. How each of the parts contribute towards the total experience is important (van Manen, 1990). Therefore, multiple stages of data interpretation were written in this thesis to allow themes to emerge. I decided early in the process that I would use the existential themes (life world themes) expounded by van Manen (2014), as they demonstrate how we live in the world and are universally understood.

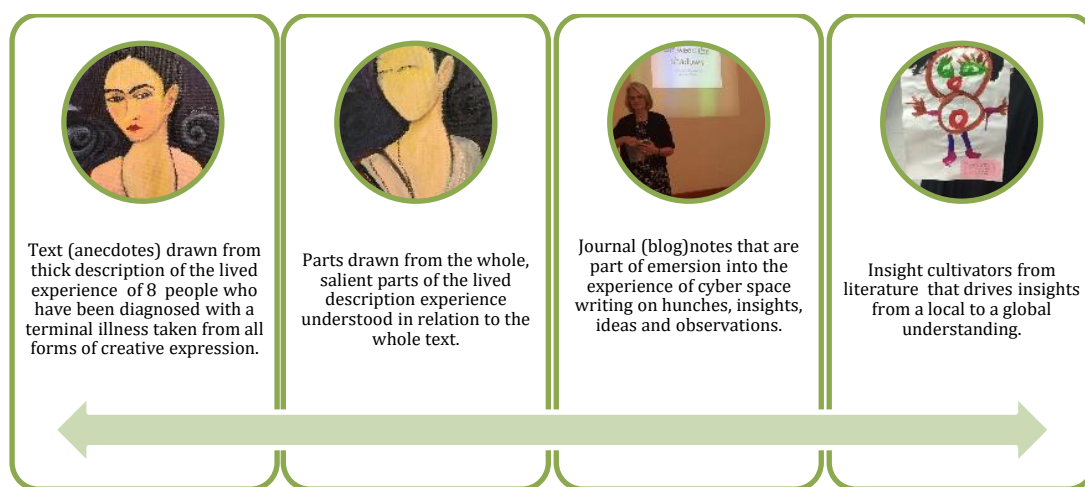


Figure 7: The hermeneutic backwards & forwards examination of data

The anecdotes within this thesis are transcribed from a narrative of a personal experience. In hermeneutics, anecdotes serve as a springboard for interpreting the lived experience. It is during the transcription of the story that the story transcends into a written form and therefore has become concrete for phenomenological interpretation (van Manen, 2014). I commenced this thesis by giving a direct description of my own personal experience in the form of an anecdote. This for me, was the catalyst that propelled insight into the lived experience. In van Manen's writings, he refers to the author Merleau-Ponty (1962, in van Manen, 2014) to validate his interpretation of the lived experience, saying that he starts the process by giving a direct description of his own personal experience in the form of an anecdote. Anecdotes may be collected in many ways, through interviews both audio, video or even imagined accounts of the

lived experience. Anecdotes were chosen for inclusion within this thesis through their descriptive ability to relate the essence of the lived experience under examination.

Staying true to hermeneutic phenomenology, the stories that are told via social media are prospective. They are written contemporaneously, if you were to ask the phenomenological question, ‘what is the lived experience towards the EoL?’ You may get a retrospective opinion or discussion (Kahn, 2000). Not in the case of social media, the stories that are shared via the voice of an enormous amount of emotion of the lived experience. Recorded at the time of experience, they are unfolding, longitudinal narratives of their true experience. These narratives are autobiographical and insightful. They explore the ontological way of being in the world living with a terminal illness as they approach EoL. Therefore, they contain the focus of the phenomena under inquiry, the meaning of human experience. Narrative data provides the richest insights that are available for hermeneutic research methods and allows the origin of the experience to be seen (Kahn, 2000, p. 60). It further reduces the influence of the researcher by not requiring further probing questions (Kahn, 2000).

Hermeneutic phenomenology is descriptive and interpretative, through the language of writing and the arts (van Manen, 2014). Phenomenology is a method of accessing the world as it is experienced, pre-reflectively. This is a critical point, it is the ‘pre-reflective or ordinary experience’ in which we, as human beings, live and are part of in our everyday experience (van Manen, 2014, p. 783). This pre-reflective experience is a part of everyone’s day, such as reading a novel or having a conversation or recalling an event. The storytellers in this thesis write and reflect on their everyday experience of living with a terminal illness. Inquiries into the phenomenality of the lived human experience requires the use of language to not just communicate information, but also to evoke forms of meaning that are poetic, elusive and that hold the essence of the story that cannot easily be described.

Resources for phenomenological analysis are drawn from many areas. Fictional examples can derive from life, literature and the arts and from the imagination. Van Manen (2014), argues that literature through language can offer expressive sources of empirical data. These include data such as anecdotes, aphorisms, and written stories, which are included within this thesis. Van Manen (2014) refers to the philosophers Heidegger, Gadamer and Ricoeur when referring to the arts as an expression of the truth. Phenomenology aims to interpret the hidden meanings that are written behind

the texts, to explore the truth behind the words or language of the mind. Further, hermeneutic phenomenological reflection also involves the arts, including visual images, art, cinema and music (van Manen, 2014).

The power of language to interpret our metaphysical world is at times, insufficient, as van Manen (2014, p. 6007) suggests, “The human science researcher must be able to maintain an almost unreasonable faith in the power of language to make intelligible and understandable what always seems to lie beyond language.” The metaphysical expressive form of the arts can move or evoke human emotion beyond words. A song or music can awaken past experiences. Therefore, it is important to remember that phenomenological research can include cinematography, photography, or stories and the study of the arts. There are also many new creative art forms that arise with the new technologies. The Internet has shown itself as a new medium for new scientific enquiry for future research (van Manen, 2014).

3.5 CRITICAL AWARENESS OF MY OWN PREUNDERSTANDINGS

In hermeneutic phenomenology, the researcher is not bracketed from the experience, rather the researcher is encouraged to write their preconceptions about the phenomena, so that they are aware of their own understanding, thereby not confusing their thoughts with those of the participants. Van Manen (2014) calls this process having a ‘critical awareness’ of your own thoughts. When I started this research, I started a journal, documenting my experiences and thoughts when caring for patients at the EoL. I know that the concept of spirituality, in the form of nature and the arts, at the EoL is very important to me and that spirituality does not mean religiosity. This notion also comes from years of meditation and yoga practice. Being aware of my own Self-identity I believe is my part of the story and it is important that I remain true to the stories of others.

I am personally very close in my work practice as a registered nurse, caring for people at the EoL, which Steeves (2000) claims is essential for hermeneutical phenomenological research, I also wanted to share the blog experience. Therefore, rather than journaling about my experiences throughout this thesis, I decided to commence a blog. When I started my blog, I was writing extremely analytical

referenced material, like I had been accustomed to. However, it wasn't long before I realised that the soul was missing. The 'me-ness' was missing, I was standing back from the process and observing, not really sharing my Self, I remained hidden. I was enthralled with other nurses and doctors who shared their experiences, yet my blog was missing something.

On reflection, I came to understand that to share deep feelings and emotion to the world takes great courage. Courage is overcoming fear; the fear of what others might think or say (Day, 2017). Letting others know your deep thoughts and emotions can be a difficult experience at the outset. It is little wonder that the philosopher Simone de Beauvoir (2006, Second Notebook, para. 2) wrote a strong introduction in her diary warning 'him' not to read her diary. She wasn't prepared to openly share her deepest emotions with others. As I shared more information on my blog, I slowly revealed more information about my Self, my life as a palliative care nurse and my insights towards the care of people in the last stages of life. I found it a cathartic experience.

My hesitancy in sharing was also linked to a deeper moral code relative to the nursing profession. All nurses are expected to sign confidentiality forms on commencing their career. Knowing this, I still decided to share my feelings and thoughts about my own experience. I realised that it is my lived experience and though I will always endeavour to protect others' privacy, I decided that I should be focusing on my own experience. I also have an individual right to share my lived experience while protecting the rights of others. Once I had let go of the responsibility to others and gained the courage to say what I thought, then the writing became easier and letting go of my limited Self became easier. I have shared here a random blog entry (Researcher reflections, 3).

I must remember that this thesis *On the Lived Experience Toward the End of Life* contains words, thoughts and expressions of those who may not be living now, and no matter what I think of my writing, the ideas expressed by the participants or storytellers in this thesis remain powerful and sacred last words. And as such must be honoured.

Researcher reflections 3: Researcher's random blog data entry
(Carter, 2017. dyingmatterswordpress.com)

I would like to also add here that my preconceptions regarding death and dying are not that it is a frightening or dreadful event but rather a peaceful natural ending. I found myself in this position after a near death experience, also known as an out-of-body experience, during which I found myself (spiritual body) being drawn out of my physical body towards a light with deep feelings of peacefulness. It happened through a hospital-induced drug overdose. I knew that the medication was over-powering me. I knew I was leaving my body or dying, but all the staff had left the room. I could not get any attention; my hand was left on the call bell. I felt my body shutting down and felt the essence of myself leaving my body, flying out, gradually, slowly at first as I became unconscious. I was not frightened but rather full of calm and thankful that I was no longer attached to the flesh lying on the table below me.

I had a choice to leave my body or to return. The metaphysical part of me spun at lightning speed through midnight blue space towards a bright white light. From this light, a kindly, authoritative male voice could be heard giving me a choice between two unborn forms, (with names supplied). I could either return to continue my earthly duty or I could choose to continue my way forward to the light. After extensive arguing and determination, I made my choice. For various reasons, including a total understanding that I had not finished this lifetime, I decided with great effort to re-enter my body, albeit a cold, creepy place to reside. How did I know that my life on earth was unfinished? That question remains with me until this day. Who was it who already knew my path and purpose during this lifetime?

When I was found by the inattentive nurses to be unconscious, a rescue attempt was made, but I had already made my return into the physical body. I was hysterical, telling people around me that I had died but it fell on deaf ears and was passed off as make-believe. Except for my husband, who was sitting beside me the whole time, feeling the life leaving my body, my hands becoming frozen cold (as he explained it). With this experience in my youth and my years of meditation, I have gained a certain peace with death. Next time I leave, I know my time will be finished.

3.6 METHOD: GATHERING EMPIRICAL DATA

As previously outlined, this thesis will be drawn from widely published EoL stories already available and in some cases widely-viewed by others. These stories are personal, important and are desperately heart-felt and told to inform us, those who are listening and wide awake, what they have to say about EoL matters. Van Manen (2015) outlines four necessary requirements to direct the phenomenologist towards gathering empirical data, outlined below (Table 4) and it is these requirements that will shape the data analysis.

Table 4: Adapted from van Manen's (2014) guide in Phenomenology of Practice

Max van Manen's (2014) Guide to Analysis	On the Lived Experience Towards the EoL
The analysis should be guided by a phenomenological question, on the lived experience.	The question asks: What is the lived experience towards the EoL?
The analysis should only be conducted on prereflective or experiential narratives.	All stories in this study are personal prospective prereflective stories that contain a direct description of the lived experience.
Thematic analysis is a creative process of discovery and disclosure, a discourse between the whole story, the paragraph and the sentence.	Anecdotes are written from individual stories towards the end of life, identifying main themes with insight cultivators. All forms of the arts will be included. Existential enquiry will guide the thematic analysis.
Phenomenological writing is the research. It involves writing and rewriting, including the aesthetic as imperative.	Writing and rewriting at different stages throughout the lived experience is an important inclusion in this thesis along with poetry, film and the arts.

This thesis on dying matters is markedly different from other academic health studies. It is situated in the stories of people who may or may not be living and furthermore, who have told their story in a variety of ways, through social media, whether it be Facebook, YouTube, newspapers or blogs. Conversations made widely available either via recorded interviews of personal stories, either audio or visual means, were accessed and anecdotes were written from the transcripts. As van Manen says, it does not matter if the experience happened or is imagined as having happened, what matters is in the writing. It is the focus on key words, the meaning behind these words and the skill of the writer to use poetic devices, such as the metaphor, onomatopoeia or alliteration. It is the ability of the words on screen, paper or through visual means to speak vocatively to transmit the emotions of the context and connect the reader with the lived experience (van Manen, 2014).

The next step in the research process was to determine the inclusion criteria for which participants who have shared their stories, should be included in the participant group. My intention was to give voice to those people who wanted to share their stories to a wider audience. Therefore, searching information within a world-view created an avalanche of potential material, an example being, when I typed ‘stories at the end of life’ into Google search engine it revealed literally millions of results (638 000,000). It seemed that I was right in my initial assumption that many people write about or share in some way with a wider audience, their EoL stories. Therefore, it was essential that I created a very clear inclusion and exclusion criteria for my participants for this thesis.

3.7 INCLUSION/EXCLUSION CRITERIA

Researching via the Internet using social media is not an easy task, there are many stories available. However, the process is made easier when adhering to strict inclusion and exclusion criteria. Therefore, once I discovered the plethora of information available on the Internet, I needed to ensure I was extremely clear on my inclusion and exclusion criteria. Otherwise I was drowning in a vicarious life, leaping from one sad, enlightening, touching story to another. Social media and the array of Internet communications and open diaries (blogs), give people a voice in a way that has not been seen before this century. Cyber relationships give people the power to connect around the world and an opportunity to join like-minded communities where they can share deep emotions. Solace can often be found within the cyber community (van Manen, 2014; Dutta-Bergman, 2006).

While undertaking a search of stories, I discovered that there were many longitudinal shares. People seemed to be sharing their experience at the transition or upon being given a terminal diagnosis through to (in some cases) the storyteller’s final words. Many people were sharing their emotional lived experience through blog sites. Most of the EoL stories were not limited to one single social media platform. Therefore, to limit the outpouring of information from all the corners of the social media world within this study, I carefully set the inclusion criteria within manageable limits of the phenomena under study, the lived experience towards the EoL (Table 5).

I also found that when using the search engine Google, it is important to search for words that I thought others might use to describe their information. I found that many people gathered in a safe place on the Internet, like a group of friends in a Café. I discovered that it is effective to open the full page to obtain all the information. In a nutshell, this is what I literally found myself doing. I was able to go from one lead to another and through this process I was directed to domain sites where most people sit and feel comfortable to share their experience on dying, like dyingmatters.com (Byrne, 2015).

Table 5: Inclusion and Exclusion Criteria

All participants have been given a terminal diagnosis therefore be presented with a definitive end of life transition
The participants express their lived experience either by word or the arts (theatre, video, poetry, paintings, music).
Stories included cover up to or over a year of recorded data for a longitudinal narrative study and explicitly state and share their stories through wider dissemination.
The stories are descriptive and contemporaneously written over many media sites.
The stories may also include interviews undertaken through the media on the lived experience towards the EoL.
The country of origin was not an exclusion, the age would be greater than 18 years as it would be difficult for children to write on their lived experience towards the EoL.

3.8 RECRUITMENT: VIRTUAL SNOWBALL EFFECT

The method of recruitment for this thesis was undertaken by the virtual snowballing technique. The word snowballing is often used to describe the way researchers overcome difficulties in obtaining representative samples for their research, and for studies where the usual method of research sampling does not apply. Snowballing is a term applied to a method of recruitment that goes from one person to the next, in this case it was from one virtual story to the next, via the World Wide Web (WWW) (Streeton, Cooke & Campbell, 2001). For this study, finding stories was not difficult. The difficulty lay in finding stories that were within the inclusion criteria. My original lead came from starting my own blog on this thesis journey, which led me to Kate's blog through the same web format. There were many snippets of information

on illness until I found my first contact, Kate, who told her story from diagnosis to death. Her story then led me to another story via her blog.

The snowball effect consists of selecting a sample of ‘seed’ contacts and these contacts then snowball into other contacts. This is precisely what started to happen as I found one enlightening story that fed into another story in my search. This is in line with the snowball effect as described by Beauchemin & Gonzalez-Ferrer, (2011). Eventually, like a snowball, the number of participants in the research grew (Figure, 8). The potential for bias in this type of recruitment (Streeton, Cooke & Campbell, 2001) is acknowledged here, however it does not apply in the context of gathering stories. Participants who do not use social media as a method of documenting their lived experience have the potential of being excluded from the study. However, using other methods of data collection such as eBooks, blogs and newspaper articles increases the potential for inclusion (Ross, 2012). Implicit in this study is that this is a social network of individuals with a common link, a terminal illness with a story to share.

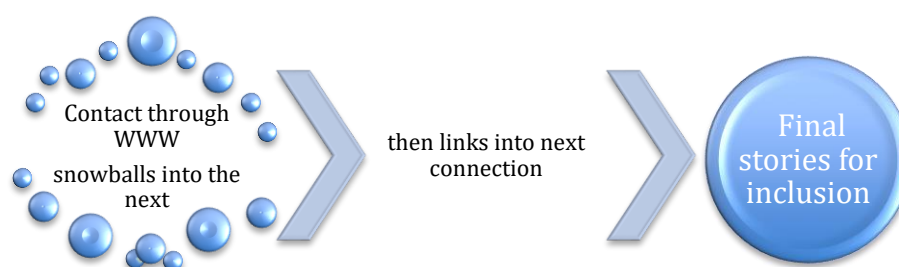


Figure 8: The snowball effect, take care not to create an avalanche

The problem with irrelevance of data can be solved according to Jones and Alony (2008), with a triangulation method of data analysis. This is an excellent method for checking synchronicity of original thoughts, as a blog is usually written in real time. Posts are recorded by the date that they are written. Then the flow of ideas is picked

up further in other literature by the same author, whether it is in the form of poetry, film or literature, validating the originality of the first diary blogs. This was the method that I used. I ensured that the storytellers in this thesis used a variety of Internet sources. Therefore, it was obvious that the stories told were real and authentic, as they were repeated in the same context word for word, and in many cases lifted from an original blogging thought and then further disseminated, usually through an eBook. Another critique is the matter of embellishment of personal issues. However, the bias will be no different to those of autobiographies. These issues are not insurmountable as the problem resolves due to the real time of the blog and therefore it must reflect honesty (Jones & Alony, 2008).

Whilst the snowballing technique is a recent addition within health science research literature, it has been successfully used to identify hard-to-reach groups (Ehlers et al., 2001; Faugier & Sargeant, 1997; Gibson, 1996; Kitson & Currie, 1996; Sullivan et al., 2001). However, snowballing in this research is different from others in the health sciences. The stories snowball into each other from the use of domain, websites or blogs that link participants and in some cases, do not have a direct link to each other but to the researcher. The snowball effect, when used for gathering data via the Internet, has been found to be a sound method of data collection (Streeton, Cooke & Campbell, 2001). In the health sciences, this is difficult to determine at this point, due to the lack of qualitative research undertaken.

I also ensured during this research, that the site from which I was gathering data was publicly available. Therefore, ensuring that consent was not required. If the blog had been discontinued from the Internet but remained online and cached (Web stored), then it should be considered not publicly available (Eastham, 2011). Therefore, I ensured that all the blogs that I were reading were still active to ensure that consent is given implicitly. Bloggers who write information on a web page and make their page public are aware that it is immediately available to a wide audience. If a password was required, then I did not use the site as it might not be publicly shared. I also checked the authors' websites for privacy considerations (Figure, 9). Prior to gathering the data, I made sure that the author of the blog stated that they wished to share their story with a wider audience. This final step ensured that I was given tacit approval for studying their publicly-available material, thereby managing consent.

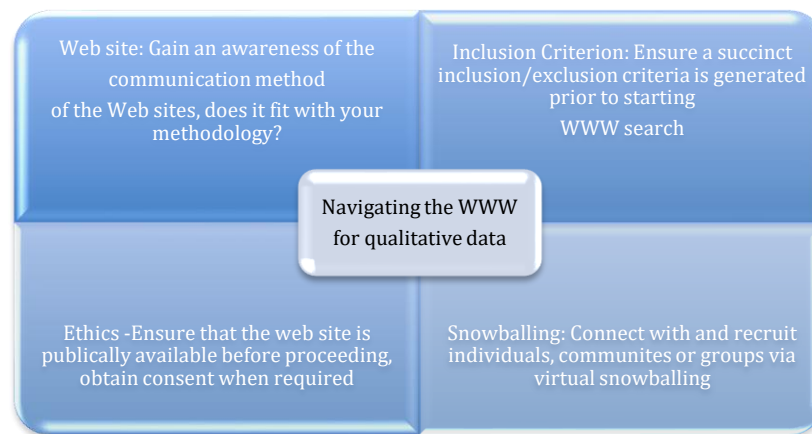


Figure 9: The four criteria required when gathering data using the WWW

3.9 DATA ANALYSIS

Conversations made widely available, via recorded interviews of personal stories, either audio or visual, were accessed, and anecdotes were written from the transcripts. As van Manen says, it does not matter if the experience happened or is imagined having happened, what matters is in the writing. It is the focus on key words, the meaning behind these words and the skill of the writer to use poetic devices, such as the metaphor, onomatopoeia or alliteration. It is the ability of the words on screen, paper or through visual means to speak vocatively to transmit the emotions of the context that connects the reader with the lived experience (van Manen, 2014). All eight participants are speaking on their own experience and have received a terminal medical diagnosis. Furthermore, as previously stated, due to the difficulty of verbally expressing the metaphysical aspect of spirituality, participants have also used poetry and song to describe feelings and emotions connected to their stories.

The virtual snowballing technique enables virtual connections that lead from the first web site into the next on the Internet, Face Book, films, and radio or in print (Beauchemin & Gonzalez-Ferrer, 2011). All the narratives were prospective and longitudinal as this elicited the richest available data. I am mindful that some of these stories are from people who have since died, and others who died before the end of this thesis nevertheless, they have recorded their stories with an explicit intention to share their experience with a wider audience and so that others might learn from their

experience. I intend to honour their wishes through further dissemination of their lived experience towards the EoL. The eight stories were collated into separate existential themes related to how the person interpreted their individual experiences on living with a terminal diagnosis and their conscious awareness of mortality.

Due to the extent of the data and the information available, the data was divided into two chapters. The first section, on data analysis, focused on the experience of the moment that shifted the participants' awareness to that of imminent mortality. It is this moment that phenomenology is concerned with, the epoché of the moment, the moment that a person becomes consciously aware of their surroundings, their body and the moment in time and space (van Manen, 2014). Each storyteller writes on their initial reaction to hearing the news of their terminal diagnosis. Their stories were transcribed, and rewritten into the five existential themes of corporality, temporality, spatiality, materiality and relationality. These themes are used in phenomenology, as they are the universal themes of life, demonstrating how each one of us connects to the people and things around us (van Manen, 2014, p. 7484). Each story commences on a separate page to honour the individuality of the person and to allow space for reflection. An image was used to further reflect the emotions held within the stories.

There are three actions when writing phenomenological texts. These are the wholistic reading approach, where the whole text is read as the researcher searches for meaning or the significance of the text. The second analysis is known as the selective reading approach where the text is read or listened to several times and the researcher looks for phrases that reveal the essence of the experience. The last or third approach to data analysis focuses on the detail, such as reading single sentences, and clusters of words to capture of the meaning that can be revealed (van Manen, 2014). Staying true to the hermeneutical process of analysing the paragraph, the sentence and the words of the storytellers as suggested by van Manen (2014), I rewrote the most significant sentences, until finally, these words were collated and summarised using a word cloud on each of the existential themes. Anecdotes were written as recorded by the storytellers so as not to distract from the intention of the whole story. Salient points were then highlighted by the researcher and validated by the research supervisor.

In the last stage of data analysis, I used a word cloud to pictorially represent the single words that were written by each storyteller. This action highlighted emotionally-laden words that were shared and repeated by all the eight participants. Each repeated

word is enlarged within the word cloud. While gazing at the word cloud, words become strong, independent and important, it is as if the single words carry the weight of the lived experience, without a need for interpretation. Although each story is unique, with many different diagnoses and varied emotionally-laden insights, there were many commonalities that were mutually shared amongst the storytellers, on their lived experience towards the EoL. It is these shared emotions, words, and experiences that provided a rich tapestry for further reflection and insights.

The two chapters on the lived experience towards the EoL are then collated and with the use of insight cultivators, known as literature, poetry and the arts (van Manen, 2014), the stories within the existential themes are explored further. Insight cultivators are sources of literature that support or aid in the reflective interpretive process. They increase the interpretation of the phenomena under inquiry. The words that were used frequently within each word cloud are also addressed. Gaining an insight from other forms of literature will explore a deeper awareness into the essence that describes the lived experience towards the EoL (Van Manen, 2014). The main themes that emerged from the data will be interpreted and discussed in the final chapter of this thesis.

3.10 ETHICAL CLEARANCE

Whilst I have been given assurance from Central Queensland University (CQU) ethics department that ethical clearance is not required, I was advised a Low Risk Ethical Clearance should be obtained in case further enquiries follow on from this research. Therefore, a low ethical clearance has been attained, Number H16/02-019. The conversations that I use in this research are widely publicly available. All websites, images and social media sites are referenced and identified, as are all images, poetry and music. All personal stories other than those that are publicly available are de-identified, and data will be kept on a password protected CQU server. The data will be deleted from the server after 5 years in line with CQU Code of Research and following the last dissemination of the results. CQU ethics board is in line with National Health and Medical Research Council.

3.11 HERMENEUTICAL RIGOUR

The Rigour of hermeneutic phenomenology does not rely on the number of participants or the codification processes as do the usual methods of validity assigned to other research methods. Having stated that, the validity of this research does rely heavily on the researcher to produce a scholarly thesis that contains interpretations that are sound and true to the experience of the individuals' voices. Van Manen (2014, Value of Validity, para. 8) clearly iterates this statement when he says: 'The validity of phenomenological study has to be sought in the appraisal of the originality of insights and the soundness of interpretative processes demonstrated in the study.' Van Manen has identified four essential qualities when it comes to the rigour of this research process. These are: the orientation of the researcher's involvement in the participants' environment; the strength of the text to interpret the story; richness, referred to as the aesthetic quality of the text; and finally, the depth of the research to represent the participant (Kafle, 2011 p.196).

To assist rigour, I have also reflected on my own experience and interpreted how my experience interrelates to the whole. I have also maintained a blog, to further explore my own emotive thoughts, thereby, identifying my own critical insights so as not to blur them with the participants'. My personal assumptions are also included within this document. Hertz (in Lavery, 2003, p.22) writes that hermeneutic research demands self-reflexivity, defined as being in the moment, but reflecting within the moment. The rigour of this thesis was further tested and validated by my supervisors when they interpreted the stories herein and validated the connections to the existential themes.

3.12 INTRODUCING THE STORYTELLERS

After traversing the world of blogs, web links, Google search engines and kindle (electronic) books, I was keen to get started and gather up a group of participants. I eventually reduced the number of participants to eight. Including more than this number would have greatly reduced the richness of the data (van Manen, 2014). I felt drawn towards their life stories and a real cyberspace connection developed as I reviewed their heartfelt EoL lived experience. I felt that I was getting to know these people through their shared stories. Most of the people snowballed into the next and that is how the connection between us started.

3.12.1 Kate Granger

Kate shared her experience from diagnosis through to her chemotherapy experience. She tells us what patients want and she was very active in the social media sphere. She shares her experience through eBooks on twitter and Facebook. I came to know Kate through using the same blog address at WordPress.com. Her story tells of the struggles that she faces at twenty-seven years of age as a doctor and wife. Because she is so closely associated with the medical profession, she can give many insights into the EoL experience.

3.12.2 Abby Brown

I came across Abbey's eBook through a blog that she had shared on Kate's blog, which in turn, led me to her story. Abby is a passionate, articulate woman fighting breast cancer. She gives an emotional description of her lived experience as she transverses through the unknown path that cancer and the treatments take her. She often thanked Zach Sobiech in her book for his courage in sharing his illness story.

3.12.3 Anatole Broyard

I came upon Anatole's story whilst searching for another book, his story stopping me in place, and I took notice. Anatole, on hearing his diagnosis became concerned that he might not be able to finish his book. He states, '*[t]hough I wouldn't say this out loud, I had promised it (book) to the world*' (Broyard, 1992, p 150). Anatole fought a long battle against prostate cancer and chose to write his story. He discusses his journey from the beginning to the end, giving the reader an insightful, enlightening experience of the EoL.

3.12.4 Clive James

I was reading a web-site dedicated to dying well, when I came across a poem written by Clive. The poem was heart felt and the message was divine, it carried a farewell message and I could not ignore his poetry as an inclusion within this thesis. Clive is a well-known Australian journalist in his 70th year, expressing his emotions exquisitely. Having received the news of his terminal illness has increased his awareness towards EoL matters.

3.12.5 Zach Sobiech

I came across Zach's story through a connection with Abby Brown in her book. Abby found a great deal of inspiration and courage in hearing Zach's story. Zach writes on Soul Pancake, a website started for people to share their stories. Zach was a young man who was diagnosed at the age of 14 years in 2009, with bone cancer. He recorded his emotions and experience through songs and in 2013 his song 'Clouds' became a number one hit.

3.12.6 Cory Taylor

I was serendipitously listening to an intriguing interview over the radio on EoL issues when I heard the voice of Cory Taylor. She is an Australian author who has spent some time living in Japan. She was sharing her story, on her struggles with coming to terms with living with a terminal illness. In this moment in time I felt an instant connection with her story. I immediately felt the essence of her struggle with coming to accept her diagnosis of melanoma. I researched the Internet and to my surprise, I discovered that she had documented her complete EoL story in an eBook, published in 2016.

3.12.7 Christine Bryden

I discovered Christine's story while scrolling through Kindle electronic books looking for another author. Christine was diagnosed in 1998 at the age of forty-six years with early onset dementia. She is the author of four eBooks on the subject, a blog and a website. This is an extremely unusual story as the short-term memory loss associated with dementia makes writing a personal story very difficult. Her insights and struggles should be read by all health professionals to increase their awareness on the difficulties of coping with a hidden terminal diagnosis.

3.12.8 Paul Kalanithi

I was drawn to Paul's book by both the title and the intriguing image on the front cover. I did not realise until I started to read the book that Paul's story was a heartfelt sharing of living with a terminal illness. As I flicked through the pages of his book, the words spoke to me as a painting might draw you into an experience. His words stopped me in place. Paul is a surgeon and no other profession is as close to the dying person as the medical profession. When they are faced with their mortality, they reflect on the number of people that they have witnessed dying and there is a lot to learn from

their stories. Paul was diagnosed with metastatic lung cancer at the age of thirty-six. Figure (10) below depicts the interrelationships made whilst snowballing virtually through the Internet. The Table (6) below is a summary of the participants, their age, diagnosis, occupation, illness and the many way in which they connect via social media.

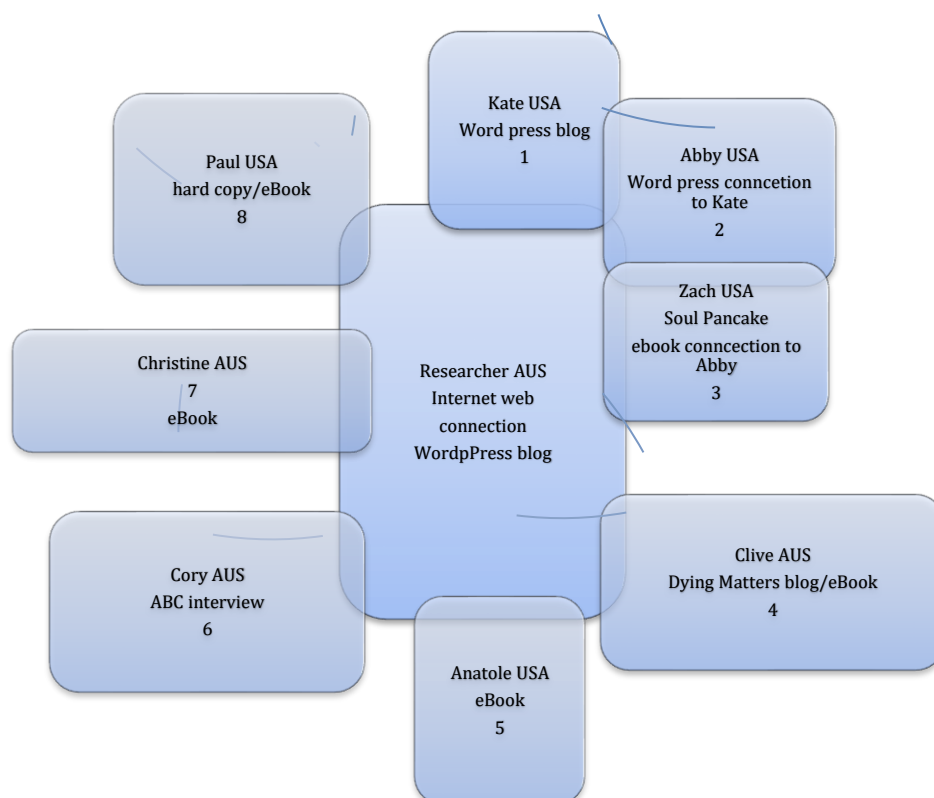


Figure 10: The snowballing virtual relationship between myself and the eight storytellers, and their country of origin.

Table 6: Snapshot of the storytellers and cyberspace connections

Name	Age at Diagnosis	Diagnosis	Occupation	Web-Contact
Kate	27	Sarcoma	Physician	Blog, eBook, Facebook, interviews, You Tube, twitter
Abby	54	Breast Cancer	Teacher	Blog, eBook, YouTube
Anatole	69	Prostate Cancer	Writer, essayist	eBook, biography-News paper
Clive	70	Lymphoma	Entertainer, Essayist	eBooks on poetry, interviews – newspaper, radio, you tube, television
Zach	14	Osteosarcoma	Student	Blog, interview, You Tube, eBook
Cory	49	Malignant Melanoma	Writer	Interview radio, eBook
Paul	36	Metastatic Lung Cancer	Physician	eBook, interviews-newspaper -hard copy book
Christine	46	Dementia	Government employee	eBook, interviews-newspaper, radio

3.12 THE IMPORTANCE OF SELF CARE IN SENSITIVE RESEARCH

I am aware of the concerns regarding researching personal stories that are written towards the EoL, especially the grief that must come with watching and listening to EoL stories. Yet, I am at the same time encouraged, enthused and totally in awe of those people who share their stories, like Dr Kate Granger and Clive James. They are an inspiration to the modern world on how to enjoy living your last days to the fullest. The stories are packed full of the dichotomy of emotions, of happiness and sadness, pain, and joy fill the pages, as they tell their stories about their experience towards the EoL. Death will come to all of us and to delve into these EoL stories is very rewarding. I usually only get to care for the person just before their death, with very little prior history into the nature of their emotions and insights into their experience. Therefore, this study brings me to a sense of purpose. I have debriefed with my supervisors and family members along the way. Notwithstanding, my own faith and belief in meditation and spirituality has always kept me whole.

Undertaking this research was an extremely rewarding process that brought love, hope and joy to the EoL story. Dying is part of living and watching and listening to people's stories, I see the whole of the person not just their death, which is my usual experience as a practicing clinician. Having said all of that, my survival plan was to debrief often with my colleagues and supervisors, one of whom is an expert on the grieving process. Below (Researcher reflections, 4) is a poem that I wrote following a difficult experience while caring for a patient in a palliative care section of a small rural hospital.

The elderly man in hospital

He's breathing fast, fast, fast
I don't understand, he comes with no notes,
Dropped off to us, in his final hours.
His eyes half closed, I place oxygen around his nose,
He is purple in colour, mouth gapping wide, air hungry.
I feed him green, bright green jelly, it rolls down his cheeks,
Oh, does anybody care:
I stand confused he has no notes.
I ask for a medical review, no one comes
He is an old, old man wiry and frail,
Mouth wide open grasping for air,
Concerned, I give morphine and call his sister
And say the end is near.
I flick through his notes and there, at the back
In a shaky hand, it says,
No hospital please for me
I just want a priest
He died the next day

Researcher reflections 4: The Nurse and the Patient

It is miserable enough to think that nurses who are people, women and men dealing with death daily in a hospital setting, have limited opportunity to debrief or discuss their experiences relating to the care of the dying.

3.13 SUMMARY

Chapter three of this thesis has introduced the methodology that forms the framework for this research. The importance that is placed on hermeneutic phenomenology and the anecdote to delicately and vocatively impart the lived experience through the voice of the storyteller is essential to the thesis. Existential guided enquiry has been outlined as the method of theme analysis. The method of data collection via the snowballing technique to gather participant's stories, which inform this research, has been introduced. This chapter has also introduced social media and the arts as a method of data collection and has explored the enormous potential that exists for using this method in the health sciences. My personal preconceptions concerning my blogging skills have been discussed and I have shared my insights on the concept of death and dying. I have also shared my NDE, which removed my own fears associated with my EoL. This chapter has described the ethics and rigour concerned with this research project.

Most importantly, this chapter introduced the storytellers and gives the reader a brief introduction into the lives of each person. At the time of recording their experiences, the participants are all living with a terminal diagnosis, which enabled a rich description of the lived experience towards the EoL. Lastly, this chapter informs the reader on the importance of self-care when working with emotive stories. The link between each of the storytellers and the researcher was also mapped. The next chapter will focus on the beginning of the EoL story, when the people in this thesis receive the news that they have a terminal illness. Everyone shares their lived experience description (LED) on hearing that they have only a few months or years to live.

Chapter 4 Part 1 Data Analysis: Diagnosis



Researcher reflections 5: Towards our goals into the unknown

Photo credit: J. Carter

The most beautiful and most profound emotion we can
experience is the sensation of the mystical.

It is the dower of all true science. He to who this emotion is a stranger,
who can no longer wonder and stand rapt in awe, is as good as dead.

To know what is impenetrable to us really exists,
manifesting itself as the highest wisdom
and the most radiant beauty which our dull faculties
can comprehend only in their most primitive forms-this knowledge,
this feeling is at the centre of true religiousness.

(Albert Einstein, 1879 – 1955, [forbes.com](https://www.forbes.com))

4.1 INTRODUCTION

Chapter Four is the first of two that describe the lived experience towards the EoL. This chapter is focused on the participants experience describing how they felt when they first learnt of their terminal diagnosis. This new experience is the epoché, or the originality of the moment in phenomenology, the jaw-dropping experience that jolts an individual into the present moment (van Manen,2014). The eight individuals presented in this thesis, share their personal experience of the beginning of a conscious awareness of their mortality. Using van Manen's (2014) existential themes as a direction to examine each story I begin with the raw data of a personal experience as described and voiced by the participants. I take care not to change the originality of the story or the meaning conveyed by the participant. This ensures that the voice of the participant is authentic and felt by the reader and their experience is then able to show itself (van Manen,2014). I reiterate salient points (in italics) from the anecdote as a method of highlighting insights that will be examined and interpreted in subsequent chapters. I commence the next section with Kate Granger's story.

4.2 KATE GRANGER: DIAGNOSIS

Kate Granger's personal story is very significant to this thesis. It is the first story that I found which connected me emotionally and honestly to the world of the terminally ill. My conscious awareness was woken, as suggested by van Manen (2014) I was able to 'feel' her experience and her courage as she shared intimate details of her lived experience, which was at times dark and difficult. I was inspired by her ability as a physician not to be inhibited rather to be empowered by her honesty and medical knowledge. From her story I was directed to others, who in turn, led me to more people, until the snowball approach no longer gave me new insights. All the stories and anecdotes shared within this thesis are precious and informative, but Kate's story was the first.

Being a nurse, I always felt gagged by confidentiality, sort of a law-abiding awareness that certain subjects are taboo. Nurses must sign a confidentiality form before they commence their employment, ensuring privacy. Kate, who is facing her death, shares her experience as a medical practitioner through her blog site. I was inspired by Kate's frankness and her courage to share her heart-breaking story. She voices her uneasiness with the medical profession, daring to say what others only

think. This story gave me the confidence to stop asking new questions on death and dying, rather instead, to focus on what was already crying out to be heard.

I had serendipitously discovered Kate's book 'The Other Side' while searching my way to her blog. I was certainly surprised to find that she had documented her illness and progress very clearly in her writings from the very beginning on hearing her terminal diagnosis to the present time. She dedicates her book to health professionals to ensure that they understand what it is to experience the other side of the doctor-patient relationship. Kate shares her initial response to her experience of receiving a definitive diagnosis and the following treatments. In Kate's case and all the people in this thesis, they have themselves chosen to write and record their lived experience and they have made their writing publicly available.

Kate's EoL story begins in 2011. She shares her EoL experience on YouTube, Twitter, Facebook and WordPress. During her discussions on YouTube, she states how, in the beginning of her illness, she was hesitant to share her experience. It wasn't until she was encouraged by her colleagues to keep a journal, that she found solace and a powerful voice through which to narrate her story. She takes the reader through her painful journey from the first diagnosis of sarcoma at the age of twenty-nine and the invasive treatments that she has endured. Her first diagnosis occurred when she travelled from London to the United States of America to visit family members. Several times throughout the pages she says: *"I am dealing with being suddenly seriously unwell in a foreign country and it seems as if it is happening to someone else"* (Granger, 2014, p113).

4.2.1 On Corporeality

Due to her expertise as a medical practitioner, Kate is aware that she is gravely ill, although it took several days and many diagnostic interventions, she quietly knew that the outcome was not going to be good. Her fears were realised when she was diagnosed with advanced metastatic cancer. Her medical knowledge sharpened her awareness of her own forthcoming mortality and her acceptance of her situation was immediate. On her mortality, she writes:

Now I knew I had metastatic cancer the decision was easy, and I definitely wanted a DNAR [Do Not Attempt Resuscitation] form. I have seen far too many people die horrible, undignified deaths in hospital where prolonged resuscitation attempts can be so messy and unpleasant just because a difficult conversation had not happened. I really do not want this to happen to me if I'm going to die anyway.

(Granger, 2014, p 617)

As a physician Kate has been a witness to many hospital deaths. Kate says that she has seen many people die “*horrible, undignified deaths.*” She does not want to experience this kind of death and she is annoyed that these deaths occur because no one has had the courage to start a conversation about dying. Kate describes her experience on her visit to hospital:

Spontaneously I start crying. My whole body is shaking. I've waited what seems such a long time for this appointment and now I'm actually here everything is just that little bit more real. I also cannot take my eye off the trolley with all the torture implements on it. The doctor enters. I thank God she's a woman. (Granger 2014, p. 318)

Kate writes: “*...I start crying. My whole body is shaking.*” Her body has imbibed the stress and she is feeling frightened about the gravity of her situation and she writes that the situation has become real for her. It is as if she must be on the ‘*outside*’ reshaping her Self view. She shows here that she is very pleased that her treating doctor is a woman. While she is not begging God to change her situation, she is thankful to God. The usual tools of her trade are causing her even greater distress and the treatments she undergoes have become the “*executioner*” as she writes; “*I cannot take my eye off the trolley with all the torture implements on it.*” Kate describes how her body image has been damaged when she says:

My gown is raised fully exposing my abdomen and an initial ultrasound examination is performed. I feel very conscious of my body today, it is noticeable that my tummy had changed shape over the preceding few weeks and I cannot help but think I look pregnant whenever I see it. I wish that I was and that all was just a mistake. Reality check Kate.

(Granger, 2014, p, 661)

In the very stages of her diagnosis Kate must give herself a “reality check” her body has become the focus of her attention and her body now reveals her illness. Kate shares, “*I feel very conscious of my body today,*” she wishes that her swollen abdomen was due to a pregnancy. The future that she had imagined for herself is now out of reach as she has lost control of her body. Her sick body has now become her focus and not her anticipated future of normality.

