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Deep Silences

A Spiritual Autoethnography

*Reclaiming inner space and silence as a
locus of the sacred*



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Abstract

Spiritual matters lie at the heart of a good dying. However, the shape and focus of spiritual care in palliative care has, I believe, shifted away from the original vision of hospice pioneers, such as Cicely Saunders. Assessing the value of spiritual care has become a priority to those who value a 'scientific' evidence-based practice. The issue this thesis addresses is whether there is a better 'artistic' way to evaluate the care given to dying people.

This thesis describes the current landscape of care and then argues for spiritual artistry, as a way to reclaim 'inner space' and 'deep silences' as sites of sacred encounters. This radical move takes the focus of spiritual care away from both evaluative endeavours and also beyond the alternative meaning-making and narrative models, which are currently offered. I hope to shift the focus towards a relational spirituality in which greater attention is given to spiritual awakenings. Dying and grieving can both be viewed as the space of spiritual quests. The challenge is to discover a new way of seeing these complex and sometimes chaotic spiritual contexts in which important things occur which sometimes are beyond measurement and communication.

An innovative methodology, spiritual autoethnography, which integrates creative arts, autoethnography and theology, is chosen to pursue this research. In the process of interrogating the silences encountered in spiritual care at the end of life new insights and understandings are generated. I illustrate the deep silences that occur in times of trauma, shame, cognitive impairment, betrayal and grief, and how understanding these sheds light on marginalised areas rarely the focus of current models of spiritual care. However, the radically new insights gleaned from this research come from the construction of inner space and deep silences as a locus of the sacred. These heuristic constructs, offer a new framework to shape the role of hospice chaplain, and the delivery of spiritual care. In conclusion, spiritual artistry, founded on a poetics, is presented as enabling chaplains to inhabit 'inner space' and 'deep silences'; to say the unsayable and delight in the gifts that accompany griefs. This new understanding of the role of the hospice

chaplain, and of the delivery of spiritual care, benefits all those confronting their mortality and their grief.

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All photographs taken by the author.

Therefore he no more troubled the pool of silence.
But put on mask and cloak.
Strung a guitar
And moved among the folk.
Dancing they cried,
'Ah, how our sober islands
are gay again, since this blind lyrical tramp
invaded the Fair!'

Under the last dead lamp
When all the dancers and masks had gone inside
His cold stare
Returned to its true task, interrogation of silence.

Excerpt from George Mackay Brown *'The Poet'*

Preface and Acknowledgements

Voices [that] begin calling you from the cave - voices of instruction and encouragement, half scripted and half intuited, half heard and half imagined. It is these voices, frightened with unresolved conversations and interrupted arguments that finally help you 'hold' the thought: and in the midst of that movement of ideas and intuitions you discover a momentary stillness. This moment of reflection is never simply the mirror of your own making, your frame of thinking, but a stillness sometimes heard in choral music when several voices hold the same note for a moment - *omnes et singulatum* - as it soars beyond any semblance of sameness.

--Homi Bhabha (2009, iv).

This creative work of curiosity, exploration, challenge, discovery, delights, unsettling and healing is not a solitary one.

I respect the 'descenders'. Those people whose voices and faces are present, but unnamed in this thesis. People who have inhabited liminal spaces, descended into depths, and discovered the sacred. You forever shape who I am.

I value the 'spiritual artists' in my community of practice - colourful, cankered, creative folk - who inspire me on the wandering way; Ewan Kelly, Roddy McNidder, Iain Macritchie, and Michael Paterson, to name but a few.

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Nothing in my life happens without my children Nicola Amy, James Alexander and Benjamin Andrew, who keep my feet on the ground and my spirits in the air.

And to Mandy, with whom I share the journey. There is no I without you.

Author's Declaration

I declare that, except where explicit reference is made to the contribution of others, this dissertation is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Signature:

Printed Name: Ian Robert Stirling

Introduction

The concern of this work is to engage with the challenges experienced in end of life care, some of which are related to a turn towards evidence based approaches to the delivery of spiritual care. It is my argument that 'scientific' models of care are not able to effectively comprehend those aspects of spiritual care that are not easily measured, articulated or defined. To offer effective and holistic care to dying people requires an artistic approach that can deal with the ambivalence and unresolvable questions that emerge in confronting death.

To develop a means of articulating an artistic model of care I employ the concept of inner space, as articulated in the work of Carl Leget (2017). Leget constructs inner space as a place for meaning making and narrative engagement with the spiritual challenges experienced at the end of life. I affirm the value of his work but argue that the pain, ambivalence and sacrality of death cannot be comprehended by models that are based on communicative processes. Dying people and their carers are often confronted instead by experiences of silence and silencing and words fail them. In this context inner space is better presented as a place for relational encounters which are able to accept and embrace what I have called 'deep silence'. I have developed this term as a means of reflecting upon my experiences as a hospice chaplain. In this role I found myself confronting many situations in which silence was the only possible or appropriate place to meet with the reality of the dying person. Whilst silence can be imposed by medical, cultural or personal factors it is not always to be understood as a negative thing. Deep silence can also be a sacred place. By marking out the contours deep silence I hope to suggest new ways of understanding the role and identity of hospice chaplains and the delivery of spiritual care.

My thesis opens with a prologue which sounds a key note for both the content and method of the work that follows. Here I write about epiphanic moments, still skies and storms, which first inspired me to interrogate the silences I encounter in hospice care. Here the reader can sense me being out of my depths, wrestling with ambiguities and seeking a way forward, by looking back, to the work of Cicely Saunders.

In chapter one I lay the foundation for my research by describing the emergence of a thin and vague understanding of spirituality, which supports an artistic, rather than scientific, approach to the delivery of spiritual care. I argue that spiritual artistry, is a way to engage with the complexities, depths, and profundities, in palliative care.

Chapter Two considers the interface between the hospice movement and spiritual care within palliative care. Having described the cultural context of death and dying, and the spiritual vision of the hospice movement, I introduce Carlo Leget's concept of inner space as the locus of the narrative work which enables a good dying. However, there are times when words are inadequate and different priorities emerge on the dying trajectory. Drawing on the original vision of hospice pioneers, such as Cicely Saunders, and referring to Paul Kalanithi's moving memoir, I now ask whether inner space and silence are better regarded as a site for healing connections. The issue is to understand better what is happening through employing the heuristic and modelling potential that concepts of inner space and deep silence makes possible.

This brings me to the third chapter which seeks new ways to explore deep silences. Here I turn to the innovative methodologies of arts-based research and autoethnography, I envision a research methodology which matches and complements spiritual artistry. I justify spiritual autoethnography as my preferred way of researching and outline a pattern of inquiry.

The spiritual autoethnographic texts, in Chapter Four, and their interpretation in Chapter Five, develop my understanding of the nuances of deep silences. Traumatic silence, leads to a loss of words, and invites a witnessing, which I justify through a reading of Shelly Rambo's theology of remaining (2010). Shameful silences, lead to fear of exposure, a hiding, and invites a saving gaze, as described by Stephen Pattison (2000, 2013). Communication silences, lead to a marginalisation of patients, and invites a reframing, or re-description of illness, as illustrated by John Swinton (2012a), which restores a sense of belonging. The silence of betrayal, if trust is broken, or patterns of dying are imposed on patients, invites consideration of the sacred in relationships. Sacred silences in grief, occur as systems and frameworks of meaning are skewed, and healed by accompaniment and acceptance. These explorations show people living in chaos rather than

coherence, and scrutinise the efficacy, or at least the uncritical acceptance that 'inner space' is best presented as the locus for narrative and story.

In Chapter Six my inquiry progresses further to explore 'threshold silences' and 'sacred silences'. Threshold silences are imaged as liminal spaces which are sublime and dangerous. Sacred silences are places of awakenings when the spiritual aspects of existence emerge in light or in darkness. This chapter moves from liminal spaces, to spiritual awakenings. Key resource for my reflections here come from Heather Walton's work on poetics. I seek to translate her ideas into the context of spiritual and palliative care in a way that re-imagines the sacredness of deep silences and also challenges the current models of delivering spiritual care.

The study concludes by admitting that my work is itself an artistic construct. Deep silences are not scientific realities amenable to evidence based interventions. They are rather constructed means of engaging with aspects of spiritual care that have not been fully acknowledged and yet which are of great importance for all who make, or share, the human journey towards the end of all words.

Prologue: Interrogating the Silences



Figure 1: *Take a moment*. Photograph of the standing stone near Corgarff Castle, Lecht Summit, Cairngorms National Park, Scotland.

This standing stone, over-looking the Cairngorm mountains, has the inscription:

Take a moment to behold

As still skies or storms unfold

In sun rain sleet or snow

Warm your soul before you go.

The words ‘Take a moment to behold / As still skies or storms unfold’ capture the waiting, and the expectancy, within spiritual caregiving. At the beginning of the day chaplains rarely know what lies in store for them as they enter unknown and liminal territory. Trusting that spiritual artistry will enable them to embrace the moment.

A glacial dip

My clothes form a haphazard pile. Back at base, daft-headed after a day in the Rockies tracking silver back grizzlies. Enjoying the caress of autumnal sun, I long now to swim. Off balance, I tiptoe across the moraine towards the glacial chill of

Lake Louise. Gingerly I sink into the waters, bracing myself for an ice shower, adrenaline coursing through my veins, heart pumping, gasping for air. Naked. 'Do I dare tumble in?' Then down and down I kick, into the turquoise shadows, surging madly, before a freedom. Deep down, all is calm, silence, I am embraced ... time slips away ... but out of nowhere comes a panic, the terrors, 'I am drowning', so I kick for the surface and safety.

Ocean depths

'Utter silence! Nothing!' Margaret's soft lament is muffled by the flow of oxygen. Her eyes glaze over. The silence lingers long. I wrestle with words. I long just to slip away. But there is no chance for that. Her faith flickers like a midnight candle. 'Utter silence! Nothing!' she whispers again. I sit speechless. I rarely swim in the depths of death. Then, shamed, I fill the moment with words. Clever. Coherent. A confabulation. 'Surface waters', I say, 'are often chaotic. It's hard to see any pattern or shape but in the deep ocean current there is hid an eternal silence.' In her look, and in the silence, I am, now, out of my depth.

The Garden Room

I retreat to the Garden Room. The still centre of the hospice. Located at the main entrance so that everyone coming or going can pop in. Peace and quiet. Set apart from the clinical space and its smells. Long windows allow light and blackbird song in. A path weaves past mature sweet-chestnut trees; bluebells push through the green grass. As I sink into the chair, exhausted by a day of descents, the late afternoon sun touches the soft pastel walls, and catches the translucent orchid's flower. Ten thousand voices sound in me like Athabasca Falls' thundering rapids. Deafening. Clamouring for attention: 'I want to die in a mist of morphine and merlot'; 'I need forgiveness before I meet my maker'; 'Dying is slipping on a new dress.' Face-to-face with a decade of dying I am being swept away by the current, drowning in the silence. It wasn't always like this.

Scream, silence and surrender

Once silence had been a friend. In a November chill, during a theological retreat, Alan Lewis re-imagined the springtime drama of Easter. Taking us to the vantage

point, not of Schiehallion but of Easter Saturday, he gifted me with a silence I can never forget. Scream, silence, surrender. Silence holds Easter together. Cross and resurrection. Foreground, background. The entanglement of abyss and the break of dawn. Past trauma and future hope are entwined in the silence. Arriving new in the hospice as a palliative care chaplain I wished to ‘inhabit’ this landscape of silence. Waiting in silence. Facing silence. Deserts, shorelines, ocean depths and peat moorlands. Living on the liminal borderlands, betwixt and between life and death. Yes, silence became my friend and yes sometimes silence was space for discovery.

Knife edges

Ron winced, gingerly rolling over. Slowly stretching, he finally relaxed, lay on his side, easing the pressure on his frail bones, and rested his head on the pillow. The morning light cast a serenity across his gaunt features. He knew his time was limited. We sat for a while entering into the moment. Waiting. ‘I would like to have faith. I would like to believe in someone ... something more. I once did. But ever since my son, Callum, died. Faith just doesn’t fit. I always knew ... one day ... he would die in the mountains. He loved the sky, the storms, the challenge, the adrenaline rush, the freedom. He died doing what he loved. I’ve no regrets about that. Living life to the full, on a knife edge. Yes, I would like to have a faith, ... but all the same ... God won’t judge me because of my vulnerability.’ And from that moment, I long for a faith that can walk knife edges. But sitting here now in the Garden Room I find that the silences are becoming more painful.

Awkward silences

Soon after my ‘day of descents’, I am sitting on a comfy orange settee facing my line manager, working through my annual appraisal. I try to communicate. ‘I need to get my head around what’s happening when people are facing their deaths. Yes, some folk find their own way. Ron says “God will not judge me because of my vulnerability.” Petya says “Dying is just like slipping on a new dress. There is nothing to fear at all.” I’m OK with these folk but too often I’m way out of my depths. Too often I don’t really know how to respond and what to say or do. Tommy says, “I want to die in a mist of morphine and merlot.” John looks me in

the eye saying, “Before I meet my maker, I need forgiveness, cos I took a life and saw the light in his eyes fade.””

An uneasy silence fills the room. ‘But Ian, this is your specialty. If you can’t do this, what is it that you exactly do?’ Silenced. I freeze. Flummoxed I kick for the surface and safety.

Soon after my father’s death, in 2008, once more I’m on the comfy orange settee, approaching Christmas. ‘I am not sure that I have anything to say at Christmas. It’s as if the story, and it is a story, has lost its meaning.’

‘If you have nothing to say, then why are you here?’ Again, the room fills with silence. *Déjà vu*. I have been here before, when words fall short.

Ben Lawyers

It’s March 1996. I’m sitting at a pine table in the kitchen of a farmhouse in Perthshire. Before me a father grieving the death of his only daughter, Sophie. Her life taken in an act of violence, at the Dunblane primary school massacre. I am waiting for words. I’m wondering what happens in the space when words fail? My eyes wandered the room, catching a child’s brightly-coloured drawing blu-tacked to the wall. Two acrylic handprints, circling a portrait, and a poem. The exact same composition of my own daughter’s drawing which she brought home from the very same nursery, and is up on our kitchen wall. Glancing up at Mick’s deep eyes; wells of sorrow and pain. I may not have words but I do have shared fatherhood. During Sophie’s funeral, I turn to Alan Lewis. ‘We are facing our own Good Friday, living in the desolation and silence of Easter Saturday and not sure that an Easter morn will ever come.’ Then at the close of the service, in the uncertain silence, ‘I want to sing for you, but really for Sophie a song of defiance in the face of evil, a song called ‘Oh freedom’. Rise up, Sophie. Sophie was never a slave. She’s always been free.’ I have never sung at a funeral since before or since.

Companions

I am alone again in the garden room. Yet what I know now, which I didn't know then, is that I am not alone and never have been. It has just seemed that way. I am neither alone in the depths of silence nor alone in feeling out of my depth. I am not alone in trying to make theology in this place.

First, there is the company of folk who are imaging the journey from life to death. Michele Angelo Petrone, the artist, says: 'Serious illness such as cancer changes everything that is familiar in our lives. The world as we know it changes overnight. It is difficult to understand what is happening, let alone what you are feeling.'¹ I remember other companions whose names I see on my bookshelf. Bieke Vanderkerckhove, who 'tastes' silence; Jean-Dominique Bauby, who lives as a butterfly in a diving-bell; Dennis Potter who notices the fragile cherry blossom. Second, there are my colleagues with whom I have enjoyed a decade of creative conversation. Collectively we map the territory of soul pain, the contours, evident and clear; the fractals, hidden. Our voices mingle. I cannot tell one from another. Hospices are 'a ghetto; a little bit of heaven for the few and there is too much f***ing terminal niceness in them.' We are 'wounded healers', often vulnerable, comforted by a bottle of Laphroig. Spiritual care is a matter of living with complexity, and risking life in chaos. We inhabit the silence of having no answers, of sitting empty handed and just waiting for grace notes. And third, there is the witness of researchers into the silences who acknowledge the experience of floundering at sea. I am not alone in being out of my depth. Michael Kearney swims down into the depths of soul pain; Irvin Yalom stares into the sun; Atul Gawande considers what it means to be mortal; Julia Lawton lingers in the place of death; Steve Nolan offers an uncertain but hopeful presence, and Erna Haraldsdottir asks why we try to avoid authentic dying. Fourth, I have discovered in testimony, story and poetry resources I need to create spiritual stores. In the arts and humanities there lie a wealth of sacred and secular sources of insight which enable me to

¹ Michele Angelo Petrone was an artist who at 30 years of age suffered from Hodgkin's disease. Nothing, he said, had prepared him for the pain, difficulty and fear that accompanied his diagnosis. So, isolated in his hospital room, he expressed the complex feelings engulfing him in art, which he collated into an art exhibition called, *The Emotional Cancer Journey*. In 2002, he founded the Michele Angelo Petrone Foundation (known as MAP), a charity promoting expression, communication and understanding of the complex issues of serious illness and dying. Petrone travelled extensively to share his art and his experiences. This quote comes from a presentation at the Ayrshire Hospice, which I attended in 2003.

witness silences and awaken me to the depth of ultimate silence. And, finally, what I know now, which I didn't know then, is that there just are times when words will fall short. Theology admits this. Heather Walton (2002), admits to 'Speaking in Signs' and it is evident when John Swinton (2007), *Rages with Compassion*.

I find a friend in George Mackay Brown who writes: 'Carve the runes and be content with the silence².'

The Millennium Bridge 2014

City lights are dancing on the water by the Millennium Bridge. The hustle and bustle of commuters, shopping bags collide, strangers slip by one another in the dark, heading home, hurrying by; my mind is also racing. It's late November in 2014: standing still for a moment, catching my breathe, I find myself reviewing the day. I'm just leaving a conference sponsored by the Cicely Saunders Institute, where an overview of the cutting edge of spiritual care in palliative care has 'set

² A Work for Poets

To have carved on the days of our vanity

A sun

A star

A cornstalk

Also a few marks

From an ancient forgotten time

A child may read

That not far from the stone

A well

Might open for wayfarers

Here is a work for poets -

Carve the runes

Then be content with silence.

by George Mackay Brown

the heather alight.’ Standing here I catch at echoes of the past. A story of silences. Christopher Saunders reminisces about his elder sister Cicely. ‘Genial, forceful, a strong nose and chin³.’ Cicely herself said that spiritual care is

giving hospitality that enables people to find their own answers. As long as people keep listening to patients, we’ll be alright. My own philosophy is that love is certainly as strong as death, if not stronger. I don’t believe as much as I used to believe, though what I do believe I believe more deeply.

Standing on the bridge I try to connect to that original voice. After the conference, we all gathered for a chat and a glass of wine. I found myself with Christopher and Dr Mary Baines who went through medical school with Cicely, and shares so much of her philosophy. She shares her memory of how Cicely wrestled with her own sense of loss and grief after David Tasma’s death and how it was in a silence, out of silence, her vision emerged. ‘Cicely read the twenty-third Psalm to David Tasma. She was very fond of him, after he died she was walking by a loch, staring at the peaty water and slipped out of time, an eternal now, she heard a blackbird singing.’ Cicely said, ‘I knew he was alright’. Her commission: ‘I had a vision to do something practical. Not desert dying people.’ And then Mary shared a memory of Cicely’s own death. How Cicely said, ‘This dying is such hard work.’ And then she died at 12 noon on 14 July 2005, as the bells in the chapel sounded for the end of a silent vigil for the victims of the London 7/7 bombing. Palliative care is born in silence.

The Garden Room

Back in the hospice, I’m once more sitting in the garden room. I’m reading *Mortally Wounded*, and come across Cicely’s words in the foreword. Still trying to grasp her original vision, I wonder about deep silences. I wonder what it may be like to witness, sculpt and dwell in the silence. I imagine gazing down from a cliff into ocean depths, and listen for her voice.

³ Both this delightful description, and the following quote, are taken from Christopher Saunders’ poignant presentation about his sister, Cicely, and the place of spirituality in her life and work, during the Spiritual Care in Palliative Care Conference, hosted by King’s College, London, which I attended on 24th November, 2014.

exposure

Leaning in, staring
over whitened
Cliffs edge, the vast raging seascape,
sinking
Into the ultramarine depths,
take time *above all to listen*.
Pay *silent attention* to mermaid voices.
Longing to step back, to 'withdraw' into safety,
fearful of the fall
submersion
have the courage to stay
a little while longer.
The way you care matters
Waves crash, and pebbles shift and thunder.
Take time to stand as storms or still skies unfold.
Exposure.
Witness.
Behold.
From time to time a lull of *deep wisdom* rises
Out of the oceanic depths
a pain
that somehow has a healing within itself.
And in time, risking all, letting go, leaning
in
The wind and the waters
Carry you home.

Words in italics taken from Cicely Saunders foreword to *Mortally Wounded* (Kearney, 1996).

Chapter One: Spiritual Artistry



Figure 2: *The gaze*

A Scottish mother makes connection with a Tibetan Buddhist child at Everest Base Camp. A connection expressed in a gaze, a touch, a smile, a holding and a sung lullaby. Such intuitive connections bridges 'I-other-Other' and is the basis of all spiritual artistry in birth, life and death.

This chapter lays the foundation for my research by introducing understandings of spiritual care as it currently impacts upon chaplaincy within the contemporary hospice context. Each section in this chapter engages with and contributes to the ongoing debate about the nature and efficacy of spiritual care. However, my intention is to go deeper than simply mapping the territory. I intend to describe and defend the 'art' of spiritual care. I believe this dimension is currently undervalued in strategic thinking, clinical practice, and professional formation; fields in which the 'science' of spiritual care tends to dominate. My fear is that a lack of 'artistry' threatens to undermine the quality of end of life care and that

rediscovering the art of spiritual care is crucial in any attempt to ‘re-humanise’ dying. As I build a case for recovering the art of spiritual care I am also seeking to create space for the ‘deep silences’ which constitute such an important part of our spiritual encounter with death. This topic will be developed and explored further in the chapters which follow.

In the first section I describe the emergence in Scotland of a generic model of spiritual care, which inhabits a liminal space between the sacred and the secular. Generic spirituality is founded on ‘thin’ and ‘vague’ understandings of spirituality which stress that spirituality is rarely, if ever, fixed or constant, but rather is ever creative, emerging, imaginative, contextual and embodied (see Swinton and Pattison, 2010). Such thin and vague understandings challenge ‘evidence-based’ research output, strategy and even the clarity of professional roles but, I will argue, support the ‘art’ of spiritual care. The second section describes the science of spiritual care. Here I note how science comes under scrutiny in the delivery of meaningful spiritual care. This leads to my third and most substantial section which describes the art of spiritual care. I then argue that spiritual artistry can be active in times of complexity, depth and profundity, such as during loss and bereavement and suffering.

Finally, a theory and a mapping metaphor are presented, to represent the interface of the art and science of spiritual care.

1 .1 Spiritual Care

1.1.1 The emergence of spiritual care

Early this century, NHS Scotland initiated a radical shift in the understanding of spiritual care (Scottish Government, 2002, 2009). This was in recognition of our multicultural context and the requirement to deliver person-centred care to individuals of any ethnicity, cultural identity, age, orientation, gender, ability/disability or belief. This new understanding enabled an inclusive strategy of care to be developed and expanded spiritual horizons beyond the territory of specific religions.

Spiritual care is that care which recognizes and responds to the needs of the human spirit when faced with trauma, ill health or sadness and can include the need for meaning, for self-worth, to express oneself, for faith support, perhaps for rites or prayer or sacrament, or simply for a sensitive listener. Spiritual care begins with encouraging human contact in compassionate relationship, and moves in whatever direction need requires (NHS Education for Scotland, 2009, 6).

This approach emphasizes that spiritual care matters to all. The move to 'democratize' spiritual care was, in its time and in its place, a significant departure from a traditional religious model and set the foundations for a 'generic' understanding of spirituality which embraces a wide spectrum of spiritualities and therapeutic interventions. This care is most often delivered through 'attentive and reflective listening and seeks to identify the person's spiritual resources, hopes and needs' (Morgan, 2015, 2). Generic spirituality is, first, a framework that is open to a variety of spiritual traditions, religious and non-religious. Second it integrates and entangles the biological, psychological and social. By expanding the horizons of care beyond the biomedical limits it allows for a spiritual dimension of care to address aspects of illness that were previously 'marginalised or neglected'. And thirdly, it offers space for acknowledging spiritual significance within the countless ways in which people experience the process of dying. Not only is this generic approach now thoroughly embedded in policy and practice in Scotland, but it has also, over the last decade, set our country apart as a groundbreaker in the field of healthcare chaplaincy. Many other health systems have followed Scotland's lead. For example, the Systematic Review of Spiritual Care at the End of Life notes that 'the model of spirituality commonly drawn on by chaplains in the UK and in the USA is broad, generic and inclusive' (Holloway, Adamson, McSherry, and Swinton, 2011, 13). In Victoria, Australia, Michelle Morgan describes spiritual care as providing 'a supportive, compassionate presence for people at significant times of transition, illness, grief or loss (2015, 2).

The generic turn has had significant impact upon the delivery of spiritual care. For example, faith communities are now wrestling with the tensions of locating chaplaincy somewhere in the borderlands between faith, the healthcare context, and wider social and cultural concerns (see Cobb, 2001, 2007). Chaplains are sculpting a new identity within health and social care which focuses on an inclusive concept of 'spiritual health and well-being' (Kennedy and Stirling, 2013). Also,

this broad understanding of spiritual care invites the whole multidisciplinary team, and not just chaplains, to contribute to its delivery. This in turn presents important challenges. Scholars dispute whether spiritual care represents an opportunity or a burden for healthcare professionals (Walter 1997; 2002). Indeed, some research suggests the wider healthcare team may lack confidence, competence and capability to adequately deliver spiritual care (Haraldsdottir, 2011).

Given the context described above, my own understanding is that the value of generic spirituality is the manner in which it ‘opens-up’ spiritual care to all and invites a more creative and imaginative approach to spiritual care interventions.

1.1.2 ‘Thin’ understandings and precise definitions of spirituality

Although spiritual care as it has emerged in Scotland has become deeply integrated into health policies and practice, spirituality continues to be a ‘slippery’ concept to define.⁴ This is both a strength and a weakness.

At the outset of the development of contemporary understandings, Chris Levison, the first NHSNES Education and Training Officer, often described spiritual care as ‘living from the inside out’, implying that spirituality connects ‘human depths’, or ‘inner spaces’, with what happens on the surface, is visible to the eye and conducive to measurement. Spirituality represents ‘the most intimate and hidden’ dimensions of personhood, but spirituality is also continuously in a relation of mutual influence with the visible: the psychological, social and physical’ (Van de Geer and Leget, 2012, 103).

However, very soon, such imprecise or ‘thin’ understandings came under criticism from those yearning for precise definitions to support a more scientific approach to spiritual care. Many researchers, strategists and clinicians were understandably left frustrated, struggling to differentiate between concepts such as the existential, spiritual and religious, and demanding greater clarity in the use of

⁴ ‘Spirituality is a slippery word these days, involving anything from monasticism to wind chimes, but I’ve never been able to resist a little tinkering under the bonnet of the soul. No longer convinced by the religious absolutes of my childhood, I nevertheless hankered after something to replace them, a workable credo with which to engage life’. Nick Thorpe in NHS Education for Scotland *Spiritual Care Matters* (2009, 6).

terms.⁵ This confusion enabled unsympathetic critics, such as John Paley (2008a, 2008b), to contend that vagueness in understandings of spirituality, and the fact that spirituality cannot and does not refer to constant ‘essences’ that can be precisely defined and measured, invalidates spirituality as a significant dimension of healthcare.

While the logic of Paley’s position would remove the spiritual aspect from health and social care entirely, and thus sacrifice much of value, I acknowledge three areas of concern that stem from contested definitions of spirituality. The first is the lack of precision in research. For example, the nursing profession enjoys a long spiritual heritage which is reflected in its formative values and is frequently rearticulated in influential texts (Bradshaw, 1994, McSherry, 2007). Yet research conducted by nurses, who uncritically adopted a definition of spirituality advocated by Murray and Zentner⁶ in the late 1980s and 1990s, is now being justly criticized for conceptual confusion (Holloway et al, 2011, 2-14). Here, the absence of definitional clarity threatens the ability of researchers to build firm evidence as to the efficacy of spiritual care. The historical lack of persuasive and reliable research in spiritual care is now widely recognized and is beginning to be addressed. For example, George Fitchett and Steve Nolan (2015) have employed case studies to describe what chaplains do in paediatrics, psychiatry and palliative care with the intention of revealing the vital spiritual roles of story and imagination. Elsewhere, Suzanne Bunniss, Harriet Mowat, and Austyn Snowden (2013) have employed participatory action research to build the evidence for efficacy of Community Chaplaincy Listening (CCL), which is a contemporary form of spiritual intervention.⁷ These researchers adopt the UK Medical Research

⁵ Mark Cobb distinguishes the spiritual perspective from the existential perspective: although the existential ‘allows for subjective transcendence it does not look beyond the “universe of human subjectivity”’ (Sartre) and Cobb is anxious as and when the two perspectives are ‘collapsed’ into a generic category that simply is a coverall for anything other than the physical, psychological or social (2001, 3).

⁶ ‘In every human being there seems to be a spiritual dimension, a quality that goes beyond religious affiliation, that strives for inspiration, reverence, awe, meaning and purpose, even in those who do not believe in God. The spiritual dimension tries to be in harmony with the universe, strives for answers about the infinite, and comes essentially into focus in times of emotional stress, physical (and mental) illness, loss, bereavement and death’ (Murray and Zentner, 1989, 259).

⁷ Community Chaplaincy Listening (CCL) is a listening service, offered by healthcare chaplains, initially for patients in GP surgeries, but now expanding into other areas of health and social care. By creating safe spaces for safe conversations, the intention of CCL is to give patients the chance to tell their story, to validate and witness the story, and then empower patients

Council's framework to build evidence for complex interventions and spiritual care evidently falls into this category. In this framework, there is a progression from theory, to modelling, to an exploratory trial, to the wider testing of the intervention before its long-term implementation.

The second area of concern is the lack of systematic evidence concerning spiritual care interventions which weakens the strategic thinking of policymakers.⁸ Unsurprisingly, the task of building systematic evidence is a key recommendation of *The Systematic Review of Spiritual Care at End of Life*, to ensure the delivery of high quality spiritual care in the future (Holloway et al, 2011, 4). To date the most rigorous evidence for spiritual interventions is found within the territory of mindfulness, dignity-conserving care and meaning-making therapy.

Finally, from a professional angle, the lack of conceptual clarity has meant that chaplains, the spiritual specialists within the multidisciplinary team, have had to expend considerable energy evidencing what is it they actually do (Mowat and Swinton, 2005). In effect, chaplains have moved away from their historical roots within faith communities, and now inhabit a space in health and social care, where their primary focus is on spiritual health and well-being. Fortunately, progress is now being made in clarifying their new role and identity. Recently chaplains have successfully collaborated with NHS NES in the Patient Reported Outcome Measure (PROM) project to construct and validate a measure to generate evidence for the efficacy of specialist spiritual care (Snowden, Telfer, Kelly, Mowat, Bunniss, Howard and Snowden, 2012). These diverse voices illustrate how a clearer definition of spirituality may support research, provide a framework for strategy, and consolidate the role and identity of professions.

However, despite the acknowledged problems, not everyone laments the absence of a precise definition of spirituality that would enable unambiguous scientific scrutiny. As I hope will become clear, there are alternative approaches in the

to move forward and gain resilience, despite continuing to experience difficult circumstances.

⁸ See B. Candy, L. Jones, M. Varaganam, P. Speck, A. Tookman, and M. King (2012), whose Cochrane review of spiritual and religious interventions revealed 'a paucity of quality research'. Therefore, the authors were unable to find any conclusive evidence for the effectiveness of spiritual and religious interventions for adults in the terminal phase of a disease.

delivery of spiritual care which view it as much as an art as a science. Whereas a scientific approach emphasizes discipline, certainty, constancy, control and specific outcomes for spiritual care, an artistic approach stresses creativity, imagination, wisdom, 'going with the flow,' living with uncertainty, and moving into the unknown.

It is as one explores the art of spiritual care that the value of 'thin' and 'vague' understandings of spirituality come to the fore. John Swinton and Stephen Pattison (2010) have championed the value of 'thin' understandings and in their groundbreaking essay on this topic move beyond definitional anxiety towards a 'thin, vague and useful' understanding of spirituality (2010, 226). In doing so, they argue that a language of the spirit is not essentialist,⁹ therefore is not amenable to firm definitions. Spirituality is a social construction, shaped and sculpted by context. This lends it a constellation of meanings, which are ever emerging, responsive and contested. Their focus therefore is on the performance and function of the language of spirituality. They ask 'What purpose does it serve?', especially in times of chaos, struggle, trauma and distress. They offer clinical examples of a language of the spirit emerging first, 'in times of illness', and second, in people with significant intellectual disabilities, dementia, stroke, or other cognitive difficulties. In both situations, the language of spirituality must move beyond clarity and certainty in order to be useful. This may happen when words fall short in illness, or are 'inchoate or ill-articulated' (2010, 229); when words stutter, creativity and imagination is required to convey such experiences. 'The task', they say, 'is to listen and to understand the function and direction of the language of spirituality, not to question its validity or right to exist and be used' (2010, 229).

What Swinton and Pattison add to the debate in healthcare is an appreciation of spirituality as a 'limit language' (2010, 231). Rather than expressing, as definitions usually do, something that is there or is present, 'limit language' hints towards a boundary or limit, beyond which it is hard to say anything intelligible. Limit language names absences rather than presences. This shift in understanding of

⁹ Essentialism is a philosophical stance, in which things, such as trees or people, have a set of characteristics, or essences, which make them what they are. The task of science and philosophy is to articulate these essences that are logically prior to the existence of their lived manifestations.

spirituality invites practitioners to consider what spirituality *does* rather than what spirituality *is*. For example, spirituality makes meaning, fosters hope, transcends, makes connections and discovers purpose; none of which are discrete, identifiable entities. Overall their work opens the horizons and boundaries of spiritual care. ‘Thin’ understandings of spirituality are a way of naming absences, recognizing gaps and challenging the delivery of spiritual care in a secular context. Such understandings of spirituality, as I argue throughout this thesis, also make space for creative arts, poetry and theological imagination to become the ‘tools of the trade’ for spiritual specialists.

This approach to spirituality is echoed, from a theological perspective, by Heather Walton (2015) who describes the spiritual as spinning threads between the sacred and the everyday. Although spirituality is embedded in diverse spheres of life, she concedes that there is no widely accepted definition of the term. Nevertheless, in a description that matches closely that presented in *Spiritual Care Matters* (2009), she states:

It often refers broadly to a person’s sense of meaning in life, connectedness (to people, nature, and/or the divine) and the quest to reach beyond the self to something that transcends the immediate and personal - regardless of religious affiliation (2015, 3-5).

Despite the lack of firm boundaries to the concept, Walton is consoled by three thoughts. First, the impossibility of ever producing a ‘universally’ acceptable definition invites one to live with ambiguity. Second, despite a lack of definition there is a body of discourse on spirituality which forms a tradition to which to turn to gain insights. And third, any close definition would inevitably limit our explorations of the spiritual domain.

In effect, there are now alternative but not exclusive approaches to employing the term spirituality. Specific definitions of spirituality and spiritual care are being crafted to support research; such as, those emerging from the US Consensus Conference:

Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose, and the way they experience connectedness to the moment, to self, to others, to nature and to the significant other (Puchalski, Ferrell, Virani, Otis-Green, Baird, Bull,

Chochinov, Handzo, Nelson-Becker, Prince-Paul, Pugliese and Sulmasy, 2009).

and the European Association of Palliative Care Spiritual Care Taskforce:

Spirituality is the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred (Nolan, Saltmarsh and Leget, 2011).