4.2.2 On Relationality

Kate personifies the cancer that has invaded her body and she describes her feelings about her future and what she envisions for herself and her family on receiving the news of a terminal diagnosis, in her blog she writes:

A terrible sinking feeling, a change, a death of the old, and new beginning will it be full of dread? Why have you come along to ruin our lives? Abolish dreams of having my own family?

(drkategranger.wordpress.com, Cancer part 4, 2014)

The “... *terrible sinking feeling*” describes her situation and she now looks towards to a change but it not sure how that new Kate will manifest, the death of the old includes all aspects of her current view of herself. Kate is frustrated on many occasions with her colleagues’ communication and here she describes how she felt

following her procedure. She overhears the nurses impersonally giving a report on her through a closed door and with music playing in her headphones. She dislikes being referred to “*as bed 27 and the Sister questions the need for me to be an in-patient as I appear so well. She clearly does not understand my case very well*” (Granger, 2014, p. 422). Kate is now the patient and she experiences the reality of the ‘other.’ She describes her experience regarding her privacy in the following paragraph:

The nurse brings the consent form for me to sign as I am about to leave for theatre, she asks me if I would like her to pray with me, I am slightly taken aback by the offer and politely decline although I do have faith it is private, and I certainly wouldn’t share my beliefs with a complete stranger. (Granger, 2014, p. 136)

While Kate does not overtly refer to a specific faith or religion in her life, she does say that she has faith saying, “*I do have faith it is private*” and she is rather affronted at the thought of sharing her beliefs with a “*complete stranger.*” Prior to discharge from the hospital, Kate describes a meeting between herself and a Palliative Medicine Registrar. She writes that his expertise is called upon because of her relentless pain. She finds his visits comfort her and writes further on his visits:

We explore my expectations around death when the time comes. He is very easy to talk to and I do not become distressed during these difficult conversations. It is a touch awkward one day when he pops by whilst my parents are visiting. I have not told them I was seeing a Palliative Care doctor, but he is very professional and explains he is helping with my symptom control instead of announcing his full title. (Granger, 2014, p. 1497)

Kate finds her meeting with a Palliative Care doctor encouraging she is not afraid to commence a conversation around her death and when approaching the subject of her death she writes; “*We explore my expectations around death*” and she writes that she is happy to meet someone who can chat about her impending mortality. As she documents in her writings, she is happy to discuss the issues that she may encounter as her disease progresses. She also describes the doctor’s compassionate response when her parents visit, explaining that this doctor is extremely helpful in helping her to understand her illness. Kate writes that she can accept her fate, but she is not yet ready to tell her family the whole truth of her situation. Following an invasive procedure that will enable her to pass urine Kate describes her frustration when discussing the treatment with her surgeon. She writes:

He is a little smug about the whole situation and it feels as though he is giving himself a virtual pat on the back for being such a great surgeon.

I know however that this is only a temporary solution to my problems.

(Granger, 2014, p.157)

Kate is obviously disappointed with her attending doctor’s attitude to her procedure, stating that he is giving himself; “... *a virtual pat on the back.*” Kate can sense the doctor is focused on the procedure, but he also appears to be oblivious to her needs as a person who experiencing EoL. After the procedure, she asks a nurse if she can speak to her original doctor, stating that:

I just want a doctor who I can have a sensible realistic conversation with, so I am glad when the original doctor appears, and I apologise for causing him any inconvenience. (Granger, 2014, p. 187)

As she clearly states, Kate wants to face her reality and confront what might be ahead for her. She says: “...*sensible realistic conversation with.*” She writes, that although she would like to share her experience with the medical profession, she also wants her life to return to normal and that she wants to remain private, she writes:

It is OK to cry and that I should be crying given the circumstance. I say this is for me to do privately and I'm not about to break down in front of a complete stranger. I think he [doctor] accepts this. (Granger, 2016, p.258)

Kate writes several times that she is a private person and that her privacy is important to her. Just because she is experiencing severe emotional and physical trauma related to her health does not negate her wishes for privacy. Following more examinations, this time done by a gentler technician, Kate writes that she is in tears, alone and frightened and then she says that no one has yet discussed her definitive diagnosis, although she knows that her kidney failure is a result of cancer, therefore she has a feeling that it must be bad news. Then she writes that the worst ever communication between herself and a doctor occurred. Kate shares that these are extremely powerful words and memories when she says:” *She (oncologist) then says something that I still cannot fully comprehend to this day. She asks me why I am upset to which I respond, because I'm 29 years old and I've got cancer*” (Granger, 2014, p.477).

Kate cannot believe what she has just heard from her physician and her insensitive nature, writing: “Her astonishing reply to my frank yet accurate answer is “*do not be silly, this won't turn out to be cancer, you are too young, it will be something benign*” (Granger, 2014, p. 478). She now knows how it feels to go through examinations and not to be given the correct information. She makes a note to herself that she will remember never to treat people in her care this way. She reiterates this point again when another doctor decided to sit on the bed beside her during her initial diagnosis, she found comfort in this friendly gesture. Kate is suffering from intense pain caused by her acute kidney failure. Being a physician, Kate is familiar with the

drugs that are used to treat severe pain. This is just one example of many throughout her book where she describes her painful experiences, writing:

She [nurse] appears grudgingly ten minutes later, I explain my symptoms and ask to see a doctor as soon as possible. She mutters something about not wanting to give me the appropriately prescribed Oramorph as she does not want to mask my symptoms until I have seen a doctor. I then lie in agony for what feels like a very long two hours before she finally reluctantly relents and gives me the Oramorph. I am made to feel like an opiate seeker, which given the circumstances I don't think very fair. (Granger, 2014, p.562)

Kate is clearly disturbed about the nurse's decision to withhold her pain relief, when she says, that she is made to feel like a drug addict “...*I don't think very fair.*” At this point in time, reducing the pain that she is experiencing has become a top priority.

4.2.3 On Temporality

In the following example, Kate shares her personal experience on hearing the extent of her diagnosis as she comes to terms with the gravity of her illness. This is before she embarks on a course of chemotherapy and without the knowledge of the severity of the symptoms of the illness that is to follow:

The hospital remains quiet and I have some time to myself to think. I cannot really comprehend everything I have been through in the past few weeks. It doesn't feel as if it has happened to me although I have the scars, tubes and pain to prove it. I feel as though I am looking in

on my life from the outside. [...] Occasionally I wake up when I have managed to sleep and for a split second, I will have forgotten all about the illness then I will remember the nightmare and am overwhelmed by a terrible sinking internal feeling. (Granger, 2014, p.1268)

In this anecdote, Kate is pleased to have some time to herself to contemplate and to make space for her thoughts. *“I have some time to myself to think”*. Through all that has happened, she needs to refocus with a renewed sense of purpose and come to terms to accept all that has happened to her so unexpectedly, interrupting her sense of self. Here she is coming to terms with a new reality. She describes a sense of disorientation, her dreams have become her refuge and her reality, is a *“nightmare.”*

For Kate, her experience has frozen in time, as if this new version of her Self is going on around her, while her life is in an upheaval. She has departed from this time and space that is linked into a reality of the now. She writes; *“I feel as though I am looking in on my life from the outside.* In the initial stages of her diagnosis and whilst undergoing many tests and scans, Kate experiences a lot of pain. After being given a dose of pain medication Kate writes: *“I cannot believe how much I have changed in my physical abilities in such a short space of time”* (Granger, 2014, p.751). Time and evidence of change draws Kate into the reality of her situation and that her life is ending.

4.2.4 On Spatiality

In the first weeks of her diagnosis, Kate writes contemporaneously on her experience of receiving a terminal diagnosis. She personifies the cancer, as her present world comes shattering down around her. Through the personification of the cancer, she can direct her frustrations towards it, as a separate invading entity. She sees her abdomen now swollen, which reminds her of her lost (imagined) future. While away visiting her family, Kate describes the idyllic space that surrounds her. The birds, the garden, the flowers and the bees but she says that the peaceful setting is disturbed by her crying, writing:

I have been sobbing my heart out now for over an hour and I know they're worried about me inside, but I just can't stop. I never knew I had so many tears. My whole world has just collapsed around me and up until this point I had been doing my very best to maintain a strong public face... I now look back on that hour as such precious "coming to terms with it," time. Emotional space would be in short supply on our return to England. (Granger, 2014, p.35)

Kate's world has "collapsed," her life as she knew it has radically changed, she describes her sadness and her understanding of "coming to terms" with her terminal illness and the strength that she has had to maintain in the face of her diagnosis. During her first stay in hospital, Kate frequently wrote about her experience of the hospital space. She describes her hospital experience as taking place in a mad-house, so much that she dedicated a chapter in her book to the 'Mad-House'. Shortly before her diagnosis, it was her place of work and now a different reality surrounds her. Whilst undergoing treatment in the hospital she describes her feelings:

My fierce independent spirit is not about to desert me just because I've got cancer and acute kidney injury. I have never really thought about what patients are feeling when they are being pushed around the hospital for various tests and procedures before I got ill. I find it an uncomfortable experience, especially today, watching the ceiling lists flash by, turning my head away from people I recognise and wondering how much it is going to hurt... (Granger, 2014, p. 645/2923)

The space around Kate has been transformed into a “*torture chamber*”. Previous meanings of this space have been replaced with new reality. This space that was once friendly, now she knows what her patients experience, and she writes how uncomfortable the whole experience is. She has renamed the treatment room, “*the torture chamber*.” From this point on in her book, Kate refers to the treatment room as the torture chamber.

4.2.5 On Materiality

It is the material ‘things’ around Kate that she dreads: her nephrostomy tubes, which were inserted in her first hospital stay, have now become an essential part of her body, and a reminder of her illness. She writes:

*I manage to get myself onto the trolley. A tiny victory for independence,
I’m starting to adjust to my new life with bilateral nephrostomies. As
I’m pushed down to the basement of the hospital a cheery theatre nurse
chats to me all the way. I’m not listening.* (Granger, 2014, p.1106)

Kate is pleased at finally getting back some of her independence when she writes: that she has experienced a “*victory*” at getting her life back although in a limited form. In this example of her experience, she is consumed with self-preservation. As the cheerful nurse chats away, it is obvious that she is not in tune with Kate. As Kate clearly says: “*I’m not listening.*” Her thoughts regarding chemotherapy now in her life are also evident when she says:

*I am a conservative Physician and believe passionately that quality of
life is much more important than quantity of life in the palliative care
setting and why would I not apply these principles to my own care. I do
not want to be hooked up to chemotherapy hoping for some non-existent
miracle when I am on my deathbed. I do however feel obliged to give
proper chemotherapy a try, more for Chris and the family than for*

myself and do not really feel I have a choice at this stage. (Granger, 2014, p 1405)

Once again, Kate uses her knowledge of the medical profession to make informative decisions. She says: *“I ...believe passionately that the quality of life is much more important than the quantity of life.”* She is fully aware of the futility in some cases of chemotherapy and writes that she does not want to have chemotherapy when it is not a cure for her illness as she says *“hoping for some non-existent miracle”* however she decides to go ahead for the sake of others, her family. There are many times during her initial experiences that Kate says she has had limited choices in her care, sharing one of her experiences when she is undergoing a scan and she must listen to music, which is chosen by the technician without regard for her preferences:

I accept the offered music but am not impressed as Amy Winehouse is piped through my headphones. The MRI tech must have been leading his own strange tribute to her as she had only recently died. I just don't like her music. (Granger, 2014, p. 381)

On this experience of being given no choice of music to listen to, she writes how disappointed she felt when she was not given a choice: *“I just don't like her music.”* Considering that Kate is now facing her impending death this is a poor choice of music on the part of the technician and shows a lack of thoughtfulness towards Kate. In another experience during a procedure that she must endure, Kate writes that she decided to go to think happy thoughts to distract her away from her current position:

This is a deserted beach in Shetland where Chris and I are holding hands and skimming stones into the perfectly blue sea. The air is fresh, and I can almost feel it blowing against my face. ...Perhaps there is

*something in all this psychological visualisation as a coping strategy
after all. (Granger, 2014, p. 973)*

This '*happy place*' is such a rewarding experience for Kate, bringing her family and a different place into her immediate awareness, has a positive effect on her ability to cope with stressors, when she writes that she can "*feel it blowing against my face.*" Although she still feels the pain, the visualization technique has helped her to focus on her family and to distract her attention away from her current treatment and surroundings.

4.3 ABBY BROWN: DIAGNOSIS

I first heard Abby's story when she replied to a comment on Kate Granger's blog. I was surprised that this was another story on living with a terminal illness. However, it was clear that Abby was connecting with Kate due to their mutual illness and cancer diagnosis. Abby Brown has documented her story of breast cancer since the beginning of her diagnosis in 2013. She began writing her story on her blog through the Caring Bridge website. The website dedicated to the Catholic community, to share their lived experiences. She was encouraged by her readers to collate her blog entries into an eBook and she wrote in the forward of her book that she wanted to share and educate others on her experience of receiving a terminal diagnosis.

As with Kate, Abby's book follows her real-time blog entries with great accuracy, therefore increasing the reflexivity of her LED. As van Manen (2014) reiterates, the importance of phenomenology interpretation is the pre-reflective nature of the experience. Van Manen (2014, p. 2375) refers to Husserl's example of musical notes being an example of an "instant of the now." To recall the event with the emotions of the event, brings the lived experience into the present moment, just as listening to a song that is linked to an event can once again bring it to life. Abby is fifty-four years of age and married with two children. Her blog opens with thanking viewers for joining her on her journey. She has just had a mammogram and her doctor, via text message, has requested that she have further checks. It was after these examinations that a clinical diagnosis of breast cancer was confirmed.

When Abbey was first diagnosed with breast cancer, her friends suggested that she document her story through an online journal. She confidently stated that it wouldn't be necessary and all she needed was a lumpectomy, then her plan was to get on with her life. However, the biopsy results confirmed a diagnosis of a high-risk cancer and chemotherapy was the only option to treat this aggressive type. This diagnosis brought about a sudden change in her current plans.

This added the word 'chemotherapy' into the necessary treatment plan. We were totally caught off-guard; the box of tissues was emptied

as the reality set in. The ‘nasty’ cancer tumor [sic] removed may have sent small cancer cells out into my body, and now they need to be dealt with aggressively. (Crap) The journey has taken an uphill climb...I’m getting FIERCE! Thanks so much, to all, for the love and support already given to allow me to proceed with GRACE. Angels watch over us! (Amen.) (Abby Brown Blog; 2013, p. 1)

In this example, Abby shares her grief as she says: “...*the reality set in*” she is also facing the uncertainty of her original path. She writes that she is determined to face this cancer with courage “...*I’m getting FIERCE!*” Abby has a strong religious faith and has chosen to share her story via the Catholic website, using the words: “*Angels watch over us!*” “*Amen*” and “*Grace*” she is determined to face her future with a fight. She is at war with the “*nasty*” cancer cells.

4.3.1 On Corporeality

Abby shares her experience on getting her hair shaved on YouTube and in her eBook ‘What About the Hair Down There? Chemo Chuckles and Treatment Tears’. As she has family member who cuts hair, she says that she will have somewhere to go when she loses her hair. Obviously, at this early stage of her diagnosis, her body image and thoughts of the impending change are beginning to loom in her consciousness. In her book, she says:

Things aren’t always what we think...perception, hopes, positive thoughts, and faith don’t always make what something is into what we believe it should be. So, despite all the indicators that the cancer was contained to my breast, reality of the tumor [sic] type straightened out our misconceptions. (Brown, 2014, p. 107)

In this example, Abby shares her uncertainty of her diagnosis when she writes that hopes and positive thoughts do not always have a good outcome. Moreover, she faces the reality of the gravity of her future when she discovers that the tumour is not contained within her breast tissue, writing: “*reality of the tumor [sic] type straightened out our misconceptions.*” Abby became very knowledgeable regarding her illness and writes about the tumour type and chemotherapy protocols that are consistent with her diagnosis. Regarding her treatment plan, she writes that she has done her homework on the disease. On the day that she commenced her intravenous chemotherapy she writes:

I’ve been poked and prodded so many times over the last month that the prep for today’s first Valentine’s Day chemo session felt like status quo. Most of the time I was able to be positive and share jokes, though it didn’t go without the emotional floodgates opening. (Brown, 2014, p.29)

Here Abby shares that her body has become so used to invasion, that “*chemo session felt like status quo*” and trying to stay positive “*and share jokes.*” However, the severity and the unknown fear of the well-researched side effects that she is expecting do not remain far from the happy disguise: “*though it didn’t go without the emotional flood gates opening.*” She writes further on her experience with taking medications:

Despite all of the anti-nausea meds, I was feeling the drugs move through my stomach, conspicuously. It signalled the reality of these drugs as part of my new challenge. I was not liking the start of that anticipated crappy-feeling (Brown, 2014, p. 29)

Abby writes that her experience was a physical reality, as she became physically aware of the drugs moving through her body “*conspicuously*.” She anxiously anticipates that sick feeling which is sure to follow. She writes that during the chemotherapy treatment at home, pets must not drink the toilet water as it might kill them, and on this she writes: “*Yep...add that to your own thoughts*” (Brown, 2014, p. 30). Abby has become acutely aware of her physical body as the medical treatments invade her body. She is suspicious of the treatments that she is receiving. This is evident when she shares the warning about pets drinking the bathroom water.

4.3.2 On Relationality

Abby shares her experience on how she felt when she was rushed to the emergency department for an appendectomy. This operation was yet another trauma that she had to endure on top of her original diagnosis. She writes in her eBook:

The tears weren't for me; I was sooo [sic] sad to be, once again, adding stress/worry into the lives of those I love. As Tony held me, and we cried, his words of reassurance were, “We will all be fine.” The we is us. It isn't something that can't be separated out with my family.

(Brown, 2014, p. 43)

Abby writes that although she was sad about her own state, she was also miserable that her illness had detrimental effect on her family unit, writing; “*The tears weren't for me...*” *The we, is us.*” She sees her family unit as a complete whole, there is not one without the other. At the same time of her diagnosis, Abby rescues a dog. She fills her days and space around her with her new love. Her attention can now also focus on something other than herself and her illness. Her relationships and having company during the difficult times of chemotherapy and illness, are extremely important to her at this point. She builds a strong close relationship with her new rescue dog, Taira. Interesting at this point that rescuing Taira is aligned with her own Self-rescue.

We gave her a pink collar with a pink nametag – she’s my girl! She will be a welcome diversion ... I am looking forward to the extra company on post-chemo days.... Last night Taira slept out of her kennel for the first time, on the floor next to my bed. It felt protective and symbolic to me. Today, she began making herself comfortable on the couch and was there watching me when I awoke from a nap in the recliner. (Brown, 2014 p. 27-31)

When writing about her new dog Abby says that he will be a welcome “*diversion*” and she shares how much comfort and friendship that her dogs give her. She writes how her children respond to her being sick at home.

My son, Tim, was the perfect caregiver when he arrived home from school yesterday; he brought me food, beverages, did dishes, and ‘tucked’ me in at bedtime... kisses on the cheek included. Matthias, too, was attentive in his own 14-year-old way. (Brown, 2014, p. 38)

Abby shares her appreciation and love of her “*perfect caregiver*” son bringing her “*food, beverages, did dishes, and ‘tucked’ me in at bedtime.*” This is her experience of receiving care from her family. Following her chemotherapy, she looks forward to returning to her profession as a teacher. She feels confident that a class full of children during the day would perk her up. Being in the company of her students helps Abby to feel the normality of the moment and distracts her as she undertakes chemotherapy, when she shares that she is trying to forget that she is “*...a chemo patient.*” (Brown, 2014, p. 40). The notion of receiving chemotherapy segregates Abby from others, so for now she prefers to think differently about herself. Abby praises her relationship

with her doctors on many occasions throughout her story. As well as going through chemotherapy, Abby goes through emergency surgery for appendicitis and writes:

As the angels would have it, my surgeon for the lumpectomy and port placement was “on call.” She watches activity from the hospital on her computer at home...She was on her way, and though it was later in the evening, she insisted on the ‘on call team’ come in for the surgery immediately. “You don’t know what this woman has been through these last weeks!” she told them. God bless Dr. Amy Fox. (Brown, 2014, p. 42)

Abby is also very appreciative of her usual doctor attending her when in an emergency when her doctor says, “*God bless Dr Amy Fox.*” Abby also writes how supported she felt by her anaesthetist after her appendectomy.

4.3.3 On Spatiality

Abby visits the local clinic for four months at fortnightly and then weekly intervals to receive chemotherapy, followed with three weekly infusions for a year. The environment that surrounds Abby after her treatment, is the familiar space of her home. She describes her experience on returning home following her infusions:

People who know me, know I am not a ‘couch potato.’ But I have dubbed myself a ‘lounge veggie’ during these post chemo days. That’s a positive twist to lying around most of the day, wouldn’t you say? The recliner serves me well for “vegging’ out-it’s a necessity to rest after the poison has been infused into my system. I am tracking side effects, and am in the “hang low days,” but have been blessed by visitors who bring meals, provide pleasant conversation... (Brown, 2014, p. 53)

Abby does not write that she associates her home with her illness, rather, she says the recliner “*serves me well for ‘vegging’ out.*” She refers to the chemotherapy as “*poison*” and she dislikes the idea that it has been “*infused into my system.*” Her home space provides her with a sense of normalcy as she writes, that she is happy to see her friends visit. However, Abby is also concerned that her family has now been affected by her treatments. The family space has changed and been contaminated by her chemotherapy treatments. She describes how the experience of receiving chemotherapy and living in the home affects her children and partner:

I am back to the practice of closing lid and flushing twice- also close “my” bathroom door for a week after chemo. I have to share, many days after my first infusion, Tim forgot and used this bathroom. He came into the kitchen in a panic, rubbing the back of his thighs. “Mom, I just sat on your toilet! Should I take a shower?” As he danced about, I reassured him that it had been enough days of flushing and simply sitting on the seat wasn’t going to harm him. Poor kid-the worries abound around here! (Brown, 2014, p. 65)

Abby’s illness and the changing environment has impacted on everyone in her home. The fear that others have, of becoming contaminated or poisoned from her chemotherapy is real when she says: “*Poor kid-the worries abound around here!*” The space surrounding her comfortable chair becomes important as she writes about “*hanging out*” in her recliner when she talks to her children. She warns that sometimes she feels “*edgy*” and that her family should keep their distance, especially at night when her resources are low. She also shares her feelings for what she calls “*a new silence I need to keep in my head.*” As comfortable as her own space is, she appreciates a change of scenery when she can leave the house. She writes:

Getting out of my pyjamas and the house for even part of a day can help I am fortunate that my parents live close; I can pack a bag for a spontaneous overnight with them. Changing the scenery has helped to keep my spirits uplifted on my 'good days' with this gloomy, cold weather. (Brown, 2014, p. 89-90).

Although she is happy to be in her home environment, Abby is relieved to have an overnight stay with her parents as she enjoyed a change of scenery. She escapes to the care of her mother and finds the change in space has helped her keep “*my spirits uplifted.*” Abby must undergo diagnostics tests at a local clinic to determine her prognosis. She shares her experience during one of her procedures:

The sun was shining through the waiting room window, at least. And it was quiet; people don't make loud conversation in clinics or hospital waiting rooms. It seems to be an unwritten rule of respect. (Brown, 2014, p. 191)

In this example, Abby is pleased that the sun was shining, and that she had found some space and through the quiet calm, in the waiting room full of patients who shared the same terminal prognosis she had found, “... *an unwritten rule of respect.*” She was thankful for the window, as it allowed the sun to shine through, giving Abby a moment in nature. Abby appreciates the silence that fills the room and the respect that is given to the patients waiting for their procedures.

4.3.4 On Temporality

Time is significant in Abby's experience as she waits for her chemotherapy appointments. These are marked by special dates in the calendar, as Abby's treatments unintentionally coincide during the year with days that are important to her. Her chemotherapy is scheduled to start on Valentine's Day, and she received a definitive

diagnosis on her illness on her husband's birthday. Her birthday is included in the scheduled visits to the clinic. Therefore, each of these dates will now be somehow associated with her illness and treatment. As she says, "*special occasions are taking on new twist this year*" (Brown, 2014, p. 22). She has a planned four months' schedule of chemotherapy. Over time, she visits the pathology services so often that she has become friends with the technical staff. On her chemotherapy treatments, she writes:

And although I feel as if I can hardly breathe with some activity, it [heart] is functioning well. ...Along with the "One day at a time mantra, I find myself daily repeating, "It's only temporary. It's only temporary." It is taking some extra effort to stay out of the looming depression, but I am working on it! (Brown, 2014, p. 89-90).

Clearly, Abby's mood is sinking, but she tries to remain cheerful, reminding herself of the temporality of this experience, she repeats her mantra repeatedly to avoid being consumed with the dread of her experience: "*One day at a time mantra [...]*." She mentions that it is difficult to not be consumed by "*depression.*" and the need to escape this overpowering consequence of her illness.

4.3.5 On Materiality

Abby heads home to have her continuing treatment administered at a local clinic. Not long after the insertion of the intravenous port, she shares a picture on her blog site of her oral medications. She writes:

I have a special "chemo-med basket." It is just the cutest container for bottles of "awful" stuff. Thank goodness, it is going to be ignored for the next week! (Brown, 2014, p. 39)

Abby has difficulty escaping from the reality of her situation, although she has placed her chemotherapy medicine in a decorated heart shaped basket, she writes that there remains a sense here of a monster or of the “*awful stuff*” lurking in the shadows. Abby becomes preoccupied with her medication regime and she has been told that her taste will disappear, she is disappointed to find that the first taste to change is her favourite soft drink. She writes:

So, my taste buds will eventually go, but why is it that my favourite TAB beverage is the first that I notice tasting different? To put it in a mild form of my sister Kris’s language: “That kinda [sic] sucks.” (Brown, 2014, p38)

With an expression of great disappointment, she finds that her favourite drink no longer tastes as it did. She says; “*That kinda[sic] sucks.*” How disappointing to lose not only her physicality but also her senses, she is being denied the enjoyment that she found in the taste of her favourite drink. She is surrounded by belongings that match her current treatment. She writes:

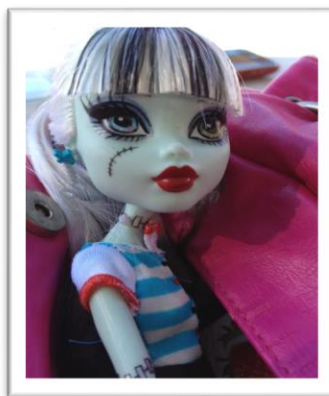
Several deliveries of meals were a part of today- one being from my Mom. She and Dad visited for a bit-she wanted to bring along the new hat she knit-up in a day. We are looking for greens to make my eyes ‘pop’ when I am wearing hats in place of hair. My sister also sent another green one...baseball style. (I am well cared for!) (Brown, 2014, p. 35)

Abby shares that personal belongings now include knitted hats, to cover her balding head when the side effects of the chemotherapy begin. Abby and her family are getting ready for the inevitable, “... *When I am wearing hats in place of hair.*”

Regarding the chemotherapy, she writes that her focus is on getting through each day as she prepares for the many assaults to her body. She sums up her lived experience of the cancer treatments, saying:

There are definitely moments when I want to shout, “STOP! I’m getting off!” it is unsettling to hear the number of women who have ‘endured’ chemo for breast cancer. Making oneself sick to get better goes against my being! I realize that chemo saves lives, but chemo does suck. (And I don’t use the “s” – word loosely!). (Brown, 2014, p. 38)

Abby says that she, like others in her situation did not ask for this experience, she writes; that there are moments when she just wants to shout out, “STOP!”, that it is an endurance test: that she must endure is counterintuitive to make herself sick to get better. She writes about the uncertainty of her future and the outcome of the chemotherapy. I chose the image (Research Reflections, 6) below because the doll like Abby is patching herself up, make up, wigs, she lies broken in the jacket, wide eyed, asking what is next to come.



Researcher reflections 6: The monster doll beautiful in patches
Photo credit: J. Carter

4.4 ZACH SOBIECH: DIAGNOSIS

Zach is an adolescent who has struggled with a diagnosis of osteosarcoma since the age of fourteen. The introduction on the Internet asks that his story be shared and over seventeen million people have already viewed the video. In May 2013, when Zach was in his seventeenth year and just a few months before he died, a film crew visited his family for their story, shared on the website, Soul Pancake. His story is widely available on Facebook and YouTube. Zach's mother has also written her story, as she lived through the experience of caring for a sick child. I first met Zach through Abby Brown's eBook, where she inserted a link to his story. The snowball approach to gathering data drew my attention to explore Zach's experience. Zach recorded his story largely through music. His song 'Clouds,' was released before his death, reaching millions of people worldwide, including reaching number one in the music charts. Through the words of the song, Zach was able to speak of his feelings and love for his partner.

4.4.1 On Corporeality

When Zach shared his experience on facing his mortality for the website *Soul Pancake*, his song 'Clouds' is playing in the background as he and his family share their thoughts on his illness. The reporter highlights that Zach just can't stop writing lyrics (Soul Pancake, 2013). Zach replies:

Every kid thinks they are invincible, I thought I was. I was ready for college. I was planning out way ahead. It turns out sometimes you can't do that. I've been told I have a few months, but I want everyone to know you don't have to find out your dying to start living. Most people live in the middle, between your dreams could come true and you're dying I guess it's a comfortable place to live. I am living on two extreme ends, so you have really good days and really bad days. I found out that I had osteosarcoma and it was unbelievable. My mum walked in to me one

day and I was lying on the ground because I didn't want to associate my bed with being sick. (Sobiech, 2013, soulpancake.com)

After being informed of his terminal diagnosis by the medical staff, Zach very wisely talks of his need to enjoy and appreciate life, despite his prognosis. He, like most young adolescents, thought he was invincible, he had his future planned out. He thought that he would follow his dreams. Instead, his body is now associated with the sick body, chemotherapy, tubes and hospital stays. His space is now filled with the cleanliness of the hospital versus the dirtiness of his disease.

4.4.2 On Relationality

Zach is interviewed alongside his very supportive mother and sister. His mother takes over telling his story when his sister becomes overwhelmed with sadness. Zach's family is extremely important to him. Being only fourteen years old and receiving such a poor prognosis, Zach is left reliant on his family for emotional support and understanding. He says:

I think with my diagnosis we have become a better and stronger family we all love each other just that bit more because when you go through stuff like that you go through it together. My friends, I don't know if they have accepted me as being terminal or not. They know if they just treat me the same everything will be ok, honestly. (Sobiech, 2013, soulpancake.com)

As Zach clearly outlines, family support and love are a crucial part of his ability to hang on as he says; "*we all love each other just that bit more.*" On his friendships, he is less sure of his friends' understanding of his terminal state, but he hopes that he

will be treated as if he is the same person, regardless. When asked by his mother if he was angry about dying and the procedures that he had to tolerate, Zach answered:

No. Actually, I think I'm the lucky one. If somebody has to have cancer, I'd rather be the one to have it than to be the one who has to watch and then be left behind. I don't think I could handle watching someone I love die. You all have it worse, and I'm so sorry for putting you through this. (Sobiech in Sobiech, 2013, p. 6)

Zach shares his insights on living at a young age while dying with a terminal illness he writes that he is “*the lucky one*.” He would rather be the person who is dying than the one who is “*left behind*.” Zach feels the pain of his cancer, he walks with a limp and endures hospital visits for treatment. Yet he is acutely aware of others and the challenges facing the observer, including the ongoing pain of memories of those people who are left behind.

4.4.3 On Spatiality

During Zach's prolonged illness he has experienced many procedures in hospital, which requires frequent visits into the hospital space. Zach required further treatment for severe pain in his hip, therefore he underwent a computerized topography scan early in his illness, which confirmed the cancer had metastasized to his lungs. He was told that he had six months to a year to live. On his experience of the frequent visits to hospital, Zach writes:

I didn't understand that it didn't make any sense to me. With the hospital it's the most sterile place in the world you just don't feel clean there at all and it was tough being there you just felt totally disconnected... (Sobiech, 2013, <http://www.upworthy.com>)

Zach describes his experience of hospital and the many visits, where he felt alienated in the hospital space. Surrounded by medical equipment, and the sterility of the surroundings, his cancer does not seem “*clean*” to him, his cancer is an intrusion. Yet there is little choice, he is forced to accept hospital care even though he felt “*totally disconnected*.”

4.4.4 On Materiality

Another escape from his situation of emptiness and disconnect, was for Zach to focus on his music. His love of music gave him a renewed sense of purpose in life, where he could express himself freely, without becoming a burden to others. During the first months of his diagnosis, Zach began writing songs:

The Music is a way I can express myself without having to burden everyone else... I find that with my situation it's harder the other end. I have closure but she [friend] won't have closure. My closure is being able to put my feelings into these songs, so they will have something to remember me by [...] (Sobiech, 2013, You Tube)

Zach finds comfort in expressing his feelings through the words of his songs and this outlet brings him a sense of peace and “*closure*.” He goes as far as to say that he has found his purpose through his songs and that he feels it is harder for others to come to terms with his death. He is trying to let others know that he is at peace with the immanent inevitability of his death, and he wants to leave “*something to remember me by*.”

4.4.5 On Temporality

Laura Sobiech in her book, ‘Fly a Little Higher-How God Answered One Mom’s Small Prayer in a Big Way,’ writes about her experience living with and guiding her son through his dark times. While talking about his friends, she says that Zach shared:

Zach: We'll be hanging out downstairs just watching a movie or whatever, and everything is fine. Then one of them will bring up college, and all I can think about is how I'll be dead. He turned his face away and pinched the bridge of his nose to stop the tears. I cupped his head in my hands and kissed the top of his head. I moved to the couch across from him, took a deep breath, and looked into this brave, weary, and heartbroken boy's soul. (Sobiech, 2013, p. 3)

Zach is aware of his immediate mortality and he is constantly reminded of his EoL. He cannot join his friends in their future fantasies and dreams, he is acutely aware that he will die sooner than his friends, “*All I can think about is how I'll be dead.*” Zach's thoughts are preoccupied with his present state, he cannot allow himself to think about his future, he only has this moment in time.

4.5 CLIVE JAMES: DIAGNOSIS

While searching the Internet for stories, I serendipitously came across Clive's poem, 'Japanese Maple', on a website dedicated to people who share their stories on death and dying. In 2010, at the age of seventy-three, Clive James was diagnosed with leukaemia and emphysema. He is an Australian essayist and author who, through the medium of poetry, shared his deep thoughts towards the EoL. Poetry can bring to life pre-reflected thoughts as they are lived again through the eye of the poet (van Manen, 2015). After receiving the news of his terminal diagnosis, Clive documented his experience through his poetry in 'Sentenced to Life' (James, 2015). During an interview in the Independent Newspaper (2014), Clive said that:

You have to have lived for a long time and be approaching the end of your life before you can see the world as I see it now, so I'm quite pleased with that even though I'm a bit terrified because it really is the mark of the end, isn't it? One's hoping to make a good exit. (James, & Dugan, 2014, Para, 4)

4.5.1 On Corporeality

The opening poem in Clive's compilation of poetry, 'Sentenced to Life', allows the sentiment in his words to be felt as he expresses his emotions of living with a terminal illness:

*Sentenced to life, I sleep face-up as though
Ice-bound, lest I should cough the night away,
And when I walk the mile to town, I show
The right technique for wading through thick clay.*

A sad man, sorrier than he can say... (James, 2015, p. 64)

In the first, title poem, Clive expresses his feelings on the changes that are occurring to his body, and the compulsion this provides for him to adjust his sleeping habits. The act of breathing becomes an effort, demonstrated in an excerpt taken from ‘Driftwood Houses’ (James, 2015, p75: 655):

*Just so, I stare into the racing field
Of ice as I lay on my side and fight
To cough up muck. This bumpy slide downhill
Leads from my bed to where I’m bound to drown
At this rate. I get up and take a walk,
Lean on the balustrade and breathe my fill
At last. The wooden stairs down to the hall
Stop shaking. Enough said. To hear me talk
You’d think I found my fate sad. Hardly that:
All that has happened is I’ve hit the wall
Disintegration is appropriate,* (James, 2015, p75: 655)

Given his diagnosis, Clive acknowledges that: “*Disintegration is appropriate.*” He accepts the results of his life-choices but remains clearly sad about the changes with which he must now come to terms. His use of the word “*muck*” is a stark reminder that it is not just a cough, but a cough that is laden with malodourous filth, muck being synonymous with dung. Such imagery resonates just like the words “*thick clay*” procure an image of slow, cumbersome lifting of heavy feet, sodden with the weight of damp earth. James must adjust his physical positions, he must lie on his side to stop this coughing, awaiting the easing of the spasms and a chance to lie in any way he

chooses. Lamenting the loss of his once-fit body, he offers his distress in poetic form, in ‘Landfall:’

*Hard to believe, now, that I once was free
From pills in heaps, blood tests, X-rays and scans.
No pipes or tubes. At perfect liberty,
I stained my diary with travel plans.* (James, 2015, p. 83: 655)

Here Clive is now coming to accept the fact that he lives with the restraints of his illness, it has become normalised to live with “*pills in heaps, blood tests, X-rays and scans.*” This was a period of reflection for Clive, whose health had declined since receiving his diagnosis. In ‘Landfall’, Clive says, “*I called it health but never stopped to think it might have been a kind of weightlessness.*” Here he demonstrates his awareness of the demands of illness as weight, his health, in contrast, had been weightless, a taken-for-granted thing (James, 2014, p. 88).

4.5.2 On Relationality

Clive puts great importance on the maple tree that was given to him by his daughter. It is a testament to the solace that he finds within nature and particularly with his family. He confirms this notion in a statement made during an interview about his illness with Mark Colvin (ABC News, 2016):

*There's no doubt that it's brought us all together, but it was really only
work that ever took us apart. And the trouble with the kind of work I did
is it took me away and I suppose there was something about me that
likes being away alone. But I always loved being with the kids when I
was and now of course I am much more often. And they tolerate me.*

*The whole bunch of them tolerate me, which is rather good of them,
considering.* (James, & Colvin, 2016)

Clive shares his feelings on his family, when he talks of the affectionate tolerance they have to his continuous presence, sharing his thanks with the word “*considering*” (James, & Colvin, 2016). This is because he admits to having behaved badly in 2012, when the news of his long-time affair hit the tabloids. He alludes to his feelings of shame on the discovery of his indiscretions in ‘The Maple Tree’:

*Here two opposing forces will collide-
Your proper anger and my shamed regret-
With all the weight of justice on your side ...* (James, 2015, p. 569)

Clive and his wife separated in 2012 when she asked him to move out of the family home. He writes of ‘*proper anger*’ and ‘*shamed regret*’ and the righteousness of his spouse’s response. During an interview with Robert McCrum in The Guardian (2015), he is asked if he is ever moved to tears. Below is an excerpt from the interview:

“No.” He seems taken aback by the question. “No,” he repeats. “*I’m surrounded by too much joy from my family.*” One of his two daughters live next door, with Prue (wife) nearby in the family home. “*We’re a funny bunch,*” he says. “*We are more likely to be moved to tears by House of Cards, when my favourite reporter got pushed under a train at the start of series two.* A small silence intercedes. “*What will happen when I go?*” he wonders aloud. “*I don’t know.*” He pauses. “*I’ll be glad to be remembered at all.*” Another pause. (James, & McCrum, 2015)

On the question of sadness, Clive denies it, alluding instead to the surrounding “*joy from my family.*” He also reflects on the future of his family after his death, extending the query to a generalised “*what will happen,*” before answering it almost immediately with the wish to be “*remembered at all.*”

4.5.3 On Spatiality

Clive had difficulty accepting the notion that he was now limited to one space due to his inability to travel as he had been accustomed. He is restricted by his declining physicality, so clearly depicted in the final verses of ‘Landfall’ (2015):

*I called it health but never stopped to think
It might have been a kind of weightlessness,
That footloose feeling always on the brink
Of breakdown: the false freedom of excess.
Rarely at home in those days, I’m home now... (James, 2015, p. 88)*

The burden of his inability to breathe freely is starkly contrasted with the freedom that he enjoyed before becoming ill, he writes: “*I stained my diary with travel plans.*” The old way of life, being healthy to fly to various places around the world at will, has now been denied. His life, he says, was once a “*fantasy...that now dies.*” Illness has snatched away his freedom and he is reminded of this by the space that surrounds him: “*Rarely at home in those days*” he says, “*those days*” being reminiscent of the lost days of his healthy state. This theme also arises in the excerpt from the poem ‘Early to Bed’ that he wrote not long after his diagnosis:

*Old age is not my problem. Bad health, yes.
If I were well again, I’d walk for miles,
My name a synonym for tirelessness.*

On Friday nights I'd go out on the tiles... (James, 2015, p. 98)

In this poem, Clive acknowledges that age is not an issue rather his ill health has now taken control of his life. During an interview with White in *The Guardian* (2012), Clive reflected on returning to Australia and about travel, saying that:

I've been so sick I'm not allowed to fly; you couldn't get enough oxygen aboard a plane to get me to Sydney. I used to be in Australia for five or six times a year but now I can't go. The wistfulness is really building up and I'm facing the possibility I might never see Sydney again. (James & White, 2012)

His physicality is limiting his ability to visit his homeland, because he is unable to travel readily by air. Travel by other means, although not specifically addressed, would also be problematic, so he is left with a growing “wistfulness” and unfulfillable desire to return to the past. His space, significantly reduced and restricted by his illness, is a continual reminder of his mortality.

4.5.4 On Temporality

Clive’s original diagnosis gave him only a few months to live. At that time, he wrote a poem, often referred to as his farewell poem, called ‘Japanese Maple.’ It went viral on the Internet:

My daughter's choice, the maple tree is new.

Come autumn and its leaves will turn to flame.

What I must do

Is live to see that. That will end the game

For me, though life continues all the same. (James, 2015, p550)

The maple tree was a gift from his daughter, so in his farewell poem, he challenges himself to live through to autumn to see the colours of the tree. Then he expects to have gone, but there is no certainty in his future, “... *What I must do is live to see that*” he implores himself. Clive is a self-proclaimed atheist and his terminal diagnosis has not altered his views on God. When recently interviewed by Paul Vale for the Huffington Post (2015) Clive clearly stated that:

You're lucky to have had a life. That's not even to say blessed because that brings God into it and God has no leg to stand on. As one approaches the end one does see things with a new clarity. (James & Vale, 2015)

Clive has discovered a “*new clarity*” in the face of his illness. During an earlier interview with Jon Snow on Channel 4 (ABC, 2013) when asked about his views on death and dying, Clive quipped, “*you don't get out alive,*” adding that he was counting his blessings that he had lived this long.

*No soul can well continue when the mind
Fades with the body. All his store is spent
Of pride, or guilt, or anything that might
Have steeled him for the non-stop outbound flight...
...And then beyond that, though he feels the power
Of all creation when he lifts a book,
Or when a loved face smiles at his new joke...* (James, 2015, p. 532)

Clive gives a glimpse into his thinking on the nature of the soul in the poem, ‘Transit Visa.’ In prose, Clive expressed his beliefs about the soul as something linked to a presence of mind. Despite his revelations about God, in his new clarity of seeing things he can feel the “*power of all creation*” in a book or the smile of a loved one.