However, the European Association of Palliative Care also highlights that the spiritual field is multidimensional and thus, inevitably, polyvalent. It incorporates, first, existential challenges, for example, questions concerning: identity, meaning, suffering and death, guilt and shame, reconciliation and forgiveness, freedom and responsibility, hope and despair, love and joy. Second, value-based considerations and attitudes, including what is most important for each person, such as: relations to oneself, family, friends, work, things, nature, art and culture, ethics and morals, and life itself. Third, it may include those concerns traditionally regarded as 'religious', such as faith, beliefs and practices, and the relationship with God, transcendence or the ultimate.

As I shall explore further, the tensions between these differing understandings of spirituality reflect the tensions between the art, science and pragmatics of spiritual care. Pragmatically, the *Systematic Review of Spiritual Care* (Holloway et al, 2011) urges practitioners to move beyond the impasse created by conceptual confusion and to begin researching interventions and outcomes. Yet, as a clinician and researcher living with complexity, witnessing, holding and waiting on deep silences, I seek to hold onto Swinton and Pattison's elusive 'thin' understanding: 'spirituality is necessarily emergent and dialectical; it is shaped and formed by the context within which spiritual language is expressed' (2010, 230). This understanding, I believe, allows for imagination, flexibility, richness and depth and fosters professional artistry.

1.2 The Science of Spiritual Care

Although my own perspective encourages me towards an open-ended and inclusive understanding of spirituality, it is important to critically assess the impact of

‘scientific’ models of spiritual care. I will now outline what scientific approaches are contributing to the delivery of spiritual care. First, I will discuss two literature reviews outlining important research conducted under a scientific paradigm. I then scrutinise the scientific approach to spiritual care and argue that lack of attention to inner spaces and silences reflects a gap in the delivery of spiritual care, which is best addressed by chaplains’ professional artistry.

1.2.1 *The scientific literature*

A cursory glance at *Spiritual Care at the End of Life: A Systematic Review of the Literature* (Holloway et al, 2011), and *Review of Literature* (Morgan, 2015), demonstrates that the science of spiritual care is becoming more refined and increasingly sophisticated. Both reviews draw on pivotal research since the year 2000 and outline many important findings. For example, C.S. McClain, Barry Rosenfeld and William Breitbart (2003) found that when existential and spiritual needs are met, requests for assisted suicide decline. Also, Scott Murray (Murray et al, 2004) underscored patients desire, in primary palliative care, to be supported by GPs in spiritual matters. And T. Balboni (Balboni et al, 2007) found that nearly three quarters of patients with a diagnosis of advanced cancer reported that their spiritual needs were minimally supported or not supported at all by the medical system, which led to unaddressed spiritual distress.

Both reviews are strongly influenced by the dominant biomedical model¹⁰ of health which regards health ‘as the absence of disease’, therefore the goal of healthcare is the ‘cure’ of illness, primarily through screening and assessment leading to referral, interventions and process. Consequently the science of spiritual care relies upon rigorous diagnostic frameworks and procedures.

The purpose of screening tools, such as FICA Spiritual History Tool, is to gauge how patients engage with their faith or belief community, draw on their spiritual stores, and opt for specific rituals or exercises to cope with facing their mortality

¹⁰ Models are intended to ‘simplify complex situations’, to image issues more clearly and enable us to respond more appropriately (Rumbold, 2012, 177). The scientific model is one of several approaches to the delivery of spiritual care. Bruce Rumbold (2012) helpfully describes the biomedical model, the biopsychosocial model, the social model and the holistic or ecological model. Each model has different orientations and horizons, which subtly influence strategy.

(see Puchalski, 2006, 237-241).¹¹ Screening is a way to discover the worldview and ‘language of the spirit’¹² that are appropriate to the patient. There is an abundance of tools to measure spirituality and its significance for individuals. However, empirical assessment of spiritual need and distress is complex and relies on validated measures, such as the Functional Assessment of Chronic Illness Therapy - Spiritual Well-being Scale (FACIT-Sp-12), which is currently regarded as psychometrically superior to other tools (see Peterman, Fitchett, Brady, Hernandez, and Cella, 2002). However, the science of assessment is coming under scrutiny. Indeed, the reviews report that practitioners have grave doubts about the efficacy and appropriateness of validated measures for spiritual care, and opt rather for narrative or ‘story-telling’ approaches. For example, Bruce Rumbold (2002) describes four ‘strands’ which inform assessment and intervention: identity questions, questions surrounding loss of meaning and purpose, belief questions, and religious convictions. These strands are best explored within safe conversations. Similarly, the *Report of the Consensus Conference on Spiritual Care in Palliative Care* advocates that chaplains take ‘a spiritual history’ (Puchalski et al, 2009).

There is a paucity of evidence on the most effective interventions designed to develop, promote and support the provision of spiritual care: the existing scholarship addresses the importance of spiritual care and suggests models for it, but does not provide empirical evidence for their effectiveness. Authors such as

¹¹ The acronym FICA can help structure questions in taking a spiritual history by healthcare professionals.

F - Faith and Belief "Do you consider yourself spiritual or religious?" or "Is spirituality something important to you" or "Do you have spiritual beliefs that help you cope with stress/ difficult times?" If the patient responds "No," the health care provider might ask, "What gives your life meaning?"

I - Importance "What importance does your spirituality have in our life? Has your spirituality influenced how you take care of yourself, your health? Does your spirituality influence you in your healthcare decision making?"

C - Community "Are you part of a spiritual community? Communities such as churches, temples, and mosques, or a group of like-minded friends, family, or yoga, can serve as strong support systems for some patients.

A - Address in Care "How would you like me, your healthcare provider, to address these issues in your healthcare?"

¹² Rachel Stanworth explores at length three features of a non-religious ‘language of the spirit’, which represent ‘happenings’ which may disclose a human or ultimate horizon of meaning. The first feature is that any language of the spirit is contextual and represents ‘being-in-the-world’. The second feature is that it is archaic, which while hard to define touches depths and carries existential weight. And thirdly, the language is symbolic, in that it mediates something of infinity through the finite (2004, 61-86).

Kernohan, Waldron, McAfee, Cochrane and Hasson (2007) highlight spiritual needs: to have time to think; to have hope; to deal with unresolved issues; to prepare for death; to express true feelings without being judged; to speak of important relationships. Organisations such as the Association of Hospice and Palliative Care Chaplaincy (2006) advocate that spiritual carers explore the individual's sense of meaning and purpose in life; exploring attitudes, beliefs, ideas, values and concerns around life and death issues; affirming life and worth by encouraging reminiscence about the past; exploring the individual's hopes and fears regarding the present and future for themselves and their families/carers; exploring the why questions in relation to death and suffering. Rumbold (2012) provides a relational model,¹³ and there is guidance from the US *Consensus Conference to Improve the Quality of Spiritual Care as a Dimension of Palliative Care* on integrating spiritual care within palliative care (Puchalski et al, 2009).¹⁴ However, there is a dearth of empirical evidence to support either interventions or to measure outcomes. Lead researchers are now trying to address this lack (Handzo, Cobb, Holmes, Kelly, and Sinclair, 2014).

1.2.2 *The science of spiritual care under scrutiny*

A scientific approach, which relies upon rigorous diagnostic frameworks and procedures, appears at first glance to enhance an understanding of spiritual care and support its delivery. But critiques of the limitations inherent in the science of spiritual care are now also being voiced. In the uncertainty, complexity and chaos

¹³ Bruce Rumbold's (2012) relational model seeks a generic model that is applicable to all. Therefore, he adopts Emmanuel Lartey's relational model of spiritual care (1997, 113), which rises above the limits of religious frameworks. All spiritual care, he says, takes place within genuine human encounters. Such encounters may be with places and things (spatial); with self (intra-personal); with others (inter-personal); among people (corporate); and with transcendence ('God', 'Something There'). The therapeutic task is to build spiritual resilience through any, or all, of these relationships. Such relational care delights in diversity and difference. The uniqueness and complexity of each encounter invites an artistic approach stresses creativity, imagination, and wisdom. Relational care which focuses on the human necessitates going with the flow, living with uncertainty and moving into the unknown.

¹⁴ The US *Consensus Conference to Improve the Quality of Spiritual Care as a Dimension of Palliative Care* (Puchalski et al, 2009) outlines specific roles and interfaces between professionals in the delivery of spiritual care. On admission to the hospital, clinicians from all disciplines may 'screen' patients and families for spiritual needs, however only those with greater spiritual care competency and experience take 'spiritual histories', and finally in complex situations, it is the role of spiritual care experts (board certified chaplains) to conduct 'spiritual assessments', and then report back to the multidisciplinary team for final discussions on the most appropriate route of referral. This may be, for example, back to community providers, or to specialists in trauma, grief, spiritual direction, mindfulness or other creative therapies.

of spiritual care, there are times when it is impossible to define either what patients are experiencing, what chaplains are contributing, and what is happening in a pastoral encounter. It is certainly impossible to calculate what is happening in the transcendent realm. Further, the limitations of a scientific approach become most evident in the context of palliative care. Some spiritual matters are beyond measure; some patients are silenced; and some long for something more than a scientific approach to death. Three areas which expose the limitations of a purely scientific approach to spiritual care are: first, assessment and measurement; second, the silences within suffering and trauma; and third, the longing for depth.

The fact that some spiritual matters, ‘the unconditional’, are beyond assessment and measurement is captured in David Roy’s foreword to Fiona Randall and R.S Downie’s *The Philosophy of Palliative Care* (2006, v-vi). Here he stresses that the unconditional cannot be marshalled, delivered, measured or quantified by the combined masses and expertise of palliative care professionals. This has certainly been my experience in both clinical practice and research. In 2011 I co-led a research project, ‘Are spiritual distress and physical pain inter-related in cancer? A prospective study,’ during which we measured pain, using the Brief Pain Inventory, and spiritual well-being, using the FACIT-Sp-12. Initial results appeared to indicate that pain correlates with increased spiritual distress (Brabin, Stirling, Campbell, Grant, Sherry and Laird, 2011). However, reflection on the experience of using the FACIT-Sp-12 assessment scale to measure spiritual well-being raised three significant concerns for me about this means of measuring spiritual matters.

First, I found that many patients simply do not understand the items in the FACIT-Sp-12 to which they are supposed to respond. When helping patients to complete the scale, I often had to explain what the items meant and patients found it extremely difficult to give a number score to items concerning the meaning of life. Second, the three domains (faith, peace, and meaning) on the FACIT-Sp scale do not fully comprehend all facets of spiritual well-being in palliative care. This may be because the FACIT-Sp was developed in another context, with input from cancer patients, psychotherapists, and spiritual experts, who were asked to describe the aspects of spirituality and/or faith that contributed to quality of life. Furthermore, the construct validity of the FACIT-Sp has not been evaluated in a palliative care population. Spiritual well-being may look very different when

facing death in comparison to engaging with a diagnosis that may possess curative options.

Second, some patients are currently ‘silenced’ by our ways of handling dying and death. Although arguably, there may be instances of ‘a good dying’, and ‘a natural course’ towards death, many people deviate from this course. The Agora Guidelines (2013) describe a natural course of dying as: an awareness of finiteness; the loss of grip on life; loss of meaning; engaging in a bereavement process; a longing for connectedness. These all occur before the emergence of a new integrated outlook which allows a person to accept death and dying. However, wisely, the guide stresses that some patients struggle to make this journey. They may deny their mortality and withhold emotions lest these overwhelm them; they may banish the fears and anxiety of death into their subconscious; and they may be deeply traumatised and thus silenced. All of these factors may lead to existential and spiritual crises which require an alternative approach to care.

Third, when facing their mortality patients are often yearning for something deeper, something more profound than science. Monica Renz contends that ‘we need a profound knowledge of archetypal spiritual processes which occur when our everyday consciousness is transcended’ (2016, 16). Despite his working life being in medicine, Paul Kalanithi wrote when facing his own death:

What patients seek is not scientific knowledge that doctors hide but existential authenticity each person must find on their own. Getting too deeply into statistics is like trying to quench a thirst with salty water. The angst of facing mortality has no remedy in probability (2016, 135).

This section succinctly conveys my conviction that there are limits to scientific approaches when facing the ultimate mystery of life. Therefore, for all its rigour, innovation and evidence-base, scientific approaches need to be balanced by artful strategies. By this I mean that in the presence of such concepts as depth, uncertainty, meaning- making, hope, and relationships, the art of spiritual care comes to the fore.

1.2.3 Rediscovering the Art of Spiritual Care

Waterfalls and buckets

Imagine yourself walking through a deep, dense wood. You are surrounded by beautiful lush foliage, the constantly changing aromas of rich shrubbery makes your head swirl. Suddenly you reach a clearing. Right in the centre of the clearing is a beautiful stream headed up by a magnificent waterfall. You stand and watch in awe at the mystery of the waterfall. Multiple rainbows dance across the glistening surface of the water. The sound of the water, the taste of the spray, the sight of the magnificence and power of the waterfall touches you in inexpressible places and brings you into contact with a dimension of experience which you can't quite articulate, but which you feel deeply and meaningfully. Eventually your gaze of wonder begins to change as your curious side clicks into action. 'What is this wonderful thing called a waterfall?' 'What is it made of' 'Why does it have such an effect on me?' So, you pick up a bucket and scoop some of the water from the falls. You look into the bucket, but something has changed. The water is of course technically the same substance in each setting: H₂O. It remains a vital constituent of your life; you need it to live and without it you perish. Yet something has been lost in the movement from waterfall to bucket. In your attempts to break it down, analyse, and explain what it really is, the mystery and awe of the waterfall has been left behind. Which is more real? The mystery of the crashing waterfall or the still waters of the bucket?

Mark Cobb, (quoted by Swinton, 2012c, 99).

John Swinton (2012c), retells this story of waterfalls and buckets to express his philosophical conviction that there are two types of knowledge, both of which are critical to healthcare. *Nomothetic* knowledge is gained through scientific method, and to be valid must be 'falsifiable, replicable and generalizable. This empirical approach enjoys primacy in healthcare. However, nomothetic knowledge cannot capture experiences such as love, forgiveness and hope. These experiences, that occur only once and are deeply unique to individuals, are represented by *ideographic* knowledge. Spiritual concepts such as meaning, purpose, hope, love and God are not observable, replicable, or generalizable. Thus, spirituality encompasses hidden and mysterious aspects of life that cannot be measured.

Interestingly both systematic literature reviews referred to in above section on the science of spiritual care do mention the art of spiritual care. The terms emerging include words and phrases such as 'process', 'presence', 'companionship', 'creating and holding a safe nurturing space', 'deep listening', and 'compassion' (Holloway, et al. 2011, 26). A dearth of empirical evidence, however, means that they are unable to develop this critical aspect of spiritual care. This lack of empirical evidence may be because science deals with objective

realism, and spirituality is the soul of being (Swinton, 2012c). This means that spirituality is becoming increasingly unsusceptible to empirical and deductive techniques.

Swinton (2003, 2013) also uses the story to urge chaplains not to conform to an uncritical acceptance of scientific methodologies and assumptions, but to ‘reclaim a mystery and wonder’ and ‘remember the soul’ of chaplaincy. Within ‘a professional, evidence based, scientifically driven healthcare system’ chaplains are present to be healers and care for a person’s spirituality: ‘that dimension of humaneness which is unquantifiable, mysterious, individual and unique’ (2003, 223). The way to do this, he claims, is to practice a narrative based chaplaincy. A storied profession, where chaplains listen to, bear and share stories. Stories, he says, reveal the way people construct their universe. Chaplains themselves embody, act out and re-tell faith narratives. And all day long they ‘cross over into strange lands’¹⁵ and ‘listen to stories of illness, sickness and suffering, happiness, brokenness, life and death’ (2003, 224). The thrust of Swinton’s argument is that chaplaincy is required to be bilingual, effective in the language of healthcare and in the language of the spirit. Chaplains are required to be both scientists and artists.

The dominant scientific biomedical model of health undervalues silence, being in the depths, or living in uncertainty. This lack invites consideration of an alternative artistic approach to the delivery of spiritual care.

1.3. Reflections on the art of spiritual care

In this section I begin by tracing the emergence of understandings of the art of spiritual care in the wider research literature and in the experience of practitioners in Scotland. I then outline two main features of this approach: spiritual care as a relational process, and spiritual care as enabling engagement with profundity and depths. Finally, by representing the interface of the science

¹⁵ John Swinton draws on David Augsberger’s (1986) concept of ‘interpathy’, which relates to a researcher or practitioner crossing over into a culture which is radically different from their own. By suspending their own assumptions which they sometimes subconsciously carry, their own world view, they are better able to make space to listen to the narratives of the other.

and the art of spiritual care, in theory and metaphor, I make a case for rediscovering the value of professional artistry in the delivery of spiritual care.

In the above-mentioned literature review by Holloway et al, alternative research, somewhat at odds with ‘practice guidance’, is identified (2011, 26). Here it is disclosed that chaplains offer a safe nurturing space, deep listening and compassion. What the authors also note, but do not develop, is that this entails practicing the art of spiritual care. This is particularly important towards the very end of life where, in the crucible of life and death, the most effective approach is companionship, or being there (Nolan, 2012). The task is to create safe nurturing spaces to allow patients to be. Empathy and compassion enables the carers to enter deeply into the distress and vulnerability of others. In the safe spaces the patient may find sources of strength and meaning, not necessarily in their suffering, but by reflecting on life more generally.

That there already exists ‘a body of opinion which opposes the ‘medicalising’ of spiritual need through an over-emphasis on assessment through standardised scales’ is significant for my research (Holloway et al, 2011, 26). And this concern is rooted in the experience of chaplaincy in Scotland. Indeed the 2013 *Consensus Conference of Healthcare Chaplains* identifies spiritual care as a relational process. Spiritual care offers space, elicits and honours story, journeys with an individual further into pain, darkness, uncertainty or unknowing, and holds other possibilities of seeing. To become proficient, hospice chaplains are required to be skilled spiritual translators or chameleons.¹⁶

The understanding that spiritual care entails spiritual artistry is further grounded in the influential work of Tom Gordon, Ewan Kelly and David Mitchell (2011), who are pillars of the healthcare chaplaincy community in Scotland over the last decade. Their landmark handbook, *Spiritual Care for Healthcare Professionals*, describes spiritual care as ‘fundamentally relational in nature and inherent in the

¹⁶ ‘To be a chaplain in a highly-charged emotional environment, such as a hospice sometimes is, one must be something of a dancing chameleon, taking on the colour and shading of others’ words, able to move lightly in and out of the linguistic modes of doctors and nurses, of patients, with their varying backgrounds, upbringing and occupational training, and the loved ones of those patients, the varying dynamics of relational networks. By body language, by tone of voice, by the sensitivity to judge a moment—when to say nothing, when to touch, when to make a joke—by facial expression, a carer must communicate what should never be said; ‘I understand’ (Wilcock, 1996, 47).

professional art’ of delivering care (2011, 1). This is seen in five areas. Firstly, self-awareness of the fluidity of spirituality, which means that any search for a definition is futile, and ‘the key to providing spiritual care is to understand what spirituality means to the person you are caring for’ (2011, 5). Faith, belief and culture, second, which invites professionals to disentangle the spiritual and the religious, allowing the horizon of spiritual care, grounded on Paul Tillich’s observation that within the human condition there is a deep longing for being ‘whole, not yet split, not disrupted, not disintegrated, and therefore healthy and sane’, to ‘re-establish a whole that was broken’ (2011, 13). Third, the art of communication, where ‘the quality of the therapeutic relationship matters (2011, 22); and fourth, being integral to the healthcare team invites imagination to work across professional boundaries.¹⁷ Finally, spiritual artistry invites chaplains to move beyond competencies towards capability of dealing with uncertainties and complexities in healthcare.¹⁸ Artistry allows chaplains to draw on instinct and wisdom in creating the conditions for spiritual care; and in the delivery of spiritual care via assessment and intervention and evaluation. Artistry also allows for engaging with depth and profundity, such as ‘seeking answers to existential questions which are provoked by human suffering’ (2011, 90) which emerge as fragments.

1.3.1 The art of care is a relational process

The emergence of concern for the art of spiritual care is very evident in the literature on processes of spiritual care within clinical practice. Ethicist Daniel Sulmasy (2012) argues that spirituality in end of life care is concerned with living life in the face of death, and seeking answers that often transcend the finitude of human space and time. Facing such limits means that spiritual care is more to do

¹⁷ Emmanuel Lartey articulates that one dimension of a chaplain’s professional artistry is to be ‘a blessed irritant for holistic human care’ (2012, 297). The riches of pastoral theology enable chaplains, who are often located on the margins of institutional power, to offer new perspectives. A chaplain may voice an understanding of spiritual health which includes inherent human worth, dignity and value. Or promote an appreciation of health as a common good. Or question health inequalities. Or join the chorus of voices clamouring for the recovery of compassionate care.

¹⁸ ‘Competence’ describes what individuals know or are able to do in terms of knowledge, skills and attitude at a particular point in time. ‘Capability’ describes the extent to which an individual can apply, adapt and synthesise new knowledge from experiences and continue to improve his or her performance. (Gordon, Kelly and Mitchell, 2011, 51).

with process than outcomes. He outlines five ethical principles of spiritual care to ensure a quality process.¹⁹ Ensuring a beneficial 'process' is also a key concern for Harriet Mowat and John Swinton. Their research, *A Process Model (2005)*, was conducted at a time when chaplaincy was in a state of flux. Older models were giving way to newer ones better shaped to fit the changing spiritual climate in Scotland. In this context, they found that the values and perspectives of chaplaincy appeared counter-cultural to the institutional language of competition, financial accountability, commissioning, targets and competencies. They argue that the core task of chaplaincy is a process of finding people; identifying needs and responding to them, rather than attaining outcome measures. This process requires chaplains having creative spiritual intelligence and antennae. The focus is on comfort, hope, enabling control, listening, understanding, empowering, valuing, being honest; offering information so that patients may find relief from distress, be able to cope, and find an inner peace.

The art of spiritual care is relational. It offers space spaces for safe conversations. Writing in the 1980s, Norman Autton, one of the father-figures of hospital chaplaincy in the UK, outlines the art of pastoral care. Its focus is the alleviation of suffering and pain. Building on the pivotal work of Buber's 'I-Thou relation', and Carl Roger's 'unconditional positive regard', the pastoral relation Autton describes is grounded in a therapeutic relationship. It embraces aspects such as discernment, integrity, communication, and being present. Being present is an act of witness, offering strength and silence, in which listening to the 'spaces' between words is crucial (Autton 1986, 125). The tone of care creates an inner space or breathing space in which the person can be all that they are. From the outset, inner space, which is the locus of deep silences, lies at the heart of pastoral relations. More recently, the sociologist Tony Walter argues that spiritual care depends on the quality of relationship rather than the way spiritual care is organised (2002), and reiterating my introduction above, 'fundamentally relational'. The key issue is what happens in the relational space. This may range from being with, to witnessing, to listening attentively and being self-aware. In the *Systematic Review of the Literature*, Holloway et al (2011, 26) identify relational care as offering a safe nurturing space, deep listening and compassion.

¹⁹ Daniel Sulmasy's five ethical principles of spiritual care are patient-centredness; holism; discretion; accompaniment and tolerance.

In the crucible of life and death, the most effective approach to care is just companionship, or being there (Nolan, 2012). But it also includes the possibility of engaging in creative conversations which sculpt and shape a person's identity.

In *The Foundations of Pastoral Counselling*, Neil Pembroke interweaves philosophy, psychology and theology to powerfully represent the pastoral relationship. In brief, there are four core attitudes of caregiving. First, respecting the absolute alterity of the other, and resisting any shift towards 'totalizing' (Levinas). What this means is the carer must resist any temptation to impose one's own self onto the other, which shrinks and suffocates the other person. Second, recognising that empathy is an embodied dance, in which there are mis-steps and moments when one takes the lead, and times of attunement and alienation. Third, appreciating that deep listening demands attention that flows from desire (Simone Weil) and an ability to wait and self-empty; and fourth, embracing dialogue at depth. The four strategies of pastoral care are: first, the revision of faulty thinking by using Socratic dialogue; second, challenging blind spots; third, discovering metaphors to express and re-frame the self; and fourth, looking beyond the individual to discover a safe and loving space in community (*ubuntu*). Like Autton above, Pembroke emphasises that personal spirituality which integrates five qualities into all aspects of care: vulnerability, compassion, availability, tenderness and integrity (Pembroke, 2017, 229). Crucially, it is the quality of relationship that matters.

Finally, the art of spiritual care creates the conditions for healing akin to those offered by art therapy, as described by Sean McNiff (2004). McNiff describes a serendipitous opening into art therapy in the 1970s prior to his discovery that art and creativity 'heal the soul'. The American Art Therapy Association says art is 'healing and life enhancing' and comes into its own when words fall short, as in the paradigmatic tragedy of Sept 11th 2001. McNiff describes the strategic importance of developing creative spaces in healthcare, safe places which function not just as a 'watering place for the soul' but enable 'the creative processes that transform life' (2004, 15-27). McNiff's creative space is the Art Cottage in the psychiatric hospital where he began his journey as an art therapist. Formerly a space of 'fresh air and light' for tuberculosis patients, the cottage now has its own atmosphere, ambience and aura and has become a sanctuary of healing. The process of art therapy is 'a complex meandering, often chaotic and

without finding goals', and which works at depth demands a 'safe place' where people can become attuned to their spirituality. One begins to trust in the process of art therapy that welcomes uncertainties, takes risks, moves into dark places and often begins with upheavals and disturbances. Fundamentally art therapy 'does not profess to rid the world of suffering and wounds. Instead it does something with them' (2004, 32).

1.3.2 *Loss and Bereavement*

The art of spiritual care excels in times of depth and profundity such as those routinely faced by hospice chaplains. Gordon, Kelly and Mitchell (2011, 102-124) describe 'loss and bereavement' as a site where professional artistry allows chaplains to engage creatively with complex quandaries integral to the delivery of palliative care. I will focus on palliative care in the following chapter of this thesis, so restrict myself here, to conveying the close links, at times almost indistinguishable, between spiritual care, bereavement care and palliative care. Working with patients facing their own death, families and carers, who are anticipating and then living with the deaths of loved ones, and staff members who are daily reminded of their own mortality, means that grief work is integral to palliative care and spiritual care (see Kissane and Bloch, 2002; Payne and Lloyd-Williams, 2003 and Renzenbrink, 2011). Here I consider the way spiritual artistry supports a response to 'loss and bereavement' through considering the work of two bereavement specialists, Kenneth Doka and Melissa Kelley, to illustrate spiritual artistry at its height. Doka and Kelley share the view that therapists, rather than being bound to classic theories of grief, derived for example from Sigmund Freud's essay *Mourning and Melancholia* (Freud, 1957), and half a century later from Elisabeth Kubler-Ross' *On Death and Dying* (Kubler-Ross, 1969), require to be more person-centred and capable of living with complexity and uncertainty. This is where artistry lies.

Kenneth Doka offers a historical overview of perspectives on bereavement and grief (Doka and Tucci, 2011, iii-xvii). First, he notes the immense impact of Sigmund Freud's essay '*Mourning and Melancholia*' (Freud, 1957) and half a century later from Elisabeth Kubler-Ross' *On Death and Dying* (Kubler-Ross, 1969) on the way society engages with death and dying. Freud emphasised working

through powerful emotions to detach from the deceased and reinvest in life. Kubler-Ross outlined a stage theory of grief: denial, bargaining, anger, depression, and acceptance. Collating insights from the most influential voices, Doka describes the considerable changes in the understanding of the grieving process that have taken place over recent years. The shift now, he says, is towards a more inclusive understanding of loss rather than a restricted focus on death, an appreciation of personal pathways rather than universal stages to journey through, the possibility of growth and transformation as well as loss, continuing bonds with the deceased rather than letting go, the multifaceted responses to loss influenced by context, culture, gender and spirituality, and being aware of the need not just to normalise grieving as a natural dimension of life, but to be cognizant of complex reactions. What this means is that therapists are required to be more person-centred and capable of living with complexity and uncertainty.

Writing as a pastoral theologian, Melissa Kelley (2010), both complements Doka and adds to his insights. She adopts the metaphor of a mosaic to identify patterns, particularities and absences within bereavement care. So, while literature illuminates many dimensions of grief, some aspects, such as disenfranchised grief, which Doka defines as being ‘not openly acknowledged, socially validated, or publicly observed’; chronic grief, in which losses are ongoing and relentless; and unjust grieving, where grief is due in whole or part to injustices caused by individuals, groups and systems, such as global poverty, is undervalued. Also, the complex and nuanced character of grief means that traditional patterns such as those described by Doka, may be limiting.

Kelley stresses that a sense of connection, to others and to God, plays a role in grief. Therapists support the grieving to create order, sense and purpose because the alternative, absurdity, meaninglessness, or a frozen story, is ‘a terrible thing’. Kelley refers to William Willimon’s observation that ‘a great trauma makes theologians of us all’ (2002, 103-113), before arguing that there are moments when faith falls short, and sometimes concepts of God add fuel to the suffering. That grief and stress, due to both environment and inner resources, may either lead to despair or growth is an important insight. Kelley describes how God is a partner in the reconstruction of meaning, and that an act of grace may transform the brokenness, shards and fragments of grief into a new mosaic. Her confidence is expressed in Leonard Cohen’s lyrics, ‘there is a crack in everything / that’s how

the light gets in'. It is therefore the relationship with the Other, the acceptance of gift and grace that gives the grieving hope for renewal. In every end, a new beginning lies hidden. Kelley argues that the first task of the carer is to ground people in God's silence: 'He is our clothing, who wraps and enfolds us for love, embraces us and shelters us, surrounds us for his love, which is so tender that he may never desert us' (2010, 138). The second task of the carer, expressed in the mosaic, 'Nebulae', which adorns the cover of her book, 'is not to remove or smooth out all the broken pieces, but rather to help the pieces come together in a wholeness that brings hope because it is grounded in the love of God' (2010, 140).

Doka and Kelley show that individual experiences of grief trouble theoretical patterns, and warn against blindly applying universal principles of grief onto individuals. In their writing we are led to understand that spiritual care demands an artistry which is able to live with complexity, uncertainty, trauma, depth and silences.

1.4. Practicing the Art of Spiritual Care

Chaplains do not have any skills that are original. Rather it is the unique configuration of attributes - listening, talking, story-construction, perceiving the spiritual, counselling and so forth - that gives them their unique place within healthcare practice. (Holloway et al, 2011, 14).

My intention in this chapter has been to explore the contemporary landscape of spiritual care and to begin to describe and advocate for the 'art' of spiritual care in this context. I believe this dimension is currently undervalued in strategic thinking, clinical practice, and professional formation; fields in which the 'science' of spiritual care tends to dominate. Even the therapeutic interventions most closely aligned with spiritual care, such as dignity-conserving care (Chochinov, 2012, , Sinclair and Chochinov, 2012a, 2012b), hope-fostering strategies (Herth, 1990; Eliot, 2012; Nolan 2012), and meaning-making therapies (Burke and Neimeyer, 2012; Breitbart and Poppito , 2014), which despite being inherently relational in nature, are being lured towards a scientific, evidence based modality, which measures outcomes and impact, rather than having the courage to stay close to the original vision of the hospice pioneers and embrace the ambiguities, uncertainties and profundities that lie at the heart of palliative

care. I explore this further in the following chapter. However, for now, my fear is that a lack of 'artistry' threatens to undermine the quality end of life care and my conviction is that rediscovering the art of spiritual care is crucial and has the potential to re-humanise dying, particularly in areas of depth and profundity.

A closer look at the defining characteristics of the 'science and 'art' of spiritual care, may offer an understanding and a way forward out of this dilemma. The tensions between the two reflects the shifting foci of care as it moves back and forth between three levels: from what is hidden at depth, to what is seen on the surface, and to what is imagined in transcendence. The art of spiritual care is suited to working at all three levels, in depth, on the surface, or with imagination, whereas the science of spiritual care works most effectively with what can be seen and measured, on the surface. The question is how to find a way to hold the art and science of spiritual care in balance.

I now introduce a theory and a mapping metaphor which suggest a way of bridging the art and the science of spiritual care. Both complexity theory and the mapping metaphor offer a way to locate the art and science on the map of spiritual care. And the insights gleaned will inform the themes that I later develop in this thesis. For example, the concepts of 'inner space' (chapter two), and 'deep silences' (chapters four and five), which are currently marginalised and hidden from view in the delivery of spiritual care, are better located in chaos and complexity, or located as fractals, rather than contours, on the map of spiritual care. The following sections develop complexity theory and the mapping metaphor.

1.4.1 Complexity Theory

While a tendency to emphasise either the art or science of spiritual care may relate to a preference for precise definitions or thin understandings, as I have argued, it is not necessary to choose between them. Complexity theory can represent the interface between the art and science of spiritual care. In a series of four articles in the British Medical Journal in 2001, a group of scholars introduced complexity and complexity theory to healthcare (see Plesk and Greenhalgh, 2001; Wilson and Holt, 2001; Plesk and Wilson, 2001; and Fraser and Greenhalgh, 2001). Over succeeding years despite some opponents (Paley, 2010), complexity theory has gained credence (Bleakley, 2010), as a framework for

understanding complex situations, such as in a medical consultation (see Figure 3), and in palliative care (Munday, Johnson and Griffiths, 2003). Complexity theory emphasizes both competency and capability: competence to deal with spiritual issues that are clear and self-evident, with a focus on doing and transforming; and capability of working in areas of complexity, chaos and silence, where the emphasis shifts towards being. This allows healthcare professionals in the one moment to be very clear about the nature of their intervention, and then in the next moment live on the edge, in liminal situations and beyond the familiar. A case study presented in a reflective practice session described when a chaplain was called in to see a young couple whose baby was stillborn. Their request for the chaplain to baptize the baby seems clear, on the surface, in that the parents from their perspective are seeking a religious ritual to mark the life and death of their baby. However, the situation soon becomes complex as the chaplain wrestles with the lack of any set of religious rituals to meet their need. In a superb moment of professional artistry, which reflects his ability to reflect-in-action, he uses the mother's tears to baptize the baby. A creative act which witnesses grief, holds the parents pain and finds a new shape to baptism.

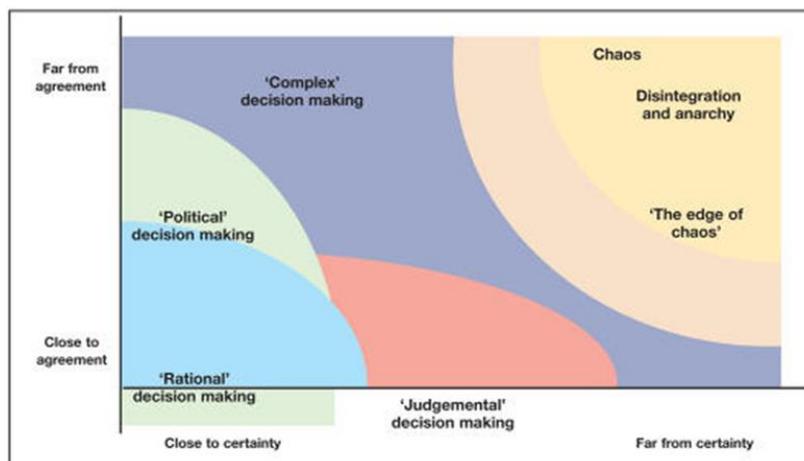


Figure 3: the Stacey Matrix: Complexity and the Consultation (Innes et al, 2005, 48).

If, as argued, there is a lack of art in the current delivery of spiritual care, then complexity theory offers a simple visual model to locate where the art of spiritual care excels. Professional artistry offers quality care in the context of complex decision-making and chaos. The art of spiritual care is often more useful than the science in the context of extreme suffering, trauma, complexity, uncertainty, chaos and threshold experiences. This is the nature of the terrain of end of life care.

1.4.2 Mapping Spiritual Care: Contours and Fractals

Over a decade ago I met informally, with leading hospice chaplains in Scotland, including Tom Gordon, Ewan Kelly and Michael Paterson, for a study day, with the ambitious task set of 'mapping spiritual pain'. I remember it vividly, so was immediately intrigued by Una MacConville's (2011), metaphor of mapping, with the innovative concepts of 'contours' and 'fractals'. I adapted them now to offer another interpretive means of comparing the art and science of spiritual care. Interestingly, Shelly Rambo also uses a spatial mapping metaphor to engage with theology (2010, 8-9). Here she relies on Serene Jones (2000) who describes theologians as 'cartographers', whose specific theologies are 'imaginative lenses' for viewing the word' and provide markers and signposts for mapping the landscape of faith' (2000, 19). But returning to MacConville; maps, she says, vary in their size and focus. Small scale maps are useful for giving an overview of a large landscape. They offer an ideal way to see broad contours, shapes and patterns across the landscape, such as mountains, rivers, coastlines, and cities. Within the territory of spiritual care, such a map may capture the core characteristics, themes and culture of spirituality. Which includes broad themes such as meaning -making; dignity conserving care and hope-fostering strategies. Contours guide travellers. Contours inform and shape the minds of strategists, because they sculpt patterns, which cover the whole territory. And they embrace every aspect of spirituality.

On the other hand, large scale maps allow for more detail. Therefore, a map may locate ancient monuments, abandoned sites and the other more unique aspects of a landscape, and the shapes that cannot be seen from a distance. This may be likened to fractals on a coastal landscape. 'Fractals' are those parts of coastline, or mountain crags that fail to appear on maps because they are too complex, intricate and idiosyncratic in detail, and demand close attention from the unwary travellers to negotiate them safely (MacConville, 2011, xvi). Fractals, by capturing hidden or marginalised areas, are more flexible to meet the unique, complex and particular, and therefore may be better suited to explore 'inner space' and 'deep silences'. Within spiritual care, the fractals reflect those unique and individual aspects of a person's life that cannot be known by another from afar.

The relevance of living with complexity or chaos, on the one hand; or in fractals, which capture experiences rarely mapped, are that these represent the 'inner space' and 'deep silences' which are the focus of my thesis.

Sometimes spiritual matters are hidden, or unspoken, or function like negative spaces in art theory, which gives composition to a picture, but is sometimes overlooked. As such it requires depth and imagination to uncover them, or to witness them. Here the value of professional artistry in the delivery of spiritual care is crucial. Practical wisdom, or 'phronesis', is a core characteristic of this mode of spiritual care. It is described as

A knowing in which skill and understanding cooperate; a knowing in which experience and critical reflection work in concert; a knowing in which the disciplined improvisation, against a backdrop of reflective wisdom, marks the virtuosity of the competent practitioner.

James Fowler (quoted in Willows and Swinton, 2000, 14).

Kelly (2012, 36) distils its essence further by saying that phronesis 'requires ongoing reflection' and an ability to draw upon 'that accumulated pool of comparative practical examples which each of us carries with us'. Thus the 2013 *Education, Training & Formation for Healthcare Chaplains: Report of an NHS Review* states its intention to:

offer innovative pointers for a formational programme which goes beyond competency based learning, attends to educational, training and personal development needs of healthcare chaplains, fosters capability and resilience within the workforce and which results in open flexible chaplains who operate as spiritual drivers and enablers in health and social care (Paterson and Clegg, 2013, 5).

The task of spiritual artistry is lending a presence, accepting silence, being willing to enter in to another's suffering, allowing a story to be voiced, a cry to be heard and a life witnessed. Spiritual artistry is fundamentally relational and embraces chaos, ambiguity, profundity. It often exists on the margins of healthcare. The creation of inner space and the holding of deep silences may be the road to what spiritually matters in palliative care. It is to palliative care and its interface with the spiritual vision of its original pioneers that I now turn.

Chapter Two: The Hospice Movement and Spiritual Care within Palliative Care



Figure 4: Cat Gates

The original entrance to Culzean Castle, Ayrshire, is through the cat gates, named after the carved sandstone leopards, which still rest above the arches. The historic gatehouses have been demolished and the beech hedges left to become overgrown. In the face of inevitable change, I wonder whether the original vision of hospice care is being lost.

Introduction

In the last chapter I discussed current debates and challenges in the field of spiritual care. I argued that, in my opinion, an emphasis upon rationalizing and objectifying care in order to generate evidence-based practice in this area was in danger of reducing our appreciation of the field as one characterized by ambiguity, intense depth and important relationships. I argued that chaplains, and other health care professionals, who seek to accompany those who are dying they will require understanding of the arts of spiritual care to engage with issues that are not easily quantifiable within conventional diagnostic categories. This does

not mean, however, that scientific attempts to assess outcomes and discern best practice are invalid. Rather, a balance between scientific and artistic approaches is required in order to deliver the best possible care for dying people and those with whom their lives are entwined.

In this chapter I develop my discussion further by looking briefly at the development of the cultural context in which we currently experience death and dying. I then discuss the emergence of the hospice movement and how the exemplary pioneers within this sought to embody an alternative ethics of care that corresponds in many ways to what I have described as spiritual artistry.

I shall then go on to consider whether the founding visions of the hospice movement are being undermined by contemporary approaches to palliative care which circumscribe and limit the potential for people to honestly and creatively respond to the chaos and grief that dying entails. I shall ask whether what began as an attempt to honestly face the realities of the dying process has become a project to impose a particular version of 'the good death' on people whose experience may be very different to what is considered ideal. Finally, I devote a substantial section of this chapter to a consideration of the work of the visionary Dutch scholar Carlo Leget, who develops the concept of 'inner space' as a locus for the exploration of the existential and spiritual challenges death raises. Leget's work is of crucial importance to my thesis, as I am able to see profound connections between his ideas and my concern to generate understanding of the place of deep silences in palliative care. However, this does not mean that I am uncritical of Leget's approach. While he helps me to clarify and extend my thinking, particularly in the realm of narrative, story and meaning-making, I believe that it is necessary to go further than current scholarship has travelled if we are to offer the most honest and effective care possible to those we walk beside to death. Indeed, I argue for a change of tack, from understanding 'inner space' or 'deep silences' solely as a locus of meaning-making, to understanding 'inner space' and 'deep silences' as the locus of 'healing connections'. I rely here on the insights of Balfour Mount, Patricia Boston and Robin Cohen (2007). They share the conviction that the presence of a sense of meaning leads to well-being and wholeness, whereas a lack leads to suffering and anguish. What they add to the debate is that meaning-based coping is

associated with a capacity to form bonds of connection, which we came to call *healing connections* in response to the evident revitalization, sense of security, and equanimity that accompanied them. These healing connections were of four types - connection with Self, others, the phenomenal world experienced through the five senses, or with God or Ultimate meaning, however conceived by that person (2007, 376).

This move recovers aspects of the original vision of hospice pioneers which are often overlooked.

2.1 *The cultural context of death and dying*

...how death is understood and what it means to die will affect not only the way the terminally ill approach their death but also the way the living attend to the dying (Cobb, 2001, 122 citing Neuberger, 1999).

Philippe Ariès's (1974, 1991), influential works, exploring how a denial of death came to be established in Western culture, chart a historical progression in approaches to the dying process. He describes the 'tamed death' of the early Middle Ages. Here, although life is described by Thomas Hobbes as 'nasty, brutish and short', familiarity with death's shadow, and living alongside it during deathbed rituals, and community gatherings for final farewells, ensure that its sting is removed. A change in focus towards what he terms 'one's own death' occurred in the later Middle Ages. Here individual dying is characterized by a spiritual reckoning, notions of judgement, and preparations to meet one's maker. The *ars moriendi* tradition, which I discuss in depth below, holds sway during this period and determines an individual's place of eternal abode. Dying 'became a spectacle reserved for the dying man alone and one which he contemplates with a bit of anxiety and a great deal of indifference' (1974, 34). With the development of Romanticism as an influential cultural movement, there came 'a new intolerance of separation' in death (1974, 59). Intrusive death severs family ties and bonds of love. Now the focus is on the meaninglessness of death and the 'death of the other'. This is vividly expressed in the poetry of the Romantics. For example, John Keats's sonnet 'When I have fears that I may cease to be' wrestles with the meaning of his death, 'then on the shore, / Of the wide world I stand

alone, and think, / Till love and fame to nothingness do sink.²⁰’ And William Wordsworth’s ‘Surprised by Joy’—with its moment of delight, then desolation ‘when I stood forlorn, / Knowing my heart’s best treasure was no more²¹’—engages the precariousness of loved ones, in the minds and memory of the bereaved (see Johnston, 2013, 1-14). This leads on to a culture of mourning exemplified in the Victorian era. In the twentieth century, however, with its combination of holocausts, genocides and medical advances, death was banished from public discourse. Ariès argues that a dirty death or invisible death produced the ‘forbidden death’ of contemporary Western culture; the challenges of which we continue to wrestle with today. His historical sketch is summarized thus:

In a world of change the traditional attitude toward death appears inert and static. The old attitude in which death was both familiar and near, evoking no great fear or awe, offers too marked a contrast to ours, where death is so frightful that we dare not utter its name (1974, 13-14).

On the one hand Ariès’s narrative might appear reductively simplistic²² or in need of revision (see Jacobsen, 2016, Walter, 2018). However, it does help to identify and frame the continuing tendency in contemporary society to banish dying from view and it provides a basis on which to critically assess our approach to spiritual care in this context.

Clive Seale (1998) deepens our understanding of the cultural denial of death by exploring three concepts or cultural discourses which help us to avoid the fundamental challenge to optimistic narratives of healing and redemption that death poses. The first concept is that produced by the construction of ‘imagined communities’. Imagined communities (like, for example, the communion of saints) offer a sense of belonging to an intangible greater whole and serve to control the fear of death because people believe they will still somehow continue to belong

²⁰ Accessed 6th September 2018. <https://www.poetryfoundation.org/poems/44488/when-i-have-fears-that-i-may-cease-to-be>

²¹ Accessed 6th September 2018. <https://www.poetryfoundation.org/poems/50285/surprised-by-joy>

²² Such coherent narratives are an ideal way to introduce an understanding of complex subjects, such as the evolving culture of death and dying. However, they can never smooth over the twists and turns of matters that are inherently complex. In a similar way, Elizabeth Kubler-Ross’s five stage model of grief—denial, anger, depression, bargaining, and acceptance—is also an aid to understanding of the complexity of grief. Yet experienced practitioners readily appreciate the need to complexify such patterns to accurately reflect lived experience.

to something larger than themselves when they die. Seale argues that the concept of imagined communities, transferred into ordinary life to include nations, organisations and institutions—schools, firms and factories— ‘offers a helpful way of understanding the attempts made by individuals in late modernity to find meaning in the face of death and bereavement’ (1998, location 808). The second concept is ‘the hope of revivalism’, in which facing dying is portrayed as an opportunity for growth. A good example of this ‘illusion’ in operation is Irvin Yalom’s classic text *Staring at the Sun* (2008). In this work, Yalom describes the anxiety which is fuelled by the fear of death, yet argues that confronting this anxiety is actually an awakening: ‘though the physicality of death destroys us, the idea of death saves us’ (2008, 7). Yalom illustrates the way people can face their mortality and begin to overcome the terror of death by focusing on power of ideas (for example Epicurean principles, rippling and fulfilling oneself). But generally, he says, ‘ideas are not enough: *it is the synergy of “ideas-plus-relationship” that creates real therapeutic power*’ (2008, 204). A further example of this revivalist process is Kubler-Ross’s concept of acceptance in the grief cycle. Acceptance is the culmination of five stages of grief (denial, anger, depression, bargaining, and acceptance). Although the cycle is not presented as points on an upward journey, this deeply influential model encourages belief that acceptance is the state that everyone should ideally achieve in a good dying. The third concept by which a cultural denial of death is sustained is through ‘resurrection practices’. In confronting mortality, people like Dennis Potter, in *Seeing the Blossom*, use all their resources of courage and imagination to rise above decay or terror. For example, describing apple blossom which is vibrantly present to him despite the acknowledgment of his impending death, Potter says, ‘I see it is the whitest, frothiest, blossomest blossom that there ever could be, and I can see it ... the nowness of everything is absolutely wondrous’ (1994, 5). Such resurrection practices capture Seale’s conviction that in culture there is an innate lure towards life, in the face of suffering and death.

The renewal of life against death in a myriad of resurrective practices is a continual and all pervasive preoccupation, in which our whole being is involved, even though it is a project of which we make ourselves largely unaware. At every moment of our existence we are living with our deaths (1998, location 1001).

Together Aries and Seale offer an interesting overview of some of the powerful ways in which the 'sting' of death has been denied and its threat accommodated within Western culture. However, it is important to remember that there are other cultural and, particularly, religious discourses that, whilst sometimes struggling to be heard, have presented the process of dying as a spiritual journey that may be undeniably painful and threatening but still opens human beings to an encounter that takes them beyond the comforting 'redemptive' narratives outlined above.

In his work on death and dying, Mark Cobb argues that the liminal place of death and dying has been marked out as a spiritual territory throughout history (2001, 48-64). Death is located on the margins of life, yet represents the permanent existential challenge. It may be portrayed as nothing other than the end of existence, or it might be regarded as a moment of ultimate destiny. In either case, it sets the limit to life and defines so much of what it means to live, and to be human. The spirituality of dying embraces many dimensions, ranging from the ending of a sacred life, to ensuring that dying is continuous with the integrity of living, to acknowledging the intensity of death. An enormous amount of thought, behaviour, art, religion, finance, science and technology, argues Cobb, is devoted to death: its causes, its purpose, its timing, its place, its consequences and its intractable mysteries. The spiritual quest, in dying, invites artistry, poetry and creativity:

beyond its surface spirituality becomes increasingly unsusceptible to empirical and deductive techniques ... and some of the best language to convey the sense of spirituality is that of poetry ... Poetry may give our deepest thoughts, beliefs, and experiences words, but it is not a medium which is commonly used in the commerce of logical discourse, and is certainly not the common parlance of palliative care despite the inclusion of creative arts within the therapeutic context (2001, 18).

Despite the cultural denials of death, or the cultural discourses that overcome its threat, the understanding of the massive spiritual significance of the dying process is one that continually resurfaces. As I shall argue, a recovery of concern for death as a sacred place was one of the key factors prompting the development of the hospice movement.

2.2 *The spiritual vision of the hospice movement*

You matter because you are you, and you matter to the last moment of your life. We will do all that we can not only to help you die peacefully, but also to live until you die.

--Cicely Saunders (quoted by Twycross, in his memorial tribute, 2006).

I also felt that a search for feeling that they were wanted and still important people was a spiritual pain. -

--Cicely Saunders (in Clark, 2018, 79).

This section describes the spiritual vision of the hospice movement which emerged from within faith communities in Britain and Canada during the 1950s and 1960s (Cobb, 2001; MacConville, 2011; Clark, 2018) and has since expanded across the world (Bradshaw, 1996; Walter, 1997; Larkin, 2011). I will do so through attention to the perspectives of a number of key individuals who have made significant personal contributions to its development.

At the heart of the hospice movement, and its understanding of the spiritual nature of death and dying, lies the founding vision of Cicely Saunders. David Clark's (2018) biography of Saunders captures her devotion, her innovation and her ingenuity: 'the effects were global in proportion and the reverberations are continuing' (Clark, 2018, 1). Three critical aspects of her story are: her care for and relationship with David Tasma, which stresses healing connections; her recovery from grief, which hints towards a sacred presence, and her radical concept of total pain, which revolutionised medicine. Saunders met Tasma, a forty-year-old Polish man with inoperable bowel cancer, in the first ward she visited as an almoner at St Thomas's. According to her,

The most important thing for him was to find somebody who would listen because he had the strong feeling that here he was, dying at the age of forty, and it made no difference to the world that he'd ever lived in it. His past was less important than where he was at that moment . . . it was just our exchange in the present moment (2018, 58).

That their relationship deepened is evidenced by his response to Cicely reading the 23rd Psalm— 'I only want what is in your mind and in your heart', said David (2018, 59)— how they fell in love and by her intense grief after his death. Despite

her strong faith, she wrestled with the dark coordinates of grief. Only after two intense turning points was she convinced that Tasma was ‘all right’, and she was now free to ‘find a way to work with the dying’ (Clark, 2018, 63).

It was as if God was saying to her ‘He knows me now far better than you do’. After that, she never worried about him again or about anybody else who died angry, sad, bitter, or unbelieving, because she was sure that, in death, they would be met with total understanding and love, and be safe (Clark, 2018, 62)

A deeper release came in the summertime. On 4 June 1948, she took the night sleeper to Inverness and travelled on to meet her father and friends at Glenquoich Lodge. Rising early one morning in glorious weather, she sat where a small burn ran into the loch, the peat-stained water rippling over shining pebbles. At that moment, she slipped into the ‘timeless now’. This is something neither past nor future, and yet something much more than the present moment. It is the changeless or eternal now. In that ‘now’, David was present somewhere. She knew David was all right and that this ‘now’ was also all right. ‘It was so strong and comforting’ (2018, 63).

These spiritual moments gave Saunders the energy and inspiration to fulfill her vocation.²³ In time, Tasma became the ‘first patient’ of St Christopher’s and the centre of a complete foundation myth for the hospice²⁴ (Clark, 2018, 59). Previously, Tasma told Saunders that he would leave her some money and said, ‘I will be a window in your home’. This inspired a gift of £500 from his will, to fund a window, and a metaphor of a window which Saunders used often in her initial

²³ Personal conversation in November 2014, with Christopher Saunders and Dr Mary Baines, who worked alongside Cicely Saunders from the outset of the hospice movement.

²⁴ David Tasma was not actually the first patient in St Christopher’s Hospice. He had died long before its opening. But when Cicely Saunders told the story of its foundation, because the idea of a hospice, emerged out of their conversations, she imagined him to be the first patient, and an engraved window, to his honour is at its entrance. In fact, there are three Polish gentlemen who inspired Cicely: David Tasma, Antoni Michniewicz, and Marian Bohusz-Szyszko.

David gave me the idea. I was interested in the dying before I started visiting him in 1948. It partly shows why I made such a quick contact with him in the ward. And so he gave me the three basic principles: the openness to challenges of the window; the mind matched with heart, science, and spirit; and the freedom of the spirit is him making his own journey. They’re basic principles which have lasted. Antoni gave me the head of steam to do it, because there’s a real creativity in bereavement (Clark, 2018, 287),

Later in life Cicely married Marian, and his artworks, such as the trytych in the chapel, for many years supported its strong Christian ethos (Clark, 2018, 293).

fundraising activities²⁵. Saunders's vision was a reaction to doctors 'deserting' their dying patients (Clark, 2018, 75):

Dying from malignant disease was synonymous with pain, but there was a pervasive hesitancy about the use of morphine, with widespread fear of addiction and unwelcome side effects. Likewise, the wider symptoms of cancer such as breathlessness, weight loss, oedema, and fistulae were poorly controlled and frequently caused great distress to patients, their families, and the professionals who looked after them. Capping it all was widespread public silence about the disease that prevented its name from being spoken and which led to concealment, guilt, and secrecy (Clark, 2018, 82).

St Christopher's opened in 1967, with 'Brompton cocktail'—a mix of morphine, gin and honey—at the heart of pain relief. But integral to Saunders contribution to thinking about the place of spirituality in palliative care is her concept of 'total pain': an all-encompassing understanding of suffering embracing the physical, psychological, social, and spiritual concerns of a person that come together in end of life care:

Well I knew from what patients were saying that this wasn't just a physical problem and I knew from my previous nursing and social work that anxiety and depression were major components. I was certainly alert to the fact that family problems were difficult, very often adding to distress and I also felt that a search for feeling that they were wanted and still important people was a spiritual pain and so, out of what one patient said, very neatly describing her pain to me, developed the idea of 'total pain' with those four components. And that seemed to me to be a structure that, although it was a whole package as far as the patient is concerned, it was almost an internal checklist for you when you were listening to them to spot the main problems of their suffering (Clark, 2018, 79).

The concept of total pain, which takes a serious account of its spiritual dimensions, has been carried forward by those influenced by Saunders. An important example of this is found in the work of Balfour Mount, the progenitor of palliative medicine in Canada (Kearney and Mount, 2000). Mount argued that

²⁵ 'A window provided Cicely with an image to take her forward, an offer to accept and a vision to fulfil. The window brings light into the building. At night, the light shines out from it. The window can also be an opportunity. It provides air and ventilation. It is the meeting place of the inner and the outer, the private and the public. 'Window' comes from the Middle English *vindauga*, meaning literally 'eye of the wind'. The window frames something, as in a painting. Yet, it also reveals an open-ness to the wider world outside (Clark, 2018, 59).

to relieve spiritual pain requires an awareness of four dimensions of care: a relational dimension (establish contact, value the therapeutic relationship, respect the patient's otherness); a physical dimension (control symptoms effectively); a psychological dimension (take a biography; identify sources of meaning; create meaning framework for patient and for family; redefine hope, examine fears / the unknown; strive for reconciliation) and a spiritual dimension (celebrate the transcendent). For Mount, this 'celebration of the transcendent' is a 'healing connection', an experience of integrity and wholeness that comes from a connection 'with anything larger or more enduring than the person' (2007, 386). This gives a timeless dimension to life, even in the face of death, and resonates with Saunderson's lochside experience mentioned above. Mount's descriptions of transcendence follow the earlier work of Eric Cassell, who says the transcendent dimension is:

a life of the spirit, however expressed or known ...Transcendence is probably the most powerful way in which one is restored to wholeness after an injury to personhood. When experienced, transcendence locates the person in a far larger landscape. The sufferer is not isolated by pain but is brought closer to a transpersonal source of meaning and to the human community that shares that meaning. Such an experience need not involve religion in any formal sense; however, in its transpersonal dimension it is deeply spiritual (Cassell, 1982, 644).

The implications of this for spiritual care are to re-align the priority of meaning-making and healing connections. Meaning-making currently takes priority in the delivery of spiritual care, bereavement care and palliative care (see Burke and Neimeyer, 2012), evident in Susan Folkman's (1997) work on coping, as well as Carlo Leget's (2017) art of living and art of dying, further discussed below. However, if Mount, Boston and Cohen (2007), are correct, meaning which enhances quality of life and spiritual well-being is actually

a by-product of a related experience, a sense of connectedness. It was not meaning, per se, that brought the persons alive but the underlying experience of being part of something greater and more enduring than the self. In each instance, movement towards a sense of integrity and wholeness was associated with an experience of healing connections' (Mount, Boston and Cohen, 2007, 383).

They argue that healing connections at any of the four levels—to self, others, the phenomenal world, or to the Other—are what transcends suffering, overcomes

death anxiety and restores integrity and wholeness. This realignment of meaning-making and healing connections has significant impact on and rebalances the delivery of spiritual care, which now incorporates the following:

- Identify sources of meaning, both positive and negative.
- Explore source of existential anguish and healing connections, before and during illness.
- Minimize uncertainty.
- Identify and support expression of fears.
- Identify ego defense mechanisms that increase distancing, denial, closure to others, blocks in opening to the hard reality at hand.
- Promote a calming, pleasant atmosphere characterized by efficiency, accompaniment, and caring, thus promoting a sense of security.
- Promote strategies that may bring the person into the present moment: meditation, music, discussion of their cherished interests, domains of creativity; consider art and music therapy (see Mount, et al 2007, 386).

I now turn to more recent contributions to thinking on the spiritual nature of end of life care and consider the inspiration behind the work of Sheila Cassidy and Michael Kearney. In her profound work, *Sharing the Darkness* (1988), Cassidy sets out to explore the spirituality of caring. Her understanding and identification with those in pain develops out of her personal experiences; of wrestling with faith and enduring fear and torture as a prisoner in a concentration camp in Chile during the military regime of Augusto Pinochet in 1975; of being the medical director of St Luke's Hospice, Plymouth, from 1982; and of facing her own bouts of depression (1998, 77-85). She writes from 'the eye of the storm' (1998, 2). Conscious that the dying 'are alone and they are afraid', hers is

the spirituality of the companion, of the friend who walks alongside, helping, sharing and sometimes just sitting empty-handed, when he would rather run away. It is a spirituality of presence, of being alongside, watchful, available, of being there.' ... (and a companion) must enter into their darkness, go with them at least part way along their lonely and frightening road. This is the meaning of compassion (1998, 4-5).

Cassidy adopts the metaphor of a 'giant wave', in danger of overwhelming carers, and 'the sea', as an image of the presence of God, to convey her conviction that sharing the darkness means having to 'learn to breathe under water' (1998, 7-9),

even without answers. 'I am quite content to remain in a state of unknowing (1998, 72).

Cassidy's spirituality of caring values the deep, extravagant and life-changing power of loving. This struck her during an Easter ritual at l'Arche, a community of cognitively-disabled people and their helpers. During the service Michel, 'the simpleton,' washed his carer's feet (1998, 47-48). This image connects with Cassidy's personal mantra, which is a Sidney Carter lyric, 'No revolution will come in time to alter this man's life except the one surprise of being loved' (1998, 24). Love brings healing connection. Her most powerful image of connection is 'patient and carer stripped of their resources, present to each other, naked and empty handed, as two human beings (1998, 63). This love is demanding and resides in vulnerability and woundedness. In her own life, she traces her wounds back to her time in prison, and her fears of dying, and her sense of being utterly alone: 'My strongest memory is of fear, the fear of pain, of helplessness, of brutality, of humiliation, of death' (1998, 87) and the experience in prison of 'what it is like to be unutterably alone and afraid of pain and death (1998, 89).

Cassidy's faith and spirituality runs throughout her reflections. Her vocation is to respond to the prophet Micah's call to act justly (be professional), love tenderly (be compassionate) and walk humbly (surrender before God in the face of mystery and suffering) (1998, 1). And it is her faith in the end that sustains her. A faith that

right at the heart of the mystery of suffering is the grace that sustains us all, carers and cared for alike. It comes as freely and as surely as the sunrise piercing the blackness of grief and despair restoring once again the hope of things unseen. (1998, 164).

This stance of keeping hold of faith in times of darkness is similar to the mystical tradition in Christianity. Peter King (1996) describes 'dark night spirituality' as a turn to the contemplative traditions of St John of the Cross, Thomas Merton, Dietrich Bonhoeffer, and Etty Hillesum, and regards 'dark night spirituality' as a new way of seeing and a new way of doing theology, in which the dark night is to be regarded as a '*kairos*' moment, an opportunity to experience God in a profound way. So for Cassidy spiritual care is a ministry of presence, which at times is impotent, mute and shares the darkness. To 'wash the feet that will not walk

tomorrow' (1998, 51). It is in doing so that one discerns the interface of depth and silence.

Michael Kearney comes from the generation of doctors trained by Cicely Saunders at St Christopher's Hospice, London. In *Mortally Wounded* (1996) he shares stories of soul pain, death and healing which have come from his experience of working at the coalface of end of life care. Kearney employs Greek mythology, particularly the story of the wounded healer Chiron whose descent into the depths brought healing.²⁶ He creatively weaves this together with Carl Jung's depth psychology. Depth psychology contrasts the surface mind, which refers to the rational and literal aspects of the mind—the ego, with the deep mind—often associated with the unconscious. Counter-intuitively, it is the deep mind which is the location of great inner resources. Soul pain occurs when a person is 'cut off from the healing power of their own inner depths'. For Kearney, the task of spiritual care, of facing the trauma of mortality, is to reconnect the surface with the depth. The 'soul is the living connection between the surface and the unfathomable and meaning-rich depths of who we are' (Kearney, 1996, 59). Kearney integrates into his work a series of poems which represent the insights that poets offer when engaging with depth and silences. These include 'Healing' by D.H. Lawrence, 'Moving Forward' and 'The Swan' by Rainer Maria Rilke, 'This to do' by R.S. Thomas, and 'Oceans' by Juan Ramon Jiminez.

Both these clinicians connect depth, soul, silences and intimacy. They advocate a spirituality of caring which does not hide behind any mask, and a way of caring that is 'aware of the depths of a pain that somehow has its healing within itself' (Saunders, in Kearney, 1996, 12). Such voices inspire a new generation of clinicians who live and work at spiritual depth and with spiritual artistry.

²⁶ Chiron, the mythological wounded healer, was born a centaur, half-immortal and half-human. Abandoned and rejected at birth he was adopted by Apollo and in time became a wise teacher. However, he was struck by a poisoned arrow leading to an agonising and unbearable wound. He searched fruitlessly for a cure. And although he could not heal himself he eased the suffering of others. Thus, he became known as the wounded healer. Then offered a way to be freed from his wound, he descended into the underworld, remaining in the darkness of death. Zeus, recognising his sacrifice, restores his immortality and he becomes a constellation of stars.

2.3 *Contemporary challenges in palliative care*

As I have shown, the contemporary hospice and palliative care movements enjoy a rich spiritual heritage and have inspired a spiritual vision which has been widely influential. It is an approach to healthcare that combines the best of medical knowledge with close attention to three other areas of holistic care: the psychosocio-spiritual. These core principles inform the World Health Organisation definition of palliative care, which has become a widely accepted reference point for work in this field:

Palliative care seeks to improve the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organisation, 2002).

This definition captures the holistic philosophy of palliative care and offers a valuable philosophical support for the integration of spiritual care in the palliative care 'quadrilateral' of the physical, psychological, social and spiritual (Cobb, 2001, 1). However, in practice the spiritual dimension is often regarded as the 'least explored and understood' aspect of provision (Cobb 2001, 1). This is an issue which assumes larger significance in relation to emerging critiques of contemporary understandings and practices of palliative care, all of which challenge the assumption that spiritual care is being well delivered in the palliative care context.

The first critique relates to normative understandings of what constitutes a good death in the hospice/palliative care context. It is argued that, in its extreme form, preconceived patterns may harmfully impose a template circumscribing the 'way of dying' on individuals. This claim is made by Lars Sandman in his important work *A Good Death* (2005). In this he argues that hospices function according to an overt ideological system which imposes a regime of 'good dying' upon others. As such they fail to respect an ethical demand to listen attentively to the voices of individuals who may hold alternative views or have different experiences of what the dying process entails. Sandman argues that any ideas of what constitutes a good death should, at best, be seen as alternatives which might inform decision-

making and are there to be discussed and debated. In each chapter of his work he systematically destabilises strongly held ideas that pervade hospice culture, including the convictions that death and dying are consistent with life and meaningful, and dignified. This may not be the case. Facing death in such a way requires both acquaintance with and awareness of death, acceptance of death, and self-control in dying. This is certainly not the case for many people. He also critiques the widely-held hospice wisdom that preparing to die entails engaging in rituals, enjoying the sense of having lived a completed life, completing a life review, and staging one's departure. However, people may choose alternatives to these processes or prefer to make no positive choices at all. It is also generally presumed that the environment of dying needs to be peaceful, public / private, and non-technological. This is not necessarily so. Many people are at home with a medicalised and technical approach to health and expect, indeed welcome, this in their journey towards death. Thus, resisting any imposition of a normative good dying, Sandman argues that the task of palliative care is to help people arrive at whatever a 'good' dying might mean to them:

palliative care should provide patients at the end of life with a good dying and a good death, but we might disagree about what this actually amounts to ... specific ideas on good dying and death should mainly function as alternatives in discussion and decision-making ... to the extent that palliative care has a goal it is essential that one is able to provide patients with help in arriving at what a good dying and death for them amounts to (Sandman, 2005, 158).

A second and related challenge is made by Fiona Randall and R.S. Downie (2006). They critique the assumption that spiritual care can be measured, quantified, delivered and integrated into healthcare competencies. The common rhetoric of palliative care, they argue, fails to match reality in this area. The challenge is to restore a balance between a dominant Hippocratic approach to palliative care, with the danger of paternalism and over complexifying interventions, and an Asklepiian approach, which emphasises a compassionate gaze and an attitude of 'you matter because you are you'.²⁷ Central to the authors' argument is the

²⁷ Randall and Downie identify two traditions in medical practice. Firstly, that of Hippocrates, the Greek physician born in 460 BCE who stresses that every disease, every human ailment, has a cause which can be discovered and is curable. This is the foundation of Western medical science. The second is the Asklepiian tradition. Asklepius is the son of the god Apollo, and people came to his temple, aware that their illness was incurable, yet still seeking relief from suffering, through two attitudes: trust in the attention of the physician and acceptance of their lot. (Randall and Downie, 2006, 201).

conviction that spiritual care resists the compression into procedure. It leans towards relational care. And a relational approach creates space where, for a slice of time, life is not about death, abyss or darkness, but the space and silences are filled with the unconditional—grace and gift and presence. This understanding of spiritual care resists the momentum towards intrusive ‘spiritual screening’ and spiritual assessment questionnaires that characterize the reliance on evidence-based interventions and reaches back towards the human work of listening, attention, relationship, and sculpting safe spaces to hold the dying person.

Such a relational slant in spiritual care in palliative care is championed by Bruce Rumbold (2012). He adopts Emmanuel Lartey’s (2012) relational model of spiritual care, which rises above the limits of religious frameworks. All spiritual care, he says, takes place within genuine human encounters. Such encounters may be with places and things (spatial); with self (intra-personal); with others (inter-personal); among people (corporate); and with transcendence (‘God’, ‘Something There’). The therapeutic task is to build spiritual resilience through any, or all, of these relationships. Such relational care delights in diversity and difference. The uniqueness and complexity of each encounter invites an artistic approach that stresses creativity, imagination, and wisdom. Relational care which focuses on the human necessitates going with the flow, living with uncertainty, and moving into the unknown.

The third challenge is found within the lively debate revolving around re-balancing ‘the art and science’ of palliative/spiritual care, as discussed in the opening chapter. As I will argue below, there is a tendency to use reductive concepts of spirituality when working from a scientific, or empirical, approach to the delivery of spiritual care. A positive way forward to embrace the art and science of spiritual care is found in Monica Renz’s important book *Hope and Grace* (2016), which locates the dying in liminal spaces between the immediacy of existential issues and hopeful transcendence; between this present world and what may lie hidden—beneath, beyond or above. Here Renz argues that the prevalent ‘spiritual-needs’ approach, to either enhance spiritual wellbeing or alleviate spiritual distress, needs to be balanced by a ‘spirituality-based’ approach to death. In spirituality-based approaches, the dying often experience ‘the inconceivable’ which ‘eludes the categories of human understanding’ (2016, 23-24). Even in the nadir of

suffering, a hopeful orientation opens individuals to moments of grace and transcendence.

Renz understands 'grace' and 'mercy' to be words that refer above all to an experience or encounter with God, the Other or the divine. Grace is not, following Pelagius, something that can be achieved, but only, following Augustine, received as a gift. What this means for Renz is that spiritual care is about 'finding an inner openness' for God to break in. Time and again, even patients who have suffered for a long time, report an indescribable sense of happiness, serenity, peace, or spirit when having such experiences. My own reading of people such as Dennis Potter and Clive James, and my observation of patients who are entranced by ordinary moments of feeling the fresh breeze across their face, or when watching a cabbage white butterfly, support Renz's convictions. Such experiences are, however, transitory and fragile and cannot be prescribed for people without becoming the death-denying 'illusion' discussed previously.

It is beyond the scope of this thesis to engage at depth with these challenges. However, such critiques are hugely significant and require serious consideration. A pattern which informs this research is emerging: a good dying, it appears, cannot be enforced and no person's experience will fully match some ideal form. Death, rather, invites attentive listening to the specific voices of individuals, located in a community, influenced by cultural mores. I am arguing for a critical and imaginative approach to palliative care. This is necessary, first, to ensure that palliative care remains person-centred, and second in order to radically renew the spiritual dimension of palliative care.