4.5.5 On Materiality

Clive continues his passion for writing and giving interviews through social media. He has essays that he plans to complete, although he is unaware of how long he has left to focus on his writing. In an interview with McCrum in *The Guardian* (2015) Clive discusses how his life has altered since his illness, during an excerpt from the interview he says that he is “...*the echo of the man you knew...*” He is grateful that he is not in pain he says:

I think I’m writing better now than I ever did. That’s where lyricism comes from. The love lyric is always full of approaching sadness “What I’ve got doesn’t hurt. I’ve been lucky. The treatment has been benign. I don’t know if I could concentrate if I was in pain.” (James & McCrum, 2015)

Clive is filmed sitting, surrounded by the images of the disease that ravages his body, but keeps his mind focused on reading and writing. He is escaping into alternate reality, claiming that his writing has improved because of this new subject matter, his impending death. He says, “*It’s quite restful. I sit there all afternoon. I can read a book and even write something, while they pump in stuff through a tube*” (James & McCrum, 2015). For Clive, the tools of writing bring him solace and an escape into an ethereal world. The image below (Researcher reflections, 7) shows the leaves of the maple tree in their autumn colours ready to fall, a reflection that is recalled in Clive’s poetry.



Researcher reflections 7: Autumn fall

Nature is beautiful in its simplicity and representative of the natural process of dying

Photo credit: Pixabay.com

4.6 ANATOLE BROYARD: DIAGNOSIS

While reading EoL stories on the Internet, especially a book written by Dr Oliver Sacks I was drawn to an interesting book titled ‘Intoxicated by My Illness’ a compilation of essays and writings on death and dying by Anatole Broyard. Anatole’s book was prefaced by Sacks and through the snowball technique I landed- upon Anatole’s book. Alexandra, Anatole’s wife, posthumously collated his work. Here was a man who was unapologetic in discussing whole-heartedly his LED on death and dying, and who fervently wanted to let the world know his story. Not only his story but he also dives into the lives of other writers who have documented their LED on death and dying. He writes on this subject matter saying, “...*writing is a counterpoint to my illness, it forces the cancer to go through my character before it can get to me*” (Broyard, 1992, p. 23).

Anatole was an essayist and editor for the New York Times for 18 years. His father died after a long illness with bladder cancer when he was 28 years of age giving him an early insight into death and dying. Anatole enjoyed good health until the age of sixty-nine when he was diagnosed with prostate cancer (Sacks, in Broyard, 1992, p. 69). His wife in the prologue of the book says that Anatole was a ‘*superb storyteller*’ writing at the time of his illness was a way that he, “*could outwit his cancer by constructing an alternative narrative that wither and erase the shadow of death*” (Broyard in Broyard, 1992, p. 125).

4.6.1 On Corporeality

Every word or thought in the essay ‘Intoxicated by My Illness’ concerns Anatole’s insights into his impending death. He has become intoxicated and fuelled with adrenaline as he writes about his terminal illness and on hearing this for the first time, he writes:

So much of a writer’s life consists of assumed suffering, rhetorical suffering, that I felt something like relief, even elation, when the doctor told me that I had cancer of the prostate. Suddenly there was in the air a rich sense of crisis-real crisis, yet one that also contained echoes of ideas like the crisis of language, the crisis of literature, or of

personality. It seemed to me that my existence, whatever I thought, felt or did, had taken on a kind of meter, as in poetry or in taxis. (Broyard, 1992, p. 143)

Anatole has written extensively on how the diagnosis of cancer affected him both emotionally and physically. It is as if the shock of disbelief and what he was hearing had woken him out of inertia and he felt a “*personality crisis*.” In this passage Anatole is coming to terms with his terminal diagnosis, he writes that he felt elated that he had received a diagnosis. Here he writes how the illness has ravaged his body and the emotions that he felt on returning to a state of relative health:

In the first stages of my illness, I couldn't sleep, urinate, or defecate- the word ordeal comes to mind. Then, when my doctor changed all this and everything worked again, what a voluptuous pleasure it was! With a cry of joy I realised how marvellous it is simply to function. My body, which in the last decade or two had become a familiar, no-longer-thrilling old flame, was reborn as a brand-new infatuation. I realize of course that this elation I feel is just a phase, just a rush of consciousness, a splash of perspective, a hot flash of ontological alertness. (Broyard, 1992. p. 6)

In the statement “*With a cry of joy I realised how marvellous it is simply to function.*” Anatole is no longer taking his daily bodily functions for granted; he has a new respect for his body. Forever the philosopher, he is wise in his assumptions that this is “*a hot flash of ontological alertness.*” He has become awakened to his mortality, a flash of insight. Later, in his essay Anatole describes his humiliation and his loss of self-respect as his body succumbs once again to be the ill body.

I've had eight-inch needles thrust into my belly, where I could feel them tickling my metaphysics. I've worn Pampers. I've been licked by the flames, and my sense of self has been singed. Sartre was right: You have to live each moment as if you're prepared to die. (Broyard, 1992. P6)

Anatole shares his feelings on being terminal he writes; *"I've been licked by the flames, and my sense of self has been singed."* Through his words you can feel a deep sense of personal physical loss, *"I've worn Pampers"* and been burnt by the *"flames"* of insult to take a deeper look at who he is, his original sense of Self has been destroyed. As he prepares to confront his mortality, he vows to live each day, each moment in preparation for the end of his life.

4.6.2 On Temporality

Being aware now the terminal nature of his illness has increased Anatole's thoughts on death and dying and temporality of his life. He writes about mortality and his newfound awareness that:

I thought that time had tapped me on the shoulder, that I had been given a deadline at last. It wasn't that I believed the cancer was going to kill me, even though it had spread beyond the prostate - it could probably be controlled, either by radiation or hormonal manipulation. No, what struck me was the startled awareness that one day something, whatever it might be, was going to interrupt my leisurely progress. It sounds trite, yet I can only say that I realized for the first time that I don't have forever. (Broyard, 1992, P.3)

In the passage above Anatole alludes to the fact that for the first time in his life he has been confronted with his mortality, as he says: *"time had tapped him on the*

shoulder.” I can only interpret this sentiment as being his “*leisurely progress*” into the inevitable slow progress of senescence and death. He is now awakened to a new sense of self as he has now been given “*deadline*” so to speak. This is the first time that he has taken some time to think about his mortality.

4.6.3 On Relationality

Anatole describes how he felt shocked on hearing his diagnosis not because he was afraid to die but because he was over whelmed with other people’s stories on illness, He writes:

A set of disconnected shocks, and my first instinct was to try to bring it under control by turning it into a narrative. Always in emergencies we invent narratives... When people heard that I was ill, they inundated me with stories of their own illnesses, as well as the cases of friends. Storytelling seems to be a natural reaction to illness. People bleed stories, and I’ve become a blood bank of them. (Broyard, 1992, p.19)

Anatole is extremely candid when writing about the change in his relationship with his friends since being given a terminal diagnosis. He writes that he felt burdened with the stories of others and that: “*People bleed stories.*” He is ill and cannot understand why his friends want to tell their stories? This is his time, his experience. He says that his friends have become somewhat distant from him and serious, they didn’t or couldn’t understand his cheerfulness. He writes:

When my friends heard I had cancer, they found me surprisingly cheerful and talked about my courage. But it has nothing to do with courage, at least not for me. As far as I can tell, it’s a question of desire.

I am filled with desire-to live, to write, to do everything. (Broyard, 1992, p. 153)

Anatole is, however, grateful to his friends for the way they have “*rallied around me*” He says that they are “*not intoxicated as I am by my illness, but sobered. Since I refuse to, they’ve taken on the responsibility of being serious. They appear abashed or chagrined in their sobriety.*” (Broyard, 1992, p. 4)

Anatole’s friends are finding the whole process disheartening he says they are “*sobered,*” however, he remains grateful for their company. Anatole writes extensively on his experience with medical staff during his diagnosis and illness. He is dismayed with the aloofness of the medical profession saying that he is not just a body but a soul as well and he would like to be treated as a complete person. He feels as if he is being treated like a machine disembodied, dissembled and then reassembled. He would like his treating doctor to know and understand the real him, the person, the artist behind the disease. Here he writes on the shock of hearing that he has prostate cancer with metastases to his lymph nodes and bones:

The knowledge that you’re ill is one of the momentous experiences in life. You expect that you’re going to go on forever, that you’re immortal. I had dawdled through life up to that point, and when the doctor told me I was ill it was like an immense electric shock. I felt galvanized. I was a new person. All of my old trivial selves fell away, and I was reduced to essence. I began to look around me with new eyes, and the first thing I looked at was my doctor. (Broyard, 1992, p.38)

Anatole writes on his dissatisfaction with his doctors, he turned towards his doctor for help in understanding his new way of being, of “*looking with new eyes*” he felt “*reduced to essence [of his former Self].*”

I would like a doctor who is not only a talented physician, but a bit of a metaphysician, too. Someone who can treat body and soul. There's a physical self-who's ill, and there's a metaphysical self-who's ill. When you die, your philosophy dies along with you. So I want a metaphysical man to keep me company. To get to my body, my doctor has to get to my character. He has to go through my soul." (Broyard, 1992, p. 40).

Anatole felt disheartened as he wants his doctor to hold not only medical authority but to also consider his humanity. Anatole pours out his deepest thoughts about his soul since receiving a terminal diagnosis, he writes: *"I used to get restless when people talked about the soul, but now I know better. Soul is the part of you that you summon up in emergencies"*. He continues to lament on the past to include priests or others from religious orders. These were men who could understand the dying process, who could talk about heaven or hell, who had a lyrical sense of knowing. Now he says he says that we must make up our own stories. He reiterates the importance of poetry and literature in the dying process. Here he writes on his view on *"the real narrative of dying:"*

Yet the real narrative of dying now is that you die in a machine. Kafka has a wonderful story called "The Penal Colony" in which a criminal is put in a machine that inscribes on his body with a needle the nature of his crime. We die through these machines, and that's not the right way. (Broyard, 1992, p. 42)

Anatole feels that the concentration centred around his bodily needs as he begins to succumb to the illness is not enough. He doesn't want to die by the hands of a

machine. He begs for someone to recognise and include his humanity in his treatments. Anatole on hearing his diagnosis has a lot to say about his medical treatment during the initial diagnosis and his feelings with coming to terms with a terminal diagnosis and illness:

To the typical physician my illness is a routine incident in his rounds, while for me it's the crisis of my life. I would feel better if I had a doctor who at least perceived this incongruity (p.43) ... Just as he orders blood test and bone scans of my body, I'd like my doctor to scan me, to grope for my spirit as well as my prostate. Without some such recognition, I am nothing but my illness. (Broyard, 1992, P.45)

Anatole laments on the neglect of the medical staff to care for his spiritual self. He feels that with the neglect of his spiritual being that he is reduced to “*nothing but my illness.*” He constantly writes on the importance of his metaphysical self, he is asking for acknowledgement of this in some form. As he says where are the priests who were able to talk on death and dying to acknowledge this part of the body, he writes; “*To get to my body, my doctor has to get to my character. He has to go through my soul.*”

4.6.4 On Spatiality

Anatole has chosen to rethink and create a new space he fills his environment with images that he creates in his mind, his personal head space. He is not courageous he says he reminds us that he is filled with enthusiasm for life, when he writes, “*I am filled with the desire to live.*” Imagery is a technique that is well known for its ability to relieve anxiety and reduce stress. He writes:

I see the balance of my life-everything comes in images now-as a beautiful paisley shawl thrown over a grand piano. Why paisley shawl, precisely? Why a grand piano? I have no idea. That's the way the

situation presents itself to me. I have to take my imagery along with my medicine. (Broyard, 1992, P.8)

Anatole alludes to his imaginary as being his “*medicine*” in the words he uses to describe his thoughts. He says that he doesn’t understand why he imagines what he ‘*imagines but he knows that it is as important to him as taking his medicine.*”

4.6.5 On Materiality

Anatole writes that art is his love. To escape his present uncomfortable situation in his hospital bed his mind wonders. Reading a passage from Shirley Hazzard’s book, ‘Transit of Venus’ he shares a letter that he has composed to thank her:

You offered me an alternative. Art is our ace in the hole. I’m eating your book for lunch, and it’s making me hungry...he goes on to write...
I put it down and went for a walk around the ward, dragging the metal rack with the IV tube and the catheter bag. From the window of an empty room I looked down at the city, which was dotted with trees. How extraordinary the real world was! Shirley Hazzard was right. (Broyard, 1992, p. 216)

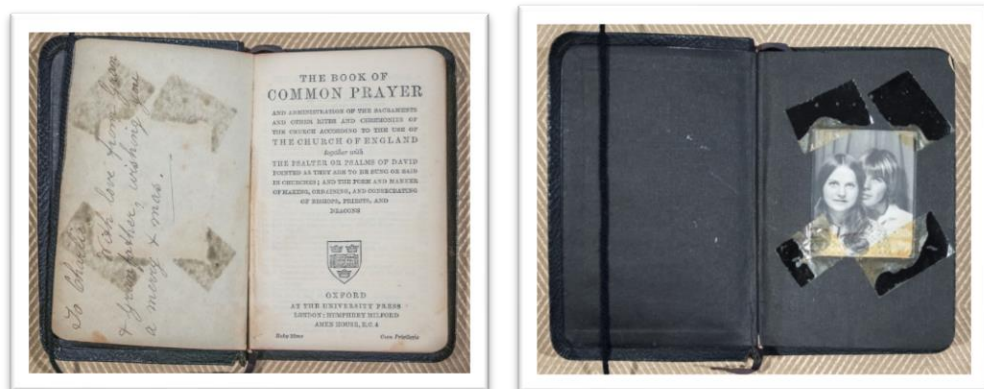
The timely reading of Shirley’s book for Anatole brought a sense of peace and escapism, which he longed for on learning of his initial diagnosis. Whilst lying in his hospital bed he turned the pages of his book, creating a new world in which to escape. He writes, “*I’m eating your book for lunch.*” Through the stories held within the pages of the book he was able to escape his present situation and he discovered how ‘*extraordinary*’ the world is. While he is fixed in place by the medical equipment that has become embodied, he chooses his own method of escapism. Anatole writes:

Her book was the prescription I needed and that no doctor could give.

I needed a dose of the sublime. From where I sat in my cranked-up bed,

the sublime seemed to be all there was left. (Broyard, 1992, p. 12)

Anatole shares his feelings on reading, he writes: “*Her book was the prescription that I needed.*” The idea of recreating a space to retreat to through the materiality of reading was important for his wellbeing and merged within the space of his imagination as he comes to terms with a new way of being in the world. The image below (Researcher reflections, 8) shows the importance that can be placed on books, to hold personal treasures. Years after death these images were found tucked inside a bible.



Researcher reflections 8: Lost Memories

Books are special places that can hold physical memories embedded into a social context.

Photo credit: Timothy Barnett (2017)

4.7 CORY TAYLOR: DIAGNOSIS

Cory Taylor is an award-winning Australian novelist and screenwriter currently residing in Brisbane. She writes in her memoir that she was diagnosed in 2005 at the age of 49 years, with malignant melanoma. For her, the disease progression had been incredibly slow, and it was three years before it showed up in other parts of her body. She says that she did not suffer from any debilitating symptoms therefore making it incredible easy for her to hide her story from anyone with whom she didn't want to share the experience (Taylor, 2016). She writes of becoming consciously aware of death and how hidden death had been to her before her diagnosis. Cory admirably articulates her feelings when she awakes to the notion that death exists:

Things are not as they should be. For so many of us, death has become the unmentionable thing, a monstrous silence. But this is no help to the dying, who are probably lonelier now than they've ever been. At least that is how it feels to me. (Taylor, 2016, p. 96)

Cory's story needs to be heard, she refers to death as being "*a monstrous silence*" her story is contemporary and validates the stories of all of those who are brave enough to write their own dying stories before death came into the spotlight.

4.7.1 On Corporeality

Cory describes in her memoir how she felt following a motor vehicle accident when she almost had her legs trapped by a speeding car. Like others in her situation imagining a different future she writes:

So many times, I've wondered what might have happened to me if I had lost my legs, or even just my right one, where my first melanoma appeared two or three years later. If I'd just been a second slower stepping away from the car, I might not be dying now. I'd be legless, of

course, but still in good health. Of these fateful forks in the road are our lives made up. We are all just a millimetre away from death, all of the time, if only we know it. (Taylor, 2016, p. 1427)

If only this and that, she writes about the direction her life has taken, now facing a slow death ‘*If I had lost my legs, if I’d been a second slower (Taylor, 2016, p.1427/1466).*’ Cory writes further on how she wishes she had been more vigilant about checking her skin, of course hindsight always gives way for reflection:

And of course, I wonder why I was not more vigilant about checking my skin, because, if I had been, I would have picked up that first melanoma before it turned bad and saved myself a lot of heartache. When I was first diagnosed, I was angry with myself for being too lazy and stupid to bother with anything but the occasional quick examination. But then I decided that kind of thinking was a waste of my time, because we start dying the moment we are born. I know that now, not in the child’s way I knew it when I saw the skink disappear down the kookaburra’s gullet, but in a dying person’s way. (Taylor, 2016, p. 1427)

Cory writes that for her after her initial diagnosis that “...*anger was a waste of time.*” She acknowledges that death is inevitable for everyone, including her and she now acknowledges the reality of living and dying not in a childlike way but an “*undeniable lived reality.*”

4.7.2 On Relationality

Cory shared that only her husband knew her devastating story when she received her first diagnosis. This was because he accompanied her to the necessary doctor’s appointments. She writes: “*I kept the details from our two teenage sons, trying, I suppose, to protect them from pain, because that was my job as their mother.*”

With the diagnosis came many visits to the hospital for the various treatments and scans and this is when Cory says that she became consciously aware of death. Cory writes that the sight of death shocked her. She wonders if there is now an aversion to the subject of death as if our own mortality can be exiled from our consciousness. She writes:

Surely there couldn't be a more futile exercise, for if cancer teaches you one thing, it is that we are dying in our droves, all the time. Just go into the oncology department of any major hospital and sit in the packed waiting room. All around you are people dying... It's a shocking sight if you're unused to it. I was as under-prepared as anyone could be. It was as if I had stumbled out of a land of make-believe into the realm of the real. (Taylor, 2016, p.91)

Cory ponders on the notion of death and dying when she received her diagnosis and the experience leaves her with a feeling that the medical profession has a certain control over the dying process. She says:

Our (Australian) laws reflect some deep aversion amongst medical professionals here towards the idea of relinquishing control of the dying process into the hands of the patient. I wonder if this aversion might stem from a more general belief in the medical profession that death represents a form of failure. (Taylor, 2016, p. 88)

Cory reflects on the medicalisation of death and dying when she writes, the Australians laws do not allow autonomy in death. She reflects on this saying that

perhaps it is a recognition of “*failure*” by medical personal to protect life. Cory writes that the only death she had previously experienced was the long drawn out death of her mother and father from dementia and her first thoughts were that she was at least saved from this type of death. She acknowledges that she was not with her mother when she died but she was there to witness the “*ravages she suffered*” *the pain and humiliation, the loss of independence and reason*” (Taylor, 2016, p. 99). Later, Cory explains that her horror at how her parents died influenced her to consider ways she might improve her own state of dying. She writes that very soon after her diagnosis of cancer she decided to join Exit International. Cory writes on the comfort and security that she found with people who are undergoing the same lived experience and why the meeting with people who have death on their mind is important for her:

It takes courage to contemplate one’s own death, and, as I said before, it is inexpressibly lonely. To find companions who share your desire to know more, to take the initiative, and to laugh in the face of our shared mortality, is a gift. How different from the experience of the hospital waiting room, where you sit in a glum herd with the overhead televisions blaring, guarding your dirty little secret until such time as your name is called. ...In hospitals we don’t talk about death, we talk about treatment. (Taylor, 2016, p. 142-3)

As she repeatedly writes that is extremely lonely when society shuns those who are dying. That the secret of carrying her impending death around with her is relieved when she can share her experience with others. She is happy in the company of friends who can laugh in the “*face of our shared mortality.*”

4.7.3 On Materiality

For Cory, there is nothing more important than her writing, it sustain her way of being in the world. She writes that she is never happier than when she is writing. That

writing, and travelling have always been in her life. On her first love of writing she says:

My real good fortune, however, was discovering what I loved to do early in my life. It is my bliss this thing called writing, and it has been since my schooldays. It isn't just the practice that enthrals me, it's everything else that goes with it, all the habits of mind. Writing, even if most of the time you are only doing it in your head, shapes the world, and makes it bearable. (Taylor, 2016, p.331)

Cory continues with this love of hers, in writing her memoir, documenting her end of life story, as she calls it her “*bliss*” a place that she has found within herself and she returns to this comfortable place as her way of finding happiness. It is little wonder that she continues to write her story. Her writing “*shapes the world.*” She is determined to tell the reader something “*meaningful*” before she dies. As soon as she was old enough, she took off alone and travelled to many parts of the world, it something that she has always enjoyed in her life. However, now has done what she intends to achieve in this life, she gives an example of her vast travelling experience. She writes:

My point is that I've travelled enough, collected enough treasured memories to be satisfied. You can never go everywhere and see everything. Even if you did, I suspect there would be a point where you grew satiated with travel and longed to be home. Because the pleasures of home can be just as real as the pleasures of travel, and there is a price to be paid for wanting to be everywhere and nowhere, like my father. (Taylor, 2016, p. 370)

Cory has found that she is comfortable where she is, she says, “...*the pleasures of home can be just as real as the pleasures of travel*” And for her, now is the time to be still.

4.7.4 On Temporality

Exit International is an EoL advocacy organisation. It is a web site dedicated to EoL choices and informs the reader on how to gather information necessary to implement their own EoL. Cory’s mother was a member of the group, however, dementia crept into her life before her choices could be made. Exit International was founded by Dr Philip Nitschke in 1997, the average age of the members is seventy-five. The inclusion of the discussion surrounding Exit International is important to people who are experiencing the EoL and how they choose to end their life. It is not a debate about the ethics surrounding different rights of the dying. What I consider of great importance here to reiterate are the reasons that Cory gives for joining this and other EoL groups:

So, another motive for joining Exit was to find a forum for simply broaching the topic, challenging the taboo that I felt was preventing my doctors from speaking openly to me about something so pertinent. Despite the ubiquity of death, it seems strange that there are so few opportunities to publicly discuss dying. Exit meetings are the only occasions when I’ve found it is possible for people to speak about death as a fact of life. (Taylor, 2016, p.129)

Cory found the camaraderie of the Exit meetings extremely helpful. She enjoyed the opportunity to share her experience and to “*speak about death as a fact of life.*” Just like a group of nurses collecting together to discuss the latest treatments in palliative care, to share stories and to laugh together over implausible life endings so too does Cory find sharing of the information important for her mental health and her

spirit. When Cory thinks of time and her current diagnosis, she is pulled in to the memories of the sunshine that she enjoyed as a child and she recalls:

Time present and time past/Are both perhaps present in time future/And time future contained in time past. It is all, according to T. S. Eliot, the same thing. I am a girl and I am a dying woman. My body is my journey, the truest record of all I have done seen, the site of all my joys and heartbreaks, of all my misapprehensions and blinding insights. If I feel the need to relive the journey it is all there written in runes on my body. Even my cells remember it, all that sunshine. I bathed in as a child, too much as it turned out. In my beginning is my end. (Taylor, 2016, p. 1274)

Cory in this passage is reflecting on the concept of time, she shares her deep thoughts poignantly of her living and dying experience, she writes, “*I am a girl and I am a dying woman.*” She is saying that there is only now, this time and space, but in this time, she also exists as the child. She writes that even her cells carry the imprint of her childhood, writing: “*In my beginning is my end.*”

4.7.5 On Spatiality

The comforting space that Cory has found in the early part of her diagnosis is with her friends in an environment where writing becomes the spoken word. The materiality of her comfort in writing becomes overtly obvious in her spatial surroundings. Cory gives a comparison in her writing when she shares how she felt after a medical consultation and how dissimilar the experience is in her Exit meetings:

I would come out of consultations feeling as if my humanity had been diminished by the encounter, as if I'd been reduced to my disease alone,

as if everything else that defines me had fallen away. (Taylor, 2016, p. 143)

When discussing how she felt following routine medical consultations she says: *“My humanity had been diminished by the encounter”* and *“as if I had been reduced to my disease.”* Cory writes lovingly about the Exit group who meets up regularly with at the local Café. Just like a group who get together to chat about the latest book they have read. In this space, people chat over coffee and cakes and share their stories of life and death and offer comfort to each other. For Cory, this third space is her church, where she meets with people with like-minded thoughts in a neutral warm inviting space. It is her sacred space where she joins others who dare to think alike and not frightened to face their mortality openly, consciously. It is not that any of her friends want to end their lives. Just that they have a choice if they should decide on that option. She writes further that she does not have a moral or religious belief. However, she can’t help but think that religious reasons lay beneath the inability of our medical doctors to discuss death and dying matters. The image (Researcher reflections, 9) shows hands being warmed by coffee, holding an image of the sacred Bodhi leaf.



Researcher reflections 9: The Comfort Café

The image of the Bodhi leaf floats on the top of the coffee, hands cradle the warm cup bringing comfort

Photo credit: Pixabay.com

4.8 CHRISTINE BRYDEN: DIAGNOSIS

This thesis cannot be completed without the incredible story of Christine Bryden. Christine was diagnosed in 1998 at the age of 46 years with early onset dementia. She is the author of four books on the subject, a blog and a website. ‘The Canberra Times’ published a story mocking Ronald Reagan, who had recently been diagnosed with Alzheimer’s. Christine was extremely upset by this and contacted the newspaper to let them know that she too had Alzheimer’s, and that it is not limited to the elderly. She called this her “*coming out*,” she says in ‘The New Daily’ (2015), Christine describes how she felt:

It gave me quite a shock to open up my newspaper that Saturday morning! I had certainly ‘come out’ about my dementia! Although I was daunted, I felt that it was the right thing to do. I thought it was important not to be ashamed of my dementia, especially if I wanted anything in the world to change, which, I realised now, I certainly did. (Bryden in The New Daily, 2015)

4.8.1 On Corporeality

It was difficult for Christine to “*come out*” as she says because of the stigma that surrounds a person with dementia. She says this clearly in the anecdote above that she did not want to be “*ashamed*” of her diagnosis. Christine was an active member of society beginning her working life as a biochemist. At the time of her diagnosis she was employed full time as a scientific assistant to the Chief of the Commonwealth Scientific and Industrial Research Organisation (CSIRO) division. She had a staff of over hundred and was a single parent of three young children. Christine’s sense of Self-identity was fading. In an interview with Jana Wendt in the Sydney Morning Herald (2015) Christine says, as a person with dementia “*you’ve lost your source of identity*”.

Since her original interview, she has undertaken many more sharing her lived experience and insights. Through her continual writings, speeches and television interviews she brings hope to others who have the condition. She appeared on the Australian Broadcasting Commission (ABC) television program Australian Story in 2014, introduced by Todd Sampson, where she gracefully shared her experience on receiving the news of her diagnosis for the first time:

Something must have looked odd because then I was sent for an MRI scan. Well, I went to see the neurologist to get my results and he looked at my scan. With his back towards me he said, "Oh. You've got Alzheimer's disease. You have to retire immediately. You shouldn't be in any responsible position. You're going to become demented in five years and then you'll go into full-time care and you'll be dead within about another three." And that's when I said, "Oh, but I'm too young. I'm only 46." She said, "Oh look. You know, I've diagnosed women who have been pregnant and in their 30s." (Bryden & Sampson, 2014)

Christine was devastated by the news and she couldn't believe the diagnosis that she was given so insincerely, in her words *"With his (medical practitioner) back towards me."* In her book 'Who Will I Be When I Die?' first published in 1998 she states that it took six months to get a second opinion on her illness, which was subsequently confirmed. Christine is courageous in her interviews and in her writing. She unashamedly shares the whole lived experience her fears and her insights as well as her brain scan images. These clearly show the degeneration of her brain. During an interview with a newspaper she said that she wished she could wear her brain scan on her shirt so that people would know that she had a brain condition. *"Who will I be when I die? Will I still be me?"* (Bryden, 2014, ABC). This statement shows us, the reader how concerned and frightened she was about not only dying but having to contend with not knowing if she would remember everyone.

The invisibility of living with the problems linked to dementia becomes extremely obvious to Christine. She writes about the insecurity on her failing memory and the fears that she now lives with every day, these remain largely hidden to others. In her thoughts, she recalls an incident that occurred with some of her friends whilst enjoying a get to together. Her friends remarked on how well she looked, and perhaps the best they have seen her in a while, Christine sounds indignant in her reply when she writes:

How did they expect me to look? How are you meant to look to the outside world when you have Alzheimer's disease? For young sufferers, we don't look to you as if we have Alzheimer's- you know, white-haired, dodderly, frail. We don't look that old, we are often fit in our physical bodies, and so you don't know anything is wrong with us...Unfortunately, I have a disease of the brain, so you just can't see the diseased bit of me. My outer shell is fine, it's just my mental powerhouse that is on the blink! What's wrong with me is inside my head. I'll probably look well until shortly before I die, when my brain finally forgets how to run my body. Unlike other diseases, such as cancer, people who don't know I am dying will see me as a perfectly fit person who just behaves a bit oddly. (Bryden, 2012, p.60)

The emotions that Christine is experiencing around her diagnosis are sending her into an inner turmoil. Although her physical body is “*looking fit*” she is frustrated because her appearance does not reflect her inner turmoil. She is battling with the fear of changing and losing her memory, and the fear of when her “*brain finally forgets how to run my body,*” decades of images that she will not be able to recall. She feels

hopeless about losing her memory and brilliant mind and at one point she writes that she would perhaps rather die of cancer when she had a small growth on her leg checked.

I am scared of the prospect of eventually not recognising my surroundings and not knowing who my girls are or being able to greet my friends. Surely that will be a lonely and frightening place to be- always somewhere unfamiliar, surrounded by strangers, and none you recognise to turn to. Will I still be able to hold onto my faith in God? You know there is no cure and no treatment, no hope that you are going to lose everything that makes you who you are, and that you will die not knowing your family or your surroundings. (Bryden, 2012, p. 61)

Christine shares with the reader her fears of the future, she feels “scared” after all that she has read on Alzheimer’s disease she is now even more frightened at the prospect of not knowing anyone, her family and her friends and perhaps even losing her faith in God. The title of a chapter in Christine’s book ‘Clinging to a Precipice with my Fingernails,’ defines perfectly how she explains her lived experience of dementia. She describes that this is not simply a moment of not recalling a name or an event but is like living in a fog, here in her words she says:

After a social chat with you when I might have seemed so incredibly well and mentally focused, after you have gone, I sink back exhausted, monosyllabic, wrung out and empty of all showmanship. It may take me at least a few hours lying down with my eyes closed to recover. My brain might be firing so much that later, at night, it simply will not switch off and let me sleep. A migraine is also very likely-my brain’s way of saying “Enough!” (Bryden, 2012, p.70-71)

Although unseen, Christine explains clearly the enormous amount of physical effort that is required to stay focused. She feels; “*exhausted, monosyllabic, wrung out*” after just a short conversation with others, she must take time to recover and frequently suffers with migraines.

4.8.2 On Temporality

Becoming lost frequently when driving her car in familiar places Bryden thought that something might be wrong, however she thought that it could be due to work related stressors and the severe migraines that she was experiencing. Christine shares how she felt on hearing the diagnosis in her book:

I felt as if time had stood still- surely this wasn't happening to me. I had to rush away in a minute and chair a meeting back at work, and I had moved to a new house over the week end and was still unpacking and sorting out. I must have misheard- he was mistaken – the scans maybe had got mixed up with someone else's...you're joking - I'm too young to get Alzheimer's! (Bryden, 2012, p. 24)

The clock had stopped, when she heard her diagnosis she said; “*time had stood still-surely this wasn't happening to me.*” Christine's changing Self-identity is a concern to her and obtaining a diagnosis was paramount. Time was important if she was to lose her memory then she requires a timely diagnosis, so she can prepare herself emotionally. She writes extensively on the barrage of tests that were undertaken to determine a definitive diagnosis. On meeting the specialist for a second opinion she writes; “*This new specialist was clearly going to treat us very much like people, not just as medical cases, and to explain as much as possible each step of the tests*” (Bryden, 2012, p.49).

4.8.3 On Relationality

Given her definitive diagnosis Christine thoughts and concerns immediately turn to her children and future grandchildren, she says; “What *was going to happen to my girls? Would I ever see them graduate? Would I ever see grandchildren or weddings? What will happen to them? Who will look after them* (Bryden, 2005, p.487/3233)?” Christine writes how she was alone in a Sydney hospital going through an endless number of invasive tests. When she awakes, she was pleased to see her friend waiting for her. She writes:

And there, sitting quietly by my side, was my best friend Karen from Sydney, ...She had a remarkable experience while praying. She was quite willing to sit there and pray all the time but had felt she was being reassured that I was safe in God’s grace and there was no need to ask for anything. This was a comfort and reassurance to both of us, giving us the peace, we had sought... I was very confused and disoriented when I finally had to make my way out into the world again and, thank God, Karen was there to help me! (Bryden, 2012, p.52)

Christine having a strong Christian faith, in which she has found solace at this difficult time through the company of her friend and in the power of prayer. She says that; “*I was safe in God’s grace.*”

4.8.4 On Materiality

Without memory and recall all material objects that we cling too are lost, images of people once so familiar become unknown. Material objects that are treasured and that mean so much to each individual person are now meaningless without the attached memory. Lamenting the losses that she now must contend with Christine writes about the changes within her memory that only she notices, the connections within her brain are broken and she is unable to recall the events of the days, weeks and months as she used too. She recalls how she remembered everything, was in the top classes at school and university, taking an intelligence test scoring as high as 200. She writes that she

was also tolerant of others, and that her memory was like a “*giant*” (Bryden, 2012. p. 72), she writes:

I can't have more than one window open at once, or more than one application running. I have to 'open up' the window or application each time you ask about these things, so it takes more time (p. 74). If I lose concentration momentarily during a task, I can get very confused and forget what I am supposed to be doing-even if it is the only thing I am attempting at the one time...When I watch TV, I often lose track of the plot because there are gaps everywhere in the storyline taken in by my brain. (Bryden, 2012, p.76)

Material objects that are important to Christine are those that keep her orientated to time and place. She uses the analogy of a computer to describe how her memory bank is now limited, she must concentrate and “*open up*” a part of her brain to recall an event. She explains how living with memory gaps is confusing.

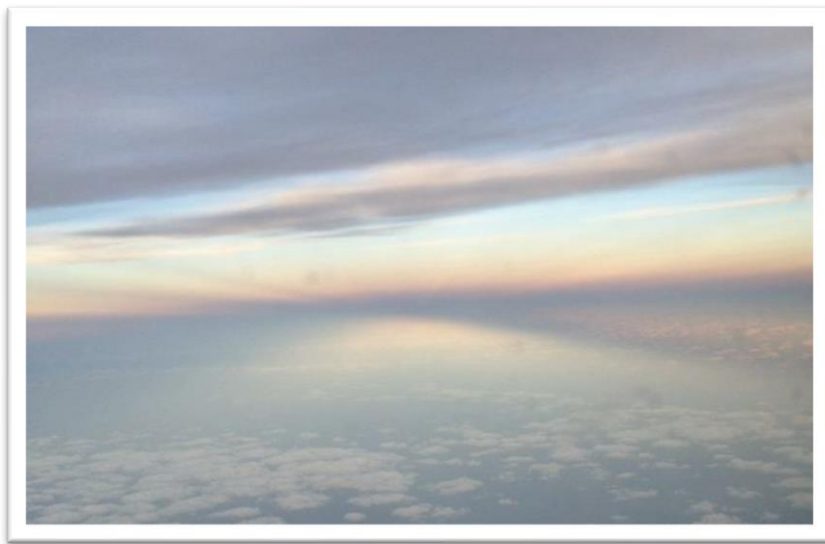
4.8.5 On Spatiality

Just as the concept of time is difficult to grasp with a person who has dementia so too is the concept of space, Christine explains:

...And, of course, all of this assumes I am taking my tablets, the tacrine, which I've been taking since October 1995. When I don't take them, and it is all too easy for me to forget them, then the world goes too fast for me to keep up. I can't even pretend to be 'normal'. I'm off-line, unable to speak or to think, lost in a foggy confusion. Ianthe describes

how I look as: ‘You just look absent, not there somehow.’ (Bryden, 2012, p.70-71)

Christine writes, that she is unable to understand her surroundings when bombarded with a simple conversation or social situation, this throws her into mental disorientation, which she describes as; “*I can’t even pretend to be ‘normal’*” she feels totally lost in a “*foggy confusion*” and she relies on her daughter to explain how she looks when she is feeling lost. Due to Christine’s failing memory she cannot retreat into her imaginative space within her mind. She must live each moment in the present and retreat into a silent world when she becomes bombarded with too much information, she is unable to “*speak or to think.*” I chose the image below (Researcher reflections, 10), an aerial view of the space between the cloud and the sky because it is a place where meaning is impossible it is above the usual worldview, not here or there.



Researcher reflections 10: In the clouds, between two worlds.

Photo credit: J. Carter

4.9 PAUL KALANITHI: DIAGNOSIS

Paul's book was unlike the others that I came upon through the snowballing technique. My eyes wondered over the book section one afternoon while attending to my regular shopping. I was drawn to Paul's book, 'When Breath Becomes Air' by both the title and the intriguing image on the front cover. As I picked it up it dawned on me that this book, released in 2016, would be an important inclusion within my PhD story. It is an articulate, heartfelt, EoL story. This story is written by Paul a neurosurgeon and is a conscious awareness of his imminent mortality. Each word carries the weight of his diagnosis. No other profession is as close to the dying person as the medical profession, therefore it is understandable that when faced with their own mortality, doctors and nurses think deeply about their experiences juxtaposed against their lived experience of assisting others to die.

For minutes, I stood reading through the pages, lost in the words on the page. I simply could not put the book down. Paul Kalanithi nearing the end of a decade of training as a neurosurgeon, decided to write his story after being diagnosed with metastatic lung cancer at the age of 36 years. Paul eloquently shares his feelings, as he transverses the path to death. You can feel both the despair and content as he nears the end of his life. He is an articulate compassionate writer and his writing can recreate the scenes within your mind. Paul studied literature before medicine; therefore, he was also fulfilling a lifelong dream of becoming a writer. Literature became his solace in the long quiet hours ahead. I was truly touched by Paul's story as I recall the moments that he shared with others through his writing and I hope that I can convey his sentiment through this thesis.

4.9.1 On Corporeality

Paul was diagnosed at an advanced stage of his illness his physical decline was immediate and obvious. He found the diagnosis extremely difficult to process as only a few weeks before his diagnosis he was operating for long tedious hours. He writes:

I was physically debilitated, my imagined future and my personal identity collapsed, and I faced the same existential quandaries my

patients faced. The lung cancer diagnosis was confirmed. My carefully planned and hard-won future no longer existed. Death, so familiar to me in my work, was now paying a personal visit. (Kalanithi, 2016, p. 120)

Paul writes that after the confirmation of his diagnosis the world as he knew it was changed forever, his “*personal identity collapsed*” and his “*future no longer existed.*” He had lost a lot of weight and had been experiencing excruciating back pain, which he thought were a result of his long hours of work. As he writes:

Severe illness wasn't life altering, it was life- shattering. It felt less like an epiphany-a piercing burst of light, illuminating What Really Matters-and more like someone had just firebombed the path forward.

(Kalanithi, 2016, p. 120)

When confronted by his treating doctor about returning to work, Paul thinks to himself that she must be crazy, he questions whether she understands his diagnosis, and he wonders how his future can possibly be discussed without a survival estimate. As he says this has been a “*life-shattering, firebombed*” experience. He feels defeated although he has seen the face of death in his patients, he never imagined this outcome for himself. Paul had an obvious change of appearance due to the side effects of the chemotherapy treatment that he was undergoing. He shares how he felt about his changing physicality when he writes:

Lucy had always loved my smooth skin, but now it was pockmarked and, with my blood thinners, constantly bleeding. Any part of me that identified with being handsome was slowly being erased-though, in fairness, I was happy to be uglier and alive. Lucy said she loved my skin

just the same, acned and all, but while I knew that our identities derive not just from the brain, I was living its embodied nature. The man who loved hiking, camping, and funning, who expressed his love through gigantic hugs, who threw his giggling niece high in the air-that was a man I no longer was. At best, I could aim to be him again. (Kalanithi, 2016, p. 136)

This is so heartfelt and truthfully written, Paul watches as his image changes, not only is he losing his self-identity, but also his physical identity is changing and this he agrees comes second to life itself. “...*being handsome was slowly being erased.*” However, he is also striving to regain the essence of who he is and writes; “...*At best, I could aim to be him again.*”

4.9.2 On Relationality

The time frame for the changes that occurred within Paul’s life following his diagnosis was very short. Within 6 months he and his wife Lucy decided to have a child. This was a decision that had to be made before Paul underwent chemotherapy: ‘...*we decided to have a child. We would carry on living, instead of dying (Kalanithi, 2016, p.144).*’ They realised the consequences of Paul’s shortened life and the painful goodbyes that would come with having a child, but for them as a family unit the potential love and joy of having a child was of greater benefit than painful goodbyes. When Paul first received his diagnosis, he writes that he asked Lucy to leave that she shouldn’t be left alone, but Lucy decided otherwise:

Lying next to Lucy in the hospital bed, both of us crying, the CT scan images still glowing on the computer screen, that identity as a physician-my identity- no long mattered. With the cancer having invaded multiple organ systems, the diagnosis was clear. The room was

quiet. Lucy told me she loved me. “I don’t want to die,” I said. I told her to remarry, that I couldn’t bear the thought of her being alone. ...We started calling family members...One chapter in my life seemed to have ended; perhaps the whole book was closing. (Kalanithi, 2016, p. 119)

Paul writes that; *“I don’t want to die...”* Yet faced with diagnosis and seeing the scan results for himself he feels the sorrow that death is closer than “*she*” seemed, she is now tangible and personified. He is not sure; perhaps he is just a ghost of himself. Hope comes from the young woman who is his oncology doctor, when she makes the image of a new future in his mind. Paul shares his experience, when he writes:

For a few months, I’d suspected I had cancer. I had seen a lot of young patients with cancer. So, I wasn’t taken aback. In fact, there was a certain relief. The next steps were clear: Prepare to die. Cry. Tell my wife that she should remarry and refinance the mortgage. Write overdue letters to dear friends. Yes, there were lots of things I had meant to do in life, but sometimes this happens: Nothing could be more obvious when your day’s work includes treating head trauma and brain cancer. But on my first visit with my oncologist, she mentioned my going back to work someday. Wasn’t I a ghost? No. But then how long did I have? Silence. (Kalanithi, 2014, Sunday Review)

Paul knows cancer; hence he personifies cancer, he has diagnosed cancer many times, and he has witnessed the struggle of his patients that have endured cancer, little wonder that he writes: *“So I wasn’t taken aback. In fact, there was a certain relief.”* He was relieved in a way to know now that he needs to focus on his immediate future. To prioritise his life and prepare for his death. Including writing long overdue letters to dear friends. Then the unbelievable happens, his colleagues give him hope by

suggesting that he return to work. *“Wasn’t I a ghost? No. But then how long did I have? Silence.”*

4.9.3 On Temporality

In the many interviews that Paul gave he mentioned that time used to be a linear concept for him but now he feels that time is a matter of space. During his illness, he wrote a poignant essay titled ‘Before I Go’ in the Stanford Medicine journal, here is a small piece of his experience of the meaning of time:

With little to distinguish one day from the next, time began to feel static. In English, we use the word time in different ways, “the time is 2:45” versus “I’m going through a tough time.” Time began to feel less like the ticking clock, and more like the state of being. Languor settled in. Focused in the OR, the position of the clock’s hands might seem arbitrary, but never meaningless. Now the time of day meant nothing, the day of the week scarcely more so. Verb conjugation became muddled. Which was correct? “I am a neurosurgeon,” “I was a neurosurgeon,” “I had been a neurosurgeon before and will be again”? ...I recently celebrated my 15th college reunion; it seemed rude to respond to parting promises from old friends, “We’ll see you at the 25th!” with “Probably not!” (Kalanithi, 2015, para 7)

Paul’s sense of himself is tied to his identity as neurosurgeon, he is now confused with this identity of himself: *“I am a neurosurgeon, I was...I had been. And I will be...”* all the uncertainty that he now faces is due to his life being cut short. He writes that: *“time began to feel less like the ticking clock, and more like the state of being.”*

Whereas before his diagnosis he had a known path and direction that seemed to be as far reaching and as clear as the horizon. He is dissecting time when he writes: “*it seemed rude to respond to parting promises from old friend*” he wonders how he could respond to his friends when time and the future was an unknowable concept for him. Paul was lost in his renewed concept of time.