2.4 Inner space as the locus of narrative

I have discussed how the palliative care movement emphasised that spiritual care was an integral part of its holistic vision. I have also shown that, in the contemporary context, aspects of this understanding are being challenged by current practice and thinking. In this section I turn to the contemporary work of Carlo Leget (2017), which offers many important insights into spiritual care in the palliative context. A crucial aspect of his thinking relates to the concept of 'inner space'. Having described the emergence, understanding, and the attraction of

‘inner space’, I note the various roads to ‘inner space’ identified by Leget, of which silence is one. Then I describe how he uses ‘inner space’ to revitalise the ancient art of *ars moriendi* and to develop a contemporary *ars moriendi* model, which fits the current spiritual landscape. ‘Inner space’ here is a place of narrative and story. As such it facilitates depth, profundity and enjoys undoubted strengths and uses. However, it is this move, which consolidates inner space as a ‘communication tool’ and the locus of meaning-making, which stirs reservations. Not about its contribution to a conversational approach to spiritual care, which in its time and place, is well grounded. Rather, my concern is the way meaning-making is becoming the priority in the delivery of spiritual care in end of life care. I am concerned about the capacity of patients in the later stages of the dying trajectory to engage in such intense conversations. I also wonder whether meaning-making needs to be re-aligned with healing connections. Following some personal insights, and by drawing on Paul Kalanithi’s (2016) *When Breath Becomes Air*, I consider whether ‘inner space’ and ‘deep silences’, rather than being the locus of narrative and story, are better seen as the locus of healing connections.

2.4.1 Inner space

Carlo Leget (2017) first conceived of the notion of ‘inner space’ while conducting research into euthanasia in a nursing home in the Netherlands. He noticed how a physician created space in a conversation to allow an elderly resident to explore her concerns about euthanasia, a term which literally means a ‘good death’. Safe space involved an ethos of trust, reflected in the physician’s compassionate gaze, and slowed time down to allow an attention to minute details that enabled the elderly woman to open up and voice her own perspectives. This vision led him to consider how important it is for dying people to come to a reflexive and relational understanding of their position, drawing upon the love, care and wisdom of others. This event led Leget to revisit his former studies into the theology of Aquinas. He sought to build a bridge between this and his current work in end of life care in the Netherlands, where he considered the process of dying had evolved into a ‘secular dogmatism’²⁸ From Aquinas’s awareness of the limits of human rationality

²⁸ By this he means that proponents of the right to assisted dying, in an enlightened fashion, excluded any reference to religion or spirituality in their debates.

and his openness to other voices, Leget constructed his understanding of an ‘inner space’:

a metaphor for a state of mind in which one is able to experience a number of thoughts, emotions, impulses, feelings and so on, without identifying with them or being swept away by them. It is a quality that has a great impact on the way one experiences the world (2017, 49).

Various characteristics of ‘inner space’ attracted Leget to employing this metaphor in spiritual care. It is simple and familiar; it is present in the mind, for example in wonder or intellectual discovery, and in the body, for example in roaring laughter and intense crying. It is not the same as inner peace because it respects ‘the inner polyphony of every human being without silencing one voice or the other’ (2017, 63). It refers to an inner process, ‘like the process of breathing in and breathing out, rather than a fixed state of being. It sits at the crossroads of disciplines, such as psychology, spirituality, ethics, and can be embraced by most. And it is connected to spiritual traditions. Leget then describes six roads to ‘inner space’.

1. Humour, the body, emotions, virtues, spiritual traditions and silence (2017, 64-78). Whereas people search for meaning and structure to make sense of life, and stories create interpretive patterns and orientations, humour—whether black, sceptical, or cynical—works at a different level, enters from the left field, and opens new horizons or interpretations of situations. Appropriate use of humour also creates playful spaces within a community.
2. Quoting Merleau-Ponty’s maxim ‘we have a body and we are our body’, Leget argues ‘the body is the medium between the visible, material outer world and the invisible, emotional, mental, intellectual and spiritual world’ (2017, 67). Therefore, physical exercises such as mindfulness, or Tai Chi, can connect the outer to ‘inner space’. And ‘the calmness of our breathing, the sound of our voice, the look in our eyes, the quality of our touch all have impact on the inner space of ourselves, our colleagues and our patients (2017, 68).
3. Emotions too reveal a lot about what lies within, what we endure, what we hope for, are shamed by, and what we long for. For example, fear reduces our inner space as we feel small, threatened and vulnerable, while love enlarges

our inner space, 'as if we could conquer the world ... to love someone is to share one's inner space with someone else' (2017, 70-71).

4. Inner space allows us to develop virtues, for example courage, or wisdom, which inform choices and behaviour. Leget's argument here is more complex. Starting with Plato's idea that 'a morally good life is connected with the four cardinal virtues of justice, prudence, temperance and fortitude', then that Aristotle made virtue 'the cornerstone of his ethics', allow Leget to identify inner space with the virtue of prudence. Prudence and inner space enhances 'the ability to make the right decision in whatever specific situation' (2017, 73-74). Prudence directs the other virtues and is integrated in the virtuous person. Leget further argues that inner space and virtue facilitate the process and the art of spiritual care, by allowing for the flexibility and imagination required to handle complex situations.
5. Spiritual traditions such as prayer and mindfulness connect the visible to the invisible. They invite people to see through the visible to the invisible. 'Both in the mystical traditions' says Leget, 'and in the works of the great theologians there is a deep awareness that God is incomprehensible and beyond the power of human intellect' (2017, 75).
6. Finally, silence connects us with 'our deepest thoughts and feelings' (2017, 77). At the heart of Leget's approach to the art of living and the art of dying is the high value he places on silence. He describes the many ways in which silence comes into life: there are background silences, such as the seasonal silences of frosty mornings, the landscape silences of ocean or mountain, and the diurnal silences of dawn, dusk and the midnight hour. There are creative silences that hold and shape, such as within musical compositions, dramatic performance, and narrative. There are intentional silences which heighten tension and bring focus in sacred and secular rituals such as during Remembrance Day. Relational silences are either easy and comfortable, such as when people know each other so well that nothing needs to be said to fill the void. Or else silence may be threatening and unwanted, such as before a storm, a scream, or when someone doesn't know what to say. And there are the forced silences of shame or trauma. The greatest literature, poetry, philosophy, music and spiritual tradition is born in silence (see 2017, 77).

The critical turn in Leget's argument comes as he works out whether inner space is a 'spiritual attitude' or a 'communication technique' (2017, 49). As a spiritual attitude, its 'a way of connecting with one's inner life and discovering the many voices that inhabit us'. As a communication technique, its 'a way of emptying oneself in order to be able to reflect the expression of one's conversational partner as well as possible (2017, 49).

2.4.2 *Inner space as the locus of story and narrative*

This section begins by examining the way inner space functions in Leget's *ars moriendi* model, detailing the strength of inner space as a locus of story and narrative, before ending by suggesting that inner space is better first understood as a locus of healing connection. Leget's first premise is that death anxiety is natural, and that people overcome this by finding meaning (2017, 21-36). His second premise is that the rational control of death is an illusion, and the art of dying needs to 'be open to tensions and ambivalences than trying to resolve them or rationalize them away' (2017, 36). He addresses this challenge by revitalising the ancient spiritual practice of *ars moriendi*, and reworking it for our contemporary context (see figure 5). For example, the original model is based on the five choices which were considered to constitute a 'good dying' in the medieval age. Couched in religious language, these choices were: loss of faith or faith; despair or hope; impatience or patience; complacency or humility; avarice or love. Today, argues Leget, these are replaced by existential/spiritual prompts: 'Who am I?', 'How do I deal with suffering?', 'How can I say goodbye?', 'How do I look back on my life?', and 'What can I hope for?'. A third concern that Leget identifies in palliative care is the danger of imposing a 'good dying' on patients. The structural frame, he argues, of palliative care is constructed by carers, marginalises the spiritual and is based on life-limiting illness. Alternatively, the inner space within the *ars moriendi* model allows decisions to be shaped by patients who are apprentices. Spiritual care returns to the centre, and the process is seen as much as an art of living, *ars vivendi*, as a way to die (see 2017, 38).

Critically, the innovation in *ars moriendi* is the way it uses the concept of inner space as a locus of story and narrative: meaning-making conversations.

As a mode of spiritual attentiveness the cultivation of inner space can be seen as a way of connecting with one's inner life and discovering the many inner voices that inhabit us. The self is basically polyphonic and being open to this polyphony can be a great gift to oneself in extreme significant. It can also be a gift to other people when it is used in communication (2017, 49).

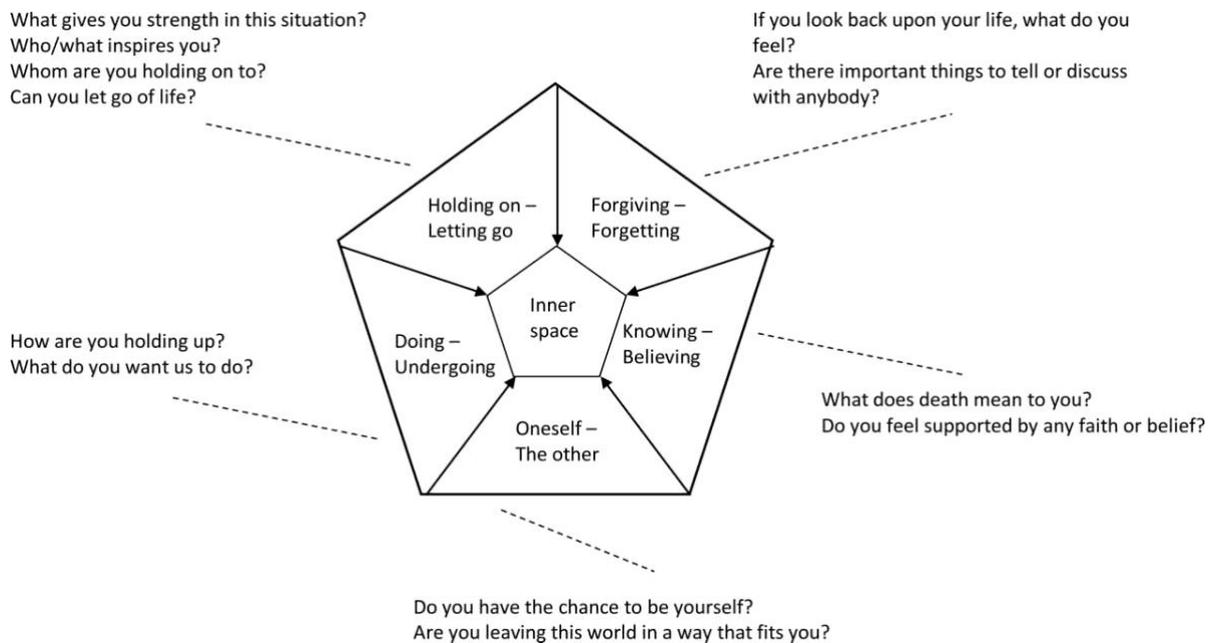


Figure 5. A visual representation of the *ars moriendi* model

(Source Leget, 2017, 57).

The combination of inner space and creative prompts allows exploration of spiritual depths and complexities, that are often unaddressed in end of life care. For example, in describing the way inner space facilitates exploration of the prompt 'Who am I?', Leget notes the tendency in palliative care to value autonomy and individual freedom. As such, dying is in danger of being regarded as a private matter. However, referring to three meanings of dignity—the ontological, in which dignity is 'inherent to being born as a human being'; the relational, in which dignity is expressed by 'the way people treat each other; and the subjective category of dignity referring to the 'self-esteem people experience'—he argues that the interpersonal category is fundamental. This indeed is the basis of Harvey Chochinov's (2012) Dignity Therapy, in which listening to and reframing a life within a social context serves to bestow a healing social dignity. Dignity is discovered in the relational space between self and other. Therefore, the *ars moriendi* model challenges the strong individualism which pervades end of life

care, and stresses that individuals are social beings. The strength of the model is the way inner space allows for the tensions and ambiguities in these existential and spiritual crises.

Leget also illustrates each prompt from his own ‘inner space’, his ‘insider’ perspective as a practicing Roman Catholic. Here a relational understanding of the self inevitably introduces a third dimension, the relationship with God, who although being an ‘incomprehensible mystery’, beyond any thought or articulation, is ‘a personal mystery of love’ (2017, 175). God is not an abstract or faceless power but a personal relational God: ‘My life story is a unique version of the universal story of every human being who discovers himself to be in a loving relationship with God’ (2017, 176).

As a communication tool, the ‘inner space’ in *ars moriendi* allows professionals to empty themselves in order to listen and reflect their conversation partner. This communicative process matches the tenor of Atul Gawande’s argument in *Being Mortal* (2014), which invites physicians to have courageous conversations in end of life care, and to ensure that the patient’s voice is heard. Similarly, it reflects the Joint Improvement Team’s intention for outcome recording (Cook and Miller, 2012),²⁹ in which therapeutic conversations are understood as facilitating a person in talking about their lives, covering the areas they want in their chosen order. Here the processes—being listened to, having a say, being treated with respect, being responded to reliably—all work together to enhance quality of life and promote positive outcomes. And as a communication skill, it aligns with a spiritual care competency (NHS Education for Scotland, 2008). Inner space makes demands on spiritual care specialists to become more aware of the grit and gifts they bring to a conversation.

Leget also identifies five immediate uses of the model, and thus the value of developing ‘inner space’ in health and social care: as a mirror; as a tool for conversations; to identify bias and preferences, to support clinical

²⁹ The Joint Improvement Team (JIT) is a strategic improvement partnership between the Scottish Government, NHS Scotland, CoSLA, the Third Sector, the Independent Sector and the Housing Sector, whose focus is on creativity, collaboration and continuous improvement in health and social care (see Improvement Hub, www.ihub.scot).

documentation; and finally to facilitate education and training events (see 2017, 201-205). Each application enhances the delivery of spiritual care.

But the critical issue, and what Leget fails to highlight, is what happens when conversations stutter and the inner space fails to open up new avenues of insight or meaning. It is here that its limitations emerge. Leget is aware of the limits of meaning-making, and is aware of an alternative relational approach to spiritual care, where dignity-conserving care is relational, or where attachment theory, in models of grief, offer insights to the prompt, 'How can I say goodbye?' (2017, 91-95, 131-134). Similarly, in his religious exemplars, he emphasises the value of connection with God. Hope is a balance between believing and knowing. Believing in Hebrew, he says, takes on a sense of trust, whereas in Greek believing is seen in relation to uncertain knowledge. The tension is felt. To trust God, we have to know who we should trust. Leget is safe in the hands of God. His inner space exudes a hopeful imagination focused on God. This alters his understandings of death, which is not an ending but a new beginning; does not destroy bonds, but connects with the community of saints; and is not a door to the great unknown, but a coming home to God (see 2017, 173-189). However, these insights are undervalued. Rather, the model relies on an ability to articulate patterns, stories and metaphors of meaning-making.

I doubt the efficacy of Leget's model when individuals lack a language of the spirit, when they are unable to articulate their deepest feelings or communicate them to others. Also, the closer to death one comes, towards the end of the dying trajectory, patients often have less energy, or capacity for rigorous self-analysis, or for the re-negotiation of belief systems (see Murray et al, 2004, 2007). The closer to the edge people find themselves, the greater the resistance to opening the Pandora's Box of their hopes and beliefs. In such times they choose to connect, to breathe, to disengage and to surrender. A longing for knowing is replaced by a desire to be.

The recovery of inner space and silences as a road to healing connections, and as a priority in spiritual care, is supported by key insights and convictions that shape the way I deliver spiritual care. Being a member of the hospice community for over a decade, I align myself with the original voices of visionaries such as Saunders, Boston, Cassidy, and Kearney. They all emphasise relational care, and

how ‘inner space’ leads to healing connections. I notice what is missed, skewed or forgotten in the development of Saunders’s concept of total pain. She describes the spiritual aspect of total pain: “I also felt that a search for feeling that they were wanted and still important people was a spiritual pain” (Clark, 2018, 79). This places healing connections over meaning-making. Second, clinically, my memory of Dr John Bass, my medical director, cautioning ‘don’t open Pandora’s box unless you can shut the lid!’, which implies that being present, being committed to accompaniment, and being comfortable with just witnessing all take precedence over intrusions. Philosophically, I am conscious of the way Randall and Downie resist energy-sapping and intrusive spiritual assessments and interventions. Strategically, I return often to Mount’s discovery of healing connections.

A profound example of someone discovering new depths of ‘inner space’ is found in Paul Kalanithi’s (2016) evocative text *When Breath Becomes Air*, with the title alluding to Baron Brooke Fulke Greville’s poem:

You seek what life is in death,
Now find it air that once was breath.
New names unknown, old names gone:
Till time end bodies, but souls none.
Reader! Then make time, while you be,
But steps to your eternity.

Kalanithi’s journey is from science to literature and the humanities, from wrestling with meaning to healing connection. As a neurosurgeon, he was grounded in science, but had a background in literature. He found in literature an exploration of what makes life worth living in the face of death, which illustrate how the dying, as people facing the abyss, are taken into depths, inner space and silence. Kalanithi argues that the limitations of science are as follows:

yet the paradox is that scientific methodology is the product of human hands and thus cannot reach some permanent truth. We build scientific theories to organize and manipulate the world, to reduce phenomena into manageable units. Science is based on reproducibility and manufactured objectivity. As strong as that makes its ability to generate claims about matter and energy, it makes scientific knowledge inapplicable to the existential, visceral nature of human life, which is unique and subjective and unpredictable. 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 most central aspects of human life: hope, fear, love, hate, beauty, envy, honor, weakness, striving, suffering, virtue (2016, 169-170),

He then outlines two different angles to dying. The first, the turn to literature and meaning-making; the second, the turn to healing connections. Working with many patients and families facing their death, he witnessed their inner quest to make sense of what was happening, often seeking more than atheism. Inspired by Nobel Prize winning biologist Jacques Monod, he writes: 'The ancient covenant is in pieces; man at last knows that he is alone in the unfeeling immensity of the universe, out of which he emerged only by chance' (2016, 170). Kalanithi saw his professional role as follows:

the physician's duty is not to stave off death or return patients to their old lives, but to take into our arms a patient and family whose lives have disintegrated and work until they stand back up and face, and make sense of, their own existence (2016, 166).

There must be a way, I thought, that the language of life as experienced—of passion, of hunger, of love—bore some relationship, however convoluted, to the language of neurons, digestive tracts and heartbeats (2016, 39).

The book shows his leaning towards literature, especially as he faced his own death,

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 the literature again: Solzhenitsyn's *Cancer Ward*, B.S. Johnson's *The Unfortunates*, Tolstoy's *Ivan Ilyich*, Nagel's *Mind and Cosmos*, Woolf, Kafka, Montaigne, Frost, Greville, memoirs of cancer patients—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 (2016, 148).

However, literature alone offered no ultimate relief to Kalanithi. What he discovered is the need for intimacy, “‘I need you,’ I whispered’ to his wife Lucy (2016, 15). Meaning is found in human connections:

Meaning, while a slippery concept, seemed inextricable from human relationships’ (2016, 31).

And his ultimate healing, when he held his new born daughter, Cady, on July 4th, at 2.11 a.m. comes from holding her. The sacred moment is the intimacy. Time stands still and the impact on him unimaginable, as expressed in his words to her:

When you come to one of the many moments in life when 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, a joy unknown to me in all my prior years, a joy that does not hunger for more but rests satisfied. In this time, right now, that is an enormous thing (2016, 199)

Kalanithi’s lived experience of dying offers illuminating insights into Mount, Boston, and Cohen’s (2007) concept of ‘healing connections’, which I described earlier. He is on a dying trajectory³⁰ and a spiritual journey which takes him from a position of denial of death, ‘we’d both suspected, but refused to believe, or even discuss, that a cancer was growing inside me’ (2016, 4), to a position of striving to find the best language to express his reality. And what he found was the limitations of science, and although at one moment, ‘it was literature that brought me back to life during this time (2016, 149), what he appreciates is the shift from head to heart, from mind to body through the course of his illness. Indeed, it’s as if closer to death, he can no longer turn to science or literature as pillars of wisdom. ‘I’ve been reading science and literature trying to find the right perspective, but I haven’t found it (2016, 190). The time eventually comes when he allows his doctor, Emma to be ‘captain of the ship’ (2016, 191), and he finds comfort in connections. In a sense, he is recollecting spiritual experiences, of belonging and connection, such as climbing Mount Tallac in his youth,

³⁰ Scott Murray (2004, 2007) and his colleagues, working in primary palliative care in Edinburgh, offer key insights into the impact of ‘dying trajectories’, for different illnesses, such as cancer and heart failure, on the delivery of spiritual care. Spiritual and existential crises are heightened at four critical stages of the dying trajectory: diagnosis, recurrence, transition of palliation, ‘care’ rather than ‘cure’ and entering the terminal phase of dying.

Craning your head back, you could see the day's blue darken halfway across the sky, and to the west, the night remained yet unconquered- pitch-black, stars in full glimmer, the full moon still pinned in the sky. To the east, the full light of day beamed toward you; to the west, night reigned with no hint of surrender. No philosopher can explain the sublime better than this, standing between day and night. It was as if this were the moment God said "Let there be light!" You could not help but feel your specklike existence against the immensity of the mountain, the earth, the universe, and yet still feel your own two feet on the talus, reaffirming your presence amid the grandeur (2016, 34).

What Kalanithi's story conveys is how over the course of an illness different priorities may take place. At an early stage, inner space may exquisitely facilitate meaning-making, along the lines of Leget's *ars moriendi* model. During early stages of the dying trajectory, he has the energy and the creativity to wrestle with existential and spiritual conundrums. But closer to death, no longer able to negotiate meaning there comes a shift towards re-connecting. Head to heart, along the lines described by Mount et al (2007). Kalanithi lives out their research. His ability to cope, now, and find meaning, now, is associated with his capacity to form bonds of connection. For example, after a time of atheism in his life, he rediscovers faith,

Yet I returned to the central values of Christianity- sacrifice, redemption, forgiveness - because I found them so compelling (2016, 171).

And his memoir closes with the so evident revitalization, sense of security, and equanimity that accompanied the healing connections of being with Lucy as she gave birth to his daughter, and then being able to hold her.

Kalanithi's lived experience of dying illustrates some of the changes that can happen along the course of a dying trajectory. My intention, in arguing for a change of tack from understanding 'inner space' solely as a locus of meaning-making, to understanding 'inner space' as the locus of healing connections, is not to undermine Leget's model but rather to re-locate it. And to re-connect specialist palliative care with the original vision of hospice care, whose focus is towards the end of life. Priorities are changing, as David Clark so eloquently describes.

Palliative care had thus become even more expansive in its goals and had sought to move its influence ‘upstream’ to earlier stages in the trajectory of illness (Clark, 2018, 270).

It could then be argued that delivering palliative care to achieve better symptom control, improve communication, and produce greater alignment with patient and family wishes had become primary goals. Only when these had been realised was it appropriate to engage with questions of meaning, mortality, and the reality of death. This seemed a departure from Cicely’s model of ‘total pain’ which had been widely adopted by hospices and in which a strong focus was on finding personal and/or religious closure at the end of life, and where a wider social goal of making society better was also being pursued in addition to providing care to patients and families (Clark, 2018, 271).

In a way, it was others who worried more than her about the putative processes, particularly in relation to spiritual care (Clark, 2018, 271).

And this shift upstream is nudging spiritual care and the moment of death, from the centre to the margins.

Summary and bridge

These opening chapters convey the value of spiritual artistry and its ability to embrace the mystery of death: its depths, ambiguities, and uncertainties. The art of spiritual care, in contrast to the science, lives with paradoxes, with what endures and that which cannot be solved (see Vermandere, 2014). In this chapter I introduced the concept of inner space as the locus of spiritual artistry. Inner space ensures ‘a good dying’. For example, respecting a person’s inner space conserves dignity; creating inner space safeguards a therapeutic relationship; forging inner spaces rekindles an artistic slant to care, opening up inner space allows people to wrestle with the voices that sculpt meaning, and filling inner space imaginatively fosters hope. While Leget’s *ars moriendi* model has helped me to clarify and extend my thinking, particularly in the realm of narrative, story and meaning-making, I believe that it is necessary to go further than current

scholarship has travelled, if we are to offer the most honest and effective care possible to those we walk beside closer to death. Leget's model, with its emphasis on conversation, inevitably carries a reliance on cognition, language, narrative and negotiated meanings. While there are times and places in the dying trajectory when this approach is efficacious, the *ars moriendi* model is exposed in the context of suffering, trauma, uncertainty, complexity and chaos, and the times when words fail, and when deep silences occur. I have argued for a change of tack from understanding 'inner space' solely as a locus of meaning-making, to understanding 'inner space' as the locus of healing connections. This move recovers aspects of the original vision of hospice pioneers which are often overlooked. It is this inner space and the silences that reside there, that I explore in the following chapters.

Chapter Three: Seeking Ways to Explore 'Deep Silence'



Figure 6: Stages on the way: Lindisfarne Crossing

The Lindisfarne crossing, on bare foot across the sands, is the final stage of The St Cuthbert's Way which winds its way from Melrose Abbey across the Cheviots and down onto the Northumbrian coast, to where the Cuddy ducks swim free. This image conveys a pilgrimage. The constant journeying, process and discovery in spiritual autoethnography is a pilgrimage in which there is no beginning nor end, perhaps just dropping away into the ocean of silence.

There is no narrative in silence. The interfolded, intertwining, intricate lines of life maze round and over and under and through. They do not end, they come back to the beginning and the end is the beginning is the end. The sea deep is the spume of the waves is the foam in the wind is the billow of the clouds is the rain on the crops is the stillness of the well is the spilled on the ground is flowing back into the depths of the sea.

The words drop away

Into the ocean

Of silence

-- Sara Maitland (2008b, 74)

Introduction

In the previous chapters I argued for the recovery of the arts of spiritual care and discussed how these arts were part of the founding vision of the hospice movement. Despite the huge influence this has had upon medical practice, I demonstrated how a reductive understanding of the role of spirituality in palliative care and normative concepts of 'the good death' were now raising serious challenges to the provision of good spiritual care at the end of life. I then went on to discuss Leget's concept of inner space as a locus for spiritual encounters with and within the dying person. Despite the value of Leget's work, I voiced my unease that his insistent focus upon narrative, communication, and meaning-making obscured the fact that at the end of life many people are unable to engage in these narrative means of ordering their lives. For such people, dying is a place of unresolved and disordered feelings and emotions. It is a site of chaos which defies attempts to express its reality in words. The pain, fear and confusion experienced do not, however, mean that death cannot be a place of sacred encounter. Its liminality may invite us to reach towards depth and to meet with transcendence. But these encounters, in my experience, are marked not by coherent narrative practices but by the profound encroachment of deep silence. This now becomes the focus of my research. What I am seeking to explore is both the brokenness and pain of deep silence and the sacred that emerges from within it.³¹ The question now becomes, 'How do I find a way to research deep silences?'

This chapter follows the following thread. First, starting from my research experiences, I convey the need for a new way to research deep silences. Then I

³¹ Mary Oliver's poem *The Journey*, (1992, 114) begins with these lines

One day you finally knew
What you had to do, and began,
Though the voices around you
Kept shouting
Their bad advice ...

And the silences capture the moment when in all dimensions of my life I longed for my own voice to express an encounter with a spiritual reality beyond the confines of any religion and grounded in the messyness of life; in the silences, a spiritual reality that connects with the depths of my being: a desire for meaning; a need to belong; a capacity to love, to live creatively with unknowing; for the courage to witness and listen to life as it is, to engage in creative play and delight in those fleeting moments when the spiritual breaks in' (IRS journal, June 19th 2018).

introduce arts-based research which has the potential to research such silences. The next section introduces and justifies autoethnography as my preferred choice of methodology. I engage with some important ethical concerns and evaluation criteria to ensure safety and trustworthiness of a project employing this approach. Finally, I make evident some developing links between this way of engaging with experience and the concerns of practical theology, to ensure that my way of being, matches my way of knowing and my way of enquiring.

3.1 A new way to research deep silences

My search for a way of a new way of researching acknowledges both a lack and an opportunity. The lack is that I have tried previous ways in the past to research spiritual care, but am conscious that these methodologies will not work for researching a heuristic concept that is deeply intuited, such as it the case with deep silences. The opportunity is that the challenge to recover an artistic mode of spiritual care may also entail developing an arts-based approach to my research project—and exciting developments are taking place in this field at the present time.

Over the last decade, my research journey has been constituted as a confluence of many streams. Each focus and each choice of methodology has taken me further in my understanding, and yet none have felt entirely satisfactory. The choices of methodology sometimes reflected my commitments and sometimes the more pragmatic concerns of the organisations and associations I have worked within. Early in my hospice career, wrestling with questions of role, identity and the interface with the wider team, triggered in part by being a participant in Mowat and Swinton's research *What Do Chaplains Do?* (2005).³² In 2007 I used semi-structured interviews, Burnard's thematic analysis and hermeneutic phenomenology to discern how the multidisciplinary team might deliver spiritual

³² Following the formal integration, in 2002, of a generic model of spiritual care in the Scottish Health Service, and the acceptance of chaplaincy as specialists in its delivery, Harriet Mowat and John Swinton addressed the lack of clarity over the role of chaplaincy in this new context. An eighteen-month study, employing interviews and case studies, led to their description of a 'process model' of spiritual care: 'The core task for chaplaincy involves *an active process of finding people who need spiritual care, identifying the nature of the need and responding to the need through theological reflection and the sharing of spiritual practices*' (Mowat and Swinton, 2005, 8).

care. The findings reflected my intuitive sense that spiritual care is a process of being and doing and that everyone in the team contributes to in one way or other—though, looking back, I lacked the language to articulate that conclusion clearly (Stirling, 2007). In 2011, conscious of the lack of empirical evidence to support the worth of both palliative and spiritual care,³³ I collaborated with the medical team to conduct a quantitative study examining the correlation between pain and spiritual distress. Although this research established a correlation between pain and spiritual well-being, the process unsettled me. I found myself questioning whether this quantitative methodology fitted the complexity of spiritual issues in end of life care. I also participated that year in an international survey of palliative care professionals to establish research priorities.³⁴ The purpose of this was to consolidate the position of spiritual care within clinical practice. In 2012, at a local level, I adopted an action research methodology to embed a 'person-centred care' project called '*This is Me*' within the hospice. In 2017, I co-authored 'From people to person-centred care', which examines the shift of chaplaincy into the community (Kennedy and Stirling, 2019, in press). These research projects all had positive aspects. This has not been a bad process and I do not regret the trajectory I have followed despite the limitations I can now identify. However, as my research journey has taken me into new spaces, I have become aware of the need for a new frame to explore 'deep silences'.

3.1.1 Spiritual care research in palliative care

A brief resume of the current challenges, priorities, gaps, and opportunities in conducting spiritual care research in palliative care as identified by Carlo Leget also challenges me to seek 'a new frame': a radically new way of researching spiritual care. In a pivotal presentation to an international conference, hosted by the Cicely Saunders Institute and King's College in London, 2014, entitled 'Spiritual care in palliative care: recent European research and future

³³ The evidence base for palliative care is relatively weak (Hanks, Kaasa and Forbes, 2010). This lack is due, in large part, to the significant barriers and complex ethical issues as identified by Kendall et al. (2007). Researchers are redressing this situation using both quantitative and qualitative methodologies (Lloyd-Williams, 2003; Scottish Partnership for Palliative Care, 2011).

³⁴ Three priorities, as identified by The European Association of Palliative Care Spiritual Care Taskforce, are: first, to identify patients' spiritual needs; second, to evaluate specific spiritual care interventions; and third, by using conversation models to empower staff to deliver spiritual care (Selman, Young, Vermandere, Stirling, and Leget, 2014).

developments', Leget offered an overview of current spiritual care research and its limitations. He highlighted six gaps which I consider may be addressed in a new frame. First the gap between the paradigms of quantitative and qualitative research. The medical sciences have thrived through using a positivist paradigm which embraces causality, effectiveness, efficiency, univocity, and quantitative outlooks. An influential piece of research within this paradigm, the Cochrane Review (Candy et al, 2012), concluded there is insufficient evidence to support spiritual and religious interventions for well-being in adults in the terminal phase of disease. Leget contends that in such research the methods used determine what can be discovered, and an alternative research paradigm is required to investigate this question. Spiritual care sits closer to the humanities, who explore meaning, value, expression, embodiment, and metaphor - all 'qualitative' in nature.

Second, Leget noted the lack of a connecting framework in spiritual care research. One example of a holistic 'synoptic model' is found in Cobb, Dowrick and Lloyd-Williams:

Spirituality is expressed and shaped through the dimensions of personhood including the cognitive, experiential, practical and social dimensions ... the spiritual is enmeshed 'in the experiences, meanings, narratives and beliefs about illness, dying and death that are encountered in the person's social and cultural context. (2012, 342).

Third, Leget addressed the gap between the disciplines of medicine and the humanities, often described as the tension between the art and science of spiritual care. Clinicians (Gordon, Kelly and Mitchell, 2011), and researchers, such as Mieke Vermandare (2014), are currently re-emphasising the art of spiritual care and this argument has featured heavily in this thesis so far. This links closely with the fourth gap Leget notes, between theory and practice. The weight of spiritual care research is academic and theoretical, employing the quantitative use of psychometric tools, variable outcomes and generalisability (Breitbart and Poppito, 2014; Chochinov, 2012). This does not engage with the actual practice of spiritual care offered from a pastoral perspective. Fifth, Leget notes the gap between faith communities and the health and social care culture. Finally, Leget questions the medicalisation and professionalisation of death, dying and bereavement which has made palliative care a specialist area when dying is, of course, a normal part of life. Most of living and dying happens in the community (Kehelliar, 2005).

3.1.2 *The turn to arts based research*

Leget's critique is important. However, some of the fundamental issues he raises are ones which are being discussed beyond the world of health care, as researchers seek to generate deeper understanding of the complexity and creativity of human lives and relationships. In this section, I introduce arts-based research as an emergent methodology which has potential not just to fill the gaps identified by Leget but to go further and to discover a new 'critical space'³⁵ to 'see well' and to research into deep silences— a subject not yet even on the horizon of research in palliative care.

Elizabeth Grierson and Laura Brearley describe methodology as

the 'how' of research, the organising system through which researchers make use and sense of data and ideas, engage critically with theories and literature, reflect on material practices and actions, ask questions and seek answers to weave research in a cohesive and systematic way (2009, 5).

Choice of methodology matters. It is crucial. As I set out on my quest to discover a new frame, I am exploring whether the strong link that can be made between the arts and spiritual care 'on the ground' justifies the choice of an arts-based research methodology as a way forward. Nigel Hartley argues that this is the case: 'The arts—music, painting, sketching, poetry, storytelling, drama—allow us to access and represent aspects of our experience that may otherwise elude recognition and articulation' (2012, 265). Hartley argues there they share a common 'language' which allows people to engage with the 'bigness' of existential questions. The arts and spiritual care both offer 'infinite room and space for a myriad of stories and experiences to be created, shared and witnessed' (2012, 270). If Hartley is correct, then arts-based research is an opportunity to enrich the field of spiritual care research. This resonates with Monica Prendergast

³⁵ I am indebted to Zoe Bennett (Bennett and Rowland, 2016, 108-136), for this introducing me to the concept of finding a critical space, as it emerges from her work on John Ruskin, who once said: 'The greatest thing a human soul ever does in this world is to see something, and tell what it saw in a plain way. Hundreds of people can talk for one who can think, but thousands can think for one who can see. To see clearly is poetry, prophecy and religion—all in one' (in Bennett and Rowland, 2016, 1). A critical space is created in the interweave of a relational life, attuned to self, other and Other.

and Carl Leggo's insistence that 'we need spaces for many kinds of research, including research that focuses on poetic knowing, the kinds of knowing that can be gained in the experience of stories and myths, art and music, dance and performance' (2007, 146). It is my hope that arts-based research may address Leget's concerns by closing the paradigmatic gap: connecting the various dimensions of spiritual care, embracing the art and science, and reconnecting both theory and practice, and the sacred and secular communities.

I now introduce some of the core principles of arts-based research.

3.2 Arts-based Research

Arts-based research is a relatively new methodology in the world of social research and still requires explanation and clarification (see Barrett and Bolt, 2007; Kara, 2015; and Leavy, 2015). Grierson and Brearley, for example, delve deep to advocate arts-based research as a legitimate source of knowledge. Their 'pedagogical aims are to position creativity and creative research as an authentic and robust condition of knowledge, and to reveal how researchers in this field navigate their material to scaffold their research projects' (2009, 2). This matches the intent of Estelle Barrett and Barbara Bolt,

we propose that artistic practice be viewed as the production of knowledge or philosophy in action. Drawing on materialist perspectives, including Martin Heidegger's notion of "handlability", our exploration of artistic research demonstrates that knowledge is derived from doing and from the senses (2007, location 118).

This new engaged knowing embraces handling, process, creativity and imagination; it is holistic and connects theory and practice. Most arts-based research methods embrace 'creative writing and/ or the visual arts: drawing, painting, collage, photography and so on. Other art forms used as the basis for research include music, drama, textile arts such as quilting and sculpture' (Kara, 2015, location 240). 'The natural affinity between research practice and artistic practice, both of which can be viewed as crafts', says Patricia Leavy, means that the creative arts 'address social research questions in *holistic* and *engaged* ways in which *theory and practice are intertwined*' (2015, location 87). The energy within this field correlates with the vision of its pioneers to extend 'the frontiers of research' (Barrett and Bolt, 2007, location 121). They are opening 'new ways

of seeing and experiencing, and illuminate that which otherwise remains in darkness' (Leavy, 2015, location 112). This means, according to Helen Kara, that arts-based research has particular potency to 'help contemporary researchers who may be facing research questions that cannot be answered - or at least, not fully - using traditional research methods' (2015, location 114). This resonates with my quest to discover a new way of seeing and knowing. However, alongside the potential benefits, there are challenges to be faced too. For example, because arts-based research is inherently subjective, emergent and interdisciplinary approach means that the "outcomes" of artistic research are necessarily unpredictable,' (Barrett and Bolt, 2007, location 160). Critical consideration of this methodology is demanded. With the overarching questions at the forefront of my mind being, "What does arts-based inquiry add to my research toolkit? On what grounds does it enable me to research deep silences?"

Leavy differentiate, arts-based research from quantitative and qualitative inquiry in a way which captures the foci and strengths of arts-based inquiry:

Table 1 Quantitative, Qualitative, and Arts-Based Research Methods. Source: Leavy (2015), 293-94.

Quantitative	Qualitative	Arts-Based
Numbers	Words	Stories, images, sounds, scenes, sensory
Data discovery	Data collection	Data or content generation
Measurement	Meaning	Evocation
Tabulating	Writing	Re(presenting)
Value neutral	Value-laden	Political, consciousness-raising, emancipation
Reliability	Process	Authenticity
Validity	Interpretation	Truthfulness
Prove/convince	Persuade	Compel, move, aesthetic power
Generalizability	Transferability	Resonance
Disciplinary	Interdisciplinary	Transdisciplinary

Creative arts embrace multiple ways of knowing: imaginary knowing, aesthetic knowing, preverbal knowing, embodied knowing, sensory knowing.³⁶ Leavy then

³⁶ What is new for me is perceiving how creative arts, such as narrative, music, visual art and dance all make natural connections between the two hemispheres of the brain (McGilchrist, 2009).

proceeds to identify six arts-based genres on a word to image arc. Narrative inquiry and fiction-based research draw explicitly on the arts, but still rely on 'the word' as their main communication tool. Poetic inquiry merges words with 'lyrical invocation'. Music picks up on the lyrical nature of poetry, and comes into being via performance, as do dance and movement. Theatre, drama, and film bridge the final space in the arc to arrive at the final artistic genre, visual art, which completes the arc from word to image. Each genre has its own special potency, for example, stories capture human experience and can transform readers' understandings of who they are; visual art can heal memories; music can integrate self. The methodology evokes, creates, represents and conveys meanings and truths which have a sense of resonance, authenticity and truth. Patricia Leavy summarises the strengths of arts-based research as including, but not being limited to:

- New insights and learning
- Describe, explore, discover, problem-solve
- Holistic approaches
- Evocation and provocation; emotional responses
- Cultivating critical consciousness
- Raising self- or social awareness
- Promoting empathy
- Unsettling or challenging stereotypes and dominant ideologies
- Accessing and representing marginalized voices and perspectives
- Promoting dialogue
- Public scholarship, usefulness, and social justice

(Leavy, 2015, 296).

What challenges me in undertaking this methodology is developing the required skills such as flexibility, openness, and intuition; conceptual, symbolic,

metaphorical and thematic thinking; ethical practice and values; and thinking like an artist ... art is something made, not something discovered (see Leavy, 2015). Notwithstanding these challenges, it is the principles of arts-based research that entice me to engage in it. I now briefly introduce two.

3.2.1 Integrating arts-based research

This section briefly describes some of the implications of integrating the philosophy and principles of arts-based research into my own work. I limit myself to three aspects: 'being comes before knowing'; 'creativity generates knowledge'; and 'the process of becoming'. Each informs my way of being, my way of knowing and my way of enquiring.

The starting place for arts-based inquiry is the studio of life. The handling of experience. Being comes before knowing. Referring to Pierre Bourdieu's concept of being 'in-the-game', Barrett and Bolt argue that production of knowledge comes after the fact; the finished product, *opus operatum*, conceals the *modus operandi*' (2007, 96, 186). This is evident in the prologue where I describe the way I live in and handle deep silences, and sometimes feel that I am out of my depth. My comprehension is limited; it is intuitive rather than cognitive; it begins in heart, body and emotions, rather than the mind. I am not alone in feeling this lack of understanding. Many people facing death or grief for the first time, live it rather than understand it. They feel out of their depth, and live with ambiguities, long before finding adequate words or images. For example, when Gawande, as a junior doctor, first encountered patients, they forced him 'to confront the realities of decline and mortality', and made him realize 'how unready I was to help them' (2014, 3). Similarly, Kearney reflects, 'while my training in palliative care had introduced me to a holistic model of pain ... I still felt utterly ill-equipped to deal with Jackie's overwhelming fear and suffering. I simply did not have the means to describe, let alone respond to, what was happening in her situation' (1996, 24). And C.S. Lewis wrote of his first encounter with grief, 'no one ever told me that grief felt so much like fear' (1961, 5). In each of these situations, being comes before knowing. I would further argue that this principle demands that I make sufficient space and time to dwell in, inhabit, and embody silences. The starting point of my inquiry is to live in silences and come back to them again and again.

The cyclical process of inquiry is well captured by Marcel Proust's observation of life,

We glimpse a stranger in the street, and the exchange lasts barely a moment. But then we go home and think on it and think on it and try to understand what the glance meant and inspect it from this angle and from that one, spinning futures and fantasies around it. (Quoted in: Iyer, 2014, location 189).

The next implication is the way that arts-based researchers handle experiences, such as death, grief or silences. This leads to my second core principle, that 'creativity generates knowledge'. The creative slant generates new approaches and new insights. Grierson and Brearley emphasise its revealing nature,

creative arts-based projects involve imagination, invention, speculation, innovation [and] risk-taking. New knowledge is made possible through the materiality of practice itself. Such practices can be of the most challenging order intellectually and technologically, the most revealing and moving emotionally, the most embodied physically or the most disquieting politically (2009, 6).

Creativity, as indicated above, takes many forms. However, for many, creativity is expressed in writing. And it may serve different purposes. For example, reflective writing seeks meaning, the '*creative leap*' of any story has the potential to discover hidden meanings as decisions are made about how to position the narrator, frame the action, include or exclude, and have open or closed endings (Bolton, 2005, 11). For bell hooks, its intent is clarity: writing 'is not to render ideas less complex', but rather 'to make the complex [more] clear' through a range of disclosive media (hooks 1999, 4). Another intent in reflective theological writing is to challenge truth. Story and poetics shifts the nature of truth towards the '*misty murk of imagination*' (Walton, 2014a, xxiv). Another is discovery: 'I write to find something out in order to learn something I didn't know before I wrote it' (Richardson and St. Pierre, 2000, 517). Yet another is getting to what really matters, or what Annie Dillard describes as 'beauty laid bare, life heightened and its deepest mystery probed' (1989, location 701). Particularly relevant to this thesis are the words of Helene Cixous: 'The writers I love are descenders, explorers of the lowest and deepest' (1993, 5). My intent in writing is to get to what matters in this research, to faithfully represent silences.

So far, I am arguing that the creative potential of arts-based research is the way it starts in the 'studio of life' and moves knowledge on, beyond current understandings. Paul Carter describes this process as invention, as 'the state of being that allows a state of becoming to emerge' (2007, 450). It is 'a perception, or recognition, of the ambiguity of appearances', and located in performance. Invention 'begins when what signifies exceeds its signification.' Invention 'or *poiesis* involves not only ingenuity (or wit) and imagination, but recollection' (Carter 2007, 503, 618). Invention moves beyond what is known and familiar. Creativity and invention may enable a thicker and richer understanding of silences. What I am arguing for so far is that the new emerges from the handling of materials and in the process of enquiry. One challenge that comes in the wake of invention is that outcomes are 'necessarily unpredictable'. However, the emergent dimension of the process is regarded as a positive feature rather than 'a flaw' (Barrett and Bolt, 2007, 159, 253).

The final implication of integrating arts-based research into my research is that the generation of new knowledge changes people and transform situations. Some initial observations and widely held assumptions in arts-based research are warranted at this juncture. The first is that individuals find their identity in context. For example, Estelle Barrett (2007, 3026, 3239) draws on Michel Foucault's account of 'author function' (in contrast to individual consciousness) to move the 'critical focus' from product to process and product. It no longer makes sense to focus on the author as the sole creator of meaning.³⁷ The creative arts researcher identifies links between current and previous projects, and traces the genesis of ideas and maps them onto a wider discourse mapping. The second is that process orientation scrutinizes any static understanding of personhood. Tessa Muncey draws from Michael Bakhtin to argue for a 'transient and illusive' sense of self (2010, 10-25, 34). She is fascinated by the 'myriad of individuals' who shape her existence. Her sense of self is affected by time and space, embodiment, emotions, social place, contexts, agency and inner values. Arts-based research assumes a 'process of becoming' and change. Paul Carter introduces two concepts which illustrate this (2007, 579-592). The Argo principle

³⁷ Lynne Pearce outlines the key principles of Michael Bakhtin's approach to dialogics, with reference first to a bridge (1994, 1-23), to argue that it is impossible to say, mean or be without the presence of another. Even if they are silent, they are still present. It is impossible to speak into absent silence.

is derived from the story of Jason and the Argonauts. By the time Jason returns home, every timber of the ship Argo had been replaced and yet the identity of the old ship survives the constant movement and change through which it was completely recreated. The Asterisk principle reminds researchers of what is absent. The asterisk is placed so that 'what seems to be omitted may shine forth'. The asterisk evokes consideration of what is left out of any representation of a person. These two principles, of Argo and Asterisk, unsettling representations of self over time and space. The choice of what fragments to include in the construction of a story about self, or others is important. This resonates with Barrett's concept of 'the dispersed selves', which imagines an author existing as several selves and situated in several positions - rather than being designated as 'a real, singular individual' (see Barrett and Bolt, 2007, 135).

A personal example of the 'process of becoming' in the research process is the change in my outlook which occurred after a series of events in the hospice led to a mental breakdown. During this time, my cognitive capacities were significantly challenged. I embraced a new orientation towards being rather than knowing. The grieving led to a gift.³⁸ Now the silences are 're-searching me' (Romanyshyn, 2013, 4). Silence is making a claim on me. When I am on Iona, at St Columba's Bay, listening to the waves break on the pebbled beach, the sound of shifting stones, the moment, the surge back into the ocean ... the silence searches me. In these silences, a state of being, and of becoming, is prior to a state of knowing.

My experience so far within the Doctorate in Practical Theology is that by dwelling in silences, and by creatively 'handling' the silences, I am beginning to know them

³⁸ Heather Walton (2015, 7-20), describes her overview of spiritual life writing as 'ancient practice, new purpose' (2015, 7). By doing so she draws attention to the shift in direction of spiritual life writing from 'establishing coherence' (2015, 9) to 'allowing for chaos' (2015, 13). What she means by this is that we are now living in 'interesting times' (2015, 7). Contemporary culture contests the vision 'of a unified and interior selfhood and offers different models of encounters with transcendence that are complicated, fragmented and partial—and are as likely to occur in the flux and flow of life as through intense interiority' (2015, 8). She develops her argument to the point where she describes two diverging responses to the current cultural context. The first 'tells a story of loss: loss of faith in all traditional structures of belief and loss of hope in radical social change' (2015, 18). In the words of David Leigh: 'an alienated seeker ... struggling with the lack of a stable sense of self ... (and) a paralyzing environment' (2015, 18). The second draws attention to the 'gifts that accompany our griefs' (2015, 19). Here rather than being overwhelmed, this stance delights in embodiment; in being immersed in a messy world; in diversity and fragility and above all discovering the 'sacred within its blemished beauty' (2015, 20).

better. I now move on to explain autoethnography as my means to explore deep silence.

3.3 Autoethnography

[A]utoethnography is not simply a way of knowing about the world; it has become a way of being in the world, one that requires living consciously, emotionally, reflexively. It asks that we not only examine our lives but also consider how and why we think, act, and feel as we do. Autoethnography requires that we observe ourselves observing, that we interrogate what we think and believe, and that we challenge our own assumptions, asking over and over if we have penetrated as many layers of our own defenses, fears, and insecurities as our project requires. It asks that we rethink and revise our lives, making conscious decisions about who and how we want to be. And in the process, it seeks a story that is hopeful, where authors ultimately write themselves as survivors of the story they are living.

Carolyn Ellis (In: Holman Jones, Adams and Ellis, 2016, 10).

The critical question in this section is 'Why choose autoethnography? What does it offer that other methodologies do not?' And as I reflect on this, and recollect the nature and nuances of deep silences, I sometimes wonder whether I am one of the people that Tessa Muncey, in *Creating Autoethnographies*, mentions: 'I rarely come across people who set out to do autoethnography but I do rather meet many people who resort to it as a means of getting across intangible and complex feelings and experiences that somehow can't be told in conventional ways' (Muncey 2010, 3). But my choice is more than just being able to witness and to re-present the deep silences. This matters more than that. This research journey reflects more and more who I am, how I see the world, and what motivates me to change the world. Reiterating Ellis' words above, this is 'a way of being' and an opportunity to 'rethink and revise' my life, 'making conscious decisions about who and how (I) want to be'.

Tell me, what is it you plan to do

with your one wild and precious life?

From *The Summer Day*, by Mary Oliver (1992, 94).

My hope is my singular voice may inspire if not a chorus of agreement then at least reach some readers who share resonances with my experience. I hope that others may trace and respond themselves to the moments when 'words fail' and 'the spiritual breaks in' their own deep silences.

3.3.1 *Some definitions*

It is in the copformativity of meaning with others that I find myself as a performative autoethnographic researcher, in the constant negotiation of representation in always emergent, contingent, and power-laden contexts (Tami Spry, 2011a, 39).

Today I want to write my way out of this history, and this is why I write my version of performance autoethnography. I want to push back, intervene, be vulnerable, tell another story. I want to contest what happened (Ron Pelias, 2011, 12)

Autoethnography 'works this territory between the orientating and disorientating story' (Craig Gingrich-Philbrook, 2016, 610).

Autoethnography is 'a form of inquiry, writing, and/ or performance that puts questions and "issues of being" into circulation and dialogue (Art Bochner, 2016, 52).

Self and Other(s) interact, relate and dance together in ways that challenge the received wisdom of more traditional social science? (Leon Anderson and Bonnie Glass-Coffin, 2016, 57).

Definitions of autoethnography abound and offer various starting points from which to understand this complex field. All, like the classic and much-quoted, 'autoethnography is an approach to research and writing that seeks to describe and systematically analyse (*graphy*) personal experience (*auto*) in order to understand cultural experience (*ethno*)' (Ellis, Adams and Bochner, 2011), are trying in one way or other to express the interface between self and other that autoethnography entails. All definitions express the intention not to focus on self, nor become lost in a narcissistic gaze, but to deepen understanding of the interface, spaces, power dynamics, and relations between selves. Most express the responsibility to revise, inspire and change our worlds for the better. Autoethnography seeks not only to understand self, or culture, or the other better (see Muncey, 2010), but also to evolve towards a temperament of critique and

resistance. Tami Spry defines embodied autoethnography as 'a self narrative that critiques the situations of self with others in social contexts' (2001, 710).

3.3.2 History of autoethnography

The historical roots of autoethnography are in anthropology and ethnography, whose primary aim is to 'observe and interpret cultural life' (see Walton, 2014a, 3-4). The early pioneers betray a methodological shift to reawaken anthropologists' established interest in self: 'By exploring a particular life, I hope to understand a way of life' (Reed-Danahay, 1997). A leaning towards self to make better sense of culture. Similarly, Ruth Behar describes autoethnography as an ethnography that includes the researcher's vulnerable self, emotions, body and spirit and produces evocative stories. She captures the lure of 'close-in contact with far-out lives' (1996, 7) by referring to Isabel Allende's story 'Of Clay We Are Created'. In 1985 Isabel Allende witnessed a landslide in Colombia which buried an entire village in mud. 'Of Clay We Are Created' tells the story of how her colleague Rolf Carie, a cameraman, went to the village to capture images of the unfolding events. In focus was a young thirteen-year-old girl, Omaira Sanchez, who was buried alive. Amidst the tragedy, no longer able to watch silently from behind the lens, he throws his camera aside and flings his arms around the girl, holding her over the next few days, as her heart and lungs collapse. They are utterly changed by the intimacy. Here she shows how researchers can no longer distance themselves and stay behind a camera lens, saying 'when you write vulnerably, others respond vulnerably' (1996, 16). More recently, Leon Anderson and Connie Glass-Coffin (2016) describe autoethnography's emergence as 'a refinement of long-standing ethnographic impulses'. This refinement is grounded in the way it adapts familiar ethnographic methods of data collection: field notes, personal documents and interviews. The writing of autoethnographic field notes involves not only the representation of the social reality of others, but also of self. Personal documents range beyond the norm of letters and diaries, and now include artefacts including evocative objects and images.

Tony Adams, Stacy Holman Jones and Carolyn Ellis articulate the core features of the emerging paradigm of autoethnography as: to foreground the personal, illustrate sense-making, be reflexive, be attuned to insider knowledge, challenge

cultural norms, and to connect with others and elicit a response (2015, 21-45). Its advocates call for narratives which shape, disrupt and inform, break silences and makes life better (see Denzin, 2003, 2014; Chang, 2008, 14-57; and Adams, Holman Jones and Ellis, 2015).

One of autoethnography's pioneers and strongest advocates, Norman Denzin, also contends that the intentions of autoethnography are to 'make sense of our fragmented lives' (2014, xi) and to change the world. He takes an existential, interpretive, and emancipatory angle of approach. Autoethnography starts in life, makes sense of lives in life, and transforms life. It begins with the here and now, with epiphanies: 'remembered moments perceived to have significantly impacted the trajectory of a person's life' (Ellis, Adams and Bochner, 2011). As such, they often capture moments of vulnerability and intensity, such as deep silences.³⁹ Ulmer's concept of 'mystory'⁴⁰ and Denzin's concept of 'epiphany' sharpen the focus of inquiry. The 'sting of memory' initiates the process, and the choice of where to begin is crucial, as illustrated by Jean-Paul Sartre:

Where to start? We must find that project, act, event, that gives primary meaning to the person's life, that event the subject seeks to understand the most. This experience gives primary meaning to the person's life. We must discover that event and see how it embeds the person in their historical moment, then we can work back into history (2014, x).

Having made sense of our fragmented lives, its purpose is to perform these meanings in life. To change the conditions under which lives are lived. There is a palpable commitment to social justice (see Denzin, 2014, vii-xi). Autoethnography is not just a neutral description or understanding, of the collisions, intersections,

³⁹ Walton (2000) sensitised my worldview to the voices of the broken and marginalised. Walton describes with great sensitivity and detail the time when she was 'in a hospital for wombs' (2000, 196), the women with her, and the gift she received of 'tall, full, wide goblet tulips. Scarlet with black at the centre. Velvet petals from scarlet to black. Flowers of passion and pain opening wider and wider' (2000, 199) and the riddle, and her realisation that 'this hospital is the same place exactly as the whole universe' (2000, 201) and it is out of this place that theology emerges ... 'you may begin to see beyond the little lights and into the great darkness. Here is your faith / God is God / Of the Living and the Dead. / This is how theology is done' (2000, 201). My challenge is to listen to the marginalised voices of the vulnerable dying.

⁴⁰ Norman Denzin builds on Ulmer's concept of 'mystory' to encourage life writing to connect with the sting of memory: 'Write a mystory bringing into relation your experience with three levels of discourse—personal (autobiography), popular (community stories, oral history or popular culture), [and] expert (disciplines of knowledge). In each case use the punctum or sting of memory to locate items significant to you' (2014, 32).

and relationality of self and others, but it is hopeful, compassionate, and liberating.

3.3.3 *How do you do it?*

Over the past few years I have come to appreciate the nuances and rhythms of autoethnography, located in the worldviews of pioneers such as Norman Denzin, Carolyn Ellis, Leon Anderson, and Tami Spry. From the increasing volume of work in this area, Tessa Muncey (2010, 26-53) and Heather Walton (2014a, 3-9) identify three distinct if related forms of autoethnography: evocative, analytical and performative. The task in this section is to explore which style best fits my research.

The roots of evocative autoethnography lie in 'vulnerable anthropology' where researchers travel into undiscovered countries and make discoveries that break the heart (see Behar, 1996).⁴¹ The leading pioneer of this genre, Carolyn Ellis, describes the process:

I start with my personal life. I pay attention to my physical feelings, thoughts and emotions. I use what I call systematic sociological introspection and emotional recall to try to understand an experience I've lived through. Then I write my experience as a story. By exploring a particular life, I hope to understand a way of life. (1999, 671)

Her first autoethnographic writing, *Final Negotiations*, (1995) is her response to living with loss and grief, triggered by her brother's death in a plane crash and losing her partner to emphysema. Ellis teamed up with Art Bochner to 'add an evocative and vulnerable heart, our intimate autobiographical experiences, and other artful and evocative forms of expression—short stories, poetry,

⁴¹ Traveler

I am like the traveler
 who reaches the port and no one awaits him;
 I am the timid traveler who walks
 among strangers embracing and smiles
 not meant for him . . .
 Like the lone traveler
 who raises his overcoat collar
 on the great, cold wharf . . .

Dulce María Loynaz (In Behar, 1996, location14).

performance, music, and art' to the qualitative research they were already engaged in (Bochner, 2016, 10).⁴²

There is a myriad of starting points in evocative pieces. Tessa Muncey's story of teenage pregnancy evokes a new imaginary and challenges dominant narratives (2010, 6-8). Arthur Frank's collation of illness narratives have therapeutic value: 'seriously ill people are wounded not just in body but in voice. They need to become storytellers in order to recover the voices that illness and its treatments often takes away' (Frank, 1997, xii). And others, like bell hooks, came to autoethnography from a place of pain: 'I came to theory desperate, wanting to comprehend—to grasp what was happening in and around me. Most importantly, I wanted the hurt to go away. I saw in theory then a location for healing.' (In: Spry, 2016, 25). These examples indicate that evocative autoethnography often begins with marginalised voices of the traumatised, silenced or shamed. The visibility of each person is intentional. What each 'individual' adds is a 'missing story' which offers a better understanding of the continuum which evokes an ethical response (see Muncey, 2010). Evocative personal accounts of a self or some aspect of a life lived in a cultural context, are carefully crafted texts which deepen understanding of complex matters, engender empathy and generate positive reactions in their readers:

In personal narrative texts authors become 'I', readers become 'you.' ... (and) take more active roles as they are invited into the author's world (and e)voled to a feeling level about the events described ... The goal is to write meaningfully and evocatively about things that matter and may make a difference ... and to write from an ethic of care and concern (Ellis and Bochner, 2003, 213).

The hardest work in this genre is to connect: to bring alive the moment, to convey its significance in such a way as 'to move hearts and change minds' (Walton, 2014, 5). Often distance and time creates an abyss, between what is seen, heard and felt and its representations. Lazy writing fails, but write vulnerably effectively and others respond vulnerably (Behar, 1996).

⁴² See also Ellis and Bochner, *Composing Ethnography* (1996), Bochner and Ellis, *Ethnographically Speaking* (2002), and Ellis, *The Ethnographic I* (2003).

Other researchers, 'believing that the pendulum has swung too far in the direction of artistic creativity and emotional expression' are more committed to theoretical analysis, which transcends specificity through broader generalization and enables researchers to theorize about the social world (Walton, 2014a, 6). Leon Anderson's influential article 'Analytic Autoethnography' (2006) led the way. This genre has five key features which hint at a return to its ethnographic roots and a 'realist' paradigm.⁴³ Analytic autoethnography, says Anderson, is ethnographic work in which the researcher (a) is a full member in a research group or setting; (b) uses analytic reflexivity; (c) has a visible narrative presence in the written text; (d) engages in dialogue with informants beyond the self; (e) is committed to an analytic research agenda focused on improving theoretical understandings of broader social phenomena. It is the last factor that dominates and differentiates this genre from evocation and performance. An example of analytic power used wisely is how Susan Wall (2008) links her personal experience of international adoption to theory, thereby challenging institutional structures. This analytic genre reacts against research that overvalues self and lacks a critical sociocultural eye. Another advocate, Heewon Chang (2008), expands Anderson's concerns. First, Chang argues culture is located 'out there' in the public arena, as much as 'in here' in the private sphere of self (2008, 18). This means that autoethnography 'benefits from the thought that self is an extension of a community rather than that it is an independent, self-sufficient being, because the possibility of cultural self-analysis rests on an understanding that self is part of a cultural community' (2008, 26). Later she argues that a 'desirable' autoethnography balances thick description of personal experiences with a sociocultural interpretation. This demands that 'creators and consumers' ask five evaluative questions: does the autoethnography (1) use authentic and trustworthy data; (2) follow a reliable research process and show the process clearly; (3) follow ethical steps to protect the rights of self and others presented and implicated; (4) analyze and interpret

⁴³ There are three options when considering epistemological stance. They lie on a spectrum of what Snape and Spencer describe as 'realism (an external reality exists independent of our beliefs and understanding), idealism (no external reality exists independent of our socially constructed meanings) and subtle realism (an external reality exists independent of us but we can only know it through the human mind and our socially constructed meanings)' (2003, 16). My stance is that of a subtle realist who waits for the spiritual to break in. I listen out, and watch out for traces of the numinous, such as spoken about by Rudolph Otto, *tremendums et fascinans*, which defies human grasp yet at the same time I strive to represent such moments in words, language and patterns of thought which are pushed to their limits (see Rowan Williams, *The Edge of Words*, (2014).

the sociocultural meaning of personal experiences; and (5) attempt to make a scholarly contribution with its conclusion and engagement of the existing literature? (2015, 443). Anderson and Chang's 'insider' voices critique autoethnography from within and are salutary. While such voices may compromise core autoethnographic ideals, they are, argues Walton, pragmatic in effecting change in a culture where social science dominates. Walton takes a moderating stance in 'Desiring Things', which illustrates how the evocative and analytic may be effectively combined (2014a, 31-42). Sarah Wall too proposes a middle ground which 'allows for innovation, imagination, and the representation of a range of voices in qualitative inquiry while also sustaining confidence in the quality, rigor and usefulness of academic research' (2016, 1).

The third dominant genre asserts autoethnography is fundamentally concerned with embodied performance :

the social world is a performed world in which people act out their lives in accordance with the 'big scripts' of race, economics, gender and so on. However, within the performance of personal lives there is always the chance to improvise, invent and change—or simply to forget your lines and thus make involuntary adaptations (Walton, 2014a, 8).

Performance understood in this way embraces the production of academic textual interventions as well as the construction of performative works that are 'staged' in less conventional forms.

Tami Spry is a leading exponent of this approach (2001, 2011b, 2016). She writes how in performance, 'I am linking body and mind, self and other. I weave together story and theory'. Here the researcher is now 'the epistemological and ontological nexus upon which the research process turns'. She links body, script and stage. Spry's craft exalts the body. 'It's the body. It's about the body ... It's always been about bodies', and the task is to get the body into the text or onto the stage. And she delights in the always new, in which the body is 'producing its never-the-same self made star over and over again (see 2016, 11-12). Performance also takes a political slant. This is a radical realignment of the research process and brings it closer to the audience and invites social transformation. Other scholars, such as Ron Pelias and Norman Denzin, share her passion for performative autoethnography as 'a way of the heart' (Pelias, 1999, 2004, 2016):

Performance is: an aesthetic encounter, a seductive coalescence that catches you in time, a luscious lure that pulls you in close and pushes you away, over and over, as you lean forward, engaged and giddy, on the top of a sparkle of light (Pelias, 1999, 111).

Performance autoethnography is ultimately about 'making sense of fragmented lives and transforming the world' (Denzin, 2003; 2014, 2016). By embodying the text in performance, you are bringing a new world into being.

For all its strength, performative autoethnography is constantly being revised. Barbara Tedlock (2016) emphasizes the relational aspect of autoethnography. It gazes inward to the self and outward to others. She shapes vulnerability and analyses human experience, with a mutual commitment to self and to others. Grace Giorgio (2016), similarly differentiates three nuances of memory which reflects a spectrum relationality: 'I remember. I bear witness. I memorialize.'. She relates these to Bakhtin's 'numerous I's' (2016, 9470). Thus 'I-for-myself', is emotional memory; 'I-and-the other' is memory in relation and bearing witness, and 'Other-for-me' is a cultural memory brought alive in ritual. In *Call it Swing*, which Spry performed at the 2010 *Congress of Qualitative Inquiry Conference*, she shows how 'awkward, anxious and entangled' she is, 'with and about the Other'. And shows her desire to 'represent the Other with the same kind of commitment as is afforded the self' (2016, 14). She is moving towards a performance autoethnography that unsettles the I, and faithfully represents the other, with equal commitment. In other words, she is blurring the binary and challenging the distinction between self/ other. What has been missing, she argues, is an appreciation of the impact of the other on self; so by engaging with the Other, this decentres self, leaving in its wake, a 'we', a 'relationality' of understanding and representation. In *Call it Swing*, by reflecting on her father's life in jazz, she puts flesh on the bones of this dilemma. You can't play jazz alone, she says. The minor chord rewrites the major chord. In the ebb and flow of jazz we become one. While improvising it's about 'just in time finding the right note'. Playing costs. Discover a language of compassion, with a melody of hope and healing. And in her father's death and in his final grace note, she discovers his jazz continues to course through her veins.

Having outlined key features of these different approaches, I confess I do not wish to select one above the others. Evocative autoethnography attracts me because

of its artistry and ability to write from life.⁴⁴ The innovation and imagination by which individuals living in messy worlds, recover their (silenced or marginalised) voices, tell their story, and bring a vibrancy and a sense of the 'really real' to their ordinary lives, unsettles the way people see the world. This may change hearts and minds, and inspire people to reshape their world for the better. This resonates strongly with the inductive slant in practical theology. Both approaches are rooted in the here and now, and are owned.

The challenge, however, is representation. As Denzin notes:

there is no clear window into the inner life of a person, for any window is always filtered through the glaze of language, signs, and the process of signification. And language, in both its written and spoken forms, is always inherently unstable, in flux, and made up of the traces of other signs and symbolic statements (Denzin 2014, 2).

Denzin employs the concept of *pentimento*: something painted out of a picture which later becomes visible again, to illustrate what is happening. 'A life and the performances about it have the qualities of *pentimento*. Something new is always coming into sight, displacing what was previously certain and seen. There is no truth in the painting of a life, only multiple images and traces of what has been, what could have been, and what now is' (Denzin, 2014, 1). The concept of self or identity is complex, and changing across space and time. How to represent, or figure out, a person presents quite a philosophical challenge. And I am wondering whether a narrative approach best captures the epiphanies in deep silence. Is storytelling the best fit for deep silences? Conventionally stories include people, in places, where an epiphany or crisis provides tension, which in the unfolding of events is resolved, and conveys a meaning. Denzin revises this understanding because this simple pattern does not always represent life. For example, in trauma, moments are relived over and over again; the memories, images and emotions do not fade, which means here 'stories, like the lives they tell about, are always open-ended, inconclusive, and ambiguous, subject to multiple

⁴⁴ I am aware of the challenge of faithfully representing lives whose identity is always in a state of flux. Keith Berry (2016), and Susanne Gannon (2016), both refer to the 'complex, knotty and uncomfortable' negotiation of identity. Berry imagines spinning a 'web' of many selves; the storied, the filtered, the breaching, the contested, the unapologetic and the hopeful (2016, 4874). Gannon draws on post-structural theory to shift the concept of an essential self to a subjectivity in which self is 'inscribed in language' and situated in many discourses, which means that there is no stable, coherent, bounded self; rather there will be many selves (2016, 5339).

interpretations' (2014, 5). This lack of coherence, and presence of chaos, allows Denzin to outline a new set of conventions which suit evocation and performative autoethnography.⁴⁵ Another dilemma is the frailty of memory. Memory of experiences, says Muncey, happen in a time and place; it is fragile, and some elements are highlighted while others are buried; and in all this I am never static but always becoming. I am so conscious of the concept of multiple lives, multiple voices. I'm now asking: 'Can a methodology that relies so much on storytelling represent the fragmentary, broken and chaotic experiences of deep silences? How can I overcome the dilemma of the frailty of memory?'

Analytic autoethnography attracts me because it interprets life. Carolyn Ellis, once said that 'autoethnography is action research for the individual' and I have enjoyed this approach in practice and seen its potency to affect positive change (Ellis, 1999, 677).⁴⁶ Here the aim of making sense, contributing to a knowledge base and transforming practice, resonates. Especially as I delve into the new territories of trauma, shame, communication and the spiritual, there is a need to connect experiences and theory. To be an 'edge walker'. Heewon Chang (2008), uses the term 'edgewalker' to describe those people who bridge self and culture. She first notes Gergen's (1991) concepts of self: the romantic self, full of depth and passion; the modern self, driven by reason and conscious intentions; and the postmodern self, saturated by polyphony of voices. Then she describes the inevitable tensions between those who value self above culture, or vica-versa—those who value culture over self. She resolves the quandary thus: as self becomes mirrored in others, so others become an extension of self. The innovative spark of autoethnography arises, she contends, as researchers become edge walkers. People who expand the boundaries and horizons of both self and culture. I am wondering whether I can become an 'edge walker'. My answer to this dilemma is to pepper my story with elements of theory, which will stimulate thinking and signpost readers to relevant areas. To follow Wall's middle way. I am aware of the

⁴⁵ Denzin's convention are: (1) the existence of others; (2) the influence and importance of race, gender, and class; (3) family beginnings; (4) turning points; (5) known and knowing authors and observers; (6) objective life markers; (7) real persons with real lives; (8) turning-point experiences; and (9) truthful statements distinguished from fictions (2014, 7).

⁴⁶ John Swinton and Harriet Mowat differentiate action research in the worlds of social sciences and practical theology (2016, 262). In the social sciences, its focus is on gaining new knowledge, and enhancing practice, whereas in Practical Theology, by seeing the world through a theological lens, action research moves towards faithful living.

added value this approach offers. Analytical autoethnography offers a coherent and rigorous method to win credibility of my colleagues, located within the scientific paradigm and less comfortable with artistry.