4.9.4 On Materiality

Paul’s life the life he knew had changed in just a few weeks. Before his diagnosis, he could walk unaided he was now confronted by his declining physicality and his material world is now filled with medical equipment that is required for his survival. He shares how he feels when it comes time to leave the hospital, when he writes:

The physical therapists left a list of items to ease my transition home: a cane, a modified toilet seat, and foam blocks for leg support while resting. A bevy of new pain medications was prescribed. As I hobbled out of the hospital, I wondered how, just six days ago, I had spent nearly thirty-six straight hours in the operating room. (Kalanithi, 2016, p. 124)

Paul’s life has become surreal, when just six weeks earlier he was looking forward to the future he now must accept a huge change in his material needs that are required to live and “*to ease my transition home*” He returned home but his home environment was now full of equipment to aid his living. This was a new world for him, the material things that surrounded him, were a constant reminder of his imminent mortality and declining physicality.

4.9.5 On Spatiality

As Paul dons the gown of the patient, never did he imagine this ending for himself at such a young age, surrounded by walls, people and things that are so familiar to him. He recognises that his old know way of being is crumbling when he writes; “*the culmination of decades of striving, evaporated*” (Kalanithi, 2016, p. 221). The hospital environment for Paul was very familiar, this space was his office, his living,

his home away from home space. What has changed for Paul is how he now perceives this space from giver to receiver, from doctor to patient. Here he describes how he felt when he transitioned from doctor to patient in one move when he writes:

I received the plastic arm bracelet all patients wear, put on the familiar light blue hospital gown, walked past the nurses I knew by name, and was checked in to a room - the same room where I had seen hundreds of patients over the years. In this room, I had sat with patients and explained terminal diagnoses and complex operations; in his room, I had congratulated patients of being cured of a disease and sent their happiness at being returned to their life; in this room, I had pronounced patient's dead...And with that, the future I had imagined, the one just about to be realized, the culmination of decades of striving, evaporated.

(Kalanithi, 2016, p. 221)

In this paragraph, Paul reflects on the hospital environment and all the ghosts of memories that were within the surroundings walls, when he shares his sentiment on the many patients that he has cared for during his time as a physician. It wasn't so much as the room, or the place that had changed only the silent memories that clung to who he was as a doctor, "*happiness, terminal diagnosis, sadness and death*" and in that minute his future evaporated. The once friendly *space* would now play a part in his own demise, and he knew it so well.

4.10 DIAGNOSIS: SUMMARY

Chapter Five on data analysis explores the lived experience description (LED) of eight individuals and their stories on receiving a diagnosis of a terminal illness. The participants share their experience openly and vividly through various social media sites. A pre-reflective lived experience contains an evocative account or the jaw dropping insights (epoché) of a remembered or recalled lived experience and it is the reduction of these experiences, which is important in doing phenomenology. What matters is the evocative language of the description of the experience whether it is prose, music or poetry that invites insights to the lived experience (van Manen, 2014).

This is the value of the Internet as a method of qualitative data collection as people turn to this medium to write about their experience in a cathartic way. The stories have been shared so that others may learn from the lived experience. The purpose of this phenomenological thesis is to let the lived experience ‘show itself’ so that others may ‘see’ this experience as it is. The participants in this chapter share the stories behind their discomfort and the turmoil behind the scenes as they discover that they have a terminal diagnosis and that their death is immanent.

It is very difficult to separate the existential themes from one another in a lived experience. To recall the original moments of receiving a terminal illness also recalls the time and the space linked to this event. The meaning of time is relevant to the conscious awareness of imminent mortality, this holds true for all the existential themes. Excluding the space from an important time when a shock occurs is impossible. Just as Zach shares that the hospital space is now linked in his mind to the sick bed and a dirty unhealthy place. We respond and react as humans to the world that is surrounding us at a given time and this is true for all the people within this thesis. Therefore, as I collate and summarise the individual phrases and words from the themes, they will at times appear to merge into the next theme.

In this chapter I also include a Word-Cloud that highlights the most frequently words used in each separate theme. These Word-Cloud images can pull the observer into the world of the other. Word-Clouds are used as a visual method for text analysis, they can provide a deeper analysis of a body of text; however, it is important to remember that they only provide a statistical summary of isolated words (Heimerl, Lohmann, Lang & Ertl, 2014). Word-Clouds have been utilised as a method of data analysis since 1995, especially in social media platforms to reduce superfluous data

(Heimerl, Lohmann, Lang & Ertl, 2014). They give a strong image of the most frequently used words expressed within the collective stories. Finally, I also collate the five existential themes into a Word-Cloud to explore words that are most frequently used by the participants on sharing their lived experience. I begin with summarising the shared experiences of each person under the existential themes, followed by a Word-Cloud image.

4.10.1 On Corporeality

There is a shared experience of emotional and physical trauma from not only the injury of their bodies but also of the humiliation that they must endure. They tell the stories of the many humiliating hospital tests necessary to confirm a definitive diagnosis, and the slow, steady loss of control that they feel. They share a desire to be heard on all levels and to be given choices. On hearing the diagnosis, while each person reacts in their own individual way they all share the same lived experience of facing their mortality. They engage the use of vocative language to try and place the lived experience into language. There are phrases that are repeated, which describe the physical experience towards the end of life. These phrases include words related to the shock of hearing that their mortality is a reality. An example of the emotive words used to share their experience are, firebombed, abolished dreams, and a conscious awareness of death, which evokes an awakening to a new changed self and worldview.

Other words that evoke the emotions related to the awareness of the physicality of their bodies are a shared experience of a physical exhaustion, the appearance of scars and tubes that poke out of their bodies. As Paul writes he now has a lot of medical equipment just to assist him to move. That his physical independence is now gone, there is a disintegration of the previous physical person. A life shattering lived experience towards facing their mortality. There is the visibility of scars that are now seen by everyone telling of the story of impending death. Except for those people whose illness remains unseen, they feel that they have been cheated in some way, that their story is important even though it remains hidden. There is a coming out that their world is now upside down, a reality check is needed, and dreams of the future become abolished as a sinking feeling occurs. Thoughts now turn to who will I be when I die, and what will my dying be like, and will it be an easy death?

Each section of the Word-Cloud can be examined closely and can provide the reader with a snap shot into the lives of the people who shared their lived experience towards the EoL. The repeated words in this cloud are: look, just, know and will, cancer and dying. These words will be explored further in chapter six, when they are once again related back to the whole story.

4.10.2 On Temporality

Most of the participants write that they feel an altered sense of time. They share the experience of a time warp. A feeling of the clock slowing down, a different time dimension. They talk about needing time to think, that time stood still, that there is a certain type of quietness that needs time. Take one day at a time is often reiterated in the stories and many personify the cancer writing as if it is separate from themselves, a monster that has come to destroy their lives, perhaps they are a ghost, and just silence.

The feeling of being a ghost like figure, not with the rest of the world but walking separately, waiting for the time to end. While others see their illness as a gift of insight allowing time for goodbyes. All the participants find solace in sharing their time and stories with others. There is also a focus on living life to the fullest given the reduced time remaining to live. They use emotive words to describe the shared experience of time on receiving the initial terminal diagnosis.

They describe their experience as facing a new and altered reality. That they now have a shared awareness of time, of looking from the outside of time and that time is no longer controlled or limited the movement of clock hands. That time is no longer considered as linear but rather explained and described as a sense of space or a state of being. There is an overriding feeling of a startled awareness of death. A new deadline, and an interruption of their usual way of being in the world, is now shaping their lived experience. There are shared feelings of submission and confusion, ‘what now’ and feelings like a new twist and a nightmare. The following Word-Cloud (Figure, 12) depicts as an image all the words used by the participants on their LED on discovering that they have a terminal illness and the temporality of the experience.

In the image above the participants most frequently written words were; doctor, cancer and family life. Other words that are highlighted are: something, time, like and death. These words paint a picture of ill health of a realisation that there is a need for courage, family and friends. As you read further into the image you will be taken on a walk into the world of the terminally ill person, who has been faced with their immortality. These words will be reviewed further in the chapter six, when they will be delved into as part of the whole story. But for now, it is insightful to read the pattern of expressed words as told by the people in this thesis.

4.10.4 On Spatiality

The participants in this thesis share a common experience on the importance of the aesthetics of their surroundings and the ability of their own comfort zone to provide an emotional and physical healing. They speak about the loneliness of hospital environment, the sights that bring fear like the chemotherapy, x-rays, machines and equipment that is necessary to diagnose their illness. Here it is necessary to segregate the words used to express emotions linked to the environment at this stage of their illness into the hospital and the home environment. The stories within this thesis that are related to spatiality issues include words and phrases that were linked to the hospital environment. This is especially important, as in most cases the hospital is where they continue to have medical treatments and where they receive their initial terminal diagnoses.

Kate refers to the treatment room as a torture chamber, and the mad house she fears the ongoing treatments that she must endure in hospital space. Zach refers to the sick bed and although the hospital space is clean, he calls it dirty, equating the space with his cancer. He felt totally disconnected from his known reality. They discuss the quality of life and insist on a do not resuscitate order to protect them from what they consider a prolonged death and decreased quality of life. They write on the lost opportunity for independence as they are not given a choice or encouraged to participate in their care. They write of the loneliness felt while in hospital. Cory expressed feeling that she was not given a choice in her dying needs. She shares that the topic of how to die is not discussed and that perhaps the reason for this is that God is frowning on individual choice on how to die. The ability of the imagination to pull people out of their sadness into a friendly more healing space was important for most people. Being lost in writing, or thought was an unexpected relief from the harsh

Prominent words depicted in the Word-Cloud (Research data, 4) on spatiality are: room, patients, just, and so on until the words melt into the background image. This image paints an immediate picture of a patient who has a terminal disease. The frequently used words to describe their lived experience on hearing that they have a terminal illness are, hospital room, thinking, not knowing, chemo and disease. This image has the immediacy to conjure up many images, painting a picture in the mind.

4.10.5 On Materiality

The participants speak of coming to know their medication on an intimate level, trying to make friends with the unfriendly (chemotherapy and medications) for their own good. At the beginning of the diagnosis there is an overwhelming focus on material objects that are linked to the arts. This is evident in the solace that individual's experiences through some form of the arts, either through poetry, imaginary, songs or reading and writing. Likewise, there is spiritual comfort found in natural surroundings, as well as within formal religious gatherings. Anatole writes on the importance of viewing the outside world from a window in his hospital room. He can forget for a minute that he is surrounded by medical equipment and connect to the real world as he describes it.

Material objects that remind them of their family and familiar surroundings are also important. Abby appreciates the hats that are knitted for her by her family, should she need them to hide her baldness. They all share a love of writing, this was not evident for all of them at first, but they came to love the freedom that writing gave them. Zach shares that through writing songs he able to express how he feels without placing the burden onto others. New objects of their illness are thrust into their lives and become the new way of being in the world. Paul shares how his life is full of medical equipment, which enables him to leave the hospital and return home with some independence. Individual independence is paramount in the beginning of their illness as they all begin the struggle to gain some control back into their lives. Kate shares that for her the quality of life is more important than the quantity of life as she moves forward. The following word cloud (Figure, 15) depicts all the words reiterated in the previous section of this chapter on materiality.

through their poetry, song and prose, via social media. This chapter has provided a preliminary analysis and descriptions of this beginning stage towards the EoL. Focusing on the existential themes, each story shares insights on the LED. Finally, this chapter shows all the words as images in word clouds. When studying, the word clouds the most frequently used words within the stories become strongly evident, giving another interpretation into the lives of the storytellers. The next chapter within this thesis continues to share the stories and restoration of lives. What is important to these participants during the next phase of their illness as they approach their mortality will be unveiled. Further critical insights adding a layer of deeper analysis will be undertaken in subsequent chapters of this thesis

Chapter 5 Part 2 Data Analysis: Restoration



Researcher reflections 11: The doctor and the patient
have many stories to tell

Photo credit: Pixabay.com

Lost in a featureless wasteland of my own mortality and finding no traction in the reams of scientific studies, intracellular molecular pathways, and endless curves of survival statistics, I began reading literature again...I was searching for a vocabulary with which to make sense of death, to find a way to begin defining myself and inching forward again. (Kalanithi, 2016, p. 148)

5.1 INTRODUCTION

In this chapter, I continue to document the voices of people who have received a terminal diagnosis and therefore, face mortality. This is a changed world for our participants who have been whisked away from their known reality or comfort zone. I have chosen to call Chapter 5 part 2: Restoration. To restore is to bring back to a peaceful state or the bringing back or reconstruction of the original form (Merriam-Webster.com, 2017). This chapter explores how these people reconcile their thoughts and lives after receiving the diagnosis of a terminal illness.

This second data section now considers the participant's stories as they face an altered reality, a new singular event. Language cannot describe a singular point in time and if an experience were expressed in ordinary prose it would lose valuable meaning because preconceived concepts have already become generalised within our language. Therefore, it is important to listen clearly to the single experience, the anecdote as it is recalled and written to understand the true meaning conveyed within the experience. The idea in phenomenological anecdotes is that the story can evoke insights of the lived experience and allow the experience to be revealed to others (Van Manen, 2014).

Due to the large volume of data, I have only repeated some of the anecdotes in full followed by the salient words related to the paragraphs. An important consideration when selecting the anecdotes was to ensure that they express the feelings and emotions that surround the lived experience. The participants thoughts must be described in such a way that that stirs the emotions of the reader (van Manen, 2014). I have documented the voices of the participants in italics, as in the previous chapter. This technique is congruent with Van Manen's (2014) interpretation of hermeneutics, that instructs to the researcher to rewrite the narrative by retaining the theme while being careful not to change or distort the text. To further rewrite the paragraph, then follow with the sentence and then the words. To ensure that the voice of the participant was heard I strengthened and refined the anecdote into the direction of the phenomenon under study, asking if this anecdote shows the meaning of the experience, or what the experience was like.

Van Manen (2014, p. 6356), states further that in phenomenology what we as researchers are doing is fictionalising factual, empirical data to arrive at a "plausible description of a possible human experience." I will leave the in-depth critical insight analysis for future chapters. In this way, I let everyone speak with their voice so that

the reader can experience their individual reality. The entire books, websites and videos will be listed so the reader can access their full heartfelt, insightful stories.

Therefore, Chapter five-part 2 is dedicated to the voices of the eight participants and how they choose to spend their remaining time, which for some maybe weeks, months or years. Many of the stories have been dedicated to the medical profession. I follow the same format as in the last chapter beginning with Kate Granger's story. I commence a new story on a separate page to give space to the reader and respect to the storyteller. Once again for the reader's reflection I have included images that I have painted, photographed, drawn or others from creative commons images, which are made freely available from the Internet that reflect the sediment conveyed within the story.

5.2 KATE GRANGER: RESTORATION

Kate Granger was twenty-nine years old when in 2011 she was given a terminal diagnosis of sarcoma, she has returned to the hospital for her first chemotherapy treatment. She is unsure whether this is the right direction to take but as she says she is undergoing chemotherapy for the sake of her family and most importantly for her husband Chris. She has become accustomed to writing her cancer story on her blog. Kate's blog was the first that I read on writing about receiving a terminal diagnosis and it was catalyst that led me to the other storytellers. During her writing, Kate frequently questions many EoL medical practices that are taken for granted, especially what constitutes a 'good death.' Kate is a physician therefore she can tell her story through the voice of the giver and of the receiver of care, she writes in her book:

Are we as the healthcare professionals trying to impose our own views of what we feel a good death is onto our patients? I am very careful regarding this, knowing full well that I would be very agitated if someone tried to tell me what they thought my death should be like. I feel it is much more important to facilitate people to make decisions

about their future by suggesting the possibilities and exploring their views without reference to our own beliefs. (Granger, wordpress.com.,2013)

5.2.1 On Corporeality

Kate is facing the decision of trying to halt the fast progression of her cancer by undergoing chemotherapy. This is not an easy choice for Kate after her first decision not to undergo further treatment. Kate has been a witness many times to the harsh effects that chemotherapy has on the whole body, hence her apprehension to begin the treatment that has been decided for her type of cancer, she writes, *“I just need to be braver and face up to the chemotherapy with all my mental strength”* (Granger, 2014, p. 1979). Kate describes in detail the effect that further chemotherapy has had on her health and her body. She has stents placed into her kidneys and to her bladder, so she is once again free to move about as she pleases.

I feel genuinely happy for the first time in a long time. I need to wee frequently and it's really sore with bladder spasms, but I don't care. It will settle, and I'm prepared to put up with a lot for the freedom from those blasted drainage bags. I take a walk around the ward and I am not quite sure what to do with my hands, they have had ten weeks of something to carry and now they have been liberated the possibilities are endless. (Granger, 2014, p. 2285)

The freedom that Kate is experiencing is still accompanied with discomfort and pain but being able to move about gives her a sense of happiness and liberation. She feels that her future maybe filled with *“endless possibilities.”* However, shortly afterwards she writes that she has, *“come down to earth”* when she struggles through further treatment to treat an infection. Her spirits were lifted with the freedom that she found in regaining some independence with her body, although she suffers with

incontinence. She struggles at the role of being the patient the one who is cared for and writes; *“you can’t take the doctor out of the patient even when I am unwell”* (Granger, 2014, p. 2294). Now without the urine bags connected to her she grabs her freedom; she has returned to work and travels with her husband. She writes that: *“Good days are precious, and I really make the most of mine. It is hard to think about more treatment making me feel rubbish again when I am so well at present, bloody Oncologists and their poisons”* (Granger, 2014, p. 2347).

This is the difficulty of working in the field of medicine, each one of us seem to choose which way we want to die. The fear comes with seeing the discomfort that some people endure at the end of their lives. In our embodied state, it is hard to understand or to experience the near conscious state. Kate writes; that for her she has accepted her shortened life span, as she says, *“I am still going to die though. Death itself does not scare me; I came to terms with the fact that this illness is going to cut my life short.”*

Kate imagines the worst death and for her it is a bowel obstruction. She has “grave” concerns regarding her EoL experience, she is “petrified” having been the witness of death. She ponders on how it will be for her. It is interesting that she is not sure why she has been *“thinking about death and dying”* now she is back to some sort of health she can take some time to reflect on the future rather than struggling in the moment leaping from one battle to another, trying to control her symptoms that were related to pain and illness.

Once again Kate finds herself in hospital with an infection, she laments that her newfound freedom had been again taken away. She writes; *“Why can’t I have a little peace? I don’t remember signing up for all this when I agreed to chemo. I am truly miserable”* (p.2452). On her WordPress blog, Kate writes about the many side effects of the chemotherapy, which she says she had to undertake to continue living. But she says chemotherapy has left lasting side effects that she is now coping with.

Kate feels disabled by the many side effects of her treatment. She is unable to play her flute due to the loss of sensation in her hands, she is annoyed that she was not informed of these side effects before her treatment. She expresses how she feels, when she writes:

So not only am I a menopausal woman at the age of 33 but the cancer and the treatment has also pilfered much of my sexuality. I don't ever feel sexy these days. I have major body image issues. I find it hard to let Chris near me. My body has become this 'thing' that gets examined, scanned and poisoned; examined, scanned and poisoned. It's almost like it's no longer part of me. It's scarred and disfigured. No matter how pretty the dress is I don't feel pretty anymore. (Granger, wordpress.com., 2013).

On her WordPress blog site titled 'Charlie (2013)' Kate writes unashamedly on her feelings about her body. She gives the reader a very clear insight on how she feels after her treatment. Kate openly discusses how she feels as the loss of her once unscarred body, "*I have major body image issues... My body has become this 'thing'*" and as a 'thing' she feels, disembodied an observer of the treatments, the essence of herself feels separate from her body. She refers to her body as "*it*" and just to add to her misery, she writes that she doesn't feel "*pretty*" anymore.

5.2.2 On Materiality

When returning to hospital for more chemotherapy Kate confides in her doctor that she is feeling miserable and fed up with the treatments and sickness associated with chemotherapy. She writes that she has been thinking further about "*the burdens of treatment*" (Granger, 2014, p.2539). She comes to the realisation that she should stop her chemotherapy, whilst she says that she is in tears about the decision she knows that she just can't go through further treatment. She has decided that she has done her best thus far to maintain her life. She shares how she feels when she writes:

I just want my old life back, even if that is just for a couple of months. I really cannot face feeling this ill another two times and who knows what

horrible painful complication I will acquire next. (Granger, 2014, p. 2546)

Kate explains her courageous decision to discontinue chemotherapy to the medical staff she is “*sick of feeling sick!*” Kate finds a peaceful comfort in her resolution reflecting on her time and says that she has learnt a lot about herself and through this experience she knows that she will be a better doctor, she writes:

Who knows how long I have but I am determined to remain cheerful, to enjoy life to the full and always to remember there is someone out there worse off than me ...As a symbolic act when we return home Chris and I banish all the no longer required medical equipment from our bedroom. It is refreshing to have our dressing table as a dressing table gain instead of a mini treatment room. I am not at all in denial about my illness, far from it, but the constant reminders around the house have been getting me down a bit. (Granger, 2012, p. 324)

Kate is appreciating the beauty in her surroundings after being couped up in a hospital for the previous six months. When she returns home, she tries to reduce the clutter of medications from sight. As she says she is not in “*denial*” rather she is trying to diminish the depression related to her prognosis.

5.2.3 On Relationality

On her WordPress blog Kate writes a letter to her child that she will never have, it is filled with regret and is strikingly poignant. Simply, Kate writes of her dream to have a son, and says goodbye to that once thought of reality. She says that she is very sad about this writing that; “*The cancer stole most of my fertility as it grew inside and*

destroyed my ovaries; the intensive chemotherapy finished off any hopes that we would ever have children” (drkategranger.wordpress.com).

Kate was encouraged by others to write a second book ‘On the Bright Side’ and she gives thanks to Chris her husband for coming up with the title. She also writes that her husband has been extremely supportive of her decision to stop the chemotherapy treatments. Other relatives she writes are not so convinced that it was the right thing to do. In her second book, she documents her story since discontinuing the treatments. She now writes that it is time for palliative care and that she would like to sort out advance care planning, she writes that she thinks it would be of benefit for her husband. Kate wishes to get back to work as soon as possible. She writes:

I am used to a busy professional life and have put so much work into my career that it seems such a shame to throw it all away and ‘retire’.
I am sure that I can manage a few days a week at work, leaving me plenty of time for Bucket List activities and seeing everyone. Quite simply I love my job and always have. (Granger, 2014, p.120) ...It is very isolating being ill and I do not think I appreciated the social aspect of work before it was taken away from me. (Granger, 2014, p. 130)

Kate sees her role as a doctor important to maintain her self-esteem and keep occupied. She says, “*Quite simply I love my job*” it doesn’t make any sense to her to give up something that you love to do. On her relationship with her husband she feels that she is unable to help him with his grief. Kate saying, “*I am the one who is dying*” as if she wants to yell these words out and she writes, “*Pull yourself together darling.*” Kate has also conjured up an awful state of dying in her mind “*facing potentially a painful, protracted and horrible death*”. Although she writes that she has come to terms with the dying there is no escape from the feelings of fear of the final goodbye. She seems confused here as she writes “*perhaps I am being selfish*” nevertheless there is a lot of unspoken emotions yet to face (Granger, 2014, p.689).

Kate shares many stories in her second book ‘On the Bright Side’ on how she has managed to improve the quality of care for her patients through the insight that she now has on death and dying and through effective communication skills. Her colleagues also acknowledge the many benefits of reading her first book and how it has improved their own doctor-patient relationship. Through having a terminal illness Kate shares how her practice of medicine evolved following her diagnosis, she writes, *“I am now much more interested in my patient’s lives as individuals”* (Granger, 2014, p. 991).

Another young woman who is also living with sarcoma was inspired to write to Kate. They arranged to meet up at the next chemotherapy clinic where over a cup of coffee they share the experience of living with cancer. Kate regrets that they have not met sooner but is grateful that they can now share their experiences. This gives them a special and unique bond. On writing about her new friend Kate. On her new-found friend who is also experiencing the same illness Kate shares that she is so happy to now share her experiences, while lamenting that she wished she had met her earlier, she writes, *“...and I hope I can stay in touch with my new-found cancer buddy”* (Granger, 2014, p. 2332). Many people have written to Kate asking where she gets her inspiration from and that they find her ‘inspirational’, but she is not sure what all the fuss is about, and she writes:

Where do I find my inspiration? What motivates me to get out of bed in the morning? My family, my work and especially my patients, my kitchen, my music... Simple things in life that allow me to be creative, to try and do some good and to live well while I have the chance...
(drkategrangerwordpress.com., 2013)

Kate’s inspiration is simple she says; *“My family, my work and especially my patients, my kitchen, my music...”* Following two years without the cancer ruling her life, Kate is once again in pain and she knows that the cancer must have grown

throughout her body. She writes a heartfelt letter to the cancer on her WordPress blog site titled ‘Dear Cancer Part Two’:

So, here’s the thing. I’m not quite ready to let you take my life yet. I have a few more things I’d like to achieve. I want to look after a few more patients of my own. I want to finish my third book. There are so many people out there I would love to meet in real life. So, I’m afraid I’m going to have to poison you again in the hope that we can shrink you a bit and send you back off to sleep. You are nothing without me, as when I die so do you, so please be obedient and let the drugs do their work on you. I know the time will come when you get your own way, but I’m not going to let that happen just yet.

(drkategranger.wordpress.com., 2013)

Kate writes that she doesn’t hate her cancer that ever since she was a young girl she has been fascinated by human cells and that even though the cancer cells are menacing and interrupting her life they are part of her and to hate the cancer would be like hating herself. Further that she cannot change what has happened. She just wants to live her life to the fullest. About her cancer returning she addresses it personally, saying: “*You are nothing without me, as when I die so do you, so please be obedient and let the drugs do their work on you*” (drkategranger.wordpress.com). By distancing herself from the cancer it enables her to find some strength to continue. The medications are her defense to fight the ravages that the cancer is causing.

5.2.4 On Spatiality

On her blog, Kate writes exactly what matters to her and what she wants to occur at the time of her death. Kate is very clear about not being in the hospital when she is dying, and she also shares her funeral wishes on a website dedicated to increasing the normalcy of death and dying within our Western Anglo-Saxon society.

I do not want to die in either a hospital or a hospice. I would like to die at home in an environment that smells familiar, with familiar things around me and the ones I love nearby. But my experience as a clinician teaches me that we are not all the same and the concept of a good death means very different things to different people.

(drkategranger.wordpresspress.com, 2013)

Kate is very strong in stating her wishes when she dies, she would like to be at home surrounded by her family. Kate has spent some time ensuring that her funeral plan is in place, she has chosen her choice of music and she writes that it is; “*my vision for a good death...*” She describes in her book ‘The Other Side’ all the treatment that she endures and the side effects. Following the treatment, she heads home only to return to hospital with an infection. She describes the cancer treatment room as being more like a hotel than a hospital.

I have been wide awake since 4am on the morning of my birthday. The box of tissues is rapidly running out. I have not had a good cry in a while. The fact I am still in hospital for the day is not really what is distressing me... I just cannot stop thinking that I will probably not be having another birthday so what's the point. (Granger, 2014, p. 2061)

She does however appreciate the bed being comfortable. Kate writes about having “*a good cry*” and the real cause of her distress is wondering if she will ever have any more birthdays, so she asks herself “*what's the point*” of going through all this treatment and sickness. She is pleased when during this treatment, she is offered complimentary therapies and is surprised on the effects that alternate therapies and she

finds this comforting. This is the first time in her illness her focus has not been on her biomedical knowledge.

5.2.5 On Temporality

Kate writes in ‘On the Bright Side’ that she has accepted her “*impending mortality*” (Granger, 2014, p.588) and that her life will be cut short. She says that she has never really felt anger about the situation although the people around her find it difficult. However, she says that people soon come to accept her attitude when it comes to dying.

They soon learn to accept my outlook though. They have to. I am cheerful and outwardly happy. Life is what it is, I cannot change what has happened to me or what will happen in the future and there is absolutely no point getting gloomy about it all... I am therefore very open about my dying and expect those around me to be too. I regularly talk about ‘popping my clogs’ even to people I am not that well acquainted with and my black humour on the subject often shines through. (Granger, 2014. p.604)

Kate is pragmatic as she continues living with a terminal illness, she writes that she is not “*gloomy*” and that she continues to hold television and radio interviews and to speak about her National campaign. She writes on her decision to accept her outcome by asking that others do the same thing, she shares, “*I am therefore very open about my dying and expect those around me to be too.*” Kate in her wisdom is giving sound advice to everyone she meets, none of us know the time of death, neither does Kate but what is Real for her is the experiences that she has gone through and the certainty that she is moving progressively towards the end of her life. However, she chooses not to be gloomy, but instead opts for happiness. Her body is showing the signs of her fragility, she writes further on knowing that her death is imminent:

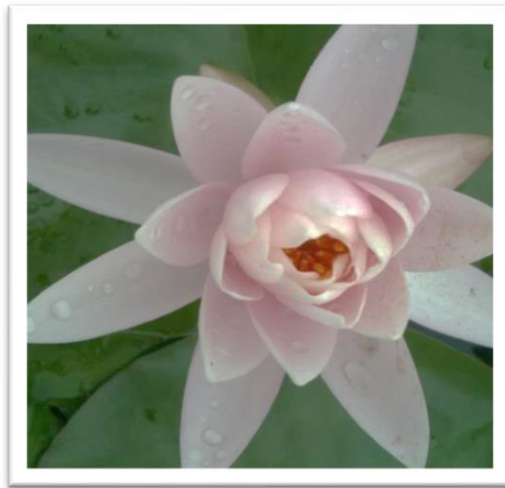
In a way I feel lucky to know roughly when my own death will occur, so I can prepare properly for it. I have been writing letters to everyone I care about for when I do die telling them what they mean to me, making a memory box for Chris and ensuring my affairs are in order...I feel more peaceful that these tasks are complete, and I can now park them at the back of my mind and crack on with living my life. (Granger, 2012.p. 624)

Kate writes that unlike others she “*has been given precious well time.*” She has put her affairs in order and written farewell letters to her family and friends. She has organised her material things so that she is not leaving behind too much stuff. And as she says she can now “*crack on with living my life.*” On her WordPress blog Kate continues to personify her cancer she writes frequently to her cancer as if on the outside looking in. She wishes her cancer a ‘*happy Christmas and New Year*’ and speaks in the third voice when addressing private issues on her posts. She writes in Dec. 2014, ‘Dear Cancer Part 5,’ that she will not let the cancer stop her from achieving her goals and she lists what she has managed to achieve since her diagnosis. Through her ‘#Hello My Name Is’ campaign, she encourages medical personal to introduce themselves to the patients in their care. This has become a National United Kingdom campaign has increased the awareness of good communication skills between medical staff and their clients. Kate also writes that the number of patients who are afraid of discussing their death saddens her.

Despite national campaigns on raising awareness of death and dying the taboos surrounding death remain strongly entrenched within our cultural norms. Being gravely ill none of her patients have been approached about resuscitation when they were well. As she says it is too late to discuss this issue at the time of death (Granger, 2012, p. 1306). The last words of this story lie with Kate as she struggles through the torment of the cancer and all that it has thrown her way.

I don't need to start this letter with the convention "how are you?" because sadly I know exactly how you are... Not only were you happy to grow all your original tumours but somehow, you've also wheedled your way back into my liver, and even taken up a new residence in my lung... As a newly diagnosed 29-year-old girl I thought I knew exactly how I wanted things to be with regards to my treatment. As hardened and experienced 34-year-old cancer patient I now know I have to face each decision at a time and cannot predict how I'm going to react emotionally to any of this. It feels like I'm on this round about that is gradually spinning faster and faster with no opportunity to jump off.
(drkategranger.wordpress.com., 2016)

On her wedding anniversary, July 23rd at the age of thirty-four Dr Kate Granger died.



Researcher reflections 12: Tears for Kate.

A lily rests on the surface of a muddy lake, raindrops like tears are visible on the petals.

Photo credit: J. Carter

5.3 ABBY BROWN: RESTORATION

Abby Brown was diagnosed with breast cancer at the age of 54 years. She is married with two children and loves her career as a primary school teacher. She is currently undergoing chemotherapy treatment at her local clinic on a weekly basis. In her book ‘What about Hair Down There’, (2014) she writes that she is about to embark on her second bi-weekly round of chemotherapy. It has been four months since her diagnosis, and she is now coming to terms with requiring regular hospital visits. She marks this time in her life by the seasons. Recalling that the thoughts of “green grass, spring flowers and warm breezes” (p. 93) she reminds herself that it was the two-month stage of her disease and now winter has set in, with snow on the fields.

5.3.1 On Corporeality

Abby’s physical appearance is changing as she endures her chemotherapy treatments. Her appearance is important to her as it is to her children, and her changing physical appearance is consuming her thoughts. During her writing shares her thoughts about her self-image and how she has physically changed throughout her illness. Abby writes:

I still find myself caught off-guard when I look in the mirror, I feel like ME on this inside. Our beings are so much more than the physical body. My mom and I talked about this a while back...how aging doesn't seem to make you feel like a different YOU. It does allow for a more mature, wiser, patient being, but there's still sameness in the essence of our SOUL. (Brown, 2014, p. 175) ...It's like dirty laundry. Life's challenges are unavoidable. Thank goodness for opportunities to immerse in soap and water. Sometimes coming out clean takes getting jostled around, but we can emerge to dry-out and take on the next mud pile. (It's better

than getting stuffed in a drawer, unchallenged, unworn). (Brown, 2014, p. 176)

Abby is witness to the physical signs of the illness, which are evident in her reflected image. Although she can see the physical changes occurring the essence of herself remains untouched by the ravages of her treatments, she writes on her interpretation of the “*essence of the soul*” and what the idea of the “*soul*” means to her, and her mother, while she knows that her appearance has physically changed during her illness she feels the same and she knows that she is greater than her “*physical body*.” She refers to her treatments as being stuck in the ‘*mud*’ she is dirty with mud but looks forward to being clean again, even it means being “*jostled around*” for a while.

While Abbey’s chemotherapy treatments continue, she gradually loses her hair. The title of her book is a testament to the changes that her body goes through. Her hair loss has a big effect on her youngest child who has taken some time to come to terms with his mother’s change in appearance. Throughout her treatments, she wears hats and scarves to hide her hair loss she describes the experience:

When I am ‘out and about,’ I am adjusting to glances from people. They don’t stare; but there is the recognition that I am wearing a hat or scarf as a cover-up of something BIG (and BAD). Sometimes you can sense they are rooting for you through their extra-warm smiles. I bet I could even get to the front of a long line via someone’s goodwill gesture-like those extended to little old ladies. I want to feel normal but am realizing I have to adjust to a ‘new’ normal for a while. (Brown, 2014, p.59)

On one occasion, she is fed up with the supposed need to hide her head, although she admits that she must become comfortable with a “*new normal for a while*.” The thoughts of her son coming to terms with her hair loss is foremost in Abby’s mind she shares the experience on how important a women’s appearance is to her and to others.

However, she does not want to be caught up in the facade of her appearance and writes that she is “*working of the guts to say, the hell with it*” her hair loss is synonymous with her illness and she finds it “*sad*” that other women cannot accept their appearance and hair loss when it is linked to illness. When as she writes if people say that beauty is on the inside, then hair loss should not determine who you are. Abby has decided to let her realness show through, hair loss and all (Brown, 2014, p. 106).

Abby writes in her book her about her ongoing struggle with feeling unwell due to the chemotherapy and radiotherapy. She had researched the outcomes of the treatments and halfway through her treatment she writes on how she feels:

Now I appear to be moving into the cumulative effect that leads to what they call chemo brain. It can be temporary, though sometimes lasts up to a year or more, and once was blamed on other things like hormone changes and aging. It's now recognized as a result of chemo treatment alone. (Shit!) What is chemo brain? (Brown, 2014, p. 113)

Abby lists a stream of symptoms related to the effects on the brain of chemotherapy, she writes, that she recognises the effect of “*chemo brain*.” She becomes concerned with the feeling of stomach acid, muscles aches and the pain that is burning her feet due to peripheral neuropathy. Feeling confused due to the chemotherapy effects on the brain she hopes that she doesn’t get lost on the way home. Abby is reflecting on the pain that she is feeling in her feet and saying that on listening to other complaints that at least she had pain, she writes; “*One from my Breast Cancer’s Bitchin’ club said her feet are still numb. I guess I can be grateful for the feeling of pain!*” (Brown, 2014, p. 119).

Abby now forgoes the headgear and writes on how her new hair growth has become a fascination firstly for herself and her family and then the fascination extends to friends and family. This new growth of hair is as Abbey says is a visible sign of recovery, she writes, “*I often find my hands checking out the new growth of hair on*

my head. I have moved into the stage of being “felt-up-there” by others, as well” (Brown, 2014, p. 129). Perhaps the importance of now showing hair is that she is letting people know that she will recover and that she is no longer wearing the ‘sick’ label. She writes on other outward signs of her body recovering from the heavy rounds of chemotherapy, like her fingernails.

Abby (2014) writes frequently on the state of being normal. She wants to feel normal, and as she says the signs of her body image, her hair, and her fingernails are all signs of normalcy for her. She writes that returning to the classroom with the beginning of the school year in the community that she loves, “*will also return me to a state of normalcy*” (p. 130). When Abby’s hair finally grows back, it becomes a conversation piece with her family and how she now looks with silver grey hair. She decided to visit the hairdresser and it is interesting that in the beginning losing her hair was difficult now with her hair growing back she has lost the “*badge of courage*” (Brown, 2014. P. 178).

5.3.2 On Relationality

Abby also had a close relationship with her rescue dog, Taira. Following her initial diagnosis, she writes how Taira brought “joy” to everyone including her children who found comfort in the dog when their “*Mom was sick,*” (Brown, 2014, p. 157). Unfortunately, before Taira was adopted she had a previous history of aggression. Taira was caught attacking another dog and the advice given to Abby was that she should be euthanized. Abby describes the incident in her book and says the “*tears flow quickly as I think of her*” (p. 157). Abby writes her thoughts on the loss of Taira:

Life is filled with love and loss. But faith puts her spirit by my side. She sent a sign through Gus that she is alright. He placed his paw on to my forearm yesterday, in the same fashion Taira always did. It’s not something he had ever done before. My Mom texted me a message, “Angels sent Taira to you.” And in a symbolic way, I see her absence in our lives as a sign that so is the cancer. I miss her. (Brown, 2014, p. 157)

Abby connected the death of her dog with her own recovery, her religious belief fortified her resolve that Taira's death was somehow linked to her cancer. Abby acknowledges the importance that rescuing her dog has made to her recovery and writes that she will. "... miss her." Abby's relationship with her mother is also important, she often refers to her mother throughout her book. Here she writes "*my mother texted me "the angels sent Taira."* She often retreats to her mother's house for a rest and to feel safe. Her father is struggling with dementia, which is difficult for the family. At the end of her radiation treatment and on the verge of returning to work Abby writes: "*Cancer is hard on families, too. But today, as my mom and I hugged and sobbed on the Capitol grounds, at least I could say, it's over. We are done with this*" (Brown, 2014, p. 147).

Abby Brown reiterates that the pain caused to others by her illness increases her anguish; "*yet our hearts ache for the pain we have unintentionally inflicted on our loved ones*" (Brown, 2014, p. 191). The distress that Abby endures is also evident through the effects that her illness has on her family. She shares an experience on watching another patient receive treatment. She writes:

It is a big deal, and my emotions became raw as I heard the nurse go over chemo effects on blood cell counts, what to do in case of fever, and so on... She was nodding her head in what I know was a fogged understanding as his eyes fill with tears. She was being brave. It took me back to the first day in the chair and I wanted to take it away for her, from both of them... (Brown, 2014, p. 163-164)

Abby recalls the experience of her first chemotherapy session through watching another person and she is thrown back into the experience, she is wiser now after all the treatments and feels a sadness for what she knows is to come. She shares how she could immediately relate to the women who was undergoing treatment for the first time and she acknowledges that her emotions became "*raw*."

5.3.3 On Spatiality

Abby has a strong religious faith and quotes her Paster's sermon on 'Holy Places' in her book. Her husband has built her a bunkhouse on their property. To Abby this is her sacred space. In this experience, her personal retreat where she can escape. She writes:

It is the last place the sun shines as it sets and is surrounded by poplar trees that whisper in the wind. Tony also built two swinging beds and a storage box for bedding. On one of our warm days this past week, I cleaned the windows and floor and was finally able to spend my first night of the spring season being lulled to sleep by the sound of the leaves and frogs peeping. Excuse my reference to the demons below, but it has been a hell of a long winter. I am grateful for this little sanctuary out back; it allows me to feel connected to the higher beings of our universe at what seems to be a 'mid-treatment' crisis. (Brown, 2014, p. 97)

Abby shares how she feels to be surrounded by the sights and sounds of nature, she writes how comfortable it was *"being lulled to sleep by the sound of the leaves and frogs peeping ..."* And she shares how grateful she feels for this interlude in her treatment, she shares how her peaceful space allows her to *"feel connected to the higher beings"*

During her chemotherapy treatments Abby takes along a doll called Tenacity, she writes that the name of her warrior doll has significance for her wellbeing as it relates to being; *"Not easily dispelled or discouraged: persisting in existence in a course of action"* (Brown, 2014, p.106). Abby is doing her best to surround her space with objects that instil courage. Abby writes that since her illness her bedroom space has become her *"recovery room."* She has a portrait of herself and her husband made which symbolises a new beginning *"a real return to health"* She prefers not to have her treatments surround her bedroom space (Brown, 2014, p. 183).

5.3.4 On Temporality

Abby writes in her book that the time she has spent unwell seems surreal. She writes that she feels only other people get cancer. She shares her experience, writing:

Despite a diagnosis and months of treatment, I still think cancer is something that happens to other people. It seems unreal to me that I now belong to an exclusive club and have an instant bond with the members I meet every day. Unfortunately, these days it is not a road less travelled. There are many of us. It's not a journey; it's a bumpy road trip. Tomorrow I return to the class room. Where has the time gone? Living in the moment can be a magic charm for getting through even the most unbearable of life's challenges. It's with faith that I have learned worrying about the future is not an effective use of energy.

(Brown, 2014, p. 147)

Abbey writes that having a diagnosis of cancer feels “*unreal*” and she now joins other people with cancer in an “*exclusive club*.” She can’t believe how quickly time has passed and writes, “*Where has the time gone?*” She also shares her experience of how the possibility of having metastasis invades her dreams. She writes:

Last night I had a parallel cancer biopsy dream. Friends in my ‘club’ have mentioned that they are nervous before their annual check-ups. I’ve said that I didn’t think this would bother me. But maybe I am wrong. In my dream the nurse was taking samples from the back of my neck. It didn’t hurt – I was being tough. The thoughts of some kind of

cancer metastasising elsewhere in my body were a part of this nocturnal experience. (Brown, 2014, p. 149)

Abby is having second thoughts about the cancer returning she thought that it didn't bother her but now she is dreaming that a biopsy revealed further metastasis in other parts of her body. On coming to terms with what she has been through in the last year Abbey describes the experience as surreal and she knows that the illness has her way of being. Now that she has been given the cancer free diagnosis, she writes that she has no intention of attending chemotherapy again.

5.3.5 On Materiality

Abby describes the drugs as they are infused into her and she names each one being familiar with their side effects. She recalls the many hours sitting in a blue chair in a treatment room and how it also requires many more walks with “*my bagged friends*” on the five-wheeled-stand to the bathroom-all strings attached (Brown, 2014, p.93.). Her material world has now become filled with the objects of her treatment regime. Abby prefers to befriend her enemy, her “*bagged friends*” are the bags of chemotherapy that are being infused into her blood stream. On her return to her teaching position Abby and her students get together and knit hats for premature babies at the local hospital. The strong memory of knitted hats reminded Abby of a time when she really needed a knitted hat through her own treatment and of a close friend who was diagnosed with breast cancer. The hats hold strong memories of her illness.

By chance, Abbey met in the local supermarket, the mother of a young man who also shared living with cancer on the Caring Bridge website. She described the experience of the meeting between them as a metaphysical knowing bet between two people who share a lived experience:

It may not be recognised in the normal settings of our lives, but the connectedness with one another on earth is apparent for some of us, in ways others may never experience. In the moment of a simple hug, surrounded by potatoes and tomatoes, I understood ours, Laura's and

mine. One day at a time, and life can shine through in writing and dancing, in songs and prayers. Angels watch over us all... I'm so glad to have finally connected with the mom of Zach, who I've mentioned several times in this book. (Brown, 2014, p. 195)

Abby throughout her book has written on the importance for her to take one day at a time. Here she finds comfort in her connection with Zach's mother, they share a link through illness, sharing a sense of a deep emotional connection. Abby continues to teach primary school and some of the proceeds of her book go to 'Caring Bridge' a non-profit organisation which offers amongst other services a free website access for journal sharing. Abby's book 'What about the Hair Down There?' was published on her 55th birthday. It is a compilation of her 'Caring Bridge' blog entries, which were released as a Kindle edition it is available worldwide via the Internet. Abby has published several videos on YouTube and writes of her experiences on the Blooming Twig website, who are the publishers of her book.

"One day at a time, and life can shine through in writing and dancing, in songs and prayers" (Brown, 2014, P. 195).

5.4 ZACH SOBIECH: RESTORATION

Zach was diagnosed with osteosarcoma in 2009 when he was 14 years old. Zach's story has been told on the Internet, through a blog site and through his music. I found Zach's story through Abby Brown's blog, where she talks about his resilience and courage to face his cancer, she drew strength from listening to his story and to his music. This is Zach's story told through his words on the final chapter of his life. Throughout the beginning of his illness he visited the hospital regularly for chemotherapy infusions, which left him feeling physically sick and very bald. Laura, his mother writes, due to the obvious signs of baldness people knew that he had cancer. A year later Zach went through surgery in 2010 to remove a tumour from his hip, which meant that he would not be able to walk without a limp. His hair grew back slowly after chemotherapy making his diagnosis not as obvious to others as it was previously.

Zach showed his determined resilience to cope with his disease when questions were asked about his limp and he would often comfort people who were consoling him. So, that he didn't have to go through this drama when he was approached by inquisitive people, he would invent a story about a car accident. This would then not elicit such a sorrowful response. If he mentioned the word cancer it would evoke an outpouring of grief-ridden stories from others.

Laura Sobiech (2014) writes that she found comfort when people acknowledged the fact that her son had cancer and how awful it must be, rather than sharing their own stories of illness and giving her advice on the subject (p.58). In the beginning of his illness no further tumours were found in Zach's body therefore, the family thought he would be clear of the disease. This understanding could not have been any further from reality.

5.4.1 On Corporality

Zach was to receive Confirmation (Catholic ritual of baptism) shortly after his chemotherapy treatment. Although he was physically tired and sick his mother writes that he was determined to go the cathedral for the service and describes his frail physical appearance.

We walked into the beautiful, cavernous cathedral with its stone arches and marble floors as fifteen hundred people were taking their seats. As Zach made his way to our reserved pew, one by one his classmates caught sight of him and hopped up to greet him; everyone was surprised at the small miracle of his presence. The next miracle would be getting through the entire Mass without having to use the restroom, as he was wearing a pack with two litres of fluid being pumped into his system. Still recovering from the hip replacement, bald, pale, and sick, the joy on his face was evident. Cancer would not win- it was just a minor setback. (Sobiech, 2014, p. 65)

Despite his illness and physical disability Zach was determined to attend his confirmation. His mother writes, that although he was recovering from a hip operation, he was still happy to be attending his confirmation and that, that he was, “*Cancer would not win- it was just a minor setback*” (p.65). Unfortunately, by the time of Zach’s sixteenth birthday in 2011 the cancer had returned. Chemotherapy was recommenced and lesions were found in Zach’s lungs. Zach’s plans for a European holiday had to be postponed. He requested his mother to shave his head so that he didn’t have to go bald slowly. Zach shares his notion on the meaning of pain:

Physical pain is a joke. It’s just Satan’s way of messing with you and trying to get you to feel sorry for yourself. Mental and spiritual pain are different. That’s the real battle where faith and prayer come in.
(Sobiech, 2014, p.94)

5.4.2 On Relationality

While at home in his bedroom Zach and his friend spontaneously planned a holiday despite his illness. Laura writes that together the friends spent a lot of time planning their trip. When they announced the trip to the family Laura writes that due to loss of employment caused by the need to care for Zach, they didn't have the available finances. Then to his mother's surprise a woman approached her who had been following her story on the Caring Bridge website (a website dedicated to people of the Catholic faith who wish to share their experiences). This woman wanted to send Laura and her family to Lourdes (a city of spiritual worship) and together with a friend they decided to plan a benefit to raise some funds for the trip, Zach shares his experience on the family trip to Paris and Lourdes:

Lourdes was so amazing. I didn't really know what to expect, but it was just so peaceful. I thought the baths were the best part. It was so weird how I felt my whole being was clean and refreshed afterward. If I lived there, I would go in the baths every day... I got everything I came for, and I am ready to go home. (Sobiech, 2014, p. 128)

Two months after the benefit, the family planned a trip to Europe (Sobiech, 2014, p. 100-101). Zach states how he feels after his trip to Paris and Lourdes that he felt his "whole being" was cleaned. A little while after the family trip it became evident that Zach's condition was terminal, and that Zach had the option of having surgery to remove his leg and hip. He declined as he did not want to spend his last days in hospital. Instead he opted for chemotherapy that would be given at home.

After a visit with the oncologist and a discussion on his illness he said to his mother on his death; "*when the time comes, I want to have another party*" (Sobiech, 2014, p.137). Zach had always played the guitar and during his illness he turned to music to find the words to describe his emotions. When writing songs with his friend Sammy he told her of a song that he had been thinking of for some time and he left the lyrics. The words written and read that day have become a song 'Clouds' that has been heard

by millions of people around the world. It was released after Zach was given less than six months to live and in 2013 ‘Clouds’ reached the number one place on the top of the charts. The video also won an award for musical composition and arrangement.

5.4.3 On Temporality

Zach was interviewed many times on You Tube and on Soul Pancake sharing his story of living with a terminal illness. His mother states that it has been translated into twenty-one different languages and has been viewed by over ten million people (Sobiech, 2014, p. 336). When being interviewed Zach shares his feelings on living and dying Zach says, that he and Amy, his girlfriend, have many dreams to fulfil he is not in denial about his impending death.

What makes you happy is seeing someone else smile because you put it there that's what is awesome about living this world. That you can help people, it's really simple actually, it's just trying to make people happy. Maybe you have to learn with time, maybe you have to learn it the hard way, but as long as you learn it you're going to make the world a better place. (Sobiech, 2013, soulpancake.com)

Zach writes that he just wants to “make people happy” before he dies. Zach and Amy plan their marriage and the number of children that they want together. Although Zach knows that this step is not likely to happen, he says, “it’s just like your ultimate dream kind of thing” (Sobiech, 2013, soulpancake.com). He shares that even if it doesn’t happen most people plan their dreams, and that four is a great number of children to have because it worked well for his family. Dreams are real, and extremely important they support living even in the face of dying, Zach is aware of the closeness of his death, but his dreams sustain him for now.

When we start to cry. That's when we sit down and plan it all out. It's like your ultimate dream kind of thing and you know mine obviously probably won't (happen) and "Till death do us part and I'm dying so we better get on this. (Sobiech, 2013, soulpancake.com)

When Zac and his girlfriend are at their lowest point emotionally, they choose to “dream” together to “plan” out their future until “death do us part.” Their dreams give them an alternate reality until they can no longer dream.

5.4.4 On Materiality

During the Soul Pancake interview Zach was asked about how he dealt with life after his diagnosis. He said that it really didn't make any sense to him and that he felt disconnected when he was in the hospital. He says when he found out that it was cancer it was “*unbelievable*”. While sitting in the hospital Zach would keep himself busy sorting out what he thought was the most inexpensive but best performing car. His father says that Zach has big dreams. His parents surprised him when he came home by hiring a car for him to drive. Zach face lights up with joy at seeing the car arrive at his house.

He is delighted at being given the opportunity to drive his dream car and says: “*Being able to experience these things, it helps a lot because you can either sit in your basement and wait or you can get out there and do some crazy stuff*” (Sobiech, soulpancake.com 2013). Zach has written songs for the people he loves at first, they were personal, private but soon the world would listen. Zach shares how he feels about music:

... Music is a way that I can express myself without having to burden everyone else. My closure is being able to get my feelings into here songs, so they could have something to remember me by or lean on when I was gone. (Sobiech, 2013, soulpancake.com)

Zach is very clear about the importance that song writing is for him at this time of his life; he fills his days with doing things that he loves like, fast cars and writing songs, facing the finality of his life, he says, “... *Music is a way that I can express myself...*” (Sobiech, 2013, soulpancake.com)

5.4.5 On Spatiality

Since being ill and following his diagnosis Zach has spent his time with his family at home, being cared for by his mother, until his final days when he once again went to hospital. Zach in the Soul Pancake (2013) interview ‘My Last Days’ (aired on YouTube) was filmed within his familiar surroundings, his home and although he does not mention this, he does not want to stay any longer than necessary in the hospital. He gives a tear-filled final goodbye to his family members and tells them how much he loves them.

Zach shares his feelings on his life thus far, and says, “*My closure is being able to get my feelings into these songs... It's really simple actually; it's just try and make people happy. Maybe you have to learn with time, maybe you have to learn it the hard way, but as long as you learn it, you're going to make the world a better place*” (Sobiech, 2013, soulpancake.com). On his experience facing his mortality, Zach, shares his insights on what death means to him.

Death is just another thing on the agenda kind of. Yeah, it's scary but the only reason it's scary is because you don't know what's next or if there is a next, so it's kind of like sitting in the dark. So, you can either choose to be freaking out in the dark and thinking okay what's out there or you can just relax and fall asleep and just be happy and content with everything. I want to be remembered as a kid who went down fighting and didn't really lose.

He says that death is just another part of life, and that it is only scary because most of us do not know what to expect, then he says, that he has chosen his path and that is to be “*happy*” and “*content*.” On May, the 20th 2013 Zach Sobiech died at home

surrounded by his family. The proceeds from Zach's song Clouds has raised over a million dollars to fund his foundation The Zach Sobiech Osteosarcoma Fund. I chose the image (Researcher reflections,13) below as an expression of Zach's love of music.



Researcher reflections13: Music is life for Zach, the guitar rests on the pillow.
Source: Pixabay.com

5.5 CLIVE JAMES: RESTORATION

Clive James was diagnosed with emphysema and leukaemia in 2010 at the age of seventy-four. Since the diagnosis his life has changed in many ways, especially his declining physical energy, therefore he throws his final years into writing. I discovered Clive's story in an interview on the Internet and he continues to be interviewed regularly giving his insights towards his death. Through his poetry, he has begun to say good-bye, producing 'Sentenced to Life' a pun on his newly discovered death sentence. In 'Japanese Maple' he writes about living long enough to see once again the flame orange and red colours of the tree. Although he was not given very long to live, he has surprised himself and others on his survival thus far.

5.5.1 On Corporeality

Clive during an interview with Andrew Marr (2014) on the British Broadcasting Corporation (BBC), says that his health is failing. He hardly ever refers to his experience with chemotherapy and hospital or his physicality, only at times it appears in his poetry where he says he treats his experience seriously. He appears frail, thinner than his usual robust build. He has a large bandage on his scalp covering a treated cancer, which he laughs off as a war wound. He says when talking about his illness in the BBC interviews that: "*The truth is I'm surviving everything I'm not supposed too.*" Then he reads an excerpt from his poem 'Balcony Scene' in 'Sentenced to Life,' (2015)

It is obvious that he is seriously describing his fragile condition in this poem, when he writes; "*Old as the hills and riddled with ill health, I talk the talk but cannot walk the walk. Save at the pace of drying paint. My wealth of stamina is spent*" (p. 558). He is not only referring to his physicality but also his spirituality, writing; "*my heart has spiritual duties too, and failed at all of them*" and he refers to the pain that he has caused on those who are the closest to him. In the poem, he also refers to himself writing, "*as a hawk now nailed to the perch*" once full of energy now nailed in place. His heart he says, "*shows nothing wrong*" (p.558), yet he is full of regret for past remises.

When Marr asked the question about a certain clarity that comes when others say they are facing the end of their life, James says, I feel the same, I feel there is new clarity, a new sanity, perhaps, but there needed to be because when I was young, I had lots of energy. I was a real bundle of energy I did everything wrong and now I have to sit back and contemplate, there's time to think and I do think... There is a lot of regret and remorse in the book (Sentenced to Life). (James & Marr BBC, 2014)

Clive agrees that he has found a new “clarity”, since his illness. He also states that he has time now, “time to sit and think”. On questioning about Clive’s ongoing health issues, Clive talks about how fortunate he is that he doesn’t have to suffer pain and if he was it would certainly make a difference to his concentration and writing. However, when he is interviewed in 2015, the bandage is now gone from his scalp leaving a large visible scar. During the interview in the Guardian (2015) Clive James reiterates: “I’ve got a lot done since my death.” Further on in the interview, Clive reveals his fears about his illness and health. On the thought of having pain, he says, “I don’t know if I could concentrate if I was in pain. I’ve never had to stop... I’m about to have some more chemo, which I haven’t had in years. I always knew that leukaemia would catch up with me” (James & McCrum, 2015).

5.5.2 On Relationality

Clive dedicates his book ‘Sentenced to Life’ to his wife Prudence Shaw. Throughout the poetry, he laments his past mistakes and makes apologies to his family. When asked in the BBC interview by Marr (2014) whether he found it difficult to discuss issues related to death James responds:

With my loved ones, I just try to be entertaining and funny, and I always did. In my work and especially in my poems I’m serious as I can about it. It doesn’t seem to me to be a forbidden subject. It’s a good subject,

it's going to happen to everyone, for example, it really is (grinning, nodding his head) universal more so than love.

About death Clive says, that it is “*good subject, it's going to happen to everyone...*” and through his poetry he can be as “*serious*” as he wishes. In the interview with Marr (2014) he shares his love for his granddaughter and how his life now revolves around bursts of love, moments in time at which he grabs with enthusiasm. Marr reads the poem that is written about his granddaughter and Clive James says that he loves it when she comes into a poem, “*like Tinkerbelle*” is how he thinks of her and that “*she is the centre of our lives*” (James & Marr, in BBC, 2014). Clive's granddaughter appears throughout his poetry.

In the poem ‘Spring Snow Dancer’, he writes that he is, “*Glad for his long life as it melts away.*” He acknowledges that we live in “*continuity*”, a certainty of life and death and that no one escapes this ending, which he is facing. He also reiterates this statement in the BBC interview with Marr (2014). He is glad that he has lived a long life and is equally thankful for living a privileged life. In the poem above he makes mention of his granddaughter and laments that; “*Though soon I will not see her anymore.*” Most of the interviews with Clive via radio, television or the Internet are splattered with the word that live within his poetry.

I'm sick now but it's at the end of a long life in which I've been able to do pretty much as I wanted so I never forget I'm a man of privilege as a poet as a writer of letters as a reader it's a lucky, lucky thing to have been so. The theme of my poetry was luck not death... I'm trying to get back to my enthusiasm, poetry can't help it, I'd be lost without it, it's the concentration of sound and meaning, concentrated prose, and it sharpens you up. (James & Marr, in BBC, 2014)

Clive continues to refer to his ill health and the importance that poetry plays in his life, in the interview above he says that he is “*lost*” without his poetry. In his poem ‘Rounded with a Sleep’ Clive after a night of dreamy sleep where he is free to wonder to the beach, he shares with his audience a small snippet on what is install for him when he wakes and the reality that he must face. The truth of his ordeal is revealed here when he says, “*All day tomorrow I have tests and scans and everything that happens will be real*” (James, 2015, 471).

5.5.3 On Materiality

Phillip Williams (ABC, 2015) asks Clive James some soul-searching questions on death and dying, to which Clive responded saying “*that the questions were difficult at times to answer but the best questions usually are.*” Williams asks Clive how he would survive if he took away his writing and his books. Clive ponders on the question and his response is:

*...I think I suppose it all goes, and I can't see well there's always braille
but maybe that'll be the time when I start listening to music again. Yes,
I might get back to the Beethoven quartet and those two-lovely quintets
by Mozart's for any music experts... it's the Apex and it totally fully
consumes the mind just the other day on YouTube I dialled up Pavarotti
and his father singing together in a Moderna cathedral many years ago
now. They're singing that thing by Franck, Panis Angelicus it is sublime
it's a message from God.* (James, in Williams, ABC, 2015)

Clive reveals his love of music and states that this break in his usual routine will give him some time to enjoy music again. The question evokes the spirit of the music that he loves. He recalls the quartets that bring him peace and sing messages “*from God.*” This is an interesting statement coming from a self-proclaimed atheist. When questioned further about his faith and belief in God, Clive says that he wouldn't go so far as to say that he didn't believe in God. He said, “*It's not a very interesting statement*

to say that God exists and even less interesting to say that God doesn't exist" (James & Williams 2015). Williams (ABC, 2015) questions Clive on what has changed for him since his illness.

On speaking about his life before his illness, Clive says, *"self-awareness-I probably didn't have any before I got sick."* He then talks about the respect that he gained during his illness and his hospital says: *"my nurses, not just the doctors but the nurses who have to clean you up doesn't matter if my job is done at all but her job is vital"* (James & Williams, ABC, 2015,).

5.5.4 On Temporality

Repeatedly whether said in jest or simply just out of curiosity, every single interview with Clive since his diagnosis comes around to his impending death, which he thought would be earlier than expected. Clive reiterates, *"I am not dead yet, but I am running out of time."* In his recent interview recorded in October 2015, Clive appears to the untrained eye well enough, however it is easy to see from a medical perspective that he is very unwell. Clive is a well-known Australian celebrity, therefore the news of his illness travelled quickly through the media, it is little wonder that he has witnessed the *"fame of his demise."*

My obituaries were so fabulous," he twinkles in an opening gambit, *"I felt more or less obliged to walk the plank."* In a spooky echo of his own last chat show, it seemed as if he had become *"the late Clive James."* *Japanese Maple caused him some embarrassment, he says, finding the joke in his situation again. "It more or less promised that I would only live till autumn [2013]. But then autumn came – and there I still was, thinking, 'Shucks!'" But then, in a cartoonish twist of fate, he wasn't "a goner", as he'd thought, after all. He was the Comeback Kid*

from Kogarah, New South Wales. This, he concedes, is “all a bit embarrassing.” (James & McCrum, in Guardian, 2015)

His obituaries made the headlines in Australia and across the planet, he said “*My obituaries were so fabulous,*” but news, becomes old news very quickly leaving behind the fragility of the individual. It is interesting that James (2015) should feel ‘*embarrassing*’ to be still living. Given his illness and diagnosis he feels that he is now “*the comeback kid.*” I think this is a testament to his resilience to survive against the odds however, his death sentence remains, and his health is on a fast spiral to further illness.

5.5.5 On Spatiality

While reading James’s poetry, you get to understand the importance he places on the natural world that surrounds him. Words like, maple trees, flowers, sunlight and dew drops, fill the pages. His love of his home country appears many times throughout his rhythm and rhyme, feeling the hot sand, sea, surf and the smell of the eucalypts all have their part to play in the story of the end of his life. Clive conjures up images that are so familiar to Australians. Now throughout his illness he must be content with the sights and sounds of his new country. In the poem ‘Change of Domicile’ James shares with the reader the space that he has come to love but now it is time to say goodbye just when he is not so sure.

He is now coming to terms with his mortality as others have done before him. Finally, in an interview recorded by the BBC in October 2015 the question of Clive’s death that didn’t happen, pops up again. Clive responds in an interview on the Australian Broadcasting Corporation (ABC, 2015), and makes apologies for still being alive however he says to the trained eye he is very unwell.

When the question of Clive’s ill health is mentioned, Clive replies, “*Yes, I’m embarrassed about it (not dying yet), sorry about this, yes two years longer than I thought I might, I’m dying I just look remarkably cheerful.*” Ironically enough, Clive James writes a regular column in the online Guardian newspaper, which he has titled, Reports of My Death. He has recently (2015) reawakened his song-writing career. Releasing an album with the singer Pete Atkin. He says he frequently revisits his past to write songs, he finds himself doing a lot more these days.

During an interview from his London home, which was broadcast to Australia because he is unable to travel, he said on his death he felt that he has been lucky, he shares: *“So at the end I feel lucky not just not desperate and not sad no sound of my failings perhaps but not sad in general I feel lucky, natural ending there”* (Clive James, 2015). The image below (Researcher reflections, 14) is a child playing with drift wood that has been washed up on the beach. This is a typical holiday scene in Australia, which, is missed by Clive.



Researcher reflections 14: Images from home.

Clive recalls the time spent with his family on the beaches in Australia.

Photo credit: J. Carter

5.6 ANATOLE BROYARD: RESTORATION

Anatole enjoyed good health until the age of sixty-nine when he was diagnosed with prostate cancer. Now after the initial shock of the diagnosis, we follow Anatole as he documents his final story, where he is losing a sense of his own self-identity to him the thought of being without a sexual identity is also haunting him. As most treatments for prostate cancer leave the person with reduced libido, he wonders what may have induced the cancer within his prostate. He had documented his dying story, which was collated by his wife. He writes on his thoughts about having cancer, saying, “*Just as a novelist turns his anxiety into a story in order to be able to control it to a degree, so a sick person can make a story, a narrative, out of his illness as a way of trying to detoxify it*” (Broyard, 1992, p.20).

5.6.1 On Corporeality

Anatole is clear on his thoughts relating to the expected feelings that a dying patient should have. He writes on the known authority of the time Elizabeth Kubler-Ross and her stages of dying. Kubler-Ross spent many hours recording the emotional experience of the dying. Her book ‘On Death and Dying’ was published in 1969, she fervently argues that her project was not research and has been taken out of context. Kubler-Ross also says that her writings are a series of dialogues with dying people (Elizabeth Kubler Ross Foundation (EKRF), 2016). Here Anatole documents his thoughts on the then understood stages of dying:

The feeling of being unjustly singled out is a cancerous kind of thinking and can't get rid of it in Elizabeth Kubler-Ross's scream room. I'm sixty-nine years old, and I've never been seriously ill in my life-what have I got to be angry about? I think sick people are more frustrated by their illness than angry and that they should think about ways to on with their lives as much as possible, rather than proclaiming their anger like King Lear on the health....Anger is too monolithic for such a delicate situation. It's like a catheter inserted in your soul, draining your spirit... I feel busy now, very usefully occupied. There are many ways a

sick person can divert and defend, maybe even transcend, himself.

(Broyard, 1992, p. 29)

Anatole writes that at his age and the fact that he has enjoyed good health until his diagnosis that he feels he has nothing to be “*angry*” about. He says that he is ‘*very busy*’ and that there are many ways that a sick person can “*transcend himself*.” Further on he ponders why there is not much literature on illness and perhaps one of the reasons for this is that doctors may inadvertently discourage stories on illness. He documents his thoughts on the sense of self that occurs along with a terminal illness:

When you’re ill you instinctively fear a diminishment and disfigurement of yourself. It’s that, more than dying, that frightens you. You’re going to become a monster. I think you have to develop a style when you’re ill to keep from falling out of love with yourself. It’s important to stay in love with yourself. (Broyard, 1992, p. 62)

I think it is important here to reiterate the words that Anatole speaks of with such a strong voice, he writes that through the “*fear*” and “*disfigurement*” of the illness it is possible to become a “*monster*” and throughout the changes that may occur it is vital “*to stay in love with yourself*.” He writes further on the losses that cancer has caused to his body saying that:

My libido is lodged not only in my prostate, but in my imagination, my memory, my conception of myself, my appreciation of women and of life itself. It belongs as much to my identity and my aesthetics as it does to

physiology. When the cancer threatened my sexuality, my mind became immediately erect. (Broyard, 1992, p. 27)

5.6.2 On Relationality

Anatole is extremely analytical and philosophical in his musings on the future and how to remain positive in his outlook, and that the dying needs to focus on the desire to live. He writes that the “*sick person’s best medicine is desire-the desire to live, to be with other people, to do things, to get back to his life*” (Broyard, 1992, p. 63). He voices his strong opinions on the end of life scenario writing:

I think the last stages of dying, the doctor should be removed and so too the grisly Elisabeth Kubler-Ross, who actually wrote to the parents of a child who had died saying how much she had enjoyed participating in the event. I would like to die in my own way. It’s my house, my life, my death, my friends. Why not? (Broyard, 1992, p. 63)

On his thoughts about the relationship between the dying man and his friends, Anatole is aware of the now changing face of his acquaintances; he is adamant that he does not want to become serious about his death. He does, however, wish to unquestionably control his own dying experience when he writes; “*...It’s my house, my life, my death, my friends*”

Like others who are dying he expresses the feelings of being a ghost he shares the same sediments: “*I have become a ghost...*” He has gained ‘wisdom and beauty’ and the ‘important thing is the patient and not the treatment.’ He writes that it is “difficult” now in his life to be “serious.” Yet he thinks his friends find a more interesting person, a person who will not be around for much longer. As Anatole shares that dying is for him, a new experience and that only the initiated dare to speak about death. Therefore, he says; he feels, “*vivid, multi-coloured, sharply drawn, and infatuated with my cancer, it stinks of revelation.*” He writes further, “*as I look ahead, I feel like a man who has awakened from a long afternoon nap to find the evening stretched out before me*” (Broyard, 1992, p. 8).

5.6.3 On Temporality

Anatole was woken by illness from his conscious slumber to the urgency of time of the importance of now, he writes that on hearing his diagnosis, that he felt a kind of relief on discovering his illness. He writes:

Time was no longer innocuous, nothing was casual any-more. I understood that living itself had a deadline-like the book I had been working on. How sheepish I would feel if I couldn't finish it. The space between life and death is the parade ground of Romanticism. The threat of illness itself seems to sound a Romantic note - I've been feeling exalted since I heard the diagnosis. All your life you think you have to hold back your craziness, but when you're sick you can let it out in all its garish colours. (Broyard, 1992, p. 353-354)

Anatole time has been reconstructed, he writes that he is now aware of having a “deadline...” He is now consciously aware of his imminent mortality and he shares that knowing this has not meant that he has become miserable on the contrary he writes that he now feels “*exalted*.” He can above all things be himself, as he writes that he can now let out his “*craziness*”

5.6.4 On Materiality

Writing was always a way that Anatole addressed his inquiring mind, and never more so than on his deathbed. He wrote about all topics related to death, and in his writings, he describes other authors who had also dealt with the topic of death. Most of which he covered in his book ‘Intoxicated by My Illness.’ On writing about others who have written their stories on dying he says:

Though he never finished his book, he gave the best reason in the world for writing one, and that's why I want to write mine-to make sure I'll be alive when I die. The sick person's best medicine is desire-the desire to live, to be with other people, to do things, to get back to his life. When I was in the hospital, I was always gazing out of the window at the real world, which had never looked more desirable. I'd like to suggest, to invent or imagine or recall, ways of keeping one's desire alive as a way of keeping oneself alive. (Anatole, 1992, p. 30)

In this passage, he tells the reader why it is important to his wellbeing that he continues to write. That he wishes to live on in the minds of others through his books. He continues to say that, the sick persons “*desire*” is to live. Anatole also writes that one of the first things that he did towards a strategy for coping with his illness was to start tap dancing lessons, he writes; “*I’ve begun to take tap-dancing lessons, something I’ve always wanted to do*” (Broyard, 1992, p.25). In taking up tap dancing, Anatole is bringing a change of scenery into his life, all the trappings that go with dancing, the music, the dress, the shoes, and fulfilling a lifelong wish. Just as he writes that in an earlier age, doctors often suggested going and traveling and complete whatever you had promised yourself while in health.

5.6.5 On Spatiality

Despite being wracked with pain Anatole continued to write a weekly column for The New York Times Book Review. He surrounds himself with his writing tools, and all the trapping of thought that provide an escape now in his life. Anatole refused radiation therapy and surgery to remove his testicles choosing instead to try alternative therapies hoping that it could reverse the cancer. His wife writes in the epilogue that Anatole struggled to keep his sense of self in the face of his weight loss and his body succumbing to the ravages of cancer, in his journal he wrote; “*With the tubes and the weight loss, I have to recapture myself and my beauty. I have to reinvent myself*” (Broyard, 1992, p. 1585). He goes further when explaining how important the act of writing is to an ill person, he writes:

For a seriously sick person, opening up your consciousness to others is like the bleeding doctors used to recommend reducing the pressure. What goes through your mind when you're lying, full of nuclear dye, under a huge machine scans all your bones for evidence of treason? There's a horror-movie appeal to this machine: Beneath it you become the Frankenstein monster exposed to the electric storm. (Broyard, 1992, p. 21-22)

Anatole describes a hospital scene where he is likening having a scan to a horror movie, he writes, *"There's a horror-movie appeal to this machine: Beneath it you become the Frankenstein monster."* Anatole lived with cancer for fourteen months and died in 1990. The last words go to Anatole on the importance of the story:

To die is to be no longer human, to be dehumanized-and I think that language, speech, stories, or narratives are the most effective ways to keep our humanity alive. To remain silent is literally to close down the shop of one's humanity. (Broyard, 1992, p. 20)

Anatole lived for fourteen months following his diagnosis, he died in 1990. At the beginning of his illness there was a sense of hope that he would live for at least ten years, however, while the treatment was able to keep his health stable the cancer spread. Before he became unwell, he travelled to France where he spent the time enjoying himself with his family and friends. When the pain increased, and his health declined he was admitted to a cancer centre for treatment. In his epilogue his wife states that he was *"alive, as he hoped, when he died."* (Broyard, 1992, p. 134).

5.7 CORY TAYLOR: RESTORATION

Cory Taylor is an award-winning writer who lives in Brisbane she was just forty-nine years old in 2005 when she was diagnosed with melanoma. Because she had no signs of cancer it was her wish to keep her secret from most people. However, in 2014 she had a seizure, which left her physically incapacitated. The disease could no longer be hidden, made visible through her failing physicality. I first listened to Cory's story via a radio interview, I found listening to her story was insightful and in perfect timing to be included within this thesis. Her newly published electronic book is widely available through the Internet. During an interview with Stephen Romei (2016) in the 'Australian' newspaper regarding her recently published memoir, Cory says that she *"...is making a shape for death, I am making dying bearable for myself, and someone might read a book or essay of mine and be touched in some way."* It is as if Cory is making dying real, believable in black and white on the page.

5.7.1 On Corporeality

When interview by Lesley Synge (2016) for the Queensland Writers Centre about her motivation for writing 'Dying: A Memoir' Cory very frankly replied:

I wanted to win back some dignity for the dying, because I don't think silence serves the interests of any of us. While my body is careering towards catastrophe, my mind is elsewhere, concentrated on this other, vital task, which is to tell you something meaning full before I go. Because I'm never happier than when I'm writing, or watching the world as a writer, and it has been this way from the start. (Cory, in Synge, 2016)

Cory's body is frail, but her mind is sharp, she wants to complete her story before she dies, she wants to let the world know of her experience towards the EoL and add some "dignity" to the world of dying. Lesley Synge (2016), asks Cory if she is scared to die. In her frank, no fuss response she says that; *"I'm used to dying now. It's become ordinary and unremarkable, something everybody, without exception, does, and I*

can't help worrying. I haven't died before, so I get a bad case of beginner's nerves, but they soon pass." She has everything in place for her death when the time comes.

Cory doesn't want any lifesaving interventions or prolonging of her life. On that she is extremely clear. Before undergoing brain surgery, she says that she was frightened that she might end up physically disabled, so she wrote a suicide note to her family, which she says is a letter of apology for ending her life. She writes that she would rather end her own life should she end up helpless and being cared for by others. As it so happened, she survived the brain surgery, the tumour in her head was successfully removed. She now walks with a limp and has survived another year. However, she says that with her health rapidly deteriorating her thoughts turn to suicide, she describes how she feels:

I started to focus on the question of suicide like never before. After all, in a first for me, I'd gone to the extent of breaking the law and risking prosecution, in order to obtain the means. My stash calls to me day and night, like an illicit lover. Let me take you away from all tis it whispers...And yet I hesitate, because what appears to be a clear-cut solution is anything but. (Cory, 2016, p. 78)

On the thoughts of her death being close Cory continues to list all the reasons why taking her own life would not be an option, and her most overwhelming feeling is of protection of her husband and sons should they be implicated in her unlawful decision. She also writes on the implications in Australia that the word suicide has rather than the honour that it affords in Japan. Cory requested psychological assistance to accept her diagnosis from her doctor and she writes:

He silently scanned the list of problems for which help was available.

'Adjustment disorder.'

I laughed. "You're making that up," I said.

He turned his computer screen, so I could see for myself. (Taylor, 2016, p. 223)

Cory writes that she was surprised when her psychologist told her that dying was an insufficient reason for receiving free psychological help from the Cancer Council, her doctor then tried to find an alternate reason to get her assistance.

5.7.2 On Relationality

Cory in her memoir writes that as soon as she became physically frail, she called the family together and discussed all the necessary paperwork, the Will and the Power of Attorney, bank accounts, and tax, she felt as if it helped her family to be useful. Although she has the means for committing suicide Cory adamantly states in her book that it does not imply that her and her group of friends are all committed to suicide only that they feel like they have a choice. Cory writes that she has excellent support services around her including the support of palliative, home nursing service and her family and friends:

I have as much support as I could wish for. If I were, however, to express a wish to end my own life none of that support would be legally available to me. I would be strictly on my own...I wonder if our laws reflect some deep aversion amongst medical professionals here towards the idea of relinquishing control of the dying process into the hands of the patient... Which is why my drug remains unused, because of some moral qualm I share with Andrew about the harm one can inadvertently do to other, by going rogue and acting alone. (Taylor, 2016, p.86)

Cory shares that she has all the support that she needs and if she used her drugs she would be placed in a difficult situation, either to use her drug or to be alone. On her thoughts about committing suicide Cory writes that the act of suicide is illegal in Australia, therefore she writes that she would die alone if she had a right to choose when to die. Cory had a strong, close relationship with her mother, but had lost contact with her father after her parents' divorce. She recalls stories of being close to her mother, of the tough times they shared together and of the comfort that only her mother can give.

At this scary time in her life Cory wanted to rest in the arms of her mother's comfort. Although her mother had died years before her illness Cory writes on the thoughts that filled her mind: *"silent night time ravings, I remember lying in bed, unable to sleep, silently discussing my options with Mum"*, she could not tell the difference between *'real and phantom, fact and fiction, I wanted a boiled egg with buttered soldiers'* (Taylor, 2016, p. 1322).

When Cory finally has a session with the psychologist, hoping to find the answers to her life and death questions she is bitterly disappointed. She writes that, *"she sat in a windowless meeting room."* When asked if she was frightened of dying, she was given *"mindfulness training"* (Taylor, 2016, p. 22), of which she says she could have quite easily obtained herself. In fact, she had a visit from a counsellor after her brain surgery and was then taken through the exercises. On her disappointment with her visit to the psychologist she records:

Or perhaps it is because people like me expect more of psychologists than they can possibly deliver, some superior wisdom about the mysteries of life and death. It was good thing I wasn't paying for my counselling, I thought, or I might have asked for my money back.

(Taylor, 2016, p. 236)

5.7.3 On Temporality

On the sense of time Cory Taylor (2016), writes that she thinks reflecting on past events is a usual practice when dying. She says that “*patterns and turning points*” (p.262) in your life story are important. In recognition of the need to write and record the past the home nursing service employs biographers to visit patients and record their stories, which are eventually presented to the families. Unfortunately, Cory’s biographer had become a great confidante for Cory died unexpectedly without any time for goodbyes. She writes of the pain that this sudden unexpected death of her friend brought, this ignites her deeper thoughts on her own long-protracted death:

A sudden death cuts out all of the ghastly preliminaries, but I imagine it leaves behind a terrible regret for all the things left permanently unspoken. A slow death, like mine, has that one advantage. You have a lot of time to talk, to tell people how you feel, to try to make sense of the whole thing, of the life that is coming to a close, both for yourself and for those who remain. (Taylor, 2016, p. 304)

Cory writes that a slow death does come with some advantages that it comes with extended “*time*”, time to say goodbye. Like most of the storytellers in this thesis, Cory is introspective, recalling that she has been given some time to talk with others and “*make sense*” of dying. Like most of the storytellers, Cory is introspective, recalling a time in her childhood when she discovered prejudices, when became consciously aware of the hierarchy between people and race. Then she explains why now she has chosen to share this part of her history, saying that:

If I tell these little histories now, it is because they conjure a feeling of what it was like to be me back then, the same but different, the body still growing up and out into the world instead of contracting and retreating from it. It’s often said that life is short. But life is also simultaneous, all

of our experiences existing in time together, in the flesh. For what are we, if not a body taking a mind for a walk, just to see what's there?

(Taylor, 2016, p. 1265/1466)

Cory writes that her memories provide a different state of mind for her, a time when she was growing and thriving, writing that, “...*the body still growing up and out into the world instead of contracting and retreating from it.*” Cory is taking her mind on a walk-through time and space, which is taking her away from her current situation. With her body frail she now relies on her memories to take a walk-through time.

5.7.4 On Materiality

Cory has a deep love of writing and it is her writing that has given her a sense of purpose throughout her life. She writes: The art of writing consumes Cory in her life, as she comes to understand what it means to confront her own mortality, she writes her memoirs, on her love of writing she says, “*It is my bliss, this thing called writing, and it has been since my schooldays*” (Taylor, 2016, p.333). She continues by saying:

For while my body is careering towards catastrophe, my mine is elsewhere, concentrated on this other, vital task, which is to tell you something meaningful before I go. Because I'm never happier than when I', writing, or thinking about writing, or watching the world as a writer, and it has been this way from the start. (Taylor, 2016, p. 344)

Cory's physical health is out of her control, but she is still able to write. Cory is “*never happier*” than when she is “*writing*” and her love of writing is what sustain her now. While writing her story, Cory was asked by the Australian Broadcasting Corporation (ABC) to answer a set of questions on screen about dying. The main

reason that she wanted to participate in this television story was because she believes that dying is currently hidden in our society.

Cory clearly states here her thoughts on the current perspective of dying in the Western world, when she writes, “*Death is a taboo subject, absurdly so. It is tidied away in hospitals, out of public view, the secret purview of health professionals who are generally unwilling to talk about what really goes on at the bedsides of the nation*” (Taylor, 2016, p. 317). Writing her final memoir, is her attempt at breaking the silence on death.

5.7.5 On Spatiality

On her current space, she writes that she has found solace surrounded by the hospice workers. The Tibetan nuns who care for Cory in Brisbane are a source for her questions about the dying process. She knows that they believe in an afterlife of which she discredits as untrue but that does not stop her enquiring after the Nuns thoughts of death and dying. Cory likes the compassion that the Buddhists nuns give and shares her feelings.

I like how serene she is, and how she looks directly at me when she speaks. I have even decided to invite her to say a prayer at my funeral, one she has picked out from “The Tibetan Book of Living and Dying.” It strikes me that this might provide an element of ritual to the occasion that might otherwise be missing. For this is one of the most lamentable consequences of our reluctance to talk about death. We have lost our common rituals and our common language for dying...I am talking especially about people like me, who have no religious faith. (Taylor, 2016, p. 211)

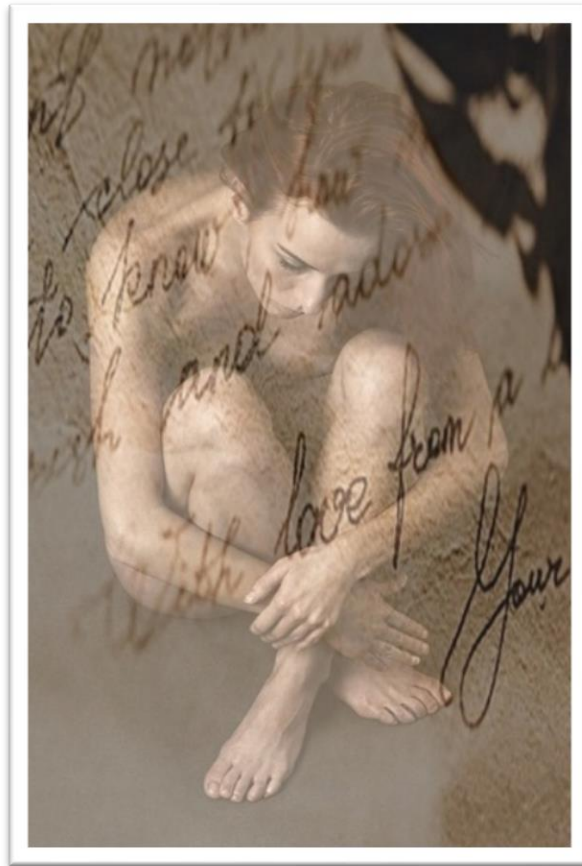
Cory writes that she finds solace and comfort speaking with others on dying and that although she does not believe in the notion of afterlife, she has been given a sense of a rite of passage, a ritual for her dying. She feels strongly that in our modernity “we

have lost our rituals” and through this loss our language related to dying is also lost. This is concerning her as she says that without being affiliated with a “faith” there is a loss of communication on how to relate to the EoL. Experience. When writing on how she feels about her current situation on dying now in her life Cory is very philosophical, she recalls present and past events her time frame has become one and she longs for the comfort of her mother.

Cory is quite clear about here about her belief in the afterlife saying; *“Dust to dust, ashes to ashes ... we come from nothingness and return to nothingness when we die.”* Lesley Synge (2016) continues to ask Cory how she feels on the publication of her last book ‘Dying: A Memoir’ at which Cory replies: *‘I will not miss dying. It is the hardest thing I have ever done, and I will be glad when it’s over...I am much like an infant now, with an infant’s dependence’* (p.536).