Performative autoethnography attracts me because it transforms life. Transformation happens as I embody my worldview and as I immerse myself within my community. Creative writers, such as Annie Dillard, Hélène Cixous, Elizabeth Smart and bell hooks first enticed me to live the deep silences. In *Remembered Rapture: dancing with words*, bell hooks speaks about the ecstatic moment (literally 'to stand outside') being one in which one is so immersed in a moment that all else falls away. One is caught up in rapture. bell hooks then shows how words can connect with this experience at different levels. Reading texts is an act of creativity in which the power and beauty of words lift off a page as one imaginatively hears a voice, and sees the person moving and breathing; the words begin to become incarnate, the silence becomes the presence of another. However, the power and impact of the text increases when one reads the words out loud. The words become embodied and engage with both mind and senses, and weaves connections with heart and soul. Further in performance what once was other now becomes present (Spry, 2001). What resonates with me is a growing appreciation that pastoral moments enjoy such rapture and ecstasy, the compassionate gaze, the kiss of touch, when all else falls away. So, in part, my intention is to write and to capture the ecstatic silences, the resurrection silences, the darklight, ... in text, image, music, (though they lie beyond capture). I write to represent the silences, though they defy any absolute representation. When and as I write, I am not neutral, I do not stand in no-man's land but on the borderlands, in the liminal spaces ... and the words come out of the explosion of my heart. Linking immanence and transcendence; linking sacred and secular; and linking dark and light. My texts become, in performance, a small bridge. My poems, images and fragments, which emerge out of deep silences, are a bridge between self, other and Other.

A second feature of performative autoethnography that attracts me is its collaborative, co-constructed and social character. Yet a real challenge in my research is how to perform deep silences. In shared silences, moments of which I am now the only witness, I wonder about how to ensure a communal slant. Lack

of community is a concern and potential weakness in my research. A solitary authorial voice lacks depth. Sings a melody but is unable to harmonise.⁴⁷

3.4 Ethics

My recognition that my own perspectives are limited and that the nature of my research deeply sensitive prompts me now to consider the ethical challenges entailed in my autoethnographic approach. This section shows that personal values, moral perspectives and ethical stances shape the way we live, the way we practice, the way we inquire and the way we write.⁴⁸ Having sketched the way ethics weaves its way through palliative care and the research process, this section highlights four specific ethical dilemmas in conducting an autoethnographic project: self-care; care for others; truth-telling and moral accountability. I then outline the way, by holding in tension a relational ethic with an ethic of truth-telling, that I will address these dilemmas to ensure safety and accountability in this inquiry.

3.4.1 Ethics in palliative care and in the research process

Stringent ethical concepts guide clinical practice, organization configuration, research and strategy in palliative care. Biomedical principles—of autonomy, beneficence, non-maleficence and justice (see Beauchamps and Childress, 2001) — and moral theories—such as consequential, obligation, communal, relational and virtue (see Sandman, 2005)—shape every discussion and decision as the palliative team facilitates 'a good dying'. The ethics of spiritual care focuses on process and relationship (see Mitchell, Kelly and Gordon, 2011). Daniel Sulmasy (2012) describes five principles for the delivery of spiritual care: being person-

⁴⁷ Here I am indebted to Gregory Clifton-Smith (2016), whose innovative text, *Performing Pastoral Care*, has opened my eyes and ears to the way music, with all its intricacies of harmony / unison; dissonance / resolution; sound / silence offer an imaginative framework to understand self, other, and Other; and the dynamics between them.

⁴⁸ In a DPT workshop in Glasgow, Stephen Pattison drew my attention to the many ways of thinking about ethics: the heartfelt and intellectual reasoning behind how people live out their lives. Ranging from what people do (descriptive); what people should do (normative); the principles by which people work out what to do (reflective); the standards against which they measure practice (legislative); the intentional ethics that arise in unique situations (deliberative) and the ethics that emerge from considering a bigger picture (teleological / purposive). By doing so he complexified an already complex landscape.

centred; adopting a holistic approach; being aware of limits and boundaries; being committed to accompany; and being inclusive and respectful of difference and alternative world-views. Ethics is an art and a science because rather than working with certainties, ethics balances complex issues, using frameworks, such as Seedhouse's (2009) ethical grid, and theories. This approach often offers a good degree of confidence and transparency in the decision-making process. As ethical complexity increases, for example, 'What is a good dying?', then the moral compass of the person/s making the decisions is crucial.

Moving from clinical practice to research, Helen Kara argues that 'to be an ethical researcher you need to think ethically before, during and after you make your research (2015, 1373). Similarly, Bennett et al. (2018) describe the way ethics—ethos, process and outcomes—weaves a thread through the whole research process. For example, choice of focus, method and analysis reflects a decision to privilege, attend to and interpret some aspect of reality while obscuring other aspects. And reflexivity enables researchers to appreciate the impact of self on the research process. Worldview, motives, aspirations, values, and strengths, are not neutral. Also, an ethic of care shifts the focus from an ethics of justice—of getting it right—to situational ethics, where the impact and consequences of the research matters. This captures the transformative and emancipatory potential of research. The focus and tension of palliative care research ethics revolves around balancing the protection of a vulnerable population with the need for new learnings.

3.4.2 Ethical dilemmas in autoethnography

While some researchers contend that ethical guidance is only just emerging in this area (see Roth, 2009; Wall, 2016), others argue there already exists a strong ethical tradition upon which to proceed.⁴⁹ The specific dilemmas that I identify in my own project concern the ethical issues surrounding caring for self and caring for the other. These must be held in tension with truth-telling and moral inquiry.

⁴⁹ Tullis (2016), observes that it shares established ethical conventions of respect for persons, beneficence and justice. However, the more nuanced ethical considerations, inherent in autoethnography, 'may not be addressed or understood by traditional ethical approval forms or committees, where beliefs and views are often polarized' (Douglas and Carless, 2016, 98).

Safeguarding self and safeguarding others

Dwight Conquergood describes autoethnography as an 'ethnography of the ears and heart' (Spry 2016, 30). This understanding demands an ethic of listening, caring and compassion, which seems straightforward enough, but delving deeper reveals a more complex terrain.

Its range of concerns is nicely described by Tami Spry in *Body, Paper, Stage* (2011a, 136-137). Autoethnography, she says, should avoid self-indulgence; avoid blaming; avoid heroics; avoid framing people as victims; avoid self-righteousness; and avoid disengagement. I simplify her descriptions into two broad categories: safeguarding self and safeguarding others.

Sara Wall (2016) argues that the trend toward evocative autoethnography increases risk to self on two counts. First, autoethnography attracts strongly motivated people who share their stories of trauma, grief, sexuality, and marginalization. Second, the stories related are ever more emotive, detailed, and confessional. This resonates with Laurel Richardson: writing stories brings us 'up close and personal' (2000, 208). Wall's concern is that 'the limits of disclosure about *ourselves*, is an issue that is scarcely considered in autoethnographic work'. The ethics of 'life writing' offers some relevant insights into this dilemma.⁵⁰ First, proponents agree that self-care is crucial. For example, Walton argues that because life writing exposes individuals, and often engages with raw sometimes vulnerable experiences, the first duty in life-writing is self-care. But she goes further to indicate how the safeguarding is ensured. This involves self-control, the cultivation of 'the wisdom of restraint' on what to include, what to omit, since 'there are always blanks and absences in writing' (Walton, 2014a, xxviii). The critical thing to remember, in considering the limits and extent of self-disclosure, is that there is no such thing as an 'authentic self', only 'the self that you are presenting through your words', so authors can always stay in control of their storytelling (Walton, 2014a, xxviii).

⁵⁰ When Paul John Eakin began mapping the ethics of life writing he found the territory 'largely unexamined' (2004, 1). He identifies four contested areas: truth-telling; moral inquiry; representing others; and acts of resistance. Heather Walton limits herself to two: the self in the text and other people's stories (see 2014, xxviii -xxxi).

The dilemma of safeguarding others arises because of the way autoethnographic texts inevitably implicate or include others, unwittingly or otherwise, in the weft and weave of a story.⁵¹ As Heewon Chang puts it, 'other people are present in self-narratives, either as active participants in the story or as associates in the background' (Chang, 2008, 68). Implicating and including others happens first, because the self exists in relation to the world and is co-constituted by the other (Roth, 2009). And second, because 'creative nonfiction and narrative ethnography is factual but written as polyphonic with the author's voice and those of the others woven together' (Tedlock, 2016, 335). Risks are alleviated by using 'strong conventions' to shape an ethical telling. Conventions which include confidentiality and anonymity safeguard the vulnerable.⁵² Once more, spiritual life writers have some critical insights at hand. Maintaining trust and avoiding betrayal in the representation of others is no easy matter, says Paul John Eakin: 'we live our lives in relation to others, our privacies are largely shared, making it hard to demarcate the boundary where one life leaves off and another begins' (Eakin, 2004, 8).

This leads to the controversy over whether individuals 'own' their lives or whether for the common good their private lives may be shared. An ethic of care invites life writers to limit inappropriate disclosure: uncensored transparency may be harmful, so there are some serious ethical reservations in relation to 'invasive life writing' (Eakin, 2004, 6). One way to protect the privacy and identity of participants is through the creation of composite characters, which is the approach I adopt in my writings. A relational ethic also ensures ongoing care for critical conversation partners (see Adams, Jones and Ellis 2015, 55-66): 'Texts live on in static form long after they are written, so there is a future vulnerability to consider' (Tullis, 2016). So, careful consideration is given to ensure that people are no longer taken advantage of, that they are represented fairly and that a creative dialogue brings self and other together. After all, 'we are all in this'

⁵¹ It is 'impossible for me to speak of myself without also speaking of others' (Wall, 2008, 49).

⁵² In 1985 Conquergood identifies four ethical pitfalls that performance ethnographers must avoid if they are to safeguard others and maintain credibility: the custodian's rip-off, the enthusiast's infatuation, the skeptic's cop-out, and the curator's exhibitionism. Cultural custodians, ransack their past looking for good texts to perform often disregarding the sacred significance of such experiences. The enthusiast's superficial stance, occurs when there is a failure to become deeply involved in the cultural setting which trivializes the other; the skeptic values detachment and being cynical often refusing to face up to moral ambiguities. Finally, the curator sensationalizes the cultural differences in a voyeuristic way (Denzin, 2014, 78-79).

(Spry, 2016). This demands significant humility. An appreciation of treading softly in the universe of being, knowing and inquiring.

Moral inquiry and truth-telling

'The reader's trust in the narrator's credibility is crucial' (Eakin, 2004, 2). In his important book, *The Ethics of Life Writing*, Paul John Eakin collates voices who explore the ethics of life writing. For example, Paul Lauritzen (2004) illustrates how accusations of lying against Rigoberta Menchu, a Nobel Peace Prize winner's, account of repression and suffering in Guatemala, and against Benjamin Wilkomirski's account of being a Holocaust survivor, undermine their life writing. Lauritzen was also accused of being a liar due to his writing about being infertile, only becoming public after he successfully conceived a child. However, the ethics in this area are not straightforward. Lauritzen introduces the concept of *testimonia*, whose intent is not the same as autobiography, but is a narrative that urgently wants to communicate issues such as repression, poverty, subalternity, the struggle for survival. To express these, life writing embraces the poetic devices of fiction. What matters is to interpret and convey meaning. And the reason to do so, argues Lauritzen, quoting Primo Levi, is 'to make others participate' (2011, 24). There is a creative tension in life writing between fact and facticity (see also Denzin, 2014).⁵³ As there is a tension between not telling the truth and telling too much truth, which may be an intrusion. For some writers, the obligation to truth telling, over individual rights to privacy arise when the 'big picture' is held to be of more value than the small one. The larger truth takes precedence. What matters here is discerning the credibility of the author to make such decisions of when to employ the devices of fiction, and when to forego individual rights for 'a larger truth'.

In his advocacy for life writing as moral inquiry, Eakin develops the philosopher Charles Taylor's maxim that the self 'is something which can exist only in a space of moral issues' (2004,4). What this means is that life writing intentionally examines a life in moral, and spiritual spaces. For example, Augustine's *Confessions* are set in a time when theology sought a coherence in spiritual

⁵³ This ethical responsibility, obligation to the truth, extends into 'nonfiction novels' where failure violates both literary and moral conventions and the reader loses confidence in the text (see Middlebrooke, 2004).

narratives, whereas Heather's Walton's *Not Eden* (2015) is set in an age when spiritual writing embraces chaos and actively celebrates the loss of innocent faith. She writes:

An embodied and relational self does not seek to lift itself beyond this messy, complicated world, but rather seeks to adore the sacred within its blemished beauty. From the traditions of spiritual life writing 'adaptive borrowers' will pick out for reuse spiritual insights formed on the margins that may be fragmented, wayward, heterodox and imaginative (2015, 20).

A way forward: holding an ethical tension

Autoethnography is a moral inquiry, that truthfully tells stories of self that implicate others, counter dominant discourses to witness, heal, liberate, and transform. The decision whether I take the risk of putting self onto the page, to engage with larger truths, inevitably comes down to balancing my own vulnerability with the therapeutic benefits of telling a story—'we often write to work something out for ourselves' (Adams, Holman Jones and Ellis, 2015, 56-66)—and with the telling of larger truths about deep silences that will change the world for the better. There are, says Walton, 'irresolvable tensions' balancing the interests and safety of others with the need to generate new understandings to improve practice. She calls for self-examination and the adopting of David Gardner's principles of the moral function of literature:

clarifies life, establishes models for human action, casts nets towards the future, carefully judges our right and wrong decisions, celebrates and mourns. It does not rant. It does not sneer or giggle in the face of death, it invents prayers and weapons. It designs visions worth trying to make fact (quoted in Walton, 2014a, xxxi).

3.5 Evaluation

The intention in this thesis is to integrate the philosophies and methods of arts-based research and autoethnography. This means that evaluative criteria come from both traditions. However, limitations of space restrict me to a too brief consideration of arts-based research, before focusing more deeply on autoethnographic criteria.

Leavy notes that the task of establishing evaluative criteria for arts-based research is 'contested' (2015, 266). Employing a light touch, she asks whether the research deepens connections, broadens horizons and makes a difference⁵⁴ (see 2015, 266-288). A key concern identified by Leavy, and earlier Susan Finley (2011) is balancing 'artistic expertism' (2011, 440) with the passion, 'active imagination, and the ability to engage in critical critique and dialogue' by the researcher (2011, 437). For example, should poetic inquiry be measured on established rules, which 'move a person into being considered a poet', (Kara, 2015, location 609) or from my stance, measured by whether the poetry provokes emotional responses, emphasizes the vividness of a moment, connects with something deep and through silences and composition adds meaning (see Leavy, 2015, 89-93).

Being in its infancy, care needs to be taken to ensure the credibility and trustworthiness of the autoethnographic project. Evaluation is 'a necessary yet contested terrain' and demands consideration of process and product (Adams, Holman Jones, and Ellis, 2015, 99). This section describes the critical space from where I evaluate my research.

When writing from life, there is a space between lived experience and the representation of that experience. Texts freeze experience. Ice differs from flowing water. Or as Denzin says, 'the corpus of experience disappears into a text that is then read as a representation of the life experiences of the individual being studied' (2014, 36). This poststructural turn means that writers no longer 'depict' or 'mirror' deep silences as they are, or as they occurred, but 'extract meaning'.⁵⁵ This opens autoethnography to criticism. Debates over legitimacy and truth revolve around terms such as: narrative, meaning, voice, experience, reflexivity, presence and representation. Critics say that autoethnography lacks explanatory power, scholarly insight or the ability to cultivate social change (see Denzin, 2014, 69- 70; Adams, Holman Jones and Ellis, 2015, 99-102). What this means is that

⁵⁴ Susan Finley similarly argues that the 'ultimate value of research derives from its usefulness to the community' (2011, 435).

⁵⁵ Language and speech do not mirror experience; rather, they create representations of experience. Meanings are always in motion, inclusive, conflicting, contradictory. There are gaps between reality, experience, and performances. There is never pure presence. We have reached the end of pure description. Description becomes inscription, and inscription becomes performance. The task is to understand what textually constructed presence means because there is only the text (Denzin, 2014, 36).

different evaluative criteria than those criteria used in 'conventional research' (in John Freeman's terms)⁵⁶ are required. Denzin too argues that autoethnography cannot be judged by positivist criteria (2014, 70). Therefore, Denzin offers new understandings of the conventional triad of criteria: reliability, validity and generalizability. Reliability now refers to the author's credibility and trustworthiness as a 'writer-performer-observer'. Validity now means that the work has 'verisimilitude', which means it conveys a sense of being true, coherent, and has resonance. And generalizability is now grounded on the response of readers, or listeners to text or performance. Is the text a universal singular? And does it motivate others to ethical action? What this means is evaluative criteria cover process, product, and impact.

A new lexicon of criteria is required to test the quality of representation, the impact of performance, and to wrestle the vagaries of memory, the illusion of truth and the possibilities of presentation (see Freeman, 2015, 1-13). Many voices, such as Tony Adams, Stacy Holman Jones and Carolyn Ellis (2015, 99- 115) contribute to the discussion. They describe criteria which reflects aspirational goals and success:

- making a contribution to knowledge,
- valuing the personal and experiential,
- demonstrating the power, craft and responsibilities of stories and storytelling
- taking a relationally responsible approach to research practice and representation

Norman Denzin turns to creative writing to discover criteria (2014, 69-78). He interweaves three strands: 'feminist communitarian'; 'literary and aesthetic'; and 'performative'. Three interconnected criteria shape feminist and communitarian representations of the world. 'Interpretive sufficiency' means possessing 'that amount of depth, detail, emotionality, nuance, and coherence that will permit the formation of a critical consciousness, or what Paulo Freire terms

⁵⁶ The most widely agreed upon characteristics of research are that it uses systematic and controlled procedures; that it strives for validity, rigour and logicity; and that it is driven by critical thought, objectivity, accuracy and repeatability (Freeman, 2015, 1).

'conscientization'.⁵⁷ Representational adequacy means being free of racial, class, or gender stereotyping. And authentic adequacy occurs when three conditions are met: the representation of multiple voices; moral discernment, and the promotion social transformation. The intent of these criteria is for texts to 'empower persons, leading them to discover moral truths about themselves while generating social criticism. These criticisms, in turn, should lead to efforts at social transformation' (Denzin 2014, 72).

3.6 The interface between arts-based research, autoethnography and practical theology

Arts-based research and autoethnography is an emerging force within practical theology (Walton, 2018). Heather Walton, for example, argues for autoethnography being 'a way of using personal experience to investigate a particular issue or concern that has wider cultural or religious significance' (2014a, xxxi). I consider that a combination of arts-based research, autoethnography and practical theology, who each seek a 'critical space' to see well, will ensure a congruence and a coherence within my way of being, way of knowing and way of enquiring. However, although they share values and worldviews, such as the intent to transform society for the common good, there are subtle differences between the traditions. Some arts-based researchers, such as Finley focus on 'performance pedagogy and political emancipation' (2011, 440), and as mentioned previously Leavy asks whether it makes a difference. And although autoethnographers, such as Tessa Muncey, hint at the spiritual dimension,

Writing that flows from the heart can transform experience into a state of bliss. The state of bliss, which gives potential access to the numinous or the spiritual in our lives, is something of a mystery to most people. It is captured in these moments when time appears to stand still, when we feel in tune with and inseparable from the universe (2010, 56).

Similarly, Denzin is attentive to the sacred:

⁵⁷ Through conscientization the oppressed gain their own voice and collaborate in transforming their culture.

A respectful, radical performance pedagogy must honor these views of spirituality. It works to construct a vision of the person, ecology and environment that is compatible with these principles. This pedagogy demands a politics of hope, of loving, of caring non-violence grounded in inclusive moral and spiritual terms (quoted in Walton, 2014a, 8).

I consider that the spiritual dimension of both arts-based research and autoethnography is undervalued; they lack a strong spiritual voice.

This issue for me is how to recover this? And here the insights of practical theology may help. Zoe Bennett, Elaine Graham, Stephen Pattison and Heather Walton identify core themes that thread their way through practical theology. The blurring of the boundaries between the sacred and secular; an owned spirituality; sacredness and sacramentality in all things; creativity; spiritual artistry and the process matters as much as the product (see Bennett et al, 2018). What they add to autoethnography is a sense of the sacred, the call of the other, the moment when the spiritual breaks in. This happens as reflexivity opens sacred horizons. A spiritual autoethnography creates sacred texts which emerge from the 'sacred spaces' where, as Bergmann says, 'God take[s] place' (Bennett et al, 2018, 4). This approach affirms my worldview of living a sacred universe (see McIntosh, 2016), and places the spiritual at the hub of the wheel. Other spiritual themes they identify are being rooted, changed, lost and claimed (see Bennett et al, 2018, 8-10). Human action and writing is redolent with meaning and expressive of deep values and action-guiding world-views: the material is suffused with signs of transcendence (Bennett et al, 2018, 30).

The choice of methodology in research is crucial to ensure its integrity. Choice is more than for pragmatic considerations alone. There is a 'swirling, mixing and mingling' diversity of inhabited worlds (see Bennett et al, 2018, 4). A mix of ontologies, the deep intuitive vision of what the universe is, and an eclectic variety of epistemologies, the imaginative ways in which people make-sense of that same universe. Specific choices of methodology and method, the angles of inquiry, 'reinforce and create ways of looking at the world as well as providing means of exploring that world' (Bennett et al, 2018, 132-133). Choice matters.

This section shows that there are many overlaps. Practical theology can learn from the creativity within arts-based research and that arts-based research can learn

from the spiritual turn in practical theology; the 'call of the Other'. By pushing the methodological boundary to embrace the spiritual turn in the research process I am re-engaging with the highly creative and potentially transformative world of practical theology which is my community of practice. Merging autoethnography and practical theology invites consideration of 'a spiritual autoethnography' whose task is to repair 'the sacred web of creation'.⁵⁸

3.7 Method in outline

The spiritual autoethnographic texts in the next chapter, which explore deep silences, follow a simple pattern, to offer some shape, but a light pattern, to allow for the inherent flow of arts-based research and autoethnography. Rather than being linear, the method is a cyclical, moving back and forth between experience and theoretical insights. Rather than being prescriptive, the inherent freedom in this method allows for generativity, of the new and not yet known. Rather than being forced, it takes time to allow evocative metaphors of deep silence to distil. Rather than being comprehensive, it allows for an accumulation of moments, or fragments, that delight in depth and vitality. Rather than presenting fixed absolutes, the handling and materiality, of encountering the sacred in deep silences, means that learnings are cumulative. This arts-based philosophy supports the following light pattern of inquiry.

- An image evokes the focus of inquiry.
- A brief introduction, supported by a quote, sets the scene.
- A story takes the reader into the deep silence.
- A poem captures my response to being in the silence.

⁵⁸ 'The task of the artist, he said, *is to keep in repair the sacred web of creation - that cosmic harmony of God and beast and man and star and planet - in the name of humanity, against those who in the name of humanity are mindlessly and systematically destroying it*'. Words in italics belong to George Mackay Brown, (quoted by Ron Ferguson, 2011, xxxiv).

Chapter Four: Spiritual Autoethnography

A note on confidentiality

This chapter is a series of spiritual autoethnographic texts about the nature of deep silences in end of life care.

Over the last decade, I have had privileged access to intimate space and deep silences of patients, families, and colleagues. The imperative to protect ‘confidences’ and keep ‘faith’ is captured in the Hippocratic Oath, which insists ‘whatsoever in the course of practice you see or hear that ought never to be published abroad, you will not divulge’. It is critical that I respect the trust with which people shared their stories.

I constantly wrestle with what can and cannot be said without betraying the confidence of anyone with whom I have encountered deep silences. The reflections that follow are all grounded in events within my clinical experience, but the patients and contexts are composite and disguised - any similarities that remain are coincidental.

The focus is on the nature of deep silences, not on myself or on others.

4.1 Traumatic Silences



Figure 7: Tree Rings

Traumatic events are extraordinary, not because they occur rarely, but rather because they overwhelm the ordinary human adaptations to life.

--Judith Herman (1997, 33).

Tree Rings. Exposed rings within a tree trunk trace the impact of the seasons, natural stress and extreme trauma on its growth. Invisible to the eye on the outside, hidden by protective bark, the impact often goes unnoticed.

This work traces the way traumatic memories are often buried in deep silence. Yet they linger, only to reemerge if a wound or a scar is reopened. In this case memories were triggered by an image of unconditional love. Mary's illness and childhood experiences silence her. Spiritual artistry enabled me to let go of a word-based approach and employ visual images to engage with her silence.

Alienation

Sometimes a shaft of pain comes down out of a tree for no reason at all. Sharp, diagonal, sudden out of a landscape, it finds the vulnerable bit to pierce into.

--Elizabeth Smart (1991, 112).

Mary manoeuvres slowly, silently, like a submariner in deep waters. Inch-by-inch soundings take her past circled chairs, chinking cups and chattering voices. In/visible. Overwhelmed by her porphyria.⁵⁹ The *Solas* lounge is bustling.⁶⁰ The staff here, observes an astute visitor, 'bring life to days'. Ladies discover their colours. Gentlemen break sweat in the gym. Jenny bends, touches and inhales the lavender. Not much lingering on here. Except for Mary. Silenced. Not so long ago Mary was the life and soul, but now is virtually imprisoned in her body. Numb. Little power, limited energy. Either bed-bound or wheel chair bound, overwhelmingly fatigued, unable to comb her hair or brush her teeth. Hiding under a carapace. Silent.

Travail

Edging her way into the conservatory, she spins like a ballerina in slow time, breathes and smiles. The morning sun breaks through the trees, highlighting the contours of her face. We've started coming here. A haven. Bird song and dappled light. I reach over to help her with her straw that bends out of her plastic drinking mug, place it in her mouth and she relishes some iced water.

I wonder how she is doing this morning. But I sense a hesitancy. A reluctance. She had asked the nursing staff if she could speak to me but the silence lingers. Long

⁵⁹ Porphyrins are critical for haemoglobin and are generated in the body by a series of specialised enzymes that work together like a team of scaffolders. If one of those scaffolders doesn't work properly, porphyria is the result. Part-formed rings of porphyrin build up in the blood and tissues bringing on 'crises', which can be occasioned by drugs, diet, and even a couple of nights of insomnia. Some porphyrins are exquisitely sensitive to light and some types of porphyria lead to a blistering inflammation on exposure to the sun, with consequent scarring. The build-up of porphyrins in nerves and the brain causes numbness, paralysis, psychosis and seizures. (See Francis, 2018).

⁶⁰ Solas is a Gaelic word which means 'a place of light, a place of solace, a place of comfort'. Solas is the name given to the day and community services in the hospice, to represent a locus of (spiritual) care.

enough for me to wonder, 'Her smile is a mask. She's hiding something. Dissonance'. But I've no idea what. We sit for what is an age. Still silence, just the bubbles rising in the fish tank. I don't know where to start, so I wait. The violinist Yitzak Perlman's hopeful words to 'play with what remains' in Mary's case seem cruel and contrary. I can't imagine any music playing in her life, major or minor, melody or harmony. The greatest gap, says the psychologist William James, 'that exists in the universe is that between one human mind and another.'

The gap is silence.

Testing the silence

but the sudden illumination

We had the experience, but missed the meaning,

And approach to the meaning restores the experience.

T.S. Eliot (2001, 26).

I wait some time longer; trusting the silence. Still nothing. Eventually, she whispers, 'I'm lost, lost for words. Not like me, is it?'

'That's OK ... sometime words ... just have nothing to say ...'

And I wonder how do I help Mary find meaning, how do I help Mary rise? Still I rise.

Leaving behind nights of terror and fear

I rise

Into a daybreak that's wondrously clear

I rise

Bringing the gifts that my ancestors gave

I am the dream and the hope of the slave.

I rise

I rise

I rise

Maya Angelou (1995,164).

Time stands still. Then I risk another tack. To break the silence. If or when words fail.

Filling the silence and space, not with intrusive words, cleverness, negotiated meanings, but playful images. I scatter some picture cards across the table and ask, 'Anything here ... catches your eye?' It's her call! And I think it catches her off guard.

Mary pauses, looks at me, the cards, back at me, then shifts her fingers on the control knob of her power chair, and it moves round a fraction. Casts her eye over the images.

After a full minute, extends her finger, pointing, 'That one's lovely'.

She picks out a puppy, 'unconditional love'.

She breaks the silence.



Figure 8: the image of unconditional love

Discovery: trauma lingers

The storm is gone, but the “after the storm” is always here.

--Deacon Julius Lee, New Orleans (Quoted in Rambo, 2010, 1).

I now have a starting point. An image of unconditional love.

I wonder but I don't yet understand.

Do I dare risk intrusion?

“Is it unconditional love that you're longing for?”

After the silence, tears flow.

And a tentative voice sounds. Then memories flood out.

‘My best friend at primary, hailed from Ardnamurchan. Spent her summer days at Sanna, swimming in the Atlantic, and whenever she got cold, ran into the shawl that her granny held out for her. How I long to be wrapped in a tartan shawl.’

I am about to learn that today is sixty years ‘after the storm’. Trauma lingers long. Trauma pierces when least expected. Trauma silences.

Mary continues, ‘I was shunted off to my grandparents, who had little time, money or interest in an extra mouth, an unwanted intrusion. After school, it was ‘get yourself’ changed, fold your clothes neat and tidy, off you go and play at the swings.’ But the love offered me there by a park attendant, and where he laid his hands, are locked away in a cold vault, never to see the light of day. And then my first man loved the bottle too much and hit me. And now, no matter what, no matter how many folk love me, it's the ‘unloved me’ I still see in the mirror.

A single image of a puppy with loveable brown eyes which has chosen her, opens the flood-gates. Tears, memories, tragedy.

And in the silence of the room. This wound, this piercing is beyond fixing. Demands listening. Witnessing. So, I stay still. I stay silent.

And in holding my silence, I discover her turning point: 'unconditional love' ... 'it's what I long for'.

And I am drawn into her whirlpool. And now I understand her funeral song, 'Chiquitita'.

Mary is enchained by her childhood trauma. Memories, emotions repeating like a stylus caught in a groove: 'Chiquitita, tell me what's wrong. You're enchained by your own sorrow. In your eyes, there is no hope for tomorrow'.

Treasure and transformation: the lens of trauma

Trauma is extraordinary. Often lying outside the bounds of normal human experience. Like a tidal wave, it overwhelms the ordinary adaptations to life. Yet often trauma goes unnoticed. Trauma ruptures, disorders, silences.

I see Mary in a new light. And remember Michael Paterson: words to allow the silenced to rise. It's as if you are 'blowing a butterfly off your sleeve'. Strong enough to move it, gentle enough to not cause any harm.

Preserve the sacred silence of trauma.

And I wonder about the holding silence, who allows butterflies to fly.

Unconditional Love

Every silence is my first silence.

the loss of my mother
my home
my childhood innocence
my scars
my ravaged body
bloodied
longing to be held

every silence screams out
for what?
for unconditional love
for listening
for witnessing
what no one should ever see
never.

every silence lingers
loiters
waiting
preparing

out of nowhere
numbing
freezing
fleeing
fighting
disrupting

every silence
every piercing
longs to be healed
sculpted
shaped anew

but how
by the first silence

the first silence
alone
holds
heals
my every silence.

--Ian Stirling

4.2 Shameful Silences

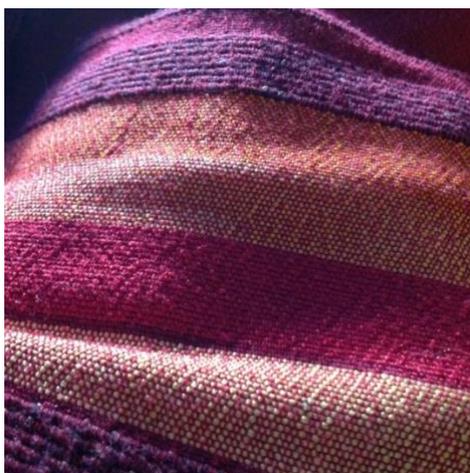


Figure 9 Moroccan Cloth

Soft, woven Moroccan cloth is a covering which warms a person in the chill of the night and protects a person from the intense midday sun. The word ‘palliative’, which comes from the Latin ‘*pallium*’, meaning ‘cloak’, allows for an understanding of palliative care as an activity which hides, conceals and disguises. The shamed, who fear unwanted exposure hide behind cloaks and bandanas.

Whoever rightly understands and celebrates death, at the same time magnifies life

--Rainer Maria Rilke (Quoted in Gordon, 2018, 3).

My intention in this short spiritual autoethnography is to rightly understand an aspect of dying and thereby magnify life. Cicely Saunders argues that the one thing that matters in dying is to be recognized as the person you are: ‘you matter’. Yet I wonder whether Cicely’s ideal rests on a disembodied conception of dying. If the non-negotiable bodily realities of dying are covered up, and hidden beneath a palliative cloak, then this is problematic. This work unsettles this understanding and illustrates how the in/visible dirty dying and un/bounded body is unwanted and often shames a patient into silence. Unwanted exposure. This shame goes beyond gender, beyond sex, and excludes and silences people, even within hospices. Shame emerges as body fluids leak, as the intimate is exposed, and as hair is lost. I wonder whether this means that we fail to see the sacred. I locate the sacred in Alison’s lumpy scalp and in a haircut; in a hesitant touch and a saving

gaze. Intentionally, I only include Alison's words in the first two sections. The poem shows how my encounter with Alison re-imagines my own outlook to shame.

But what a daring thing to do, God: to make such a flimsy, vulnerable, decayable, corruptible, demanding delicate casing for the soul (spirit).

--Elizabeth Smart (1991, 90).

Shame is a wound felt from the inside, dividing us both from ourselves and from one another.

--G. Kaufman (Quoted in Pattison, 2000, 1).

Bandanas

Visiting Alison for the first time I never knew what to expect. Her home is chaotic. Scattered clothes, dishes lying everywhere, people coming and going, mobile phone going off endlessly. Never a moment. She's dropped her boy, David, off at the local primary school, and her toddler, Chloe, is now sleeping upstairs. So, she offloads it all: 'I'm knackered, I'm frightened, strained'. Her former lover, and son's father, is still dealing drugs; she's all at odds with her current partner, not yet revealed that he isn't her daughter's father. But it takes her fifty minutes of talking before finally she slows down, quietens, and after a long silence finds the confidence to speak about what really matters.

Scene 1. At home.

Alison: Can you refer me to get some bandanas?
I got my wig last week from the hairdresser.

I'm going to go up later this afternoon
to get all

all my hair cut off

It's falling out

in clumps

I had so wanted it to last till the next treatment
But over a week to go
it was all over my clothes,

all over the floor

I've picked up some

and put it in a wee box,
to put in my memory boxes,

so that the kids

know what my hair was like

I hide behind my hair

My eyes are darker ... I think it's the medication

I spend hours sorting my hair in the morning
Run down the stairs
Then I'm not happy with it
So, I'm back upstairs
straightening it
Drives Pete mad cos he says
"It's just the same ... I can't tell the difference!"

I am as low as I've ever been.
I'm just trying to be strong for my mum and dad

Been waiting since 9am for the district nurses to come
2pm and they phone to say that they're not coming,

the Beatson doesn't want them to take bloods
and they will flush out the pic line on Thursday.

It's good to be able to have a rant and a rave
I feel comfortable with you

She glances at the floor:
Can you feel the lump in my scalp?

I move across her lounge, she removes her wig, I lay my hand on her head, and feel the curve, and the heat, and touch the cancer. In that moment, that touch, the distance between us vanishes.

Scene 2. In the salon, with our hairdresser Susan.

I open the door to welcome Alison and her mum (not sure that I was expecting her mother).

Then introductions to Susan. Susan is our hairdresser.

IRS: Come in. Can I take your jacket? Do you want a cup of tea?
Thanks

IRS: I fetch tea and two coffees, milk and two sugars

'Clap your hands' comes the cheery call across the room as I bring the cups in.

Then as soon as our eyes make contact, the tears flow

**I'm going to be a baldy
ugly ...**

Alison sits there facing the mirror in the salon, bright lights illuminating all her facial features. She's wearing a pink bandana, wrapped and draped down, silver ring holding it in place. I think 'Stunning, elegance, fashion sense' yet the lump on her scalp, my heart felt in her home, remains.

Then says Susan, "Try tying it like this, and you can have a fringe

Alison is silent.

What about the purple and mauve stripe?

Alison is silent.

The red?

Alison whispers, “No! I'm not a red”.

Silence descends into the room

Susan like a magician, brings out another from her bag of tricks.

Oh, that's beautiful I love it, dreadlocks silver and blond ... I never wear my hair up

What about a night hat?