Cory begins to imagine her final days, what she might feel like. She presumes that she will be lucid until the end but realises that this is probably not the likely outcome. She says clearly that she has refused antibiotics and declined feeding, so she presumes that she will most likely starve to death: Of all these awful imagined stories of *‘dying of starvation and being reduced to a bag of bones’* (p. 1445). Cory finds comfort in her Chinese drug. This offers her a freedom, a piece of mind that she has an *“alternate way to go.”* On her suicide drug, she writes: *“I am grateful to have it. It helps me to feel that my autonomy is still intact, that I might yet be able to influence my fate. Even if I never use the drug, it will still have.”* (Taylor, 2016, p. 1446).

The final words Cory writes in her book, ‘Dying: A Memoir’ (2016) she imagines and writes her own dying scene as if in a movie, she says that she has always loved movies because they show rather than tell a story: *“I’ve come to the edge of words now, to the place where they falter and strain in the face of dying’s terrifying finality.”* (p.1450). I chose the image below (Researcher reflections, 15) because it has a strong introspective appeal. The colours are subdued in sepia, and the girl is wrapped in her writing, writing is important to her now, she is naked, except for her writing.



Researcher reflections 15:Time to Go
Photo credit: Pixabay.com

Post script: Only a few weeks after publishing her last book, in July 2016. Cory Taylor died peacefully at the age of sixty-one, in the Hospice surrounded by her family.

5.8 CHRISTINE BRYDEN: RESTORATION

Christine Bryden is an Australian woman who had an influential career before her diagnosis at the age of forty-six with early onset dementia. She has continued to document her story, since publishing her first book in 1998 on her experience of living with younger onset dementia, publishing two more books within a few years. Christine's story is remarkable in that her dementia is progressing very slowly allowing her time to write and share her insightful experience. She is an advocate for people who have dementia and shares her story extensively via YouTube, in eBooks and on her blog. After the release of her first book in 1998, 'Who Will I be When I Die,' and following a lot of publicity in 2003, Christine became well known in Japan, a country who has a large aging population. Christine was still relatively unknown in Australia, and she found that it was important for her to disclose her illness to people to shatter the stereotype that accompanies dementia. As Christine writes; "It was all too easy to believe the stereotype of dementia; *"It was the first time anyone in Australia had 'owned up' to having dementia. I had 'come out', disclosing my disease"* (Bryden, 2005, p.38-39). Since this revelation, Christine has been a constant spokeswoman for people who experience dementia.

5.8.1 On Corporeality

Dementia is a hidden disease caused by brain damage in which, the person is often tired and withdraws from societal demands for some time to enable them to cope with everyday living. The stages that a person will go through when having dementia are well documented and Christine shares her experience of being shunned at a meeting because she did not fit the usual definition of dementia. She writes:

Christine asks many questions regarding her disease, writing; *"I will still have similar symptoms caused by brain damage... and be suffering from a terminal illness for which there is no cure. But if I had gone public with, say a diagnosis of breast cancer, would my diagnosis then be questioned? Would people want to see the lump, see the scars, receive proof of my illness?"* (Bryden, 2015, p. 48). She writes further how upset she was when at a conference the speaker before her presented neatly the set stages of dementia excluding the individuality of the person.

Being categorised into one of the well-known and discussed stages of dementia causes further stressors to Christine when she writes; *“And such charts and graphs and stages deny me my individuality, stripping me of any credibility at still being able to speak after years of living the journey of dementia”* (Bryden, 2015, p. 48). After initially been given the diagnosis of Alzheimer’s disease Christine has been given a new diagnosis of fronto-temporal dementia, which affects personality traits, like speech and memory. Christine overcomes general stereotyping when she gives a lecturer on dementia by displaying her medical scans, writing; *“The pictures clearly show atrophy (wasting away of the brain) in the frontal and temporal lobes, ‘pictures are worth a thousand words! Usually there’s a sort of hushed silence...”* (Bryden, 2015, p. 92).

Christine shares her experience of living with confusion throughout the pages of her book, summing up by writing; *“We are confused, we have problems with our sight, without balance, with numbers and with direction. It is a real disease, not a normal part of aging”* (Bryden, 2015, p. 14). She documents every activity that causes her anxiety and stress just to complete simple tasks and shares how exhausted she feels trying to concentrate on making it through one day at a time. In her first book following her diagnosis, Christine was questioning the medical assumption that a dementia diagnosis assumed that there is a loss of the Self. Christine writes in her book ‘Dancing with Dementia’, that she is not just the physical body but much more, she describes her experience as she come to accept her fate:

Dementia is often thought of as death by small steps, but we must ask ourselves what is really dying. Hasn’t the person with dementia reached that place of ‘now’, of existing actively in the present? ...Beneath this increasingly jumbled layer of emotion is the true self that remains intact despite the ravages of dementia. This is my spiritual self or the transcendent self. It is the ‘me’ that relates to the beauty of a garden, of the leaves or the flowers; it is the ‘me’ that relates to God; it is my spirit, the essence of me. (Bryden, 2005, p. 158)

Christine eloquently describes that her true self is not the outer layer that others see or hear it is her connection to the world of spirit that is her true inner self; and that underneath all the “jumbled” layers of emotion she experiences her “...*spiritual self or the transcendent self.*”

5.8.2 On Relationality

Christine contributes much of her everyday survival to her husband, daughters and friends. She is reliant of her family and friends for everyday living, but she is determined not to be a victim of dementia but rather to look for the positive aspects, she writes:

The love of my family and friends-most importantly Paul and my daughter-helps me through each day and gives me the security and hope that I need for the future. I have lots of deficits, but Paul compensates for these, adjusting his every response as my care-partner so that I can function to the best of my ability...I choose a new identity as a survivor. I want to learn to dance with dementia. I want to live positively each day, in a vital relationship of trust with my care-partners alongside me. To live with ‘the fear of ceasing to be’ takes enormous courage.

(Bryden, 2015, p. 168-169)

Christine shares how important her family and friend are to maintain her way of being in the world, she writes on her decision to “... *choose a new identity as a survivor.*” Her dementia support group also plays a vital part of her life. She has spent twenty years since her diagnosis travelling to different places around the world advocating for people who have dementia. Digger, Christine’s dog is also an important part of the family unit. She is often photographed with her little dog beside her. She shares how comforting he is, especially when she suffers with anxiety, she writes; “*My*

little poodle Digger is very comforting. Reaching over and rubbing his woolly tummy can soothe me in my struggle for sleep” (Bryden, 2015, p. 2770).

5.8.3 On Temporality

. Christine is aware that she is gradually losing her memories and she writes frequently how she copes with this by living in the present moment. For her the past is the past and the only moment is this present moment. She writes:

We have no sense of time passing, so we live in the present reality, with no past and no future. We put all of our energy into now, not then or later. ...But this fact that we live in the present, with a depth of spirit and some tangled emotions, rather than cognition, means you can connect with us at a deep level through touch, eye contact, smiles.
(Bryden, 2015, p 98)

On living in the present reality Christine writes that to a person with dementia it “*means you can connect with us at a deep level through touch, eye contact, smiles.*” In ‘Dancing with Dementia’, Christine explains further on her experience of coping as she lives in the present moment. She describes what it feels like to live without the pressure of what was and of what might be to be living in the present. She writes:

Like a bud, my true self encapsulates all the potential of what it means to be me, in an eternal realm, not only in this earthly temporal existence this being in the present continually and eternally, is a new way of living, maybe even the essence of living. (Bryden, 2005, p158-159).

Christine discovers that her “*true self*” is present in every moment and for her it is the “*essence of living.*” The past and the future have merged into the present.

5.8.4 On Spatiality

Christine feels that once again time is running out for her, and she finds solace when she visited the once familiar surroundings of Canberra. Christine found peace and contentment within her natural surroundings. She writes:

I felt very relaxed and happy, and found that the beauty of the natural environment, the plants and the landscape forms, were strong visual memories which somehow restored my spirit. The beautiful gum trees, the possums, the parrots and the crisp cool air gave me a very spiritual time, and I felt a great peace filling me. (Bryden, 2015, p. 99)

Christine found “*peace*” being surrounded by the natural environment, which enabled her to make a spiritual connection through the “*strong visual memories*” that she found within the landscape. Christine is also adamant when she writes on her need for a quiet stress-free environment, she explains; “... *I need a restful, calm environment, with no visual or aural distraction, to listen to what you say and to be able to speak to you*” (Bryden, 2015, p.137).

5.8.5 On Materiality

Christine frequently refers to her group of friends who suffer with dementia, the Dementia Advocacy and Support Network International (DANSI) and she works tirelessly to support the foundation. She has managed to travel, with the help of her husband, to many places worldwide and teach people that having a diagnosis of dementia is not a reason to be shut away from society. After her first appearance at a conference, where she spoke on the effects of dementia, she received an overwhelming response, which was the beginning of her experience of changing attitudes on the diagnosis of dementia.

The participation in the conference although very tiring for Christine was life changing, giving her further reasons to pursue her goals of changing attitudes towards

the medical view of dementia. She writes; “*The first step towards changing attitudes towards people with dementia had been launched in the autumn colours of Canberra*” (Bryden, 2005, p. 83). In 2003, Christine was elected to the Board of Alzheimer’s Disease International to represent people with dementia and in her book, ‘Dancing with Dementia,’ she shares that she is trying to do all that she can to change the perceptions the medical world has of dementia.

Although writing her books has been a huge physical and psychological battle, as it has occupied a lot of time and energy, in her life. Writing has been her focus and drive and has propelled her forward increasing the awareness for others of the lived experience of dementia, she writes: “*But I know that in the first part of this dance with dementia, I did what I could with the energy I had left...By writing this book, as well as my first book, and giving many talks, I have done all that I can to help change attitudes. But this book has been an enormous struggle to write.*” (Bryden, 2005, p.11).

5.9 PAUL KALANITHI: RESTORATION

Paul Kalanithi had a promising career as a neurosurgeon when at the age of thirty-six he was diagnosed with severe metastatic lung cancer. Although he had a strong suspicion for a few months that he was gravely unwell, he pushed it to the back of his mind. When he received the definitive diagnosis of a rare fatal lung cancer that had metastasised or spread throughout his entire body, he immediately started writing on his experience towards the EoL. He was always drawn to write as literature was his first career choice and he utilised this catastrophic change in his circumstances to record his thoughts. After his initial diagnosis, he ponders on his future and writes:

Had the confirmation of my fears-in the CT scan, in the lab results, both showing not merely cancer, but a body overwhelmed, nearing death-released me from the duty to serve, from my duty to patients, to neurosurgery, to the pursuit of goodness? Yes, I thought, and therein was the paradox: like a runner crossing the finish line only to collapse, without that duty to care for the ill pushing me forward, I became an invalid. (Kalanithi, 2016, p. 125)

Pauls thoughts ruminate on his present situation, he has finally reached his goal (final year of medical residency) on his way “*to the pursuit of goodness...*” only to find that it has been taken away from him, the paradox of his situation leaves him feeling that he has become “*... an invalid.*”

5.9.1 On Corporeality

There were a lot of opportunities that are now out of the young surgeon’s reach, however, he did not let this stop his drive or will power to live the best life that he could. On his return to his love of literature he describes his feelings around how he was pulled back towards his writing. He says:

Lost in a featureless wasteland of my own mortality and finding no traction in the reams of scientific studies, intracellular molecular pathways, and endless curves of survival statistics, I began reading literature again...anything by anyone who had ever written about mortality. I was searching for a vocabulary with which to make sense of death, to find a way to begin defining myself and inching forward again...I felt that to understand my own direct experiences, I would have to translate them back into language. Hemingway described his process in similar terms: acquiring rich experiences, then retreating to cogitate and write about them. I needed words to go forward. And so it was literature that brought me back to life during this time. The monolithic uncertainty of my future was deadening; everywhere I turned, the shadow of death obscured the meaning of any action.

(Kalanithi, 2016, p.149)

Paul had lost interest and found no solace in his usual mode of existence, he turned to literature not only to “*make sense of death*” but also to translate his lived experience into “*language*.” He was trying to find a new self-image to face the shadow of death. With the onset of his chemotherapy in the form of a tablet Paul began to feel physically stronger he states that he gained weight and although the pain had not left he was feeling a little better. He describes how humiliated and exhausted he felt attending physiotherapy. He writes:

It was exhausting and humiliating, my brain was fine, but I did not feel like myself. My body was frail and weak-the person who could run half marathons was a distant memory-and that, too, shapes your identity.

Racking back pain can mould an identity; fatigue and nausea can, as well...In the face of weakness, determination set in. (Kalanithi, 2016, p. 140-141)

Paul's physicality had been challenged although once it was not an issue in his life it was now on centre stage, he writes that his frail physicality was shaping his "identity." When a CT scan revealed a reduction in the tumours in Paul's lungs and when his physician reassured him that the cancer was stable. Paul writes how relieved he felt and that he could feel the "chaos" of the past months "receding." With a sense of hope he decided to return to his work as a surgeon (Kalanithi 2016, p.146).

5.9.2 On Relationality

Despite being questioned about returning to work by his colleagues Paul decided that returning to work as a surgeon for him was the best option that he had, and for him this was important, albeit in a modified form. He describes his experience on returning to work when he writes:

Every day, each case felt familiar but moved a little more slowly...Over the next couple of weeks, my strength continued to improve, as did my fluency and technique. My hands relearned how to manipulate sub millimetre blood vessels without injury, my fingers conjuring up the old tricks they'd once know. After a month, I was operating a nearly full load. I ended my days exhausted beyond measure...but the truth was, it was joyless...the pleasure I'd once found in the operating was gone, replaced by an iron focus on overcoming the nausea, the pain, the fatigue. (Kalanithi, 2016, p.155)

Paul described his experience on returning to work since his diagnosis, as “joyless” “replaced with nausea, pain and fatigue.” This experience is the opposite of his feelings expressed as a surgeon prior to his diagnosis of cancer. Although he is mentally capable to return to work, the cancer has left him physically drained or “exhausted beyond all measure.”

Paul continued operating although he found it difficult, he desperately wanted to achieve his goal of graduating, he writes; “I only had to keep up this relentless pace for a couple more months, I told myself, and then I would graduate from residency and settle into the comparatively calmer role of a professor” (Kalanithi, 2016, p. 162). Paul was always surrounded by his family and before he commenced chemotherapy, Lucy his wife, fell pregnant. He writes that during his daughter’s birth he was too weak to stand, on his experience. He writes:

I lay down on a cot in the delivery room, heat packs and blankets keeping my skeletal body from shivering. For the next two hours, I watched Lucy and the nurse go through the ritual of labor {sic}... There would be so many absences in Lucy’s and my daughter’s life-if this was as present as I could be, then so be it...” Can we put her on your skin, Papa?” the nurse asked me. “No, I’m too c-c-cold,” I said, my teeth chattering. “But I would love to hold her.” (Kalanithi, 2016, p. 195)

Paul writes on his love for his baby girl and his wife. He shares his thoughts on the absences that he is experiencing and being as “present” as he could be with his wife during the birth of their child. He writes that he thought about writing her letters but that he didn’t really know what she would be like in the future. Rather, he thought he would like her to know the joy that she brought him, during his life, he writes to her saying:

When you come to one of the many moments in life where you must give an account of yourself, provide a ledger of what you have been, and done, and meant to the world, do not, I pray, discount that you filled a dying man's days with a sated joy that does not hunger for more and more but rests, satisfied. In this time, right now, that is an enormous thing. (Kalanithi, 2016, p. 199)

The short paragraph that Paul wrote to his daughter encapsulates what he wished for her to understand how he feels at this moment in time, that she has; *"filled a dying man's days with a satiated joy..."*

5.9.3 On Materiality

Writing consumed the end of Paul's life. He wrote on his lived experience of dying, until he could write no longer, his wife editing his manuscript posthumously. It is difficult to say what else was materially important in Paul's life now. On his love of writing and the sciences he writes that when he asked his doctor how much time she thought he had left he wrote; *"If I had some sense of how much time I have left, it'd be easier. If I had two years, I'd write. If I had ten, I'd get back to surgery and sciences"* (Kalanithi, 2016, p.137). He writes further on his struggle about not knowing the outcome of his diagnosis. Paul writes, *"I had to face my mortality and try to understand what made my life worth living... I struggled, while facing my own death, to rebuild my old life-or perhaps find a new one"* (Kalanithi, 2016, p.139).

Christianity had been in Paul's life as a young child, however, he left this belief behind him when he commenced medical school. He argues that his study of the sciences without a doubt made him question his belief in God and the doctrine of religion. However, he returned to the church with his parents before his death. Here he explains why he returned to his faith:

...Science may provide the most useful way to organize empirical, reproducible data, but its power to do so is predicated on its inability to grasp the central aspects human life: hope, fear, love, hate, beauty, envy, honor [sic], weakness, striving, suffering, virtue... Yet I returned to the central values of Christianity-sacrifice, redemption, forgiveness- because I found them so compelling. (Kalanithi, 2016, p. 170)

Paul was drawn into the empirical world of science and medicine, however he returned to Christianity as his illness progressed. He was unable to find “*the central aspects of human life*” in the scientific paradigm.

5.9.4 On Temporality

Unsure of the amount of time that has left to live, Paul has a feeling of loss; he faces it with courage and a knowing of something deeper than he can explain, he continues his role as a surgeon as long as he was physically and mentally able to withstand the stress of work, he describes his feelings in the anecdote below as he prepares to operate:

The morning passed, and I scrubbed for my last case. Suddenly the moment felt enormous. My last time scrubbing? Perhaps this was it. I watched the suds drip off my arms, then down the drain. I entered the OR, gowned up, and draped the patient, making sure the corners were sharp and neat... (Kalanithi, 201, p.178-179)

Time has slowed down for Paul, what was once done without thought had become conscious in the moment and he somehow knew that this would be the last time he would operate. Time became subjective, it slowed and felt “*enormous.*” Paul writes further on the concept of time:

...Part of the cruelty of cancer, though, is not only that it limits your time; it also limits your energy, vastly reducing the amount you can squeeze into a day... With little to distinguish one day from the next, time has begun to feel static... These days, time feels less like the ticking clock and more like a state of being... now I don't know what I'll be doing five years down the line. I may be dead... so it's not all that useful to spend time thinking about the future-that is, beyond lunch. (Kalanithi, 2016, p. 197)

Paul at 36 years of age thought that time was on his side, he had reached the pinnacle of his career and he was looking forward to his future as a neurosurgeon scientist. Following his illness, he no longer thinks of time as being in the future, only now, the present is possible for him to contemplate, he writes, that time feels more like “*a state of being...*” and that time is dependent on the amount of energy that the ravages of Cancer permit.

On facing his mortality both Paul and Lucy (his wife) have life altering decisions to make, decisions that would impact on their future, one being on becoming parents. Both consulted each other with their fears and decided it was better to feel the pain of love than not to love at all, they said; ‘*... we had always remained very much in love...we talked it over we decided to have a child. We would carry on living, instead of dying*’ (Kalanithi, 2016, p. 61). Having a child was always important to them and having cancer was not going to change this. Paul described the impact that his impending mortality had on his life:

Death may be a one-time event but living with terminal illness is a process. It struck me that I had traversed the five stages of grief-the ‘Denial-Anger-Bargaining-Depression-Acceptance’ cliché-but I had

done it all backward. On diagnosis, I'd prepared for death. I'd even felt good about it. I'd accepted it. I'd been ready. Then I slumped into a depression, as it became clear that I might not be dying so soon after all, which is, of course, good news, but also confusing and strangely enervating. (Kalanithi, 2016, p. 161)

Paul describes here what it is like to have a terminal illness and how frustrating it is not to know when and how you will die. He shared how he had been through all the stages of dying, only that he had done it all “*backwards*” and then that he found that preparing himself to die and then not dying was extremely “*depressing*” “*confusing*” and “*strangely enervating*.”

Paul is very clear when he says that his values are constantly changing, he is living with trying to discover what matters the most at this point in time, life is still constantly changing and like Paul says; “*I was having to learn how to budget. You might decide how to spend your time...but two months later, you feel differently.*” Paul writes; “*death may be a one-time event...living with a terminal illness is a process*” (Kalanithi, 2016, p.160). It is almost like he is running out of time, or running with time albeit slowly, but time is still occurring. He no longer knew what he wanted in life because he was not able to control the advancing cancer.

After spending his short life caring for others, working ceaselessly on brain surgery to save lives, Paul has something he wants to tell the medical profession, something that has presented itself in face of his own mortality he writes; “*the physician's duty is not to stave off death...but to take into arms a patient and family whose lives have disintegrated and work until they can stand back up and face, and make sense of, their own existence*” (Kalanithi, 2016, p.166).

5.9.5 On Spatiality

Family and familiar surroundings were important to Paul, being comfortable with his place of work, was not an issue when he was admitted to hospital, in fact he writes of the sadness he felt when he had to leave the place that he had become so familiar with during the seven years of residency as a neurosurgeon. After seven months of returning to surgery Paul's symptoms returned and a further Computerised Tomography (CT) scan showed a new growth, which would require him to undergo

intravenous chemotherapy. On having the scan Paul wrote; “*This is my last scan before finishing residency, before becoming a father, before my future became real*” (Kalanithi, 2016, p. 173). He was prior to receiving his chemotherapy treatment consciously aware of the last time he would walk into the operating room (OR). He writes:

I left the OR shortly after, then gathered my things, which had accumulated over seven years of work...Tears welled up as I sat in the car, I turned the key, and slowly pulled out into the street. I drove home, walked through the front door, hung up my white coat, and took off my ID badge. I pulled the battery out of my pager. I peeled off my scrubs and took a long shower ...Later that night, I called Victoria and told her I wouldn't be in on Monday, or possibly ever again, and wouldn't be setting the OR schedule. (Kalanithi, 2016. p.178-179)

Paul is saying goodbye to what was so familiar to him, he writes how sad it was to say goodbye to his usual way of being. Perhaps on a deeper subconscious way of knowing Paul understood that this was his final goodbye, to his place of work. Here was an epiphany, an insight, which dawned on him, without really knowing the certainty of the time that remained.

This moment in time was pivotal in the trajectory of his illness. Following the results of his last CT scan Paul and Lucy meet with his oncologist. Paul writes that he was aware that the medical follow up required, a biopsy, and chemotherapy however he admits the real reason that he met with his doctor was, as he writes, “*was for her guidance.*” He felt that he was finished with work (Kalanithi, 2016, p. 179). His doctor reassured him that his condition was not any worse, and only to stop operating if he wanted to focus on other things.

This place that now surrounds Paul is the room where chemotherapy is given, he is the receiver of care and treatment instead of his usual role of the carer, the physician. He sits idly, as he describes: *“I passed the time napping, reading, and sometimes blankly staring... The other occupants of the room were in various states of health-some bald, some well-coiffed, some withered, some spritely, some dishevelled, some dapper”* (Kalanithi, 2016, p.18). This is going to become part of his surroundings and life for at least three weeks. Unfortunately, Paul’s chemotherapy treatments proved to be detrimental to his survival and he found himself feeling extremely ill. Just before his final graduation ceremony from medical school he fell violently ill, his wife Lucy, is two weeks away from the birth of their child, he describes this experience.

Paul writes; *“The day arrived. As I stood in our bedroom, dressing for graduation-the culmination of seven years of residency-a piercing nausea struck me.”* This was to be a changing point in his life thus far. Up until now this time and space he had control over his experience, now everything was changing. Although he does not express his disappointment you can almost feel it in when he says, *“I would not be going to graduation, after all.”* Paul spent the next few weeks in hospital surrounded by his family undergoing treatment. He writes that he was frustrated many times with his treatment and that he was giving up with his control of his disease. Relinquishing it to his doctor, on his treatment in hospital. He writes:

Confusion yielded to anger. Some kid two years out of med school, no older than my junior residents, was really arguing with me? It’d be one thing if he were right, but he wasn’t making any sense. “Um, didn’t I mention this afternoon that without that pill, my bone metastases become active and produce excruciating pain? I don’t mean to sound dramatic, but I’ve broken bones boxing, and this is far more painful. As in, ten-out-of ten pain. As in, I-Will-Actually-Soon-Be Screaming pain.
(Kalanithi, 2016, p. 186)

Dismayed at his treatment regime, Paul shares how upset he is with his care by a young doctor who really does not understand the treatment that he requires, he writes that this doctor “...*was really arguing with me?*” Paul does not write about the strangeness of his environment only of the treatment that he undergoes. He is concerned about the continuation of his care, and describes the feelings, on one of his last days he writes:

I was being rehydrated, but not quickly enough. My kidneys began to fail. My mouth became so dry I could not speak or swallow...I was transferred to the ICU. Part of my soft palate and pharynx died from dehydration and peeled out of my mouth. I was in pain, floating through varying levels of consciousness, while a pantheon of specialists was brought together to help...The nephrologists disagreed with the ICU doctors, who disagreed with the endocrinologists, who disagreed with the oncologists, who disagreed with the gastroenterologists. I felt the responsibility of my care: during bouts of consciousness, I typed out the sequential details of my current illness and, with Lucy's help, tried to corral all the doctors to keep the facts and interpretations straight.

(Kalanithi, 2016, p. 189)

Continuity of care is vital in these late stages of illness as Paul shares that he is feeling that those who are caring for him are not in control of his treatment, he fights to remain consciously aware as he clings to his role as a physician. On the return of his usual physician who had always taken control of his treatments. He writes; “... *I finally relaxed*” (Kalanithi, 2016, p. 191).

When his daughter was eight months old, Paul Kalanithi entered the emergency room for one last time. He chose not to be intubated (a tube inserted into the airways to assist breathing) instead he chose to be kept comfortable and he made sure that a do not resuscitate order was in place, he asked to see his daughter one last time and he died twenty-two months after his diagnosis, surrounded by family.

5.10 SUMMARY

In Chapter six, eight participants share with the public their lived experience on dying following the initial diagnosis in Chapter five. They share their inner turmoil, pain, joy and love of life. Although everyone has a different diagnosis many share stories on the sameness of the lived experience when coping with a terminal illness and the struggles with their activities of daily living. I applaud the bravery of these people to share their experience on such a taboo subject, in our current biomedical understanding of dying. In most cases writing and sharing their stories was cathartic and provided a sense of purpose for people who felt a need to write prose, poetry or song and use social media to share their lived experience and insights towards their mortality with the rest of the world. They have a lot to say and continue to write their words of wisdom through difficult circumstances, each with a personal experience to share.

In this summary, I collate their words into the existential themes further refining their words but not changing their interpretation or context. As Van Manen (2014, p, 1261) states, the purpose of the phenomenological thesis is to let the lived experience “show itself” so that others may “see” this experience as it is. This is what these participants do in this chapter. They share the stories behind their discomfort and the turmoil behind the scenes as they face their death. The data will be represented as an image using Word-Clouds.

In the final summary of the two chapters on analysis, I use word clouds to let the most frequently used words within this thesis to show them-selves. Word clouds and tag clouds are used as a visually appealing method for text analysis. Used in many forms and in many contexts on the Internet, they collate data to the most frequently repeated words. Word-Clouds can provide a deeper analysis of a body of text; however, it is important to remember that they only provide a statistical summary of isolated words (Heimerl, Lohmann, Lang & Ertl, 2014). Word clouds have been used

in various ways in data analysis since 1995. They are relevant to social media platforms as they can reduce extraneous data. As a teaching and learning pedagogy word clouds enable a quick visual assessment of written responses (Brooks et al., 2014).

Two reasons that increase the effectiveness of Word-Clouds are their ability to provide an access to represent words that repeat. These words appear in bold, larger type allowing for an instant visual representation of the word (Bateman, Gutwin & Nacenta, 2008). Text applications of Word-Clouds have been used as patient analysis, where Word-Clouds are used in a static way to visually summarise text documents. Tag clouds are also utilised for data analysis and most often the tags are hyperlinks that will lead the user to other resources within social media that have been labelled with the tag (Bateman, et al., 2008). For this study, static visualisation of word clouds has been used to increase the critical analysis of this study.

5.10.1 On Corporeality

The eight individuals shared their experience on their positive and negative LED of the medical and nursing treatment and the hope that they found when they glimpsed a small return to health. They share a need to be brave and strong to face chemotherapy, to transcend death. The following image (Figure, 16) depicts the words that each storyteller used in their LED on corporeality as they were written in this thesis.



Figure 16: Words on corporeality

The participants want to feel normalcy again in their lives. They talk of transcending their self, and of finding a new clarity amongst the illness. The importance that dementia is recognised as a terminal illness is discussed as is the 'coming out' or the shame attached to the stereotype. Also, there is acknowledgement that dementia is a slow road to death equally important to the sufferer as is a diagnosis of terminal cancer. Each word that was written was placed within a Word-Clouds

recalling that the greater the frequency that the words are written, the larger the words appear. This does negate the importance that is placed on all the words that are written by the storytellers. Words depicted frequently are, identify, body, back, normal, and new.

5.10.2 On Relationality

The participants confirm that their closest family members are important in their final days. This also includes their pets as they share unconditional love and acceptance of their changing physicality. They speak of the joy that their animals also give their family members through times of severe illness. Their place of work and the connections that come with their employment are also important as is their sense of self, which is attached to who they are at work on a day-to-day basis. They speak of the cancer being real, and the hard days on chemotherapy. They also share a common thought on becoming or transcending a new self. They cling to a sense of hope and find an inner strength to continue. They write on a new wisdom of living and finding peace and joy in each moment.

The following image (Figure,17) represents the words as they are written, and included within this thesis, by the storytellers. Recalling that the greater the frequency that the words are written, the larger the words appear. This does negate the importance that is placed on all the words that are written by the storytellers. It must also be said this is only a small sample of the material available throughout their stories. The Word-Clouds on relationally highlights the frequency of the words: cancer, death, filled, dying and joy.

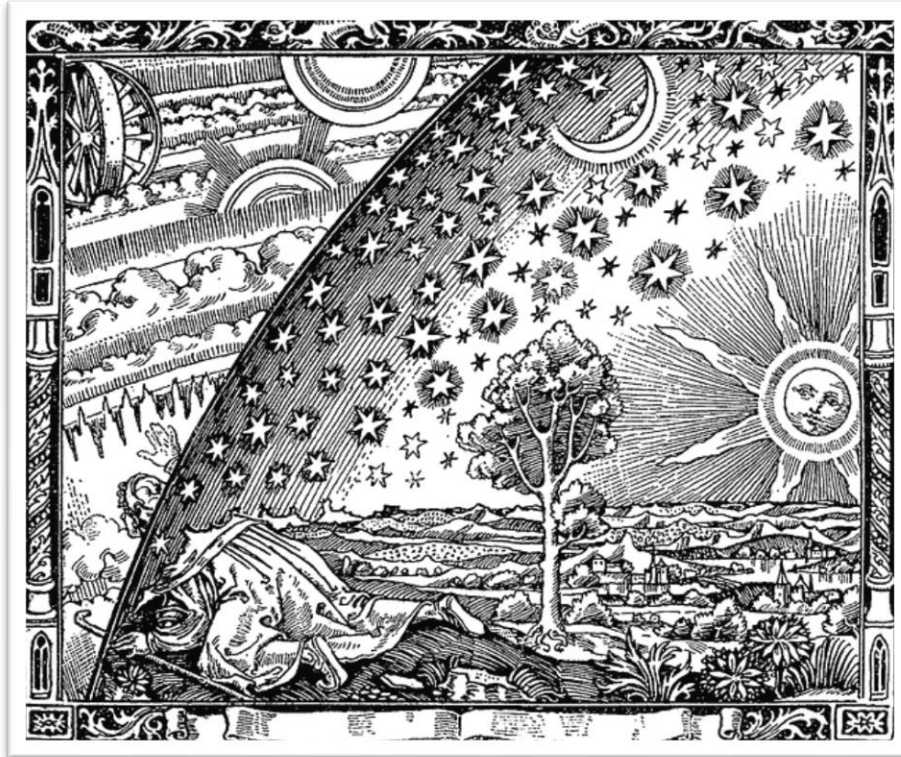


Figure 17: Words on relationality

5.10.3 On Spatiality

Most of the participants write on the importance of the natural surroundings for healing and for self-awareness. They fill their surrounding spaces with familiar objects that hold memories of good times. They recall the nurturing experience of their mother's embrace, whether living or dead. They walk familiar paths in their mind jolted by present objects. Music is soul soothing, as is the music of nature. Tenacity is strong and a must to survive the turmoil of the moment. They speak of a restoration of spirit through nature and through Christianity, and of responsibility of care until they can no longer fight. The following image (Figure, 18) represents the words as they are written in this thesis, remembering that this is only a small proportion of the stories that have been shared. This word cloud highlights the frequency of the words dying, environment, and world, just and visual.

Chapter 6 Insight Cultivators: Discussion



Researcher reflections 16: Between Two Worlds

A Flammarion woodcut: depicting an image between two worlds where a shepherd in the Middle Ages who has found the point where the astral bodies and earth collide.

Photo credit: Pixabay.com

For the Celts there was never any shadow of doubt that these two worlds, the visible and the invisible, the material and the spiritual, were one.

The invisible was separated from our sense perceptions only by the thin permeable membrane of consciousness.

(Silf, 2014, p.13)

6.1 INTRODUCTION

Chapter six of this thesis explores deeper insights on the lived experience towards the EoL. The aim of this chapter is to integrate the findings of the data analysis presented in the two previous chapters and provide a deeper analysis. Chapter Four described the data analysis related to the experience of receiving a diagnosis and Chapter Five described how the participants experienced restoration (moving on from the shock of the diagnosis). This chapter provides a discussion of the findings and re-examines the lived experiences, using insight cultivators from the literature. Insight cultivators are sources of literature and other theories that support or aid in the reflective interpretive process (van Manen, 2014), thereby increasing the interpretation of the phenomenon under inquiry. Insight cultivators include philosophic texts, theories and other sources in the humanities and the arts, they enable the interpretation of the lived experience. Gaining insights from other forms of literature facilitates a deeper awareness of the essence of the lived experience and enables the phenomenologist to see new possibilities and reveal new insights that might not have been previously considered. (van Manen, 2016).

The powerful predominant implicit themes of Resilience and Personal Intelligence (PI) were evident throughout all the existential themes. Therefore, before examining the existential themes, it is necessary to define these concepts and explore how they sit within the context of contemporary EoL issues. Although resilience has not been typically associated with the EoL in the literature, in this study it was a vital factor in the participants' discovering a peaceful restoration when living with a terminal illness. Following an analysis of resilience and PI, the existential themes and their subthemes are introduced and discussed. Each existential theme includes a synopsis of the stories told within this thesis and discusses the subthemes that were raised within the collective stories. The words that were used frequently in each word cloud related to the existential themes is also examined further.

6.2 RESILIENCE TOWARDS THE EOL

The overarching experience that shows itself vividly through these collective stories is that of resilience. Resilience originates from Latin roots that denotes,

springing back from adversity in the face of traumatic circumstances (Fleming & Ledogar, 2010, p.7). Participants describe finding a richer meaning to life, despite the trajectory of their lives being shortened and the many disruptions and discomforts they face both physically and psychosocially during this experience. Adversity and adaptability are two elements that create the space for resilience to occur (Cohen et al., 2011).

A contemporary understanding of resilience is that it is more than being a personal trait and more than just adapting to changed circumstances (O’Grady et al., 2016). It is understood as a process that people go through when confronted with many risks that affect their ability to adapt to their lived experience. There has been a move, in recent years, away from early understandings of the phenomenon of resilience. Although the debate continues, it was previously thought that resilience was an innate ability that resides within people, enabling them to survive when surrounded by hardships. Resilience is now understood to be a dynamic and complex process of adaptability to real-life dramas (O’Grady, 2016 et al., 2016; Reich, Zautra, & Hall, 2010; Shaw, et al., 2016). For the purposes of this thesis, resilience is defined as the adaptive response to a traumatic episode. In the case of this study, the traumatic episode is the conscious awareness of death. How resilience was a significant phenomenon in the lived experience of EoL will now be examined in detail.

6.2.1 Resilience and the Systems Approach

Contemporary theories define resilience as a set of interrelating systems that work together, overlapping at times and being fluid in nature. The systems approach of resilience grew out of ecology studies in the 1960s, where resilience is seen as being robust, adapting and responding to new environments (Folke, 2006). Individuals interact from the microsystem of a single world of interpersonal roles, experienced within a setting such as the family. They also move into mesosystems that are an interaction with two or more groups, such as family groups and social networks. All systems are encircled by the macrosystem, which are patterns of subcultures, including the exosystem of environmental forces. This is where external forces within the environment can affect individuals, such adverse climate patterns (Shaw et al., 2016; O’Grady, et al., 2016).

Resilience factors include the ability to overcome risks that reduce emotional and physical health and wellbeing, and to further forge new trajectories through

opportunities that present themselves because of emotional, physical and environmental turmoil (Folke, 2006). Being resilient is related to how we as human beings live and communicate at the microcosm level and within a wider community and within our culture at the exosystem level (Shaw et al., 2016). Overcoming risks could include extremes in the environment, such as after a flood or the ability to find meaning within the traumatic experience (Fleming & Ledogar, 2010; Shaw et al., 2016). It has been demonstrated that the construct of resilience protective factors can be taught to people, arming them with the knowledge of how to cope when they are faced with traumatic experiences (Tuck & Anderson, 2014), as in the case of this thesis, EoL.

Although studies have been undertaken to examine resilience in people who survive traumatic events, there is very little known about the relationship between resilience and the lived experience towards the EoL. Most studies examining resilience are quantitative in design and focus on trauma and survival through childhood. There has been a recent focus on community trauma, with a few studies dedicated to resilience and elderly citizens (Hildon, et al., 2010; Hildon, et al., 2008; Masten, 2001; Seery, 2011). Further resilience studies focus on elderly women and spirituality, although they do not specifically engage in conversations on EoL concerns (Blieszner & Ramsey, 2003; Kinsel, 2005; Manning, 2013). Recent research undertaken in New Zealand by Moeke-Maxwell, Nikora, and Te Awekotuku (2014) examined the resilience of Maori carers when providing care for a family member towards the EoL.

Resilience for people who are dying is not concerned about returning to a previous level of function as a counterpoint to the usual way of interpreting resilience. Rather, it is about adapting and responding to a new way of being with self and others (Folke, 2006; O'Grady et al., 2016). Resilience can be interpreted from a systems perspective when applied to the living experience towards the EoL. Each participant within this study found strength from within themselves, enabling them to move forward and to personally re-examine themselves in the light of changes that were occurring on all three levels of risk: personally, and interpersonally; socially, within a broader community, both within their environment and culture. Cory demonstrates the concept of resilience when she kept her terminal diagnosis to herself, not telling her

children or her wider community about her diagnosis until it became physically obvious. She has a secret that only she and her doctor knew. This adaptive mechanism of secret-keeping, enabled Cory to have some control over her disease, thereby increasing the potential for her resilience to adapt to her new way of being in the world.

Likewise, on a wider societal level of resistance, it was not until Christine spoke out about her experiences of living with dementia that some of the issues related to the stigma of the disease were addressed. As Christine writes, it was the first time anyone in Australia had “*owned up*’ to having dementia. I had ‘*come out,*’ *disclosing my disease*” (Bryden, 2005, p.38-39). Since this revelation, Christine has a sense of purpose and she has reached personal goals that she previously thought were impossible. Through her adaptive response, she was able to increase her resilience and overcome severe depression to achieve new goals, as she shares her lived experience towards the EoL. She has become a spokeswoman for people living with dementia, and she is the author of three books about living with dementia. She is breaking down the walls of stereotyping on a wider community level.

6.2.2 Transformation Through Personal Intelligence

The participants, through their reflective practice of writing, began to have an enhanced awareness of the self and their relationship to others. Reflective practice in this thesis can be thought of as a transformative process of learning, rather than learning through acquired knowledge and skills (Carey, 2016). The construct of Personal Intelligence (PI) (see Research Data, 11) is therefore created through the spontaneous practice of story writing, which is demonstrated by the participants in this thesis. Recovery and transformation from their traumatic episodes occurred as they wrote their stories of living with a terminal illness, creating an environment of continual reflective practice. There are several factors, identified by Illeris (2013) that are associated with transformative learning. These are critical reflections of self and others, understanding the context, participating in further dialogue and a need to put new ideas into action. Therefore, “transformative learning brings a change in knowing, being, and doing” (Carey, 2016, p. 53). The construct of PI is therefore enhanced through the reflexive practice of story writing (Mayer & Faber, 2010).

On a personal level, the construct of PI to create transformative learning is integral to increasing resilience. PI addresses an individual's understanding of the emotions, feelings and passion and the understanding of her or his motives, self-

concepts, dreams, and imaginings (Mayer & Faber, 2010, p. 100). There are four abilities that enable personal growth towards resilience, transformation and PI, these being: the ability to recognise personally relevant information: the ability to identify their own and other personalities to personally guide their own choices: and the ability to systemise those choices and goals for good outcomes (Mayer & Faber, 2010). The next section will address each of these four concepts and how they are relevant to the participants' lives.

6.2.3 Recognising Personally, Relevant Information

The first concept related to increasing PI is that the person can recognise personally relevant information that can guide them towards making good outcomes. The participants all demonstrated this through their reflective output. This enables people to give voice to their illness (Frank, 2013), which allowed these individuals to reflect on their experiences. They also wrote about their imagined lives, their dreams and how they felt when they were achieved or not. Paul demonstrates his PI when he identifies why he turned to writing his experience towards his EoL, revealing: *“I began reading literature again...I was searching for a vocabulary with which to make sense of death, to find a way to begin defining myself and inching forward again”* (Kalanithi, 2016, p. 148). This came through his PI, which initiated his resilience with a personal response to his situation.

Through her writing, Cory says that she is: *“making a shape for death, I am making dying bearable for myself, and someone might read a book or essay of mine and be touched in some way”* (Taylor, in Romei, 2014). Whilst Cory is making dying tolerable, she is also making dying real, making it believable in black and white on the page. Christine, through her PI, was adapting to a new way of being and doing in the world, whilst living with a life-threatening illness. Through her writing, Christine was re-examining her way of being in the world and how she related to others. Her PI is creating a transformational experience of being in the world, discovering a sense of her authentic self (Illeris, 2015).

The participants, through their stories, shared that they felt a sense of relief when their terminal diagnosis was confirmed. There was a sense that they innately knew something was wrong. Although hearing the news was shocking, life shattering, and

like an explosion, they felt relieved on hearing the definitive diagnosis. Receiving the diagnosis initiated a change in conscious awareness. They began to document their stories through social media. Clive, when confronted with questions about his death, was able to respond using humour through his ability to recognise his situation. He is repeatedly asked the same question about his dying. He first confirms that he is still dying, Clive replies, “*Yes, I’m embarrassed about it (not dead yet), sorry about this, yes two years longer than I thought I might, I’m dying I just look remarkably cheerful*” (James, ABC, 2015). Through Clive’s initiative and PI, he was able to reassure the interviewer that he was still slowly dying. It was as if he recognised that he was being chastised for not dying sooner.

6.2.4 Recognising Self and Other Personalities

The second concept related to increasing resilience through PI is the ability to recognise their own and other people’s personalities (Mayer & Faber, 2010). This concept can be seen when Zach, through reflection, was able to understand how other people’s emotions were affecting him, and in turn how he was emotionally affecting other people. In his story, he described how he would often have to comfort people who were consoling him. If he mentioned the word cancer it would evoke an outpouring of grief-ridden stories from others. He became aware of his own emotional response. Eventually, he invented a story about a car accident, which would deflect further questions concerning his diagnosis. Therefore, he didn’t have to go through repeated emotional trauma when people who were inquisitive about his limp, approached him. Not telling people he was dying would then not elicit such a sorrowful response. Zach was recognising his own emotional state and then, identifying the personalities of others through their outpouring of emotions and using these insights to build his own personal resilience (Mayer & Faber, 2010, p. 100). He chose not to share his true story with others until he was ready.

Anatole writes that he was tired of listening to other stories of illness when his friends heard of his plight. He preferred to stay happy and jovial, although at times, his cheerful attitude was not understood by his friends and family. They expected his response to illness to become one of sadness and disappointment. Through his imminent death, his friends were reminded of their mortality (Kaminsky, 2016, p. 1564). Both Zach and Anatole were able to identify their emotional response, then, through their PI, they were able to determine the most useful way to be with others in

their daily living that did not compromise their own wellbeing. This is a different way of being resilient, as it is transformative and led them to self-recovery, which aligns with the central tenets of resilience: of facing adversity and through a complex fluid process of adapting.

6.2.5 Personal Choice

The third concept that is related to PI and increasing resilience, is to personally guide one's own choices (Mayer & Faber, 2010). All the participants chose to document their lived experience via social media, reaching out to others during an arduous time in their lives. They were choosing their own personal option to share their lived experience. Christine demonstrated this concept further, when she decided to '*come out*' about her illness and to show others her brain scans. Likewise, Cory decided to keep her cancer a secret from others who were close to her. In this way, she could take back control of her situation. She would speak about the cancer on her grounds. Clive, when asked about his death, said that he doesn't want to discuss the issues, that one could read his poetry. He is choosing to share his personal deep insights in poetic form. Abby decided to return to the classroom as soon as possible to be surrounded by familiar sights and sounds.

6.2.6 Goals-Creating Good Outcomes

The fourth and final concept that aids a deeper awareness of PI towards increasing resilience and transformation, is to systemise choices and goals to facilitate improved personal outcomes (Mayer & Faber, 2010). The participants were all, in a small way, moving forward: setting goals and taking back some sense of personal agency over their dying experience. Paul demonstrated his ability to set and achieve small goals, even if they were only for a few weeks. He was thrilled to go back to work, which gave him a sense of personal gain. It also allowed him to make the final decision when to leave work. Zach also chose to have a family trip, and to make small steps towards achievable goals to increase his happiness. He chose to return to school, no matter how difficult it was, and he was also determined to put his final words into songs. Kate also returned to work, albeit at a reduced capacity. She was achieving the goals that she had set in taking back control of the cancer in some small way, thereby increasing her resilience. During a later stage in Abby's illness, she chose to take time

off from the classroom to increase her personal physical strength. She was making her personal choices and setting goals based on decisions that increased her quality of life towards the EoL. The following Figure (21) depicts the necessary steps required to gain PI.

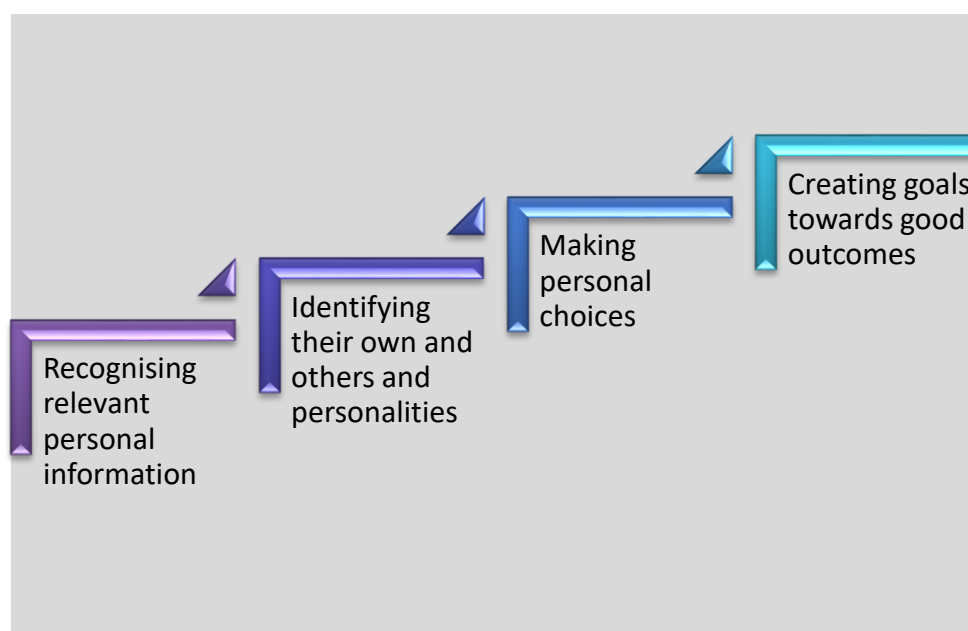


Figure 21: The steps towards Personal Intelligence adapted from Mayer & Faber (2010)

6.3 EXISTENTIAL THEMES AND RELATED SUBTHEMES

The existential themes in this thesis were employed as a means of identifying the most frequent and relevant issues related to the ontological and epistemological way of being and knowing the truth of dying in our contemporary society. Each separate theme revealed shared insights and generated further subthemes of rich data as the participants moved towards the end of their lives. These subthemes are explored further in this chapter to gain a deeper insight on the lived experience. The first themes (chapter 5-diagnosis) related to the original diagnosis and the subsequent themes (chapter 6-restoration) were concerned with moving beyond the initial diagnoses and embracing a new way of being and living with a terminal illness.

These themes are now collated in the following section. Each theme begins with subthemes that were identified by the participants as being important to their wellbeing as they move towards the EoL. Further insights are gained from other sources of literature (insight cultivators) to enable a deeper examination of the insights gained through the themed data analysis (van Manen, 2014). Finally, the singular words that were written by the participants, which were shaped into word clouds, will be further explored. It must be recalled that these words are independent from their original intention. They are by the nature of the word cloud, singular and repetitive. The powerful intent of the words can be visualized through their repetitive nature, as the frequency of use dictates the size of the image.

6.4 ON CORPOREALITY

Through examining the existential theme on corporeality, I was able to identify through continuous reading and rewriting, several subthemes that were consistent with each participant. These were: rupture of self-identity through an epiphany; searching further within themselves to transcend their physical experience; withdrawing from the wider society while they adapted to their changing physicality; and confronting the medicalisation of dying. As Clive, Christine, Cory, Anatole, Abby, Zach, Kate, and Paul shared, they had developed a new insight into what it means to live with a conscious awareness of their mortality. As their artistic output demonstrated, they now had a clarity of mind regarding what it means to live, knowing they have limited time.

6.4.1 Rupture and Self Identify an Altered Body Awareness

The participants in this thesis began with a breach from the existence that they knew, a disturbance in the familiar and the comfortable. This change was extremely evident in their individual physical changes, ensuring that they were not allowed to continue their previous existence. They were coming to terms with losing their physicality. This experience created a sense of a ruptured self-view, demarcating what they knew from what was yet to be known. The epiphanies or epoche created through hearing their terminal diagnosis, also creates a rupture of daily life (Denzin, 2014, p.53; van Manen, 2014). Denzin goes further, to suggest that there are four rituals associated with an epiphany: the breach, crisis, redress, and reintegration. There has

now been a 'schism' created, enabling a crossing from one space to another. This can also be likened to Bourdieu's (1996) work on 'habitus', where there is a separation from a self-constructed internalised view of the social world. Paul wrote when he learned of his diagnosis:

I was physically debilitated, my imagined future and my personal identity collapsed, and I faced the same existential quandaries my patients faced. The lung cancer diagnosis was confirmed. My carefully planned and hard-won future no longer existed. Death, so familiar to me in my work, was now paying a personal visit. (Kalanithi, 2016, p. 120)

Through this sense of a ruptured self (Denzin, 2014), they have, for a moment, a new reality. They have gained clarity, a new awareness of life, due to insights that are critical in gaining a higher order of conscious awareness. It is this newfound awareness and the associated reflexive practice of writing, that enables a significant transformation towards resilience at the EoL (Denzin, 2014; Zautra, Hall & Murray, 2010). There is a sense of a new clarity, which sharpens their identity of who they are in this world.

This epiphany, this major event, has created a crisis, a rupture of their known internalised view of their world, which has altered the fundamental meaning of life. They stand for a moment in time fixed between what was previously understood as health, with its taken-for-granted experience of life, and what has now passed and opened an uncertain future (Denzin, 2014, p. 53). Paul wrote: "*Severe illness wasn't life altering it was life-shattering. It felt less like an epiphany - a piercing burst of light; illuminating What Really Matters - and more like someone had just firebombed the path forward*" (Kalanithi, 2016, p. 120). Through documenting their autobiographical experience and in the context of the Western sociological imagination, they are challenging our current social malaise on matters related to dying. Personally, each of the participants has undertaken the first step towards

accurately recognising personally-relevant information, which enables movement forward to an understanding of the life-death continuum (Mayer & Faber, 2010).

Contemporary biomedical and Eastern understandings of conscious awareness are different in their values and meaning towards sustaining wellbeing (Kellehear, 2014). Historically speaking, in Western society death was understood as being the most challenging part of living (Kellehear, 2014, p.47). In contemporary society, the dying experience is not celebrated, and usually does not come into conscious awareness until the later stages of dying (Gawande, 2014; Kaminsky, 2016; Kellehear, 2007). This sudden conscious awareness after learning that they had a terminal diagnosis, stirred deeper transformative thoughts within each person in this thesis, as they grappled with the new meaning of self, knowing death was imminent. The neglect and the invisibility of dying in modern Western society became extremely evident when Cory was diagnosed. She discovered that dying does not fit into a Western paradigm of psychological services, which is not able to assist with understanding the essence of living with a terminal illness. Demonstrating her PI and her personal choice towards setting new goals and putting her plans into action, she took her dying into her own hands. She achieved this by making sure she had a drug available, just in case she needed it to end her life.

6.4.2 Physical Withdrawal and Retreat

It was essential for each participant to withdraw from the wider mesosystems of life to enable a personal shift in their own conscious awareness of their life-threatening situation (Folke, 2006). This step was important towards building their resilience, allowing their subtle inner body and the mind to catch up their new physical identity (Mayer & Faber, 2010). Withdrawing from the wider society, allows the participants to reflect on the changes that were occurring both on the outside and personally, to redefine a new bodily self-awareness and gain a new self-identity (Stanworth, 2006). This sounds simplistic, however, to sit and be still with silence can be difficult. This practice can produce states of deep reflection, leading towards deep peaceful resolutions (Stanworth, 2006).

The internal sense of ‘Self’ as Mead (1934, p. 173) suggested, consists of “me” and “I”. The “I” is imagined through another person’s experience of who we are. Van

Manen (2014, p. 1563), argues that the individual “I” does not appear in our thoughts and actions until we wonder whether it was actually “I” who undertook an action. That when we are in the moment of doing and being, we are not considering the individual Self. In this way the “I” does not become recognisable until the “me” reflects on what I have done. Such as when we are extremely tired and in an altered state of consciousness when driving, we might ask ourselves, ‘how did I get home, I don’t remember.’ Anatole’s friends demonstrated this when he had to withdraw from their company. Their version of him did not resonate with his own newly-found sense of self. The ‘Me’ is the internal sense of emotions, memories and values that make up just who we think we are when we reflect on “who am I” (Kellehear, 2007, p. 26). Both these two concepts merge throughout the lived experience. Phenomenology proposes that there is a reflective method that aims to access the singular moment to moment of time, which is referred to as the reduction. Phenomenology is concerned with exploring how language, assumptions, temporal and bodily existence and habits shape and mould our lived experience and our beliefs (van Manen, 2014, p. 1584).

Anatole shares his feeling on his changing physical appearance, saying that it was necessary for him to forge a new self-identity, to fall in love with his changing self-image, but to do this, he needed to withdraw from others. As he stated, his usual way of being in the world was wrapped in his sexual identity. His disease took away this masculine identity, therefore he created a new identity and a new meaning, based around his new self-awareness. Anatole is demonstrating his personal self-recovery by reflecting on and making sense of a new situation. This is putting into transformative action a new sense of self (Glover, 2012).

Paul’s and Kate’s identities, their ‘me’, was their life as doctors. Others also knew them as doctors, therefore they needed to rediscover who they were. In phenomenology the meaning of the self lies in the relationship that is experienced by and with ‘things’ that surround us in our everyday lives. The space that had previously held the participants identity of themselves was comforting. Positioning themselves back within their own historical space and place, enabled them to gauge the reality of their situation (van Manen, 2014). Returning to their place of work, albeit in a reduced capacity, allowed a transition towards acceptance of a new physical identity, reflecting on who am I now I am living with an illness or a new me. Abby also found the need to return to her profession as a teacher until she took time to withdraw from her social

surroundings and discover a new sense of ‘me.’ Clive and Anatole continued to write. However, the focus of their writing was now related to the dying experience.

6.4.3 Medicalisation of Dying

As Cory confronted losing her physical existence, she felt trapped in a society that continues to medicalise the dying process (Germov, 2014, Hillman, 2017). She wanted to find some dignity and self-control over the dying experience. She turned to the philosophies of the Eastern traditions. In Eastern philosophies, the lived experience of dying is valued as a chance to experience emotions and to feel the experience no matter how difficult this is, whilst discovering the joy or happiness in each moment whilst moving towards death, as the body fades away (Zautra, Hall & Murray, 2010). Cory demonstrated these insights when she shared how she felt when learning about the ancient art of dying in the Buddhist tradition:

For this is one of the most lamentable consequences of our reluctance to talk about death. We have lost our common rituals and our common language for dying...I am talking especially about people like me, who have no religious faith. (Taylor, 2016, 2014/1466)

The industrialised world has seen a burgeoning of the privatisation of dying, which is managed by small groups of professionals rather than family members (Kellehear, 2007). Adding to this social construct of death is the hidden nature of death within a Western hospital or nursing home environment (Marcella & Kelley, 2016). When a person dies, it is customary for nursing staff to quickly shut all doors and to pull shut all the curtains that separate the living (Kaminsky, 2016). This action ensures that others do not see the dead body, death remains hidden from our conscious awareness, as it is wheeled away through the wards. Social conditioning ensures that the practice of hiding the reality of death continues. Miller, in the Zen Hospice (USA), in direct contrast to the current practice, has initiated a protocol of reverence for the dead. Here, they cover the body in flower petals as a sign of respect and sacredness of

the dying process. The body is not whisked away from view. Everyone, family, and friends are welcome to share in the practice before the body leaves the facility (Zen Hospice project.com, 2017).

In Western culture, euphemisms are frequently used and created to shift the topic away from the reality of death (Gawande, 2014; Kaminsky, 2016; Kellehear, 2007). Death or dying in the modern world is often thought of as a ‘taboo concept’ called by any other name, such as, ‘passed’ or ‘lost’, ‘gone’, ‘fallen from the perch’ and ‘kicked the bucket’ to name a few (Hillman, 2017; Kellehear, 2007; Kaminsky, 2016). Cory highlights this through her lived experience of the nature that death takes on in our Western world. She said: *“Death is a taboo subject, absurdly so. It is tidied away in hospitals, out of public view, the secret purview of health professionals who are generally unwilling to talk about what really goes on at the bedsides of the nation”* (Taylor, 2016, p. 317).

For Cory and the other participants, resilience is realised through their PI as they attempt to break the silence on death by writing and reflecting on the nature of dying in our Western society. They have all experienced an awakened awareness of the nature of death and dying within their physical body and they share the lived experience with others, thereby increasing their own resilience. Cory and others find their own agency through the ability to control their final ending, even if it is imagined. For these reasons, Cory finds comfort in her Chinese drug. This offers her a freedom, independence and agency towards controlling the physical death of her body.

A large independent study undertaken in Australia, revealed that most hospital deaths occur in intensive care, where the stress and memories leave lasting negative effects on family members (Saul, 2016). Kate and Paul, as physicians, were aware of the process of dying. They did not want a long drawn out death. Kate signed a do-not-resuscitate form immediately upon hearing of her terminal diagnosis, as did Paul in his final days, when he also refused treatments that would prolong his death. Immediately, this gave both Kate and Paul a sense of control and autonomy over their bodies at the final stage of dying. When Saul (2012) studied the medical records of those who died in Australian hospitals, it was noted that no reference to EoL care was found. Australia is not alone in this phenomenon: over eighty percent of United Kingdom (UK) citizens have not considered their EoL care (Warner, 2013).

6.4.4 Corporeality Word-Cloud

There is a distinct difference between the frequencies of words used by the participants, when referring to the word clouds on corporality. The words on the first Word-Cloud following their initial diagnosis, described their feelings of the physicality of death. They were; look, just dying, know, will, don't, cancer, and body. This perspective is consistent with a new awareness that now has a focus on the fragility of life, as well as the rupture of habitus that is being experienced (Bourdieu, 1996; Denzin, 2014). When compared to the second Word-Cloud on restoration, the words were: identity, self, feel, body, back, normal and new. There is a sense of optimism in the words used in this second word cloud. There is an acceptance of the changes to one's body at this point, re-defining self-identity and taking this new identity and feeling normal about this new image of one's self (Mayer & Faber, 2010). When visualising the Word-Cloud, the words swirl deeper within the clouds, describing the expressed emotions within this thesis.

6.5 ON TEMPORALITY

The shape of time became a strong focus for all the storytellers. The concept of time was subjective for all the participants. Through the individual subjectivity of time, each participant was able to transcend limited time. Time became more than the hands of the clock, time was perhaps, the most thought-provoking esoteric theme for the participants. The main subthemes that I identified that were shared by the participants on temporality were: shaping their own existence through their imagination; an Out-of-Body Experience (OBE); and the experience of cosmic time. These subthemes are discussed in the following section.

6.5.1 Shaping Existence Through Imagination

The participants in this thesis were comforted through the evocation of positive thoughts and images, outlined by De Petrillo and Winner (2012) as either recalling past experiences, or through writing or imagining an alternate life pathway. This concept can be explained through the Health Realisation Model (Kelley, 2003). Van Manen (2014, p.11093) poses that all theory starts from a human experience and that as such phenomenology uses theory as a means of examining the relationship of the

hidden fragments of human existence that lie beneath the theories. Pre-existing theories, rather than providing the framework of interpretive structure provide a means of examining the humanness supporting the theory. Known as insight cultivators, theories assist the phenomenologist to interpret and exemplify and give light or creative insights to the lived experience.

The main principles of Health Realisation assert that all human behaviour can be understood by the inter-relationship of three principles: mind, thought and consciousness. Thinking or thoughts are the continuous creation of life, therefore thoughts are being expressed through consciousness. Consciousness then transforms thought or mental activity into a subjective experience through the senses (Kelley, 2003, p.380). The mind in this instance is thought of as the Universal Mind, which is formless spiritual energy, our life force, our human connection to the Divine (Pransky & Kelley, 2014). The ability to reshape time gave each person a sense of ‘telos’, the term referred to by Aristotle as a purpose, the goals and wishes that each one of us strives towards in our lives (van Manen, 2014, p. 7566).

The major tenants of the Health Realisation Theory are to focus on self-empowerment and self-help through positive thinking (Kelley, 2003). These concepts align closely with those of PI. This strategy was evident when Kate's positive thoughts reduced her fear during medical treatments, and her imaginings of having a child. It can also be seen in Zach's dreaming of a future. Both Kate and Zach found comfort in imagining their future. They stated that they were aware of the outcome, but that their imaginations were extremely important at this time, to increase their sense of happiness. It is little wonder that this had a positive outcome for their lived experience towards the EoL, transcending beyond the material world. Bringing positive thoughts, dreaming and reminiscence into conscious awareness through the physical senses, created a magical liveable world. This is extremely important as a counterpoint to being locked into the present time (van Manen, 2014).

6.5.2 Out-of-Body Experience (OBE)

On temporality, the participants described an OBE, a time warp, transcending to a new dimension, limited time, and enjoying what time was left. Most people experiencing the EoL in this thesis stated that they were cheerful, happy, and further that time feels like a state of being, an eternal being. Kate, after receiving a terminal diagnosis wrote that she felt like she was stepping out of her body. This notion of

stepping outside of our-selves, of looking from a different time perspective, of time slowing and witnessing life from outside, is a known phenomenon and Kate is not alone in her OBE.

In Western literature, the OBE, or transcendence, is referred to as the Astral body (Latin root from star linked to auras), the soul body or the spirit (Brennan, 2003). The astral body is the 7th auric layer within the Human Energy Field (see chapter 2). It is thought that this body is the same as that which continues to exist after death (Lindsay, 2007). One of the most common findings in OBE research was the reported witnessing of the body and surrounding area from above, by survivors of near-death experiences (NDEs), who also described the astral (etheral) body travelling distances away from the body (Alvarado & Zingrone, 1999). It has been reported that the OBE can occur because of a sudden emotional shock, illness, and accidents, prayer and meditation (Alvarado & Zingrone, 1999).

The OBE is referred to in Shamanic (Medicine Man) terms as ‘journeying’ and there is little difference between an NDE and an OBE (Woolger, 2004). The Astral body (not a physical body) is another way of addressing the Soul. From the ideas of Socrates, Plato and Jung, the Soul transverses across Western society, yet continues unexplained by science and therefore remains an elusive phenomenon. Many people experience the phenomenon of being out of their body during and illness, however it is only recently that some have written about their experiences (Alexander, 2012; Hemsley, 2003). Within our current health model, if a person relates an NDE story to a physician, they are most likely given a scientific reason about their brain’s struggle to hold onto life (Alexander, 2012). As previously elaborated, cultural interpretations in understanding time are important for considering cultural differences in resilience. In Eastern philosophies, the OBE is a sign of a connection with the Divine and is regarded as an important process towards enlightenment or becoming one with Shiva (Lord). It is also known as the Witness State (Kripananda, 1998).

6.5.3 Cosmic Time

The feeling of time slowing, of being outside the body and looking in, of time walks and moving between two worlds was understood in ancient Celtic mythology. The ancient Celts believed that they lived between two worlds with one foot in this

world and one in the other (Silf, 2014). The Celts had a strong belief of a connection that existed between the mind, the body and the spirit, with the spirit being the tie between the body and the mind. If you were born with a gift, it was thought that you could travel between the two worlds (Silf, 2014).

The understanding of time as being cosmic, is common in Indigenous cultures where time moves slowly, and relationships are more important than the future (Figure, 22). Time is thought of as cyclic: it rises and sets with cosmic cycles of the sun and the moon (Ellerbe, 2009). The seasons are not limited to four. There are many festivals that honour the summer and winter solstice and equinox. The cycles of time and mysterious connection between people and nature are organised in sacred festivals and temporal maps (Judge, 2014). This concept differs from modern Western cultures, where time is thought of as linear. Time progresses from the beginning of the calendar year to the end in a linear fashion. Time takes greater priority than relationships. The hands of the clock measure the modern world of time and time runs from one minute to the next in chronological order. We wear time on our wrists to watch time, just in case we are not on time, or we run out of time (Judge, 2014).

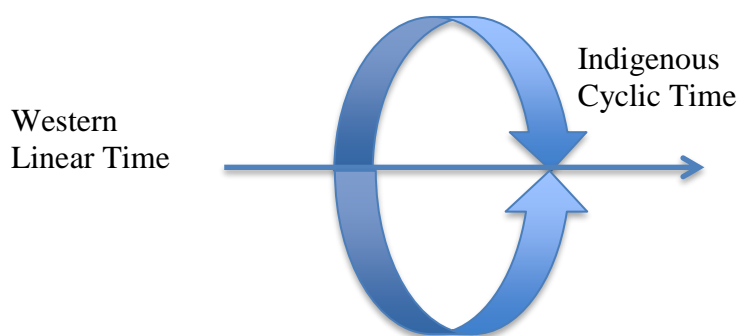


Figure 22: The concept of time as cyclic and linear

The Indigenous concept of time is thought of as cyclic and creates a connection where there is no beginning and no ending. There is a point where past time mingles with future time, therefore creating only the present moment in time (Kellehear, 2007). This is the space that was created for the participants in this thesis. As they moved

towards the EoL they found a new clarity, a new sense of time. Time was a priority and every second was considered precious. For Christine with dementia, there was only this minute. Personal goals changed towards a focus on individual choices and the participants made the choice to take more time for themselves and their families, which allowed space for time. The need to make the step from ‘Chronos’ (clock) time to ‘Kairos’, or timelessness or infinity (Stanworth, 2006), was extremely important for all the participants.

The subjective nature of Time was experienced by Paul when he had a feeling of loss as he walked into the surgery. He is not quite sure if it will be the last time. This moment in time seems surreal and he faces it with courage and a deep inner knowing of something that he cannot explain verbally. Zach also shares how temporality is important to him, believing in an imaginary world he can dream and walk his mind into happier times. Zach’s resilience is fortified with his imagined world. Through his PI, he can create a new world of unlimited, unending times of happiness. Time was a central focus for all the participants, time became a commodity that Paul describes: *“I was having to learn how to budget. You might decide how to spend your time...but two months later, you feel differently.”* Paul continues: *“death may be a one-time event...living with a terminal illness is a process”* (Kalanithi, 2016, p.160). He knows he is running out of time, or running with time albeit slowly, but time is still occurring.

6.5.4 Temporality Word-Cloud

The Word-Cloud, related to temporality and diagnosis, prominently feature the words: like, much, time, will, temporary, tense and dying. There is a sense of urgency that surrounds time in this Word-Cloud related to temporality. Following their initial diagnosis, their perspectives related to time had been altered and they experienced a shock which has initiated an OBE, a time warp. The second Word-Cloud on temporarily featured words like: time, like, living, existence, can, cancer, energy, and death. Here can be seen clearly the word cancer, and energy and like and living. This begs the question: can time be manipulated? When examining the different words on the clouds, there is a focus on time and how much time there is to live. The word time is literally surrounded by death, existence, living and cancer.

6.6 ON SPATIALITY

The subthemes that were revealed through the participants' stories, relating to spatiality, focused on: the space surrounding the dying, metaphysical energy, the natural environment, and the importance of music and the arts enabling transcendence. All the participants in this thesis reflected a desire for the hospital space not to be the dying space. The space and place of dying was discussed by all the participants and highlighted the need for conversations to commence between health professionals and their patients on these hidden topics. These subthemes are discussed in the following section.

6.6.1 The Dying Space and Place

The burgeoning medicalisation of death and dying in contemporary society has increased the number of people who die within the walls of hospital, away from the home and all the extended members of the family (Carter, 2016; Carter & Carey, 2018; Gawande, 2014; Germov, 2014, Hillman, 2017). In ancient Celtic times, the act of dying was included in the sociological imagination and was regarded as a time for spiritual preparation for what might lie ahead. Priests, healers and wise women who understood the needs of the dying, cared for the sick. The natural sounds of the environment and of the fragrant oils that were used to soothe their bodies filled the dying space (Warner, 2011). In years past, death was not a stranger. When families cared for their dying relatives, they knew the sight, the sounds and the smell of death. The art of dying was understood by the family as a safe environment, where the key point on space was that is needed to be filled with family and friends and not medical equipment and strangers (Warner, 2011).

In recent times, the ancient art of the Soul Doula has been awakened. There is a movement in the United Kingdom that involves training people from all parts of the Western world, who are interested in the art of the Doula. Known as Soul Midwives, they are a "group of non -medical companions to the dying" (Warner, 2011, p. 51). They ensure that the patient has a dignified death, supporting their physical and metaphysical needs. They attend to the soundscape, the touch, colour and the smells of the environment. This is akin to a whole systemic movement of care (Warner, 2011,). There are currently a few Australian Soul Doulas who are trained in the art of care of the dying.

Modern day medical interventions and public health maintain longevity (Carter & Carey, 2018; Gawande, 2014; Hillman, 2017; Warner, 2011). However, increased longevity does not necessarily determine an increased QoL towards the EoL. Likewise, surviving accidental death and disease will not provide a clear or accurate explanation of how or when we will die (Gawande, 2014; Kellehear, 2007). Cory reflects on the concept of living longer with a reduced QoL when she shared that she did not want to die like her parents. Hence, she has taken control of her dying space, increasing her PI and thereby increasing her self-determination and resilience. The fear of dying has increased as people now die in a hospital environment. The best solution, offered by Warner (2011), is to replace the fear of dying in hospitals with care in a home environment. Likewise, Zach decides to spend his last days at home in a room surrounded by his family, and that it is full of his things that bring comfort.

6.6.2 Metaphysical Energy

Many studies (Klohn, 1996; Koenig, 2008; Koenig, & Perez, 2000; Manning 2013; Maston, 2001; O'Grady, et al., 2016; Pargament, Werner & Smith, 1992) have found that spiritual and or religious beliefs and practices provide a protective factor that assists in resilience and recovery following traumatic experiences. This finding is also consistent with the participant experiences in this study. They all describe an uplifting metaphysical spiritual energy within the natural environment. They speak of the restoration of the spirit through poetry and prose. They write on the strength of spirituality and religious beliefs that sustain them, of peace and comfort and familiar smells within their environment and the joy and peace found in music, which was described as soul-soothing. In contrast, for the participants in this thesis, the hospital environment filled them with dread. It is a reminder of the torture chamber, of the bags of fluids and of painful procedures and most importantly, of their loss of control.

6.6.3 Natural Environment and Biophilia

An important subtheme revealed through the stories on spatiality in this thesis, was the sacredness that is felt, being in the presence of the natural environment. When surrounded by nature, most of the participants shared that they felt happy, joyful and content as they moved towards the EoL. The participants were experiencing Biophilia, a human innate ability to connect with nature that goes beyond providing basic needs

(Wilson, 2003). The natural environment is considered extremely beneficial to wellbeing, so much so, that even virtual exposure through screens or a window can improve psychological health (Brymer, Cuddihy & Sharma-Brymer, 2010).

Divinity within nature found by human beings, holds true for all cultures and is demonstrated by the many sacred sites that can be found around the world, each providing many people with a sense of awe and spiritual wellbeing (Ryan et al., 2010). The river Ganges in India; the enormous rock Uluru in Australia; the Mahabodhi tree in Bodhi, India; Mount Kailas in Tibet; and Stonehenge in England are examples in a cultural context (Newton, 2007). Human flourishing at the EoL sounds like a dichotomy of terms, however the participants in this thesis have discovered that it is possible to flourish, as they move towards the EoL. Human flourishing is linked to increased resilience through self-agency, PI and setting goals that include a wider cultural belief in the spiritual link through connection with the natural environment (Tuck & Anderson, 2014).

6.6.4 Sound Vibration and Transformation

Most of the storytellers wrote about the transformative power within music: the ability of music to be soothing to the soul; and to speak through music until death. The power of vibrations through sound has been understood since long before the science of Quantum physics (Bunt and Daykin, 2012; McClean). Hermes, the Greek God, revealed his wisdom through meditations and his principles of philosophy, including the metaphysics of sound in the form of vibration and rhythm (Goldman, 2002). It has been demonstrated that sound vibrations can provide a temporal reality to the listener, transporting them through an imagined reality (Goldman, 2002).

An Australian hospital soundscape is often full of noise and alarms, which can produce stressful situations (Short et al., 2016). Nursing pioneer, Florence Nightingale (1860), documented the importance of music therapy in the treatment of illness. She especially noted the voice and stringed instruments as being beneficial towards recovery. She writes, "...Home Sweet Home...on the most ordinary grinding organ will sensibly soothe them (ill)" (p.40). Whilst some independent nursing scholars advocate for the introduction of music therapy into the hospital environment, the movement has been slow to evolve (Brown et al., 2015; Lyendo, 2016; Ratcliffe et al., 2013), excepting in the case of operating theatres, where surgeons can fill their soundscape with the music of their choice (Yamasaki et al., 2016). Kate was

disappointed when the surgeon ignored her choice in music, thereby adding this to her feelings of being alienated from her treatment choices.

Modern practices of health care are extremely important for survival and longevity. Nevertheless, this should not negate traditional practices that connect humans with metaphysical healing concepts. The roots of medical science are grounded in spiritual and religious concepts (Koenig, 2008). Western Gregorian chants have, for centuries, been breaking the silence in sacred places and escorting their participants to an ethereal world. The high frequencies of the chants were found to sustain the monks physically over long periods of time (Goldman, 2002). The Tibetan, Vedic, and Native Indian cultures include chanting practices to produce altered states of consciousness, and Aboriginal Australians' Song Lines link communities across the country (Eckermann, et al., 2012; Koopsen & Young, 2006; Warner, 2013). Karakia (Maori chants) are considered healing and uplifting in the face of adversity and are extremely important to individuals during illness. Chants or prayers are important at the time of death, to maintain the sacredness of the space and to connect the living and nonliving with the metaphysical realm (Moeke-Maxwell et al., 2014).

Research testifies to the ability of music to increase the QoL, by reducing both anxiety and the effects of high blood pressure (Bradt, Dileo, Grocke and Magill, 2011). Music in all forms has been found beneficial to health and is not limited to instruments alone. Voice and singing are beneficial for both psychological and social wellbeing, increasing positive emotions (Clift et al., 2010). Positive emotions over time can reduce, in small increments, the effects of negative emotions on the cardiovascular system, thereby increasing QoL (Fredrickson & Levenson, 2011). Therefore, music therapists can play an important role in addressing the spiritual needs of patients at EoL, as music can offer creative, lyrical, and symbolic means to address existential and spiritual needs during the process of dying (Magill and Luzzato, 2002).

It is not within the scope of this study to include all music and arts and the role they play in contemporary society, rather, it is to clearly articulate that music, through instrument or voice, is an important inclusion within the concept of spiritual literacy. There were many stories within this thesis that told of the existential power that is held within music, and of the power of music to relay emotions that are sometimes difficult

to communicate through words alone. Zach, through the power of his music and PI, was able to speak and share his emotive voice with others worldwide. He set goals of writing music one song at a time, thereby increasing his resilience through sharing his lived experience and reaching out to a wider audience. Clive also shared his emotional voice through the power of his poetry. Through his emotive words and with rhyme and rhythm, he shares his personal lived experience as he moves towards the EoL.

6.6.5 Spatiality Word-Cloud

The words frequently used within the first Word-Cloud by participants on the topic of spatiality were: room, dying, patients, now, just, don't look, people. There is focus on the room and on being a patient. This compares with the most frequently used words on the second cloud, which were: environment, dying, visual, nothingness, thing, common, and world. In the second word cloud the focus has shifted from a personal level of awareness to focus on the words; environment, the world, nothingness and dying. Suggesting that there has been a change in focus from a microsystems level of Self towards a more incorporates a worldview (Folke, 2006). When visualising the words on the second Word-Cloud related to spatiality, the words, world, environment and dying, appear to overwhelm and consume the cloud, this could suggest a new awareness towards transcendence.

6.7 ON MATERIALITY

Insights gained from the stories relating to material objects, presented in this thesis, are like those related to spatiality. The material symbols that surround the participants hold importance for their sense of place. The participants want to surround themselves with familiar objects that bring them to a world that is filled with 'things' that do not remind them of their illness. Subthemes on materiality, shared amongst the participants, included the arts, noticeably, writing stories, poetry and voice. The importance of an imagined reality was also central to the participants' wellbeing. They derive comfort in memories of familiar objects. Objects that have been in their world and that can fill their minds with comfort and memories, these objects hold a place within the space.

Clive writes about the comfort he finds in looking at his Chinese screen, the memories that it holds for him. The maple tree that grows outside his window blooming in autumn shades of colour, reminds him of his dying experience as its leaves

lose their colour and fall from the tree. Abby's sacred space was her garden, where she would retreat to make time to be with herself, listening to the animals. It is vital that consideration of the cultural space within the social/human sciences be given a stronger focus when caring for someone at the EoL (Green, 2010). It is the cultural space, filled with rituals and symbols (materiality), that gives purpose and meaning to individuals to make sense of their world-view.

6.7.1 The Power of Storytelling and the Arts

The power of storytelling is an ancient tradition, stemming from a human need to make meaning of their experience and to make new connections. Each person who tells a story speaks from their 'biographical position' and is unique as the storyteller (Denzin, 2014, p. 55). Stories were passed from generation to generation before the written word. Stories, or narratives, assisted in the survival of cultures by retelling warnings of potential threats. They are intrinsic to all cultures, whether they are written or verbal (Nathanson, 2006; Struthers, 2006). The importance of writing stories for the participants in this thesis, was paramount. Through emotive descriptions of their personal struggles, they could reach new horizons towards self-discovery. The act of storytelling can impart a metaphysical presence that can provide a sense of spirituality in the communication process (Snyder & Lindquist, 2006; Uys, 2014). Storytelling in any form, was an intrinsic method of making sense of the internal dialogue in participants' personal lives. Most of the participants (Anatole, Christine, Zach, Paul and Kate) have a desire to write their stories until the EoL.

Storytelling has been described as an expression of human consciousness and as such, can guide the person towards healing the spirit. In telling a story, people create links between themselves and the world of others. It is a means of creating order and temporal sequences to life events (Bosticco & Thompson, 2005). The physical act of journaling, as in writing a blog, is therapeutic, as it involves every aspect of the person. It requires the physical mechanics of the body, through writing and the concentration of the mind to recall events (Snyder, 2006). Journaling or writing blogs is, by its nature, cathartic for the writer, allowing emotions to be released (Bosticco & Thompson, 2005; Snyder, 2006; Uys, 2014). The stories in this thesis reflect the PI of the storytellers as they turned to writing as a form of interpreting their emotions,

witnessing their thoughts as they recorded them. Aristotle (1992) and Freud (1928-1961) both believed that the arts held a purging effect, which leads to resolved personal crises. The cathartic ability of the arts has been found on many occasions, to improve mood through PI and thereby increase resilience (De Petrillo & Winner, 2012; Uys, 2014).

6.7.2 Materiality Word-Cloud

When visualising the Word-Cloud on materiality, a change in perspective can be perceived. When comparing these Word-Clouds at the beginning and the end of their illness, the words following the initial terminal diagnosis concentrated and centred around the individual. These are: I'm, can, get new, stuff, real. These words indicate that there is 'stuff' and 'things' to consider and that getting 'real' (as highlighted by the participants) is now on the agenda. The second word-cloud, on restoration, visualises an alternate viewpoint, with the words highlighted being: writing, life, just, music, day, talk, people, thing and dementia. There is a sense of finding alternative ways of being in these descriptive words. It is the first time that the word 'life' is highlighted in the word-clouds. The word, writing, is prominent and that is not surprising, given that all the participants are documenting their lived experience through writing. Music is also evident amongst the shared words on materiality. Again, this word is reflected in the participants' statements on the importance that the role of music played in shaping the lived experience towards the EoL.

6.8 ON RELATIONALITY

Relationships with others were extremely important to the participants as they shared their lived experience through stories. Subthemes that were revealed through the stories were their relationships with the medical profession, the shared relationship with family members, including their animals, and with the wider community. New life trajectories were created through being involved with social networks and a new peaceful awareness towards understanding dying.

6.8.1 Relationships with Health Professionals

Most of the participants in this study wrote and reflected on the inability to form meaningful relationships with medical or nursing staff. The participants were surprised and dismayed that most health professionals were unable or unwilling to discuss issues around the dying process. There was angst for the medical professionals living with a

terminal illness (Kate and Paul) as they realised that their emotional needs were not being considered within a biomedical model of health and illness. This turmoil was juxtaposed between medical statistics, treatments and survival rates and the realistic life ending tragedy.

Both Kate and Paul who were health professionals, found that there was an awakening of the importance of preparing people with a terminal illness for their mortality. Rather than the focus being on technology, there was a desire to discuss deeper realities of dying, hence they turned to writing and sharing their lived experience through social media. Kate started a campaign on the importance of the doctor introducing themselves prior to treating a patient or client. The National campaign was undertaken in the UK and was called 'Hello, My Name Is.' Similarly, Paul was desperate for other health professionals to responsibly and compassionately make competent medical decisions on his care, so he could rest his mind as he faced his mortality.

It is purported that EoL issues are written into current medical and nursing curricula, albeit in small doses (McEwen, 2004) however, this was not demonstrated in practice. Very little has changed in this regard since the large study undertaken by Glaser and Straus (1965) when, after six years of intensive fieldwork interviewing patients, nursing and medical staff, they concluded that physicians were reluctant to discuss EoL issues and that nurses were not allowed to, unless they were authorized by a medical practitioner. While this is not the case in current nursing practice, there remains a secrecy surrounding dying (Andrews, 2016; Glaser & Straus, 1965). As discussed in chapter one of this thesis, studies report that spiritual concepts are difficult to define and are often not discussed by nurses in clinical practice (Kellehear, 2007; Koenig, 2013).

The participants who were not medical practitioners (Clive, Zach, Christine, Abby and Cory), were extremely grateful to have caring people looking after their bodily needs, it being a new lived experience for them. To hand over their independence to strangers, they were eternally grateful and new relationships were created. In most instances, they struggled to regain some independence. Any opportunity to be considered or included in the decisions made, while they were in the

hands of health professionals, was appreciated. Nonetheless, whilst Anatole and Cory were anxious to discuss their emotional dying needs with health professionals, it fell on deaf ears. The participants in this thesis understood they were dying, and, in most cases, they were eager to discuss their insights and thoughts with the medical and nursing professions.

6.8.2 Shared Relations: New Life Trajectories

The perseverance of relationships and creating new relationships becomes profoundly important for wellbeing towards the EoL (Holling, 1973). The rupture in an individual's life through a traumatic experience, can create a new life trajectory (Denzin, 2014, Folke, 2006). Cory demonstrated her PI when she made a stand to take dying into her own hands by joining the group Exit International. Feeling lonely and isolated and unable to discuss dying with her relatives, or the medical profession and her peers, Cory turned to a group of people who share the same needs of having an open and honest discussion on dying. On a mesosystems level of resilience, it is vital in moving forward, that people share their lived experience with like-minded individuals (Folke, 2006; Mayer & Faber, 2010). Through recognition of her needs to share her story with others, Cory was able to forge a new way of being and a renewed sense of living until the EoL. This ability to adapt was, for Cory, facilitated by establishing positive connections through her social world.

Prior to the medicalisation of dying, the usual place to die was at home, surrounded by the company of relatives and friends, and the 'things' within the environment that felt familiar and provided a sense of comfort (Germov, 2014; Hillman, 2017; Warner, 2011). The participants within this study all requested to die at home surrounded by family members and the environment that brought comfort to them. Animals were also an important inclusion within the realm of the family and the home environment, for giving and receiving unconditional love and acceptance. This human loving contact with animals lies deeply embedded in ancient Celtic culture (Ellerbe, 2009). It was once considered an essential part of the natural environment, when harmony with nature was a sign of godliness. The mythical creature Pan, half human and half goat, was the escort of nature and animals. Pan guided all the mythical creatures of the wood and worked in harmony with fairies, elves and devas. Pan played the panpipes, which filled the woods with enchantment (Ellerbe, 2009).