Then Susan brings out the wig ... Shapes it and tighten net, combs it

The chat is slowing. Alison is just breathing and looking at the mirror.
Relief.

**I am so glad that I called you
I am so glad I came here**

Scene 3. The scissors

Susan, moves around the chair, opens a drawer, and takes out silver scissors. She catches Alison's eye, which shifts from mirror, to scissors, to floor and back to Susan.

Are you ready?

Are you happy for me to cut your hair?”

**No. I'm not happy ... but it needs done.
I was always wanting to keep hold of *it*, as long as I could
but it has been torturing me
better to get it off
then I can get on with the next stage**

Starting at the back

Susan combs Alison's hair smooth,

lifts her hair, slowly in her hand

up,
away from her neck
and cuts

and then takes a razor
and shaves
moving over the curve of her scalp

Sitting at the back of the salon.
Watching closely every move, the ritual carefully choreographed,
The distance between the three of us vanishes.
My in(visible) tears flow in the silence
As the shame is exposed.
And I compose a poem
to take away the shame

*bandana**IRS to AJS*

If you ever need me to ...
I will cut your hair ...
I will take my time to wash it first,
then comb it
then massage your scalp,
then slowly starting at the back snip and snip and snip

and
your dark locks will fall silent onto the kitchen floor
dark slate catching strands of beauty ...

And I will catch your diamond tears
and
I will hold your firm in an intense hug that lasts for an hour

Then we will face the unbearable
and
gazing into your eyes
I will cut your precious locks

The locks that won my heart those years ago,
the first thing I ever noticed about you,
and I will cut them off slowly to make
the transition
the shift from this beauty into the next ...

And I will cut them
it is for me to do
this my gift to you

4.3 *Communication Silences*

Waiting for the fog to lift



Figure 10: Market Day

The ability to communicate and to socialise lies at the heart of all humanity, and yet in illness, old age and end of life care the onset of dementia, or neurological wear and tear of any description can silence the conversation. When this happens the gift of friendship, with one another, with time, with memory is invaluable.

The picture is of a social gathering on market day in Pollença, Majorca, where the ‘old worthies’ of the town drink coffee and watch the world go by.

But these people remain tightly held within the memories of God

--John Swinton (2012a, 15).

We are not called by God to do extraordinary things, but to do ordinary things with extraordinary love

--Jean Vanier⁶¹

⁶¹ Cited by L’Arche UK, on 30 September 2017.

<https://twitter.com/LArcheUK/status/914145788728676354> Accessed 11th September 2018.

This spiritual autoethnography grapples with the vast silences that come in the wake of the neurological wear and tear prevalent in end of life care. For many this is a living death. The loss of voice and memory. A silencing. And a longing for what once was. Time lengthens and long silences linger. But for a few who focus on what remains, and re-frame what it means to be human—in relation—discover that even though a man or a woman's former self vanishes before their eyes, still they can be held tight in the ordinary gestures of life and love. This 'musical composition' takes the reader from a silence to a story, to a song to a sacred moment. And illustrates how music can break the silences.

Scene: Geordie's bedroom in the hospice

A shock of grey hair, bushy eyebrows, and light blue eyes is sat motionless in the corner. Staring into space. All a canker. Bent double with years of potting delphiniums, and digging up prize leeks. Geordie's allotment, a breathing space away from the pit. A haggard face, I think, underneath the cap, which he still wears at an angle. Age spots and deep crevices. Geordie has done the rounds, of 'head to tail' sleeps with his four brothers in the family's butt and ben, National Service earning the King's shilling, holding his own on the fitba' park, with the scars on his shins and no medals to show for it. And now he sits, so still. Like a Henry Moore sculpture. No signs of life at all, just breathing, just, as I edge closer and introduce myself, 'Hi, my name is Ian.'

Geordie's room is bare, folded pyjamas, neat on the pillow. Single vase in the window. Only the one sepia photo of his wedding day perched on his locker. Standing tall and proud in his squaddie's uniform, Florence, on his arm, leaving the church. Not many clues here, to who the man was or is. But most of all his room is a silent chill, and Geordie an iceberg floating off the Newfoundland coast.

And in the silence of the next ten minutes, I wonder 'How much of Geordie is still here?' When body and mind wear and tear and crumble. For a second I swap seats and I wonder 'Who will tell my story, when I have forgotten who I am?'

I turn, as Florence, Geordie's wife, walks in. She spent an hour with me yesterday, in tears and in smiles, filling in the 'This is me' documentation. Not an easy thing

to do, but the 'This is me' gives the team an inkling of what matters, who matters. And it makes all the difference for negotiating silences.

'If there was a table to dance on, he'd be the first on it. If there was a job to be done down at the allotment, he'd have his sleeves rolled up. And come back with the barrow laden. Every Friday night, the wage packet was on the table.

I've been thinking more about our chat yesterday. I forgot to say that Geordie and his brothers, you know they loved their football. But the thing was they followed different teams. What a laugh, especially on a Saturday night when the scores came in. I've a photo, here in my bag. See, there's Tam wearing the blue of Rangers, Sandy, in the middle, with the green of Celtic, but for Geordie, it was the deep maroon of Hearts.'

Connection!

Being a Jambo, a follower of his team, I immediately found myself humming, and then singing the song which has captured the hearts of the Tynecastle crowd for generations.

This is my story this is my song

Follow the Hearts and nothing can go wrong

O some say that Celtic and Rangers are grand

But the boys in maroon are the best in the land.

I wasn't prepared for what happened next. For a moment, as if the fog lifted, Geordie opened his eyes, turned his head and hummed along. The fog lifted and he was playing extra time.

As I left Geordie's room, I made my way down the corridor to my office, a story came to mind of Yitzak Perlman, the Israeli violinist, who had polio at the age of four and had to wear leg braces from then on. Undaunted, he became a virtuoso. Once, so the story goes, he walked out onto the concert platform to play a concerto. Laying down his crutches, he began tuning his violin. But there was an

audible twang as a string broke. Everyone thought he would send for a new string, but no, instead, he indicated to the conductor to begin, and Perlman proceeded to play the concerto entirely on three strings. After receiving a standing ovation, his one comment was ‘our task is to make music with what remains’.

Making Music⁶²

I thought this was yesterday.

let me count the ways I’ve lost you,⁶³
 after your days lost their clarity.
 empty eyes, vacant expressions, a stony face
 aggression sniping away at all the rough edges.
 wild accusations.

*It’s like being on a long road
 getting further and further away from myself.*
 catch the moments as they fly
 make music with what remains before your small
 blue boat slips its moorings and floats
 into the grey mist never forget the thrill of being alive.

I’ve reached a stage where everything is nothing.
 where do your memories now reside? of,
 winter snow whirls sliding down bannisters
 husky harmonies dazzling smiles
 which no longer flame out
 like shining from shook foil.

I’m disconnected.
 confabulation
 a muddle of words

*I’m scared of the unspoken
 of not knowing what’s going on*
 but music the first sense in the foetus
 the last to go at death your soundtrack your

⁶² I am indebted to Sally Magnusson for the inspiration for this poem, which collates together fragments of *Where Memories Go*. This memoir, of living with her mother Maimie’s dementia, resonates with the silences faced by hospice patients who have dementia. The words in italics are Maimie’s; and several phrases in the poem are taken either from headings* or Sally’s own words. Sally’s appreciation of how music influenced her mother’s mood, awareness, cognition and sense of identity has led to the setting up of UK charity Playlist for Life. Constructing and then delivering a playlist to someone with little memory requires talking, listening, finding out, trying out and observing; it demands personal interaction of a kind much needed by people at every stage of dementia (Magnusson, 2014, 377).

⁶³ In 1901, August Deter described her existence to Alois Alzheimer in this way, ‘I have lost myself’ (Magnusson, 2014, 59). It is from his analysis of Deter’s brain and ongoing research that he identified the illness named after him, Alzheimer’s. ‘Dementia was first coined by Philippe Pinel in 1797, taken from the Latin *de mentis*, ‘out of one’s mind’ (Magnusson, 2014, 76).

playlist of life
is still going strong.
In music, as if in amber⁶⁴
your silent self
is nudged back into the light.
melody, harmony, lyrics, rhythm
jazz, folk and blues
reawakens your soul.

--Ian Stirling

⁶⁴ Magnusson quotes Oliver Sachs as saying, 'the past, which is not recoverable in any other way, is embedded in the music as if in amber' (2014, 280).

4.4 *The Silence of Betrayal*



Figure 11: Constructing towers

The trust that sustains the therapeutic relationship is built up carefully over time. Every moment consolidates, witnesses what is happening and creates safety. It only takes one misplaced word or conversation for the tower to come tumbling down.

I know all the theory of everything but when I paint

I don't think of anything except the subject and me.

--Alice Neel (2016)

The encounter with the widow, stranger or orphan is simultaneously a human ethical relation and an intrusion of a hidden/revealed Other who always/only comes through this sacred, proximate encounter:

The Justice rendered to the Other, to my neighbour, gives me an unsurpassable proximity to God ... One follows the Most High God, above all by drawing near to one's neighbour, and showing concern for 'the widow, the orphan, the stranger and the beggar.

--Emmanuel Levinas (quoted in Bennett, et al. 2018, 53).

The tendency in spiritual autoethnography is to sculpt positive memories. However, to avoid the complex or broken dimensions of spiritual care threatens balance and composition. This brief work reflects a difficult moment in the trust between myself and Jane, a family member, whom I supported through her husband's illness, death, funeral and bereavement. I strived to build confidence with Jane over months, but this was shattered in one single day, by sharing confidences about suicidal ideation with the wider healthcare team. Reflection on the power dynamics, and on my identity as a holder of confidences, has led to a change in my practice.

Shattered silences: A conversation and a relationship 'spiraling out of control'

Scene 1: Funeral text.

Life is eternal and love is immortal and death is only a horizon and a horizon is nothing save the limit of our sight.

Scene 2: Bereavement follow up telephone call

IRS: How are you feeling?

Jane: I'm just missing Colin so much, we got on very well together. I'm hurting like hell inside.

Ever since Colin died. We had made a suicide pact.

Suicidal thoughts are there all the time ... when I'm going to bed.

But there are various things I want to settle first, personal letters, tidying up the house, the loft to clear out.

I'm being rational.

If and when! It's my decision.

And I don't want any medication or anything else.

IRS: How best can I care for you? Where are the tablets?

Jane: In my bedroom. I've thought about it before but just lacked the confidence to go through with it. I wasn't sure if I had enough tablets. If I'd wake up.

IRS: Who is there for you?

Jane: No-one.

I can't be bothered. I've had enough with the system. I don't want counselling. I don't want to talk to my GP. When Colin was diagnosed with pancreatic cancer, Colin imploded, ran out of the surgery and self-harmed. There was little support for him, no matter how loud I shouted out for it.

IRS: Jane, I know how difficult this is for you, and it sounds as if you are at the end of your tether, but it's my duty of care, as part of the hospice team, if anyone shares suicidal ideation, I have to share the information with others who can be there to help you.
I have no option.
I need to share this information with your GP.

Jane: I'm not being irrational, if I intend to do this it is premeditated. It's nobody's fault if I decide.
Don't talk to him.
I'm not going to mention that; I shouldn't have said it ... it's something I've got to decide for myself ... I'm not going to mention it to anyone.

Scene 3: Evaluations

Adverse Incident Report:

The Hospice Chaplain did fulfill his duty of care in line with the *NHS Scotland Code of Practice on Protecting Patient Confidentiality*. However, the role and responsibility of the Hospice Chaplain was not made explicit at the outset of the professional relationship, or during any face to face or telephone conversations.

Jane: He was reckless.

Hospice letter:

His actions were well-intended but misguided.

My letter:

I sincerely apologise for my part in the process and for how I have let you down and broken your trust and confidence ... and while I may not be able to repair the hurt I have caused you I trust that I may do better for others in the future.

Jane's text:

I av no bad feelings 2wards u at all - just hurt as it was, and is, a very sensitive time 4 me ... So sad and sorry at what has happened.

GP letter:

There is nothing in my opinion, that suggests that Jane is at high risk of suicide.

Scene 4: at my desk

There are no unsacred places;
There are only sacred places
and desecrated places.
--Wendell Berry (2018, 101).

Those who are unhappy have no need for anything in the world but people capable of giving them their attention. The capacity to give one's attention to a sufferer is a very rare and difficult thing; it is almost a miracle; it is a miracle
--Simone Weil (in Pembroke, 2017, 70).

I wonder how to preserve sacred silences. I write a poem, *The Saving Gaze*.

The Saving Gaze

I'm learning
to look with a soft gaze
scanning
wound, scar, disfigurement
just
in the passing,
a glance
rather than a stare.

A stare does not see

you see
the one who sits
before you

the other who is you.

I'm learning to listen
with a still mind
for difference and sameness
listening to
inner voices, speech
that ebbs and flows

in silence

I'm learning to look with my heart
a sacred reflection
in the brokenness
in the darkness
in the spaces
between you and I
that merge into one

I'm becoming skilled
in sacred gazing
in seeing you and I
in the Other.

I'm learning to preserve the sacred silences

Ian Stirling

4.5 Grieving Silences



Figure 12: Clock face

The clock face on Grasmere church marks the passing of chronological time, which differs from the cycle of the seasons, as represented by the shadows of bare trees, and differs from the sense of time in grieving. Sometimes a sense of the sacred happens as time stands still.

I'm really getting depressed and angry and in a muddle.

--Cicely Saunders, describing her complicated grief (in Clark, 2018,124).

Grief reconfigures time, its length, its texture, its function: one day means no more than the next, so why have they been picked out and given separate names? It also reconfigures space. You have entered a new geography, mapped by a new cartography. ... you lose the sense of your existence ... you feel absurd.

-- Julian Barnes (2013, 84).

This short spiritual autoethnographic work explores the silences of grief. I take the reader on a journey into moments when time stands still, to a cathedral where faith collapses around someone's feet, like a shattered window, to kitchens, bathrooms and bedrooms where people wrestle to put the pieces back together again, and finally to a blank page, where margins speak louder than words. I offer not the security of a safe arrival, but a hopeful journeying. Carve the runes and

trust that in the silences the sacred is there. In chaos, confusion and uncertainty, the spiritual breaks in.

Scene 1: Time stood still

Avril: I think I told you before ... I had another child ... I had been working for months with children with leukaemia ... so they, the doctors, just thought I was being over anxious ... but I knew. Something wasn't right. Sometimes mothers just know ...

It's 21 years on Tuesday ... ritual? Mmh!
I thought that I had got over it ... but the memory and emotions are still with me

Still born ... I don't want to talk (silence)

Silence

IRS: Sometimes the time just isn't right to share. Or when you do, what you share, which means the world to you, is just lost on others. Last week, Christmas Day, Mandy was in tears, sharing Michel Faber's poem, 'Risotto', hurting after his wife's death ... 'Today I took out your last risotto / and savoured every swallow, / every grain of what was once / a storage problem, / and how I wish there was enough / for more.'
I was in tears, the kids got it, but not everyone did.
Sometimes I don't want to talk.

Silence

Avril: The delivery went on for three days ... John was there ... surrounded by staff going in and out
I couldn't hold her, I had already carried her for nine months ... silence ... just couldn't bring myself to. I was exhausted.

But I found myself in the room with Eilidh, and there was a moment, something, ... felt a peace. Time stood still.

I wonder whether it'll only be when I die, that I'll be able to hold her now.

Scene 2: It's my faith that got me through.

Shona: When I started out as a nurse, up in the Victoria, I never imagined myself working with the dying. But the twists and turns eh!
Here I am thirty years on, in with the bricks.

I never imagined working with the bereaved, or with the Red Cross, being called out in a crisis, to offer counselling, last time it was the explosion in Glasgow ... horrific.

I suppose I've come to being able to live with dying, live with grieving. Cuts to the core.

It didn't come easy.

My own baby, my own son, Charlie, died.

I was distraught. For years. Lost. Lost my faith. Couldn't even mention his name without bursting into floods of tears. I can now.

I distinctly remember, as if it were yesterday, a year after he died being down in Yorkshire on holidays. I wandered into York Minster and stood under the immense Rose Window. The light shining through the glass.

And suddenly, and this sounds strange, I was the only person there, and the whole window had fallen in, the stained glass shattering on the stone floor, and me on my knees, screaming out, and touching the shards, the fragments ... thinking there is no way I can put it back together again.

But you know, over the years, it's my faith that's got me through.

Scene 3: Ten thousand shards

Soon afterwards. Early in my research, still wrestling with the impact of Dunblane and my father's death, in a moment when time stood still, I wrote this poem. It captures a slice of time—my understanding of dying, death, grief and faith, as it was then. I handle softly Shona's metaphor of a shattered window. But where Shona, in time, restores the window and holds onto her faith, for me, in that intense moment, a shattered stain glass window portrays the seeming impossibility of putting my life and faith back together again: 'ten thousand shards of broken beauty where once I saw her face'.

ten thousand shards
(The Rose Window, York Minster)

once in yesteryears
my sparkling eyes would lift heavenwards
the alluring radiant colours of coherent faith captured safe
in lead and glass and sacred architecture

now within without I gaze intently into a darkened abyss
the glaze of her absence
ten thousand thousand shards
of broken glass scattered at
my feet, cradled in my bleeding hands, cutting my heart
each an intimate memory.

there are no tomorrows
for
how can I ever piece together the fragments of her life
my faith
once a beautiful rose window
whose light attracted my lasting love and eternal gaze

on this melancholy day I can do no more
than stay in the shadows of swirling grief
once more I lower my eyes
ten thousand shards of broken beauty
where once I saw her face.

Ian Stirling

Scene 4: a hole in my window

Laura: It's when I go into the kitchen and see the baking tins, empty on the shelf; or climb the stairs up into the bathroom, she'd spend an age in the morning getting herself ready for work, and see her hairbrush still lying in front of her mirror. I haven't been able to move a thing. Or I go into her bedroom, lie on her bed and cuddle her pillow.

IRS This is a poem I wrote after Shona shared her story with me ... Ten Thousand Shards, 'broken beauty where once I saw her face'.

Silence

Laura: It's lovely.
But I for me, now ... I can't see any beauty. I'm not even sure I can see Claire's face anymore. I'm scared its fading away.
For me there will always be an empty space, a Claire shaped hole in my window.
It'll always be there, it can never be filled.

Silence

Scene 5: The truth of this silence is not easy to write.

I gaze at the blank sheet of paper, pencil in hand.

I sketch, scribble, circle, trace and throw words which are at breaking point onto the page.

And I think, 'The truth of this silence is not easy to write'.

Grieving silences. Witnessing. What is it to compose sacred grief? I wonder whether Frances Young has her finger on the pulse,

God 'is the ocean of love that can absorb all the suffering of the world
and purge it without being polluted or changed by it'.

But as soon as I hear myself saying her words I fall silent again.

How hard to bring the silencing of grief into speech?

And as a consolation, I am reminded of the ending of one of George Mackay Brown's poems, A work for poets,

Carve the runes

Then be content with silence.

So, I write my silence, a silence in the lona wave, that sustains me in all my unknowing, and in all my grieving.

St Columba's Bay, Iona 25th March 2017

the waves surge
 ocean depths
 flowing
 into the cobbled beach's
 welcoming arms

S.	P.	R.	A.	Y.	I.	N.	G.
C.	R.	A.	S.	H.	I.	N.	G.
E.	C.	H.	O.	I.	N.	G.	

then standing still
 against the westerly
 I wait
 longing for the

s i l e n c e
 .
 .

before
 once more
 marble
 stones collide

S.	H.	I.	N.	G.	L.	I.	N.	G.
E.	B.	B.	I.	N.	G.			
F.	A.	D.	I.	N.	G.			

this is the breathe
 pulse
 rhythm
 of life

I'm held in rapture
 standing on that shore

surge	...	silence	...	shingle
surge	...	silence	...	shingle
surge	...	silence	...	shingle

holding the universe
 holding me
 in place.

Yes, the truth of this silence is not easy to write.

Ian Stirling

Chapter Five: Deep Silences



Figure 13 Entangled

Deep silences are not neat and tidy, rather they are frayed at the edges, and worn.

Contemplative inquiry begins by paying attention, by looking and listening longer than I would normally allow myself, and by allowing my mind and heart, cognition and affect to be expanded by the world of possibilities and of multiple meanings (Paterson, 2016, 29).

Each section in this chapter on deep silences begins by highlighting what challenges my spiritual autoethnographic texts raise about each differing type of silence. I first record what I see and what I wonder about, and then draw on wider literature to enrich my understanding. Here I am indebted to the insight of Michael Paterson, whose interpretation of John 20 has gifted a contemplative model of spiritual care to chaplaincy. This way of seeing situations afresh has informed my reflective practice for almost a decade, and now guides this interpretive chapter (see Leach and Paterson, 2010, 36-41; Paterson and Kelly, 2013, 51-68). The template is based on the three levels of seeing in John 20, reflected in three different Greek words, *blepo*, I see, *theoreo*, I wonder, and *horao*, I understand. Each word represents a deeper level of insight.

Three levels of insight

1. *Blepo*: on the surface. I see the silences just as they are. 'I see' is the first level of seeing and works with the incontrovertible, the facts of the matter. I see, what is right there before my eyes in the silences. This level of seeing is sometimes neglected since it appears to be too simple and offends the need to appear sophisticated. But being able to state the obvious can result in a breakthrough of insight.
2. *Thereo*: being curious. Wondering is the second level of seeing and focuses on whatever arouses my curiosity in the silences. Deep silences provoke my imagination and cause me to turn things over in my mind. Wondering is not the same as interpreting. Whereas interpretation tells people what they *should* be thinking, and constricts the imagination, wondering opens horizons and enlarges the space for exploration.
3. *Horeo*: depth of insight. 'I understand', I get it now, is the third level of seeing and focuses on making connections between the deep silence and the literature. It's about making connections between my experience of silence, myself, my values, wider wisdom and God's presence and absence. It looks for the penny to drop, for things to fall into place, the fog to lift and clarity to dawn. Deeper understanding of the nature of deep silences enhances faithful practice.

The final turn to literature prepares the ground for introducing further theological reflection which may offer new understandings of deep silences.

5.1 Traumatic Silences

Reflecting on this text I see three key elements which describe an intensity, sufficient to locate Mary's experience in the field of trauma rather than the suffering I regularly encounter. The first is that Mary is overwhelmed and drowning, but it is not so evident why, which makes me wonder, 'What is the focus, or trigger of her suffering?' The second is the long silences which convey that, despite asking to see me, Mary lacks a voice to express herself, which makes me wonder, 'How can I connect with her in a creative way to break her silence?' And the third is that the visual image triggers Mary's past comes to surface like

floodwaters. Her storm lingers, which makes me wonder, ‘How can I hold her and heal her?’

Insights from ‘trauma literature’⁶⁵ offer a deeper understanding of the conversation: of what was happening to Mary, and to myself. These now inform the way I handle silences and hint towards innovative ways to deliver spiritual care. The first is the need to establish a sense of safety. And the second is recognition of the limitations of narrative models or redemption models of spiritual care. I turn to trauma theory because it resonates with my sense of Mary being overwhelmed, lacking voice, and relates closely with the content of her words, as she teased out why she felt ‘unloved’.

Trauma begins with an event or series of events that are too much to bear. The experience is beyond the “edge” of what is possible to perceive and respond to, beyond what we are able to include in our identities, as individuals or communities. (Arlene Audergon in Rambo 2010, 18).

Judith Herman’s (1997) *Trauma and Recovery*, Bessel van der Kolk’s (2014) *The Body Keeps the Score*, and Gordon Turnbull’s (2011) *Trauma: From Lockerbie to 7/7: How Trauma Affects Our Minds and How We Fight Back*, clearly convey that while adversity and stress are a normal and natural part of human life, trauma is extraordinary, often lying outside normal human experience because trauma overwhelms the ordinary human adaptations to life.

The piercing of trauma leads to three symptoms of stress: ‘*hyperarousal*, reflects a persistent expectation of danger; *intrusion* reflects the indelible imprint of the traumatic moment; *constriction* reflects the numbing response of surrender’ (Herman, 1997, 33-35). In turn, the physiological response, ‘characterized by an increased heart rate, increased breathing rate, increased metabolism, increased oxygen consumption, and increased brain wave activity’ mobilises a fight or flight response (Fricchione and Nejad, 2012, 367). Or, if neither of these are possible, then freezing may occur. In freezing people may become numb, time may slow

⁶⁵ There is a lack of consensus concerning a definition of ‘trauma literature’. It ranges from first-hand experiences, such as Joan Didion’s (2005) *The Year of Magical Thinking*, which describes traumatic grief, to novels, such as Elie Wiesel’s (2006) *Night* which witnesses an experience of the Holocaust, to trauma theory, which is an interdisciplinary approach, embracing disciplines such as psychology, humanities and theology to model the process of trauma (see Rambo, 2010, 2017; and Turnbull, 2011).

down, and the mind may dissociate from the body. In such situations memories are fragmented, chaotic, repetitive and non-linear. This embodied response to trauma significantly affects the capacity of people to make sense of the experiences they are facing.⁶⁶ They are silenced. And long for safety. This description of traumatic stress resonates with my memory of Mary. Something was happening, something lingering from her past, which was hidden, and un-uttered, yet clearly having a profound impact on her behaviour. Trauma therapy emphasises the provision of safety. For real change to take place, people need to believe that the danger has passed and to live in the reality of the present. But even if a sense of safety is created, unless this happens very close to the trigger moment, recovery is rare. In most situations the memory of trauma lingers, is hard-wired into our brains, and narrative therapies to re-vision what has happened inevitably fail.

‘The study of trauma is the study of what remains’, of when, in Paul Celan’s words, ‘the world is gone’ (2010, 15-21). Shelly Rambo describes how trauma threatens meaning-making therapies by disorienting time (‘distortions in time constitute the wound’); living in the body, which ‘experiences trauma in ways that escape cognitive functioning and awareness’; and affecting the ability to communicate using words, with a ‘loss of one’s ability to register the event’ (2010, 19-21). Trauma is often embodied rather than articulated. What this means is that words alone cannot articulate the depth or content of trauma. These features of trauma raise considerable challenges for spiritual care. This is because the past does not stay in the past but is re-enacted in the present, and there are two clocks, the first of the real world (chronological time), and the second, the world of trauma, where time stands still (kairos time), this means that there is a non-linear temporality to trauma therapy. This impacts on more traditional meaning-making therapies which rely on the construction of linear narratives founded on memories.⁶⁷ Memory processing too is affected by anxiety and trauma, in that

⁶⁶ This radical altered state of being was the trigger for Gordon Turnbull’s (2011), examination of trauma. His conviction that the mountain rescue team at Lockerbie did not ‘*en masse*’ have an inherent predisposition to psychological weakness. They are ‘tough beyond belief’. Yet Turnbull was summoned to help because people were seeing things, the same things, and the things they were seeing would not go away.

⁶⁷ Nicola King (2000) explores the complexity of remembering the self. Two ways memories are reconstructed in narrative are: first, the metaphor of digging for treasure, excavating layer upon layer until one discovers the actual self in the particular moment. This relies on the principle of the preservation, and timelessness and unchanging character of the moment. And second, deriving from the term *Nachträglichkeit* (*afterwardness*), this way relies more on a

long-term stress erodes memory, while short term stress enhances memory. So, memory may fade, blur, and become a blank; or in a fraction of time people may see their whole life pass before their eyes. With trauma, events and experiences are revisited with changed and changing emotion and understanding. These alterations constitute the lens of trauma which offers a radically new way of seeing. Familiar frameworks of delivering spiritual care are shattered and events resist being 'brought into speech'.

Some theological responses to trauma, particularly those which emphasise narrative, I believe miss the mark. For example, Ruard Ganzevoort's *Scars and Stigmata* (2008). In this he describes situations, from accidents to natural disasters, where trauma is a natural part of life. Trauma, he says, disrupts the course of life, disrupts identity and shatters integrity. The issue is how to respond to it. Here he identifies two options: through scars or stigmata. If meaning cannot be found, then trauma 'scars' and wounds. But, if meaning is found, say by locating the experience within a larger story, or God's story, then trauma takes on an 'attributed identity' of stigmata, and is overcome. The meaning placed on trauma is crucial. While some people can find a meaning, and a resilience and a coping strategy to face whatever comes their way, what Ganzevoort undervalues is the way trauma shatters meaning-making.

Serene Jones (2009) and Denise van Husinger (2015) also fail to convince me, in their case by over-emphasizing participation in God's story, the victory of the cross as a way to overcome trauma. They cover over the lingering of death in life. Husinger argues that the sorrows and crucifixion of Jesus means that trauma lies 'at the very heart of the Christian imagination' (2015, 1). Consequentially the task of pastoral care is to re-orient people to the hope and grace of faith. Trauma is elided by standing within God's story. Such voices overlook the lingering nature of trauma.

re-transcription of memories. There is both the uncovering of the past, but within a dynamic process of ongoing interpretation. So, there is a complex relationship between past, present and future in human consciousness. King speaks of the illusion of a momentary return to a lost past. Thus, remembering the self is not a case of restoring an original identity, but a continuous process of 're-membering', of putting together moment by moment, of provisional and partial reconstruction' (2000, 175).

Returning to the theorists, Turnbull argues for a relational approach: listening is the secret. If the rapport is good and encouraging, then people tended to perform well. Take the pressure off and they will tell you the things you need to know. They usually knew already what was going on and just needed an opportunity to tell the right person; no need for guessing or esoteric interpretations. And the right person is going to be trusted, because they create safe spaces, are not trying to be in control, and resist making judgements. Turnbull exposes the limitations of Jones, Husinger and Ganzevoort's theological approach to trauma. Limitations become conspicuous as and when coherent narratives, or storylines, crumble. Alternative theological voices endorse the concept of witnessing, and include Pamela Cooper-White (2011), Daniel Nuzum and colleagues (2017) and Christopher Turner (2017). However, I find it is the work of Shelley Rambo who most enriches my understanding of traumatic silences and how to respond to them.

In *Spirit and Trauma* (2010), and *Resurrecting Wounds* (2017), Rambo takes seriously the insights of trauma theory to develop a theology of remaining. Life after trauma is more 'uncertain, tentative and murky', which means the spirit is more 'fragile and unrecognizable' (2010, 13). This theology embraces four key elements: a non-linear temporality, which resists the triumphalism within the traditional Easter narrative; Holy Saturday, as a symbol that something of death remains and extends into life; the middle, as the critical site of insight and becoming, and the imperative of witnessing, on the cusp of life and death. Such an approach resists the temptation to cover over, or elide, trauma or suffering.

These elements offer a new imaginary to interpret Mary's silence and my witnessing of it. Two relevant insights that Rambo develops are those of 'witnessing' and the 'middle spirit'. Starting from an understanding of a witness as being a spectator, where "'to witness" means to observe, to stand by, and to look on' (2010, 23), she describes how the Holocaust led to a "collapse of witnessing", where the experience is beyond words: 'how can we speak, write, communicate, and teach given the profound shattering of language and meaning in trauma? The speechlessness that survivors experience demonstrates the instability of the word' (2010, 28). She then turns to the Gospel of John, and the story of Mary Magdalene and the beloved disciple, to re-envision witnessing as 'remaining in love' (see 2010, 81-110). This offers a new understanding of being a

witness: rather than giving testimony to certainties, witnessing invites the carer to 'remain in love', with no answers.

At its shore, the very edge of the *tehom*, the ancient oscillation of religious language between assertion and negation, utterance and silence, takes on a tidal rhythm. The Spirit, instead of securing, navigates a third way in more tenuous terrain; in this way-making (2010, 125).

The concept of 'middle spirit' builds on the work of Catherine Keller's *Face of the Deep* (2003). There Keller challenges orthodox understandings of creation as having pure beginnings *ex nihilo*, which tame the *tehom* waters, and silence the chaos. Rather Rambo introduces the *ruach elohim* as the spirit which hovers over the abyss and keeps the 'divine open and in process' (2010, 116). This reconfiguration of theology offers a new way of interpreting trauma. Chaos blurs with coherence. Rather than heal trauma, or recover from it, the task is to embrace it and to discover the sacred in the darklight. The feminine spirit, which 'is the vibration, the flow, the flight and the unfolding of God', lives in the space between, and in the silence, witnessing to a lingering death (the undertow)⁶⁸ and imagining a new poetic language.

Combined, these two insights offer a creative way to engage with Mary's silence. They indicate that spiritual care is a process of witnessing from this middle space, or holding the silence. Rambo describes how her work on trauma has changed the way she moves in the world. She feels its fragility and feels connected to people in new ways (2010, xiii). Trauma is also moving her theology in a new direction: she is reconfiguring the Easter narrative into a space where death lingers in life: a new language is needed, she says, to do justice to trauma's open wound. Rambo writes, 'I am seeking a picture of redemption that adequately accounts for traumatic suffering (2010, 6). And spiritual care, rather than being a redemptive narrative, operating in a linear fashion, now witnesses to what remains. What remains is 'the excess, or remainder, of death in life. Her 'theology of remaining'

⁶⁸ 'Much has been lost, inconceivably and irreversibly lost. We grieve our losses so that we ourselves will not get lost. Already in the grieving the generativity of genesis, the flow of beginning, begins. The undertow of *tehom* can be painful. The pull of new beginning may seem to add insult to injury: to rub in our faces not just in dead actualities but the lost possibilities, all that might have been but cannot be. The water wears a dark face; we are mirrored mysteriously back to ourselves, deformed and aswirl. We are out of our depths.' (Keller, 2008, 66).

is innovative and enriches my understanding. Rambo frees me from dishonest resolutions, traces a healing pathway and describes spiritual caregiving as witnessing to the depths and abyss.

This section has considered how trauma overwhelms Mary. It was the image of the dog, which she labelled unconditional love, and my exploration of whether Mary felt unconditional love in her own life, that enabled the utterance of traumatic wounding and childhood rejection. This scenario illustrates that trauma is a wounding; psychological, physical, social and spiritual. A skewed sense of time, invasive memories, by trauma being buried in her body, and by impeding language; trauma leads to chaos rather than patterns and coherence. Trauma undermines a narrative approach to spiritual care. Trauma theory and a 'theology of remaining' offers a new lens and a new imaginary to understand and respond to traumatic silences. Trauma is best addressed by creating safe spaces (distancing patients from triggers) and by witnessing (listening).

5.2 *Shameful Silences*

Reflecting on this autoethnographic text, I see three key elements in the scenario. The first is the frenetic feel to Alison's home, which makes me wonder, 'How do I listen out, amongst all the distractions, for what really matters to her?' What I understand is that by waiting, by just staying with her, she found her own way and pace to find her voice, which makes me confident that, 'By witnessing, by remaining in love, people will fill the silence I create with what they need to say'. The second is what happens in the moment she asks me to touch the lump on her skull, something I have rarely done before or since. This makes me wonder, 'How does touch create connection, even intimacy, effect healing, and dissipate shame?' And the third is the tension between the unwanted exposure of her cancer that happens as her hair is shorn, and Alison's compulsion to find a wig and a bandana to cover up her dirty dying. This makes me wonder, 'Is it possible to address shame when its presence is hidden away?' My poem, *Bandanas*, which imagines me being in that situation with my own wife, illustrates how being with the dying changes me.

Now that I have eyes for it (shame), I see it everywhere.

--James Fowler (quoted by Pattison, 2000, 1).

There is no place where people are more vulnerable to shame than in a hospice. Yet, despite its prevalence, shame often falls beneath the radar, and lives in a deep silence. Remarkably, there are very few insights from either the palliative care or theological literature to offer critical insights into what was happening for Alison and myself in this scenario. However, I turn first to Julia Lawton's classic research, *The Dying Process* (2000), and second to a critical companion Stephen Pattison, whose trilogy, *Shame* (2000), *Seeing Things* (2007), and *Saving Face* (2013), uncover rich insights for handling shameful silences. Two key learnings are to connect—to 'bridge the boundary' between myself and the other—and to proffer a 'saving gaze'.