This closeness with animals was forgotten over time, after Pope Innocent VIII ordered pet animals to be burned along with the witches (healers) in 1484. It was imagined that animals were the agents of the devil (Ellerbe, 2009). Nursing pioneer, Florence Nightingale (1860), reawakened animal therapy into nursing practice when she noted that keeping a small pet was excellent therapy for the sick. Through the validity of the scientific paradigm, Animal-Assisted Therapy has reasserted itself in recent times. There is a multitude of studies (Allen, 2002; Calvert, 1988; Carmack, 1998; Cole & Gawlinski, 2000; Heimlich, 2001), which can attest to the validity of pet therapy to improve physical and psychological health, through the animal's ability to interact with their human owners. Animal contact, be it fish, birds, cats and dogs, enables a space for companionship for humans, decreasing loneliness, increasing exercise, emotional devotion, and reduced anxiety, and an opportunity for therapeutic touch (Allen, 2002; Calvert, 1988; Carmack, 1998; Cole & Gawlinski, 2000; Heimlich, 2001).

6.8.3 New Awareness Towards Death

The stories within this thesis tell of discovery of a new awareness, or insights and understanding of a new way of being, a deeper more authentic relationship with self and others. The traumatic experience in these people's lives will not dissipate, go away or fade as in a traumatic experience that replays itself within the human psyche. Embodying dying requires a deep movement within for acceptance (Denzin, 2014). As Christine stated, she now lives in the present moment, with a connection to people that goes beyond the physical appearance, she knows people on a deeper level, she writes:

I felt very relaxed and happy, and found that the beauty of the natural environment, the plants and the landscape forms, were strong visual memories which somehow restored my spirit. The beautiful gum trees, the possums, the parrots and the crisp cool air gave me a very spiritual time, and I felt a great peace filling me. (Bryden, 2015, p. 99)

Most of the participants, felt that there were moments of regret, however their diagnosis brought relief. There was not so much a bargaining with God, as proposed by Kubler-Ross (1965), rather, a deeper, insightful intelligence emerged. The experience of a shock or epiphany was necessary, enabling each to move towards a new peaceful, knowing self, finding a new way of being and experiencing the world (Denzin, 2014; van Manen, 2014). As implied by the participants, death is understood, yet it remains a hidden secret that we all must face one day, and they, the participants, have achieved that experience: facing death. Zach, at the age of fourteen years, became acutely aware of his imminent mortality. His words speak of his insights when he said shared that, *“you don’t have to be dying to start enjoying life”* (Sobiech, 2012, soulpancake.com).

Christine, whose illness, which was not immediately obvious to others, wished for an alternate disease so that others could appreciate her struggles. Indeed, such new-found confidence and self-identity, which she discovered through wider social circles, pulled her out of a deep depression. Using her PI, Christine made a choice to speak openly about her lived experience. Further, she set goals that would ensure that others have an insight into the lived experience of dying. Through her personal intelligence and insights, she found a way to move out of depression and isolation. The wider community embraced her struggles and appreciated Christine’s personal knowledge of her illness and her willingness to share her story.

Likewise, it wasn’t until Cory found a group of Buddhist Nuns who were willing to discuss her dying needs, that she found comfort in the dying process. Being able to discuss her impending death with the group of like-minded people at Exit International, also gave Cory a sense of peace. Relationships with cyberspace were also important for participants in this thesis, each one of them reached out either by song or prose to connect with others. As dying is part of a social imagination, the introduction of social media within our contemporary society is changing the way death and illnesses are socially constructed (Germov, 2014).

6.8.4 Word Cloud on Relationality

When comparing the Word-Clouds related to relationality, there is an obvious distinction between the two. The focus of words related to the initial diagnosis is

centred on people, family, staff, doctor, cancer and relationships. The second word-cloud shows the words: filled, hope, death, dying, joy and life as being more prominent. These words express emotions linked with spirituality (Gijsberts et al., 2011). This move from the focus of their immediate surroundings of people, staff, and hospitals, to sharing words like hope, joy, death, and life, demonstrates a shift from dependence to independence. All the participants connected through their music, poetry or writing skills with others from a wider community

6.9 SUMMARY

Chapter six has synthesized the two chapters on data analysis, diagnosis and restoration to extricate the most important subthemes, words and phrases that are shared by the eight storytellers presented in this thesis. There were many commonalities that they experienced towards their EOL experience. Using the literature to cultivate further insight into their experience was an enlightening task, which invaded my dreams and uncovered a plethora of material for discussion.

This chapter had allowed for many insights into the lives of the participants in this thesis to emerge. It has identified the strength of each person's ability to reach restoration, such as an awakening into a deeper awareness, personal intelligence, the importance of hope, dreams and imaginations, and of the arts in sustaining their spirit, music, writing, and poetry. Resilience was a significant part of the EoL experience as the participants adapted, achieved new goals and experienced agency in the face of death. This is a powerful reminder for health professions to assist people who have a terminal illness to understand that, as people advance towards EoL, they can still move forward towards living the best life possible and achieving new goals. Furthermore, this chapter has highlighted the sequestering nature of the spirit in Western societies. Chapter eight will conclude this thesis, synthesizing the findings from the stories into a way to move forward and further discuss future areas for research as well as identify possible limitations of this study.

Chapter 7 Conclusions: Demystifying Dying



Researcher reflections 17: Lord Ganesh the remover of obstacles from the path

Photo credit: Pixabay.com

There is a mysterious power that pervades everything.

I feel it, though I do not see it.

It is the unseen power that makes itself felt

And yet defies all proof, because it is so unlike all that

I perceive through my senses. It transcends the senses.

Mahatma Gandhi, (1931, motivationmentalist.com)

7.1 INTRODUCTION

This final chapter begins with an experience in the metaphysical realm. A moment that two people share together, a space that is unknown, unseen, and unfelt by others. Incredibly, and as unplanned as this experience was, it brings this thesis full circle from its conception to the conclusion. Here, starting this final Chapter I recall a personal experience between myself and my mother, which became the stimulus to write this final Chapter. The connection between the aims and purposes of this thesis and the insights that have revealed themselves through hermeneutic existential enquiry are presented for the final time. This chapter then proceeds to summarise the major findings of this research and to discuss how this research contributes to the current body of knowledge. This chapter also outlines the limitations of this study and identifies future areas for research. This thesis concludes with the argument that it is time for a paradigm shift within health professionals, particularly the nursing profession who work closely with those who are moving towards EoL. There is an urgency to initiate new policies and procedures for the care of people who are living with a terminal illness, so that living with a terminal illness includes setting new goals and being filled with possibilities and transcendence.

As I commence this final chapter, my mind is full of the words and experiences that the preceding years, writing this thesis, have given me. I had no idea how to piece this information into a cohesive whole so that the insights may be shared. My mind was in turmoil, so I sat for meditation. I found a peaceful spot in the house, the summer heat was intense, the light was intense, and somehow, I managed to draw myself inwards to a quiet still dark place. As I sat, I allowed all the thoughts to swirl around and come to rest within my mind. Out of the darkness and into the stillness, I found myself watching a scene that happened many years ago, a time that I had completely forgotten about. It must have been at least twenty years ago, that my mother and I were in India, spending some time together in an Ashram (monastery). I sat silently, connecting to my breath, watching the images in my mind, asking no questions, just being:

As I sat in the stillness, I watched silently as my mother came slowly
forward, her outstretched arms were full of flowers to offer the beautiful

murti (enlivened statue) of Ganesh. Polished in white marble, he sat surrounded by the beautiful gardens, gazing out offering peace and love to all who came forward. I found myself quietly peeking through a veil that was hiding this scene, I lifted the edge ever so slightly so that I could see. Tears poured down my face, I didn't know why, I couldn't explain this experience. Only to sit with it for a while as I slowly watched the images fade, I was in awe of the mystery of the images. I recalled the solace that my mother found in the murti when she was living and how she found peace in a life that was full of angst. I recall feeling full of love at this sight of my mother absorbed in and surrounded by peace.

Researcher reflections 18: Full Circle

I wondered why I had this vision of Lord Ganesh, the elephant headed deity of India. Following further research, I found that in Kashmir Shivism (Indian philosophy), he is the deity of New Beginnings. He is the remover of obstacles on the path forward and the patron saint of the arts and sciences known as the Deva (God) of intellect and wisdom (Heras, 1972). On reflection, it was as though my mother's offering of flowers to Ganesh was to help me to move forward in my writing. I felt the blocks move gently aside. I immediately experienced a sense of renewed enthusiasm and excitement in piecing this thesis together. Concepts and images flowed through my conscious awareness. Through this meditation and the universal power of connection and creation I was pulled out of my reverie and propelled forward in my writing.

7.2 AIM AND OBJECTIVES

The aim of this thesis was to inquire into the lived experience towards the EoL through examining the longitudinal stories of people who are living with a terminal illness. Through the power of van Manen's (2014) hermeneutic phenomenology and through a rigorous existential reduction, paragraphs, sentences and finally the words,

held within the anecdotes, were explored. I have unveiled many fundamental aspects of these experiences from this group of eight participants. These findings are discussed further in the following section. All the stories were provided through the power of social media.

The stories the participants shared were most suitable when using van Manen's work (2014) for many reasons, including how the participants themselves questioned and reflected on their own experiences as they recorded their own lived experience. The questions that the participants asked were related to moving forward following their initial diagnosis. These questions included: how do they make sense of this life changing experience? how will I look and feel towards the EoL? will I experience a peaceful death? what will happen to the people I leave behind? how do I approach death? how do I want to die? They expressed, through their stories, how they were able to redirect their lives towards a peaceful resolution through resilience. In most cases, they answered their original confronting questions. The following sections address the findings of this research and a summary of the main subthemes that arose during the data analysis.

7.3 SUMMARY OF THESIS AND FINDINGS

Chapter one was essential in setting the scene and introducing the personal anecdote that propelled this thesis into being. The anecdote was central to the background context, which placed this research in contemporary Western society with all of what we have come to understand and know about dying and death. Relevant concepts that were related to dying in modern society were discussed. It was revealed that death is an elusive subject that can be witnessed through the media yet can be simultaneously remote to the individual personal experience (Gawande, 2014; Kaminsky, 2016; Kellehear, 2007; Koenig, 2013; Saul, 2014). The aim of this thesis was to explore the lived experience towards the EoL from personal stories that are publicly available through social media sites.

Metaphysical concepts were fundamental principles considered during this research, as this provided understandings about the vital link between religious and spiritual health and wellbeing, especially as death draws closer (Feldstein, Grudzen,

Johnson & Le Baron 2008; Puchalski, et al., 2014; Whitehead, 2003). Religious and spiritual concerns are heightened when dying is imminent (Gawande, 2014; Koenig, 2014). Therefore, a clear definition of both metaphysical and spiritual concepts was provided in the first chapter to avoid any confusion between the notions of religion and spirituality (Koenig, 2013). Chapter one included a succinct definition of the meaning of a person, which dictates a holistic view, including psychosocial perceptions (Watson, 1996).

The second chapter provided a contextual overview of the pre-modern society and the link that connects with the modern view of health and illness. It is important to say that one cannot interpret the contemporary understanding of dying until it is examined within the context of a historical perspective (Denzin, 2014; Frank, 2013; Koenig, 2013). For example, the Western philosopher Rene Descartes introduced the concept of Cartesian Dualism and delegated care of the spiritual matters to the Church (Descartes, 1664; Gawande, 2014; Germov, 2014; Kaminsky; 2016). Until as recently as the last Century, the care of death and dying remained the responsibility of family members (Germov, 2005). There was a shift towards the medicalisation of death and dying, which has witnessed many people dying in a hospital environment, with strangers caring for them (Frank, 2013; Germov, 2014; Kaminsky; 2016). Compounding these factors is the slow evaporation of the nature of the spirit within the medical paradigm and nursing has followed suit (Gawande, 2014; Kellehear, 2007; Koenig, 2013).

The ancient art of metaphysical Human Energy Fields, which survives in all cultures, was introduced in Chapter two. Indigenous philosophies of health and illness have always included metaphysical spirituality concepts although through colonisation many have also adopted religion (Koopsen & Young, 2009; Moeke-Maxwell, 2014; Snyder & Lindquist, 2006). A literature search revealed the extent of what is known, within the profession of nursing, regarding the EoL in contemporary society (Dose, et al., 2014; Kaminsky, 2014; Koenig, 2013). A literature research revealed many articles of information pertaining to personal care at the EoL. However, there was a noticeable gap in the knowledge of understanding the spiritual and psychosocial needs of the lived experience of people towards the EoL. The Internet and blogs were identified as modern methods of research exploration that is expanding in the health

sciences (Mewburn, 2017; Udtha, Nomie & Sanner, 2015; Walker, 2013; Hunter, 2012).

Chapter Three of this thesis introduced the underpinning methodology and methods of this research. Hermeneutics is considered a creative methodology of research, which employs the arts thereby enabling the lived experience to show itself through the voice of the storyteller (van Manen, 2014). The snowballing effect proved to be an effective method of participant recruitment (Streeton, Cooke & Campbell, 2001). Identifying my bias was important, therefore I shared my initial tentative experience of writing a blog.

Chapter Four, termed diagnosis begins the analysis section and is dedicated to the first time that the participants learn of their terminal diagnosis. This is the *epoche* of the moment, the breaking of *habitus* (Bourdieu, 1996), the known understanding of the self and social world the moment each participant hears the news of their imminent mortality, which creates a rupture in their world (Denzin, 2014). This rupture gave space for the participants to begin the transformative search for an authentic self (Denzin, 2014; Illeris, 2014). Van Manen's (2014) existential themes of corporeality, temporality, materiality, spatiality and relationality, provided the starting foundation for data analysis.

Each existential theme documents the unabridged writings of the eight participants. Their emotions, feelings, concerns, sometimes heartache and absolute feelings of awe and love are shared, which is consistent with hermeneutic data analysis (van Manen, 2014). The essence of each story was revealed through intensive rigorous data analysis and through the rewriting of the anecdote and removing extraneous material to vividly show the essence of the experience, aligned with van Manen's (2014) hermeneutic phenomenology. All the words that were written by the participants were depicted in a word cloud image, demonstrating the power held in the voices of the repeated words.

Chapter Five was termed 'restoration' and was dedicated to the findings that presented themselves through existential enquiry. The focus in this chapter was on examining how the participants pieced their lives together, following their initial diagnosis. The participants continued to share their insights through storytelling on

social media as they moved towards the EoL. A major and new finding was related to the shared experience of resilience that moved the participants from a sense of ruptured self towards a transformative experience as they discovered a new sense of self.

Chapter Six, termed ‘insight cultivators’, combined the first two chapters on data analysis to identify relevant subthemes related to the overarching existential themes. Resilient factors are revealed within the stories, which enable the participants to move forward and to live a fulfilled life. When applying the systems approach to resilience towards the EoL, the participants forged new trajectories through adapting and responding to a new way of being with self and others. Through the interpretive process of literature, poetry and the arts, rich insights can be revealed from the lived experience description that was recorded by the participants (van Manen, 2014). Subthemes expressed as important by all the participants were: spiritual and religious practices; the OBE; the metaphysical health benefits of the natural environment and music; and the inclusion of the arts and family relationships to enhance their lives.

This final seventh Chapter, termed ‘demystifying dying’ concludes this thesis by abridging the most relevant themes that showed themselves through the words of the participants. These themes are outlined below in the following section, which also discusses the theoretical processes that can be applied to guide nursing practice. This chapter proceeds to discuss the awakening awareness towards dying in modern society. The limitations associated with the writing of this thesis are acknowledged and future research has been identified.

7.4 INSIGHTS REVEALED: DEMYSTIFYING DYING

There is a noticeable shift in the conscious awareness of understanding mortality for the participants as presented in Chapter five, Part one. This is where hearing the diagnosis of a terminal illness for the first time creates a pause in time, time viewed from a different world perspective (Denzin, 2014), for the participants. This pause in time is sometimes referred to as an OBE (Alvarado & Zingrone, 1999). Following this new awareness, personal insights were gained, shifting goals and creating new goals in coping with facing death. There is a move towards a conscious awareness of imminent mortality for each participant (Denzin, 2014; van Manen, 2014), which creates space for personal intelligence (PI) to interpret and experience this new world

(Mayer & Faber, 2010; Shaw et al., 2016) from a new and altered perspective by those overtly approaching EoL.

Increasing resilience towards the EoL seems counter intuitive in our present social construct of dying. However, the participants in this thesis demonstrated resilience and flourished in their personal endeavours as they continued to live full lives. Resilient factors such as PI and HR, when framed by the systems approach of resilience, allows for a personal transformation towards a new sense of self (Folke, 2006; O’Grady, et al., 2016; Reich, Zautra, & Hall, 2010; Shaw et al., 2016).

A new sense of self was possible through sharing stories. Sharing stories is a transformative process through reflective practice that makes a temporal life progression from the chaos of illness (Denzin, 2014; Frank, 2013; Illeris, 2014). The participants achieved a sense of resolution through their ability to reflect and write their stories. This reflexive practice enabled them to embody their experience to give voice to the illness of the body.

A “multifaceted existential spiritual unfolding” (Warner, 2013, p. 178) describes how these people living with a terminal illness have embraced profound new spiritual insights, which is evident through telling their life stories. Although some of the people in this thesis were not religious, they all described a metaphysical transcendence connection with being in the world. This was expressed by the participants as feelings of awe, awakening, a new sense of peace, and a deep connection with the love of natural surroundings, music and the arts. This is consistent with previous studies that describe spiritual concepts (Gijsberts, et al., 2011; Goldman, 2002; Luzzato, 2002; Magill and Wilson, 2003). This notion is congruent with all Indigenous cultures that still maintain a strong spiritual link, known as a life force, within the natural environment (Eckermann et al., 2006; Koopsen & Young, 2009; Mikaere, 2011; Moeke-Maxwell, 2014).

It is important here to say that healing, when one is facing terminal illness, is not being free from disease, rather, it infers a wholeness which includes mental health and well-being and effective resilient coping strategies (Tuck & Anderson, 2014). The author of this thesis argues that the concepts of PI (Mayer & Faber, 2010) and HR (Kelley, 2003), including spiritual concepts (Dose, et al., 2014; Dobratz, 2013; Koenig,

2013; Kruse, 2007; Neimeyer, et al., 2011; Puchalski, et al., 2014; Wynne, 2013) and biophilia (Wilson, 2003) assist people to increase resilience moving forward towards the EoL. Nursing theorists in the modern age are slowly re-introducing spiritual metaphysical concepts into nursing theories (Newman, 1974; Rogers, 1970; Watson, 1988). A handful of health scholars are now writing about the benefits of metaphysical energy as healing modalities within the health professions (Dose, 2007; Hemsley, 2003; Jackson, 2012; Watson & Smith, 2002; Whitfield, 2009;).

The participants in this thesis were clear about the vital role that family members and like-minded community groups play in supporting the creation of a new self. This was coupled with the importance of the arts, music, writing and poetry, to construct imaginary worlds of deeper insights and a connection to a higher consciousness (De Nora, 2012; Frank, 2013; Mclean, et al., 2012; Snyder, 2006; van Manen, 2014). The participants strongly advocate that others listen closely to their personal experience. Listening is hard, especially as it is not a story that we want for ourselves (Frank, 2013). However, listening in the modern world is a moral imperative. The participants wrote on the importance of carers and health professionals in offering words of hope and encouragement and assisting in setting new life goals, rather than lamenting on their own personal losses or personal experience.

The trajectory of resilience and how the individual moves through the shock of hearing the diagnosis for the first time until restoration of life is depicted in the image below (Figure, 23). The first half circle represents the fluid movement of the systems approach moving forward to resilience (Folke, 2006; O’Grady et al., 2016; Shaw et al., 2016).

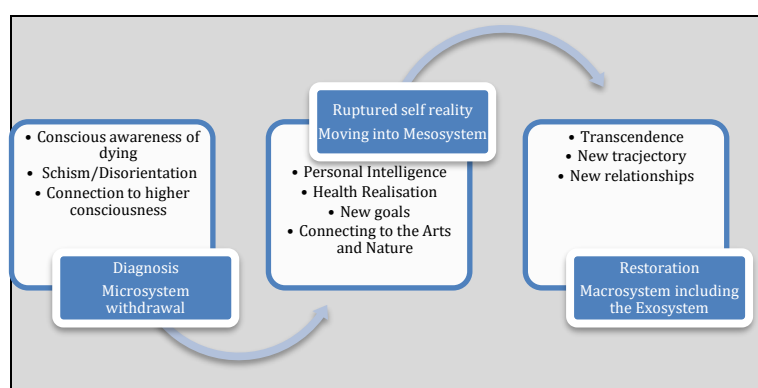


Figure 23: The trajectory for resilience using the systems approach towards the EoL

Movement can take place in either direction, depending on the adversity that is being experienced and the strategies used to achieve restoration. For the person who is living with a terminal illness, there is a transformative new way of being and knowing in the world (Illeris, 2014). In the initial shock and confusion, the participants required time to be centred within the microsystem of their world (Denzin, 2014).

The second half circle represents the forward movement to resilience, through the reflexive practice of story writing, enabling transformative learning (Illeris, 2014). Through finding a natural human connection and a spiritual life force within the natural environment (Moke-Maxwell, 2014; Wilson, 2003) and setting new goals within the wider systems approach, the participants were able to increase their PI (Folke, 2006; Mayer & Faber, 2010; Shaw et al., 2006). The participants need time and space to reconnect to others and to move forward towards making new goals and transcending their limited reality, reaching out to wider social circles.

I used the existential themes related to the lived experience at the EoL to analyse and present the themes related to EoL. Through the insights gained from the stories within this thesis, I can increase the body of knowledge related to the EoL. The existential themes have created a whole picture of what is important to people as they prepare for their death. As can be seen in Figure, 24, the existential themes are centred on corporeality. All the existential themes are integral to each other. Temporality floats above corporeality staying connected by the other existentials all are grounded within corporeality and rest on relationships for strength.

The participants, through their stories in thesis also provided insights about understanding the anxiety of facing the EoL and how to find a peaceful resolution. They clearly state that the reason for sharing their stories is so that others might gain insights from their lived experience. The act of writing and telling their stories to a wider audience encourages resilience during a traumatic experience (Wimberly, 2011). I have hesitated to write the word journey throughout this thesis. I have seen it written many times throughout the stories in this thesis, that the participants do not choose to use the word 'journey.' After analysing this data about EoL, I have concluded that EoL is not a journey, rather it is a new living experience, living and evolving in the present time, as shared by Abby, who supports this realisation, when she writes: "*One day at*

a time, and life can shine through in writing and dancing, in songs and prayers”
(Brown, 2014, P. 195).

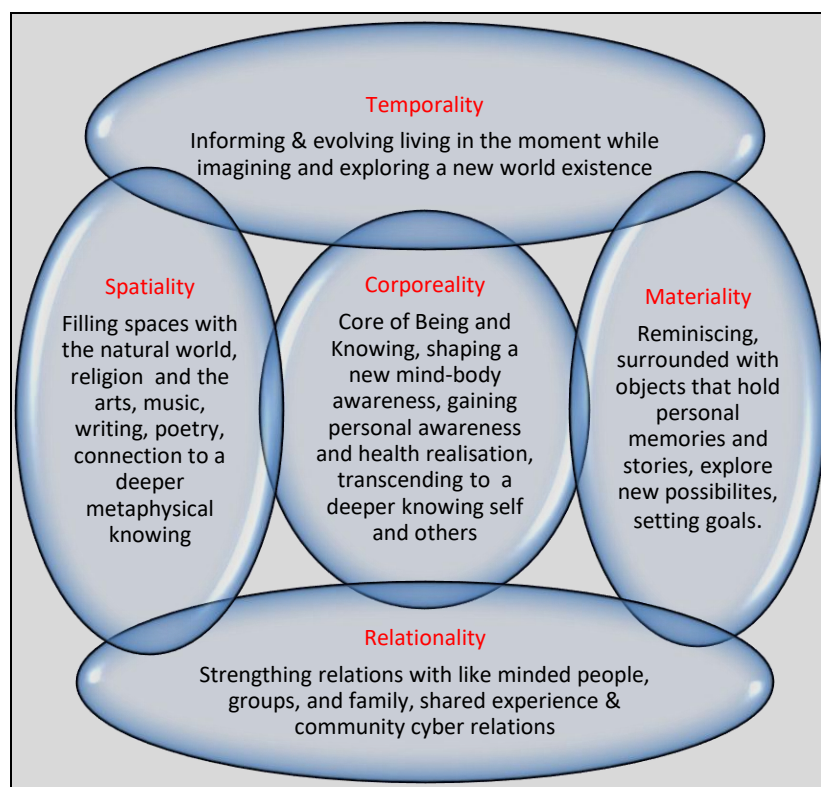


Figure 24: Five-core interwoven themes on the lived experience towards the EoL

7.3 AWAKENING AWARENESS OF MORTALITY

Since beginning this thesis, there has been a paradigm shift in the awareness of being mortal in Western society. Three years after the commencement of this thesis, Palliative Care Australia initiated a project titled, ‘dying to talk’ a web site for people to share their stories. They explicitly say on the website that ‘dying to talk won’t kill you,’ (dyingtotalk.org.au).

The ancient Celtic art of the Soul Doula has seen a recent revival and people are being taught how to care for others who are living with a terminal illness, through the skills of the doula (Warner, 2013). The doula embraces all forms of healing, in pursuit of discovering healing of the spirit and increasing well-being towards the EoL (Warner, 2013). The normalisation of the taboo subject of death has started (Kaminsky, 2016). This is highlighted in the stories that have been shared with a wider

community. As reiterated in this thesis, some members of the medical profession are championing the stereotypical dying and death scenario that currently exists within our biomedical paradigm (Alexander, 2012; Bute, 2017; Gawande, 2014; Granger, 2013; Kalanithi, 2016; Kaminsky, 2016; Miller, 2015; Sacks, 2015; Saul, 2014) through telling their stories worldwide via social media. Most of the members of the health profession who are speaking out, demystifying dying, are doing so because of a personal EoL experience (Alexander, 2012; Bute, 2017; Gawande, 2014; Granger, 2014; Kalanithi, 2016; Miller, 2017; Sacks, 2015; Saul, 2016).

Social media sites on death and dying are burgeoning amongst the public. Death Cafes commenced by Jon Underwood in 2011, opened discussions about all things related to death and dying and exist in most countries. From an initial slow start, they are spreading throughout many European countries. There are currently over one hundred and fifty Death Cafes in Australia, with over four thousand worldwide. Social media sites such as Facebook currently post recent stories and links to Death Cafes. Facebook also has live feeds of people who want to speak about their terminal illness. Lisa from the Facebook sites, Terminally Fabulous and Driving Ms Norma, are just two cases that come to mind. There are many, many more. Society is moving forward in a world that is experiencing a burgeoning of people heading towards EoL.

The movie by Dan Krauss, 'Extremis' (2016), shared a snapshot in the day of the lives of doctors, families and patients in intensive care. It depicts the real-life everyday decisions made between the medical team and their patients. The movie confronts encounters that are experienced in our current Western worldview on death and dying. It challenges us to find new and imaginative ways of coping with the reality of death. Another documentary sharing the lived experience towards the EoL is 'Be Here Now', the story of Andy Whitfield (2015), who was Spartacus in a Television series. At the peak of his career and at the age of thirty-nine, he was diagnosed with leukaemia. The audience follows his story from diagnosis to death. Andy lived a life full exploring all the non-medical and medical options for treatments before he died.

7.4 PERSONAL INSIGHTS: SELF-REFLECTION

I have been encouraged by my supervisors to share my personal experience of being consumed by and constantly being engaged in EoL stories. Furthermore, reflection on how this has impacted on my lived experience was encouraged. As I have shared in the beginning of this thesis and through my own practice of yoga and meditation, I am not afraid of death. I believe that every story is individual, that we all live our individual stories from birth until death. However, this does not dispel the pain of saying goodbye nor should it.

As van Manen (2014) reiterates there is a difference between the reading of the story and not being of the story. As I read and write and reflect on the stories, they inevitably impact on my psyche and there is a deep feeling of knowing the participants. This knowing feeling emerged later when I discovered that one of the participants had died. It is through the rich experiential descriptions of the lived experience that I began to know the storytellers. I recall reading Paul's words repeatedly as I was struck by his emotive voice, in which he was able to describe his innermost feelings and concerns as he continued to write until his death. In true hermeneutic phenomenology, epiphanies could be seen and reflected on to make a difference for future generations (van Manen, 2014).

I recall one day as I sat to write, I wondered how Kate was doing. I decided to read her blog on WordPress, to check in with her and see how she was coping with her illness. I really felt like I had connected to her, as many others would have done through social media. I was surprised to discover that she had died. I immediately recorded my sadness on my blog. I revisit that blog entry now at the end of this thesis to recall my own experience that I share here:

Farewell Kate: Posted on September 9, 2016 by Jennifer Carter

Today while reading through my work, I decided to check Kate Granger's blog on WordPress and to my surprise, I found a small one-line message saying that Kate had died, how sad. I knew that she was not well, that she was or had been unwell for several years and that she had been through awful, painful procedures, yet still the news comes as

a blow. How sad, for her family and friends and those of us who know the work that she had done. Firstly, in raising awareness for people like herself who are living with a terminal illness and secondly for raising money towards a cancer charity. She was an amazing woman who will not be forgotten, rest in peace Kate.



Researcher reflections 19: Daisy image reflecting the brightness of Kate

WordPress Blog: Jennifer Carter Dying Matters
Photo credit: J Carter

Phenomenological rigour does not refer to the summary of findings, rather, it refers to the researcher's ability to embody the material. As Van Manen (2014, p.8722) writes, the researcher should evaluate the research by 'meeting with it, going through it, encountering it, suffering it, consuming it, and as well being consumed by it.' This thesis was guided by participants stories, which induced a sense of contemplative questioning about the lived experience towards the EoL. The stories within this thesis

offered a deep descriptive richness that provoked insights into the lived experience of EoL. These participants became the voice to the lived experience of dying within the modernity of the Western world.

Since beginning this thesis four years ago, I have experienced the death of two-sisters-in-law, of a very young nephew, two brothers-in-law and the death of several pets. I am consciously aware that we are all going to experience the EoL. Throughout my nursing career, I have been an advocate for speaking honestly to patients as the EoL approaches. Death is not a stranger to me in both my professional and personal life. My father died a violent fiery death when I was six years old. I had no concept that death was permanent at that age. I was not, by the virtue of social conditioning, at that time involved in any part of his dying or his death. I imagined as a child that the sight of a dandelion was his return to this world to say hello. Perhaps this early childhood experience of death has led to my passion on speaking openly and being an advocate on the normalisation of dying and death.

On reflection, following the deaths that I experienced over the last few years, I did exactly what the participants in this thesis have done. I hesitantly started writing a blog, which turned into a cathartic experience. Writing a blog allowed for my own lived experience, my own drama to play out, without imposing my thoughts on the participants' experience. I was guided unwittingly in this thesis, by the participants' lived experience. I shared every death and birth on my blog, as they did.

The participants' stories all begin with receiving the news of having a terminal diagnosis in the context of modern society. Stories on ill health also become social stories that enable others to witness the changes that were occurring (Frank, 2013). This is congruent with writing phenomenological texts that begin with an epiphany and then continue to reflect on that and other epiphanies (van Manen, 2014). The stories herein made a deep impression on me as I imbibed them, consumed them and lived with them. Staying in line with hermeneutic phenomenology and the heuristic reduction, I rigorously wrote and rewrote the stories as they were told.

7.5 STRENGTHS AND LIMITATIONS OF THIS RESEARCH

The eight stories in this thesis allow the lived experience towards the EoL to show itself by the sheer number of people who were echoing similar lived experiences. The strength of this research resides in the methodology of the data analysis and the

essence behind the vocative voices of the participants. The longevity of the stories strengthens the depth of analysis and intent of the storytellers to share their experience to a wider audience. The amount of data collated through the longevity of the stories also contributed to the limitations of this thesis by providing vast amounts of data with a finite time to spend on analysis.

It is also acknowledged here that the experiences documented within this thesis have been written contemporaneously throughout the EoL experience, and therefore, excludes people who have chosen not to share their story via social media and to a wider audience. The shared LED from the participants was not all glamour and sparkles, there were many documented incidences within this thesis that demonstrated facing the EoL was difficult, dark, depressive and a shock. However, it is also noted that knowing the EoL was near did become a lived experience of life and an acceptance of the natural birth death continuum. Surprisingly, in some LED's it was a relief to finally have a diagnosis and to have a conscious awareness of death and to embrace their approaching EoL.

7.6 IMPLICATIONS OF THE RESEARCH FOR NURSING PRACTICE

This research enables the voice of people who are experiencing the EoL to be heard. It gives honest and insightful details on how to guide nursing practice on EoL needs. Receiving a terminal diagnosis should never render a person invisible or left walking the Earth as a ghost or living in the shadow of death. Nor should it preclude people from receiving quality care towards the end of their lives. Transformative learning towards living with an illness can occur at this pivotal moment in time. Nursing care that focuses on both physical and psychosocial care needs, has the possibility to facilitate ways to live an enriched life until death. Curriculum changes need to focus on nursing interventions that enable people who are living with a terminal illness to live their best life (Figure 25).

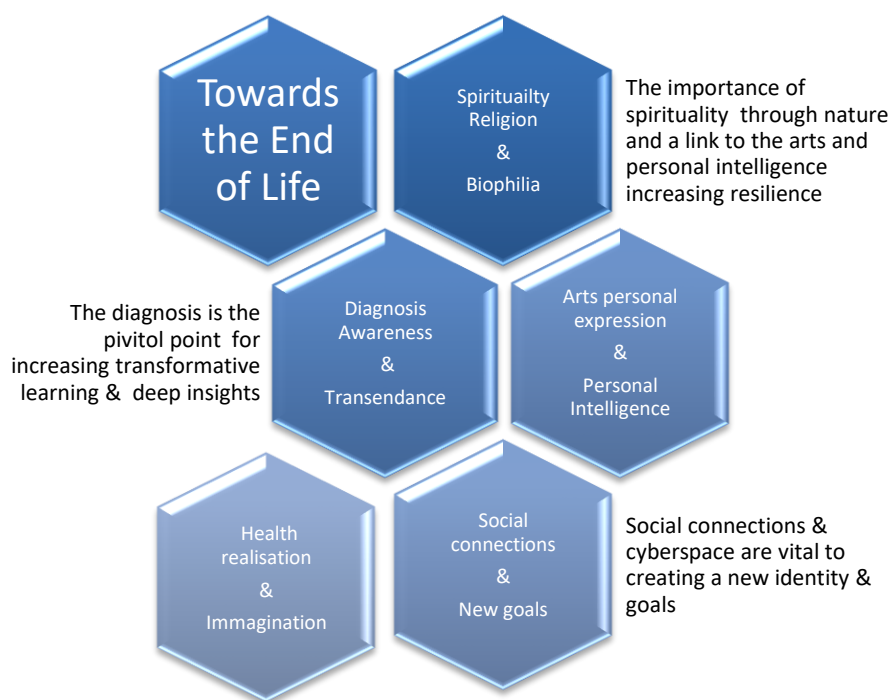


Figure 25: Putting the pieces of the EoL jigsaw together, implications for practice

Through the analysis of the data in this thesis, five key themes were revealed, which are relevant to shaping future nursing curricula, using the CARIE acronym:

- Commence personal psychosocial nursing care at the point of diagnosis to increase transformative learning and PI on how to live with illness.
- Appreciate the natural environment's ability in care to enhance transcendence and to increase resilience towards the EOL
- Reduce the medicalisation of health practice in nursing to foster health realisation through contemporary nursing health practices, such as visualisation techniques, reiki, acupuncture, massage and meditation
- Include the arts in care practices, with a greater focus on spiritual and or religious needs towards the EoL, to increase resilience
- Encourage a focus towards close personal and social connections (including animals) to foster new relationships with like-minded people making new goals towards EoL

7.7 RECOMMENDATIONS FOR FUTURE RESEARCH

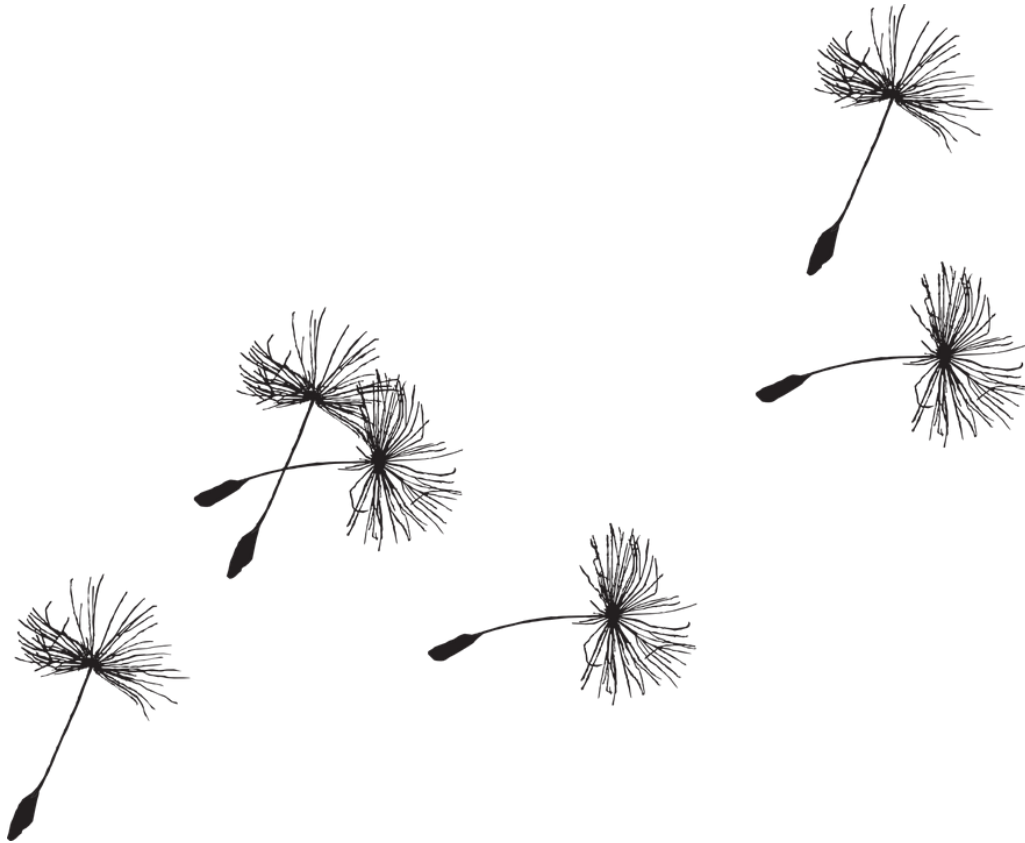
There remains much to be researched on the lived experience towards the EoL. The challenge for the nursing profession is to chip away at the dominant medical paradigms within our contemporary society. Further research into the concepts of: personal intelligence (PI), and health realisation (HR) need to be undertaken within the nursing profession. Research needs to consider the progress of how far society has been awakened to the dying experience. Birth and death deserve equality and shared sacred experiences in Western society as it is within other cultures. There is an exciting future for the nursing profession towards further research into the factors that increase resilience towards the EoL.

7.8 CONCLUSION

The data retrieved through the stories shared in this thesis have the power to transform nursing practice, and to reform the way the Registered Nurse communicates the concept of death and dying with patients. There are many possibilities that arise from this thesis that prove nurses can make a difference in people's lives as they move towards the EoL. Open and honest conversations on dying needs to begin. Nurses are well placed to provide this type of support as they are the front-line health professionals and as such, are likely to have more opportunity to engage in these on-going conversations. The people who shared their stories on living and dying with a terminal illness within this thesis are confronting the modern age with a vision of how they want to experience living until death. By removing the veils that exist behind the experience of living until dying they are beginning the process of normalising dying and encouraging and facilitating the best possible lived experience towards the EoL.

I am extremely grateful for the shared stories that are included within this thesis and words cannot express how living with each of the participants has impacted on my emotional self, evoking compassion and love. My intention was to respectfully disseminate the essence of the stories throughout this thesis, to increase the body of knowledge so that the profession of nursing takes the initiative to move forward in embracing the sacredness of death. I conclude this thesis with the image of Dandelions (Research reflections, 20). Their seeds are blown by the wind and are said to hold the

spiritual attributes of growth, healing, vibrancy and joy. They are often used to represent the path of the human cycle, of growth, communication and moving towards transcendence.



Researcher reflections 20: Dandelions

Photo credit: Pixabay.com

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Appendix

HUMAN RESEARCH ETHICS COMMITTEE ETHICAL APPROVAL PROJECT: H16/02-019 ON THE LIVED EXPERIENCE TOWARDS THE END OF LIFE

The Human Research Ethics Committee is an approved institutional ethics committee constituted in accord with guidelines formulated by the National Health and Medical Research Council (NHMRC) and governed by policies and procedures consistent with principles as contained in publications such as the joint Universities Australia and NHMRC Australian Code for the Responsible Conduct of Research. This is available at http://www.nhmrc.gov.au/publications/synopses/_files/r39.pdf.

On 12 February 2016, the Chair of the Human Research Ethics Committee considered your application under the Low Risk Review Process. This letter confirms that your project has been granted approval under this process, pending ratification by the full committee at its March 2016 meeting.

The period of ethics approval will be from 12 February 2016 to 30 July 2016. The approval number is H16/02-019; please quote this number in all dealings with the Committee. HREC wishes you well with the undertaking of the project and looks forward to receiving the final report. The standard conditions of approval for this research project are that: (a) you conduct the research project strictly in accordance with the proposal submitted and granted ethics approval, including any amendments required to be made to the proposal by the Human Research Ethics Committee;

(b) you advise the Human Research Ethics Committee (email ethics@cqu.edu.au) immediately if any complaints are made, or expressions of concern are raised, or any other issue in relation to the project which may warrant review of ethics approval of the project. (A written report detailing the adverse occurrence or unforeseen event must be submitted to the Committee Chair within one working day after the event.)

(c) you make submission to the Human Research Ethics Committee for approval of any proposed variations or modifications to the approved project before making any such changes;

(d) you provide the Human Research Ethics Committee with a written “Annual Report” on each anniversary date of approval (for projects of greater than 12 months) and “Final Report” by no later than one (1) month after the approval expiry date; (Forms may be downloaded from the Office of Research Moodle site -

<http://moodle.cqu.edu.au/mod/book/view.php?id=334905&chapterid=17791>.)

(e) you accept that the Human Research Ethics Committee reserves the right to conduct scheduled or random inspections to confirm that the project is being conducted in accordance to its approval. Inspections may include asking questions of the research team, inspecting all consent documents and records and being guided through any physical experiments associated with the project

(f) if the research project is discontinued, you advise the Committee in writing within five (5) working days of the discontinuation;

(g) A copy of the Statement of Findings is provided to the Human Research Ethics Committee when it is forwarded to participants.

Please note that failure to comply with the conditions of approval and the National Statement on Ethical Conduct in Human Research may result in withdrawal of approval for the project.

You are required to advise the Secretary in writing within five (5) working days if this project does not proceed for any reason. In the event that you require an extension of ethics approval for this project, please make written application in advance of the end-date of this approval. The research cannot continue beyond the end date of approval unless the Committee has granted an extension of ethics approval. Extensions of approval cannot be granted retrospectively. Should you need an extension but not apply for this before the end-date of the approval then a full new application for approval must be submitted to the Secretary for the Committee to consider.

The Human Research Ethics Committee wishes to support researchers in achieving positive research outcomes. If you have issues where the Human Research

Ethics Committee may be of assistance or have any queries in relation to this approval please do not hesitate to contact the Secretary, Sue Evans or myself. Yours sincerely,
A/Prof Tania Signal Chair, Human Research Ethics Committee.