Julia Lawton (2000) had little 'first hand exposure' to death and dying prior to her ethnographic study, which meant that she came with the benefit of fresh eyes. But she was unprepared for 'the visible signs of bodily decay; the stench of incontinence; the lethargy and despondency of patients, many of whom had struggled with their illness for months or years; and the burnout and exhaustion experienced by their families and friends' (2000, vii). By unmasking dying, as it is, 'the non-negotiable effects of a patient's bodily deterioration on their sense of self', *The Dying Process* challenges the naïve belief that hospices are places where people 'live until they die'. Lawton isn't alone. Leget too contests the romantic image of hospices as being places where people rise above death, or grief. This 'does not represent the experiences and struggles of real patients' (2017, 31-36). In contrast to the aim of 'living until you die', some patients 'live too long'; 'I don't like the idea of lingering. If it's going to happen let it happen; not all this hanging on dying inch by inch, fighting every scrap of the way' (2000, i). Patients' reluctance to live too long comes from the radical changes in experiences of self, body, space and time that alter from the time of diagnosis to the time of 'bed-ridden' deaths. Lawton describes this spiraling journey as 'a sea of irreversible changes' which induce a lingering sense of shame (2000, 35).

One of the silenced aspects in the process of dying is how often patients feel shamed. And one of the unspoken aspects of palliative care strategy is how it covers up shame and dirty dying. This is evident even in the very word 'palliative', which comes from the Latin word, '*pallium*', meaning 'cloak'. This infers that, at

its core, palliative care hides, conceals and disguises (2000, 144). And this is evident in actual hospice structures. For example, day care offers a 'safe retreat' which masks the shame of stigmatization, and social and temporal isolation. A social dying arises as patients cease to be enmeshed with, and are dislodged from, webs of kinship. This unsettles the security of being in a constellation of interpersonal ties. The provision of day care palliates social dying by offering a 'new social world' in which a sense of self and integrity can be sustained even when the old social self has passed away.⁶⁹

The dissonance between the rhetoric and reality of a good dying, the transition from personhood to patienthood, hits home on entry into the hospice. There, visible signs of bodily decay, stench, burnout and 'the protracted period of suffering' are prevalent, and radically exposes an unbounded body. Unbounded bodies emerge as people lose autonomy, physical control, and this often induces shame. Lawton gives the example of Annie, whose fistula resulted in faecal leakage and the literal erosion of physical boundaries: the offensive smell as she 'rotted away below' led to feelings of shame, loss of dignity and feeling worthless (2000, 122-147). Lawton's findings expose, rather than cover, an alternative reality; how in hospices, as patients move closer to death, there is a new reality of shrinking spaces, static time and unbounded bodies. For many, like Annie above, shame overwhelms, and patients switch off, turn their face to the wall or disengage. In these circumstances, shame consistently silences.⁷⁰

Interestingly, there are very few theological responses to shame, which means that I rely heavily on Pattison's innovative work on shame to take my reflections further. This offers both a theoretical slant and a spiritual response to the lived reality of dirty dying, described by Lawton above.

⁶⁹ A social dying takes many forms, including, for example, 'degenderisation'. Though Lawton observed that 'gendered differences' were not prominent in her study because 'patients often experienced a disinvestment of their 'masculinity' or 'femininity' even in the early stages of their illness and deterioration (2000, 166).

⁷⁰ For a few patients, the crisis of shame triggers another reaction, the need to renegotiate identity. The re-negotiation of identity often involves a disengagement with the body, as seen in the memoirs of Jean-Dominique Bauby (1997), and Bieke Vanderkerckhove (2010).



Figure 14: Marion Patrick, *The Cross* (c. 1968)⁷¹

Shame itself is an entrance to the self. It is the affect of indignity, of defeat, or transgression, of inferiority, and of alienation. No other affect is closer to the experience of the self. None is more central to the sense of identity. Shame is felt as an inner torment, a sickness of the soul. It is the most poignant experience of the self by the self, whether felt in the humiliation of cowardice, or in the sense of failure to cope successfully with a challenge. Shame is a wound felt from the inside, dividing us both from ourselves and from one another (Kaufman 1985, ix-x).

Stephen Pattison's starting point is his own experience of shame, the abuse and neglect of childhood: 'I believe myself to have been a shame-bound person for most of my life, regarding myself as unworthy, valueless and defiled, with a deep desire to hide myself away from the "legitimate" negative judgement of others' (2000, 5). By 'rendering visible the authorial self', in a 'loosely autoethnographic approach', Pattison ensures that shame is not regarded as 'a distant phenomenon' that occurs elsewhere, but shame is evident, or hid, in the here and now, close to home.

Pattison presents a theoretical orientation of shame: a shadow side of existence, is conceptually confusing. In part, this is because shame is an emotional experience. And emotions, or passions, have an ingenious capacity to change, distort and resist coming under any rational control. It is for this reason that a dualistic attitude emerged in philosophy, where reason tended to be kept apart from emotion. However, more recently philosophers like Martha Nussbaum (2001)

⁷¹ This painting depicts three little girls looking dejected and wearing simple grey tunics and no shoes. They are standing on a grey pavement and behind them in the distance is a cross. This painting was hung in the offices of the House Governor/Deputy House Governor at The Maudsley Hospital until 1985/6.

recover an embodied knowing and lived wisdom.⁷² In part, shame is elusive because, like an onion, ‘shame is made up of enfolded and overlapping, but also discrete meanings and understandings; there is no ‘essential onion’ or ‘essential shame (2000, 38). And in part shame is elusive because it is ‘like a subatomic particle. One’s knowledge of shame is often limited to the trace it leaves’, thus limited to fleeting glances (Lewis, 1992, 34). So, while a strict definition of shame is elusive, this does not obscure its significance. Pattison helpfully introduces the concept of ‘family resemblances’.⁷³ For example, the family of resemblances within ‘the existential emotions of anxiety-fright, shame and guilt (which) all have to do with meanings about who we are, our place in the world, life and death, and the quality of existence’ (2000, 26). Applying family resemblances to shame is liberating for Pattison because, ‘instead of trying to identify a single determining essence or definition, one is free to accept that there is a legitimate plurality of concepts and approaches’ (2000, 63). So, there are all kinds and instances of shame, which share a common pattern, but are not identical. What matters is the consistent way in which shame silences.

A refined understanding of the structure of emotional experiences may illuminate why shame silences in three ways. An event sparks a physiological reaction, which in turn is accompanied by ‘a visceral arousal’, which shapes subsequent behaviour, which for the emotion shame is a silencing. Three characteristics of shame explain the prevalence of silencing. First, in shame there is ‘an acute sense of unwanted exposure’, which means that there is a strong compulsion to cover up, hide or flee from whatever triggered the reaction.⁷⁴ The idea of hiding is inherent in shame. Second, there is the failure of words. Shame lives in pre-linguistic experiences, and being prior to, or without words, the subject lacks a vocabulary to describe it. And third, shame has too often been assimilated into the concept of guilt. However, whereas guilt derives from a discrete specific offence, in contrast shame struggles to be securely located. From a psychoanalytical perspective, Erik Erikson

⁷² This interweaving of physiology, emotion, thinking and behaviour is the premise of Cognitive Behavioural Therapy, which is a key therapy in palliative care.

⁷³ The philosopher Wittgenstein first proposed that concepts could be approached along the lines of family resemblance. This strategy resists the notion that each and every use of a concept enjoys the same meaning and has the same content (Pattison, 2000, 62).

⁷⁴ The word shame is derived from a Germanic root, *skam/skem* with the meaning ‘sense of shame, being shamed, disgrace. It is traced back to the Indo-European root *kam/ kem*, ‘to cover, to veil, to hide’. The prefix ‘s’ adds the reflexive meaning ‘to cover oneself’ (Pattison, 2000, 40).

sees shame as ‘essentially rage turned against the self’. This may arise because of a failure to live up to inner ideals, which haunts and threatens self-esteem. Similarly, but extending its horizons, from a sociological perspective, the wound of shame is not just opened by self-judgment but by the fear of incurring the scorn or contempt of others, which leads to a fear of ‘abandonment’ (Pattison, 2000, 46-53).

It is only as one encounters shame, such as I have described above with Alison, and evident in the minutest of details, such as her glancing down to the floor, that one begins to appreciate why it silences. Shame includes a sense of ‘diminishment’, ‘being unloved and unloveable’, ‘uncontrollable exposure’, ‘loss of face’, the ‘violation of trust and internal security’, all of which linger in an ‘unending present’, which means that individuals may freeze, become powerless, long to hide. But most significantly for this research, ‘shamed people are left without words or the capacity to use them (see Pattison, 2000, 59-78). Shame is a relatively wordless state. The experience of shame often occurs in the form of imagery, of looking or being looked at. Shame may also be played out in imagery of an internal auditory colloquy in which the whole self is condemned by ‘the other’. The wordlessness of shame, its imagery of looking together with the concreteness of autonomic activity, makes shame a primitive irrational reaction, to which there is difficulty in applying a rational solution (Lewis 1971, 37).

If shame silences people because they fear exposure, it lacks a vocabulary, and triggers self-loathing and a fear of judgement. The issue now is how to enable people to respond more effectively to shame-filled people. From a theoretical angle, if shame is understood as ‘a condition that denotes alienation, isolation, defilement, depletion and pain, both individual and social’ then these can be overcome by transcending the sense of shame in individuals, through rituals, creativity and touch; and by addressing the social factors that cover up a dirty dying in palliative care (see Pattison, 2000, 154- 184). This thesis focuses on the individual rather than political aspect, so argues that the relational aspect of spiritual care is crucial. Pattison offers two key learnings: to reconnect, to ‘bridge the boundary’ between myself and the socially isolated other, and to proffer a ‘saving gaze’:

If shame and stigma are conferred by human beings, human beings are the only means of acceptance and valuing for the shamed. In the restoration of face, one might hope that Christianity has an important part to play (Pattison, 2000, 184).

Seeing the face of God or that of another person is an apposite, profound metaphor for having a close and intimate encounter, for experiencing full presence in which we are recognised, known and seen for what we are, with love (Pattison, 2013, 2).

Both work towards reintegration and inclusive relationships that overcome shame's silenced and hidden nature. The pastoral task, says Pattison, 'is to help to include those who are rejected and marginalized within God's loving gaze' (2013, 3).

In this section I have considered how shame casts its shadow over Alison. She fears exposure; lacks a vocabulary to express her loss of self-worth. Shame undermines a narrative approach to spiritual care. A theology of shame should seek to reintegrate people into a community, offers a new lens and a new imaginary to understand and respond to shameful silences. Shame is best addressed by bridging boundaries (reconnecting) and by loving gaze (revaluing).

5.3 Communication Silences

Reflecting on Geordie's silence, various things strike me. The first is the undoubtable challenge to spiritual care that the radical silencing of neurological wear and tear brings. Cognitive strategies such as 'making-sense to make the most of' fall short. This makes me wonder, 'How do I change my tune to allow me to connect to people like Geordie?' What I understand is the necessity to reframe spiritual care from abstract concepts and philosophies to gestures. This leads to my second learning which is, 'When words fail, music connects'. This realisation critiques my practice, 'Do I over-value words in spiritual care? Are there other creative ways to connect?' And finally, 'If spiritual care is loving the person who remains, do all the hospice team, the "Christa community",⁷⁵ intuitively deliver spiritual care in gifts of time and gestures of love?

⁷⁵ I am indebted to Nicola Slee (2011), for the term 'Christa community'. She takes inspiration first from the women in the gospels. For example, the story of Mary Magdalene, who finding in Jesus her healing, expresses that love extravagantly, and in the silence of the resurrection

The 'fabric of meaningful human existence' extends beyond reason to hope, love, becoming and belonging.

--John Swinton (2001, 8).

To be human is to be in relation with YHWH⁷⁶, our creator.

--John Swinton (2012a, 166).

The benefit of opening and sustaining channels of communication, to enable a good dying, and a good grieving, is well established in the philosophy of palliative care. Many interventions, such as by the speech therapist Sandrine below, lean towards restoring words. This resonates with the view of spiritual care as conversational. However, neurological attrition, such as a brain tumour in *The Iceberg*, or due to dementia in Geordie's story, calls for an alternative holistic approach. This section reframes the intention of spiritual care from meaning-making to healing relationships. Jill Harshaw argues that people with profound intellectual disability have 'an ongoing relationship with God' (2016, 13, see also Swinton, 2012b); Gregory Clifton-Smith introduces music as an alternative way of delivering spiritual care. Music connects in a different way to words and is 'a beacon of hope and a means of survival' (2016, 72). Then I highlight the work of John Swinton, outlining three learnings: to reframe spiritual care from being philosophical to practical; to re-describe spiritual care as being relational; and to reconfigure time.

Good communication enhances quality palliative care. The courage to engage in difficult conversations is nowhere better stated than by Atul Gawande, in *Being Mortal*, the expanded version of the BBC Radio 4 2014 Reith Lectures, *The Future of Medicine*. Gawande makes a persuasive argument about the limitations of medicine in helping society face mortality, and the need for courageous

garden, lets go of the hem of Jesus' garments to discover a freer Christ. Then Slee further witnesses the faithful voices of women who imagine a female Christ figure, a Christa. The Christa 'is simply one of a myriad ways of incarnating and re-imagining the humanity and divinity of Christ' (2011, 3). She asks, 'Why is the Christa always suffering, broken, dying?' and wonders 'Where is the risen Christa?' and is curious, 'When she comes to us, will we know her?' (2011, 1). Her quest inspires me to look for the Christa community within the hospice. And to seek the invisible Christa in the lives of those who sometimes are beyond the boundaries of religious faith.

⁷⁶ In the Bible the name for God is often written using the four Hebrew consonants YHWH, which in Exodus 3:14 are translated 'I am who I am'. This name is never spoken.

conversations. ‘People have priorities,’ he says, ‘besides simply prolonging their lives’ (2014, 155). But not everyone can engage in courageous conversations. ‘The wall of silence’ is a constant threat in palliative care, whether due to the taboo of dying, a reluctance to engage ‘authentically’ by staff (see Haraldsdottir, 2011), or because of associated fears and anxieties (see Heaven and Maguire, 2003, 18).

Whenever there are silences the tendency among professional is to restore words. This can happen to great effect. For example, in *The Diving Bell and the Butterfly* (1997), Jean-Dominique Bauby’s stroke puts him into a coma. He describes ‘locked-in’ syndrome as ‘something like a giant invisible diving-bell holds my whole body prisoner’ (1997, 11). In an extreme world of silence, he is lonely and revolted by his body; ‘not only was I exiled, paralysed, mute, half deaf, deprived of all pleasures and reduced to a jelly-fish existence, but I was also horrible to behold’ (1997, 33). The radical turn in his circumstances happens with the arrival of his speech therapist, Sandrine, who becomes his ‘guardian angel’ by wrenching him ‘from the void’ by enabling him with the blink of his eye to communicate (1997, 47-49). Despite this form of communication being exhausting, particularly when there is misunderstanding—when asking for his glasses (*lunettes*) they wondered what he wanted to do with the moon (*lune*)—being able to communicate allows Bauby to cling to fragments of hope. His cocoon becomes less oppressive and his mind can take flight like a butterfly. Bauby becomes a mythmaker. He manages to make sense of life and death, such as when he says that although he can no longer ruffle his children’s hair or hold them tight, still ‘even a rough sketch, a shadow, a tiny fragment of a dad is still a dad (1997, 78), or when he alludes to the silences that envelop every dying: ‘when blessed silence returns, I can listen to the butterflies that flutter inside my head’ (1997, 104). However, Bauby’s case is rare.

For many patients, illness and neurological wear and tear takes them deeper and deeper into a world of silence. In *The Iceberg* (2014), Marion Coutts describes her husband, Tom, dying from a brain tumour. It is a vivid illustration of a silencing that comes with the loss of cognition and voice. Tom is physically estranged from himself, silenced and frightened. But the tragedy above all is his loss of communication. Communication is his life: ‘The getting of things exactly right with words, refined and compacted, is my job of many years standing. It is my

pride' (2014, 117). This loss of communication makes Coutts question the nature of personhood.

How do we recognise another person? At its most basic, by shape, by colour, by outline, by dark and light, by smell. Or by nuances of tone, by the way the face looks in repose, the cadences of the voice, full of small interior knowledge, the way they hold their mouth while listening, or by the way their gaze holds yours. By what their eyes say when they are not speaking (2014, 121).

Understandably Coutts struggles to see anything beyond language.

What else is there apart from language? Let me list: music, touch, the great inter-cosmos of the eyes, running and jumping, sex, cooking, friendship, eating. There must be other things but I have come to a stop. It's a short list. We will devise another language and in it we will talk (2014, 131).

The poignancy heightens as their son Ev gains speech just as Tom loses speech. And the silencing most evident when Coutts says 'I too am not fluent. I am speechless' (2014, 247).

Coutts writes into chaos rather than achieving coherence. There is certainly no happy end, no moral neatness, no rhyme. Traumatic illness lacks coherence. She says 'the deed is done before knowledge can release its meaning. Various metaphors replace a coherent narrative'.⁷⁷ *The Iceberg* illustrates the way deep silences are grounded in the swamplands of life. They emerge from profound existential and spiritual crises. *The Iceberg* has no mention of any god, nor any sacred story to immerse their shared experience in. Coutts just sees everything within the natural order of things. She speaks of the transience in life: we are mortal; you will lose everything that catches your eye (2014, 2); and what comes across forcefully is the immediacy and ordinariness of death; 'the beat of death in all things' (2014, 111).

⁷⁷ Metaphors such as living at such an altitude at which she cannot breathe; a shifting compass, or the loss of coordinates on a map of life; and changing orbits. But the most chilling of all is the description of death approaching like 'a drifting iceberg', 'I am nearing the iceberg. My tears are sonar. They release on impact a faint understanding of what lies beneath: a vast solid, the floating mass of ice that is still to come. These are early days' (2014, 50). This metaphor suggests that there is an ocean's depth of unknowing beneath the surface.

At death, the world does not alter, no shift of earth or change in colour, no noise, no shimmer of light, no falling or collapsing of physical objects. The tree standing there still stands (2014, 282).

The deep silences in *The Iceberg* are ontological realities, which are lived, breathed, felt, surrendered to prior to any epistemological understanding or representation. Representation of deep silences pushes language to the limit and often takes the form of metaphor or poetics. Rarely do they solicit coherent narrative or they are certainly beyond the capacity of quantitative measures.

A challenge for palliative care, as it engages with people with cognitive impairment, is to think out of the box, and to reframe spiritual care from meaning-making to healing relationships, and from words to music. This is already happening. For example, Jill Harshaw, in *God Beyond Words* (2016), reframes theologically an understanding of people with profound learning disability.

Neither cognitive impairment nor any other aspect of the human experience has any power whatsoever to undermine the theological foundations of human personhood (2016, 17).

She is hesitant of speaking about intellectual disability ‘as if a person would be better off without it’ (2016, 11). Similarly, Harshaw yearns for an alternative to a God story whose intent is to remove it or heal disabilities. Such approaches emphasise deficits rather than celebrating the sacredness of human personhood. Imagination is required to overcome marginalisation with a sense of inclusion, welcome and belonging. Her preference is ‘for ‘spiritual experience’ to connote a life-giving encounter and ongoing relationship with God’ (2016, 13).

If Harshaw stresses relational care, then Gregory Clifton-Smith (2016) reframes spiritual care from words to music. He gives numerous examples of how people can overcome darkness and rise above suffering by finding meaning. For example, Dietrich Bonhoeffer’s Sabbath rest—‘buoyed up by glimpses of the outside world; sunlight, the stars, a bird singing, the ringing of a church bell’— and Victor Frankl’s will for meaning in shared bread and a winter’s sunset (see 2016, 19-35). These are inspirational stories. As are his illustrations of how bereavement, loss, disability and dementia can be helpfully re-interpreted by the latest theories

which support meaning-making.⁷⁸ However, he argues that some people, such as those with dementia, find words confusing. His project explores and finds that music, its melody and harmony, its sounds and silences, its rhythm, blues and lament, can represent and even wrestle with the presence and absences of God in illness, suffering and darkness. And, significantly, when words fall short: 'Music both arises out of and returns to silence' (2016, 61). Music engages creatively with people with cognitive impairment.

Both Harshaw and Clifton-Smith demonstrate considerable imagination. Another innovative voice in this field is John Swinton, who reframes cognitive silences. Swinton works extensively across health and social care, bringing new social imaginaries into being. This includes rediscovering the 'forgotten' spiritual dimension in mental health (Swinton, 2001), and reframing theodicy from being a philosophical debate to encourage faith communities to engage practically with suffering and evil. For example, lament offers sufferers 'a hopeful language in which they can wrestle with God, self and others as they attempt to make sense of the confusion' they are facing. It enables a shift from silence into speech, speech that initially rages at God and then finds comfort in a God who is with them in their suffering (see Swinton, 2007, 90-129). Swinton seeks also to reframe time, which is at the centre of 'the ways in which we understand, construct and try to make sense of the world (Swinton, 2016, 1). The loss of linear time, in dementia, or lingering time, in trauma, require alternative approaches.

But for my present purposes, it is the way Swinton reframes dementia that is particularly helpful in thinking about what is happening with Geordie. His core argument is that there are 'two ways of looking' of looking at dementia. He illustrates this using Michael Ignatieff's (1993) *Scar Tissue*, which tells the story of two sons living with the onset of their mother's Alzheimer's. The scientist son sees his mother's dementia in objective and empirical terms, as a medical entity, with an etiology, prognosis and cure. The philosopher son cannot separate what

⁷⁸ For example, Elisabeth Kubler-Ross describes a process by which people adjust to illness: denial, bargaining, depression and acceptance. Colin Murray Parkes, describes a process of grief; numbness, pining, disorganization, despair and recovery. Peter Speck stresses how other losses, such as disfigurement, can lead to stigmatization and loss of esteem. Jean Vanier, Nancy Eiland and David Pailin reflect on disability, where a new perception 'painstakingly honest and lovingly constructed' to argue for a common humanity which re-negotiates a view of disabled as damaged goods (see 2016, 37-58).

dementia is from who his mother is and is becoming. This leads to two stories: 'You keep telling me what has been lost, and I keep telling you something remains' (Swinton, 2012a, 32). Out of his reflections, Swinton constructs a theology of dementia, which he terms 'living in the memories of God' as a counter to the cognitive silencing of dementia described by the scientist son. Dementia is as much relational and social as neurological; it is located on the interface of self and other, including God. And the silencing of dementia is healed by living in the memories of God and by spiritual carers, learning to live in the present moment: 'Presence is where the other's spirituality finds silent actualization' (2012a, 239). The new focus of spiritual care is 'the presence of something: the presence of God-in-relationship. And God's story re-defines dementia.

Dementia happens to people who are loved by God, who are made in God's image, and who reside within creation. The task of theology is to remind people of that distinction and to push our perceptions of dementia beyond what is expected, toward the surprising and the unexpected (2012a, 8).

Swinton not only challenges a faith system which relies on 'an individuated, experiencing, cognitively able self, perceived as a reasoning, thinking, independent, decision-making entity' (2012a, 10), he also challenges the standard paradigm of dementia. He offers a new way of engaging with people silenced by dementia: people are living in the memories of God. What this means is that 'knowing *about* God may not be as important as *knowing* God, and that knowing God involves much more than memory, intellect and cognition' (2012a, 15, italics in text). Therefore, caring for people with dementia, like Geordie, requires a reframing of spiritual care. From being philosophical to being practical, from being cognitive to being relational, and to being concerned with linear time, past, present and future, to living in the present moment. For Geordie, experience happens before understanding.

5.4 *The Silence of Betrayal*

Reflecting on my spiritual autoethnographic account of the silence of betrayal two themes emerge. The first is of a complex relationship, once secure, 'spiraling out of control'. And not recovering, despite the best efforts of systems and procedures. This makes me wonder, 'How did this happen? What was working and

what was lost?’ On the surface, the scenario is about process and best practice around suicidal ideation, a prevalent concern in end of life care. But underneath, it’s all about broken trust and confidences. A massive conflict of interests, and the silence of betrayal. This quandary leads me further, to ask, ‘Are the holding of relationships sacred?’

I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel.

--Maya Angelou (quoted in Booth and Hachiya, 2004, 14).

There is something in a good relationship that accepts silences. Such silences are hospitable safe spaces for creative and courageous conversations.⁷⁹ The text however describes a counter-story: a broken relationship which forces silences. This can happen when professionals overstep boundaries, engage in intrusive questioning, or when trust breaks down.⁸⁰ I turn to Lars Sandman, whose ethical scrutiny of a good dying discloses how often normative hospice values override individual preferences. Can these insights explain this scenario? Having argued that the conflict of interest arises from an imposition of values, I search for a better way forward. This is found in the voices of Donald Winnicott, who values ‘holding’ over ‘interpretation’ within the therapeutic relationship, and of Daniel Nuzum and Neil Pembroke, who advocate witnessing. Witnessing, or attention, is a gentler yet demanding therapeutic relationship sought, but is likely to avoid betrayal.

⁷⁹ Ewan Kelly’s (2012) *Personhood and Presence* explores the therapeutic use of self and argues that spiritual care ‘begins with an awareness of who we are’ (2012, 1). Self-awareness allows carers to quieten their inner voices which, in turn, allows them to be more attentive to others, as expressed by Henri Nouwen, ‘What does hospitality as healing power require? It requires first of all that the host feel at home in his own house, and secondly that he create a free and fearless place for the unexpected visitor’ (Nouwen, 1979, 89). See also Gordon, Kelly and Mitchell (2011, 125-138), who argue that self-awareness and self-care enables spiritual care.

⁸⁰ Randall and Downie argue that such intimacy may be harmful, causing unnecessary stress on both patient and carer, with repeated exposure to loss and trauma (see 2006, 149-181). They argue that Cicely Saunders’s vision of a relationship founded on love derives from a time prior to the establishment of healthcare, and that an alternative relationship based on the concept of client-counsellor is better suited to contemporary practice. Grounded on empathy, which involves being able to sense accurately and appreciate another person’s reality and to convey that understanding sensitively; respect, in that each person is worthwhile, unique and valuable; and genuineness, by which carers convey genuine concern and trustworthiness, they advocate for a relational stance of ‘professional friendly interest’ (2006, 179).

Not only does witnessing suggest a safe approach, but it lures us towards a sacredness that exists in relationships.

Sandman (2005) illustrates the prevalence of power differentials, conflict of interests, and threats to relationships, as and when organisations impose normative understandings of a good dying onto individuals, which 'influence people to die in a way that is not of their choice' (2005, 1). For example, 'it is an open question whether a consistent dying' will mean a good dying (2005, 33), or that there are normative aspects of a meaningful or dignified death' (see 2005, 26-59). Similarly, when he explores what it means to face death: being acquainted with, aware of, accepting of, or in control of death:

We do not find strong support for any specific way to face death and we might have reason, depending on circumstances and our own values, to face death in a number of different ways (2005, 108).

Sandman extends his argument into other areas such as optimal rituals or environments, and again arrives at the same conclusion and hesitancy about imposing values onto others. Even when we consider an idea like dying without suffering, which seems to find strong support, it might be the case that we cannot realize this idea, since it sometimes conflicts with other ideas that might be important to the dying person, such as remaining conscious and lucid (2005, 158).

It seems evident that the imposition of values around suicidal ideation has triggered Jane's sense of betrayal. Is there a better alternative? The critical question is whether spiritual care should focus on interpretation or being witnessed and held. Winnicott's preferred stance is holding. Sensing a lack in Sigmund Freud's analytic psychotherapy, which relies on the interpretative capacity of the analyst, and conscious of the challenge to accurately interpret another's experience, Winnicott conceived a new approach to psychotherapy. De-emphasising the 'interpretive' slant, he emphasises 'holding', which allows the person's true self to emerge (see Anderson, 2014). Witnessing is similarly valued in trauma studies. For example, Hunsinger (2015), refers to the depth psychology of Ann Ulanov, and insights of nonviolent communication, who outlines a threefold response to break free from the vicious cycle of trauma: 'whatever we are afraid of, it requires our attention; we must go down into it, look around, not knowing if and how we will come out' (Ulanov, 2007, 38). First, carers need to be attentive

to whatever the traumatized fear, to allow them to give voice to their experience. Second, they need to offer a companionship which can bear anguish. And third, to listen and wait, resisting any intrusion or offer of empty platitudes. And by doing so, live in uncertainty. The slow pacing of such encounters is crucial: ‘the slower you go, the faster you go’ (2015, 10-11). And again, witnessing is becoming prevalent in pastoral care (see Nuzum et al, 2017). Daniel Nuzum is a healthcare chaplain specializing in perinatal and palliative care ministry in Cork, Ireland. Stillbirths raise significant existential and spiritual issues for all involved. Deep spiritual needs emerge in stillbirth, such as a quest for God’s love, overcoming a sense of injustice, renegotiating childhood theodicy, and facing up to anger and abandonment. Facing the trauma of still-birth, the task of chaplaincy is accompaniment and witnessing. Chaplains witness suffering and inhabit the space of pain, without any agenda, or compulsion to fix it. This is a threshold liminal experience which bridges the human and divine. Nuzum resists imposing harmful answers on unbearable experiences.⁸¹

The theme of witnessing harks back to Saunders’s iconic words, ‘watch with me’,

I have tried to sum up the demands of this work... in the words ‘Watch with me’. Our most important foundation for St Christopher’s is the hope that in watching, we should learn not only how to free patients from pain and distress, how to understand them and never let them down... but also how to be silent, how to listen and how to just be there (Saunders, 2005, 7).

And witnessing deals effectively with the unknowns in dying. For example, Mieke Vendermare (2014) identifies three key outcome measures of spiritual care, which invite witnessing. First, the extent to which the patient feels that he or she is being heard or taken seriously; second, the extent to which the patient experiences that there is a place for that which is insoluble; and third, the extent

⁸¹ There are significant new angles of approach to theodicy, which enhance the locus of witnessing as an alternative to imposing harmful beliefs. For example, John Swinton’s *Raging with Compassion* (2007) sets out the central philosophical and theological dilemma of how one faces suffering. Either create a theodicy, which he refutes because of its abstract character, at one remove from the lived experience of the suffering; or accept with indifference a meaningless world as it is, with no fixed direction or purpose. Swinton dismisses any theodicies which ‘take human pain out of the world of experience and into the world of ideas’. His ‘third way’ is to present suffering which can be ‘resisted and transformed’. The strength of this argument arises from his close connection with pastoral perspective and his priority of a practical theodicy over against a philosophical one.

to which the patient experiences that there is a place for that which cannot be said.

I wonder whether an understanding of witness needs to go further still. Do such intense relationships enjoy a sacred dimension? Once again this seems to be the case in Cicely Saunders's mantra, 'I love you just because you are you'.⁸² An illustration of the sacred happening in the act of witness, after a death, is in Maylis de Kerangal's *Mend the Living* (2016). This book tells the story of a young man, his untimely death and the events leading towards subsequent organ donations. The story is peppered through with rituals where the spiritual breaks into the clinical medical procedures. This comes to a climax when Thomas, the transplant nurse, sings over Simon's body as he finally prepares his body for being returned to his parents for burial.

Thomas's song confers a presence, a new meaning. Because this body that life has shattered becomes whole again beneath the hand that washes it, in the breath of the voice that sings; this body that has undergone something extraordinary now becomes part of the greater death, the company of others (de Kerangal, 2016, Locations 2698-2724).

Both Pembroke (2017), and Bennett et al (2018, 53) turn to the philosopher Emmanuel Levinas to argue that relationship is at the heart of spiritual care: 'It is in the face-to-face relation that the I encounters the infinite otherness of the Thou' (Pembroke, 2017, 17). Levinas argues that the awareness of the 'face of the other' evokes a feeling of solidarity, a recognition of difference, and is the basis of an ethic which moves the relationship beyond communication or moral convention, towards a spiritual encounter. Towards the sacred.

Ethics is not a moment of being; it is otherwise and better than being, the very possibility of the beyond. ... His absolute remoteness, his transcendence, turns into my responsibility for the other. And this analysis implies that God is not simply the 'first other', the 'other par excellence', or the 'absolutely other', but other than the other, other otherwise, other with an alterity of the other, prior to the ethical bond

⁸² 'On 1 August 1960, the diary records: And I said that I was a doctor and he was my patient and we couldn't ever be alone and I couldn't come as often as I wanted and he said, 'For me, it is enough'. And I said, 'There has not been anyone like you'. And I tried to say, 'There won't be very long', but it was so hard to quench his dawning hope. He said, 'I do not understand. I have never done anything for you'. I said, 'I love you just because you are you'. He said, 'Thank you'. 'Cicely Saunders (In: Clark, 2018, 118).

with another and different from every neighbour, transcendent to the point of absence (Levinas in Pembroke, 2017, 21).

In this section I have lamented the way people are betrayed and silenced by the imposition of values. Then I have explored a better sort of therapeutic relationship founded on the concept of witnessing. This matches the character of spiritual artistry and resonates with an understanding of spiritual care which lends a presence, accepts silence, is willing to enter suffering, and discover a sacredness in witnessing.

5.5 *Grieving Silences*

Reflecting on this spiritual autoethnographic text, what impresses me is not that grief affects people in different ways. This is already well known: ‘we absorb the impact of loss within our unique life circumstances and as the individuals we are (Attig, 2011, xii). And not how the metaphor of a stained glass window dances like light across a cathedral floor, reflecting how metaphors facilitate ‘reframing and a move towards new possibilities’ (Pembroke, 2017, 193).⁸³ But what strikes me is the way that grief reconfigures space and time. This is a radical shift in understanding the nature of grief and challenges traditional patterns, going far beyond Kelley’s ‘quantum leap’ of understanding (2010, 3) and Doka’s ‘new perspectives’ (see Doka and Tucci, 2011, iii-xvii). What I notice in each scene is ‘time standing still’. This insight forces me to ask, ‘the closer I am to grief, do my concerns shift from questions of meaning to lived experience? From mind to heart and soul?’ And I also wonder, ‘What is happening, when time stands still, in the deep silences? Is this when the sacred breaks in?’ This leads on naturally to another quandary; ‘How hard it is, to represent the sacredness of grief!’ In the end, I carve the runes, and am content with silence.

To Know the Dark

To go in the dark with a light is to know the light.

⁸³ Pembroke, (2017, 184-207), explores the metaphors we live by, how they express life and what lies beyond the reach of human thought and language, the sacred. From the origins of metaphor in Aristotle to its use in counselling.

To know the dark, go dark. Go without sight,
and find that the dark, too, blooms and sings,
and is traveled by dark feet and dark wings.

--Wendell Berry (2018, 37).

Works of art ... cannot be reached through criticism. Only love can grasp them and go on to hold and interpret them aright ... in the dark, in the unsayable and unconscious, in experiences unreachable by reason alone - and with deep humility and patience, awaiting the our when a new clarity might come forth: this alone is what it means to live artistically, in understanding as in creating.

--Rainer Maria Rilke (2016, 1)

In the opening chapter, I have described how spiritual artistry excels in comprehending the depth and profundity of grief. In this section, I introduce Kelly's iconic 'mosaic of grief', Nebula, to broaden understanding and to see how healing emerges from brokenness. Then I turn to Thomas Attig's understanding of grief as 'relearning the world', not in a cognitive way, but rather as 'learning how to be and act in a world transformed by loss' (2011, vii-viii). These voices encourage me to move beyond normative understandings of grieving as a process, or journey, to consider the critical moment of grief, as being when 'time stands still'. Asking, in this silence, when time stands still, 'Is this the locus of the sacred?'

Kelley (2010, 4-6) introduces the mosaic as a metaphor for grief. This offers a visual frame to locate individual experience against wider culture. She describes mosaic as an art form: the combination and arrangement of many small pieces of material, such as glass, tiles, ceramic, and gemstones. The fragments are called *tesserae*, and the spaces between *interstices*. The numerous ways of combining the elements in a mosaic—material, colour, pattern—makes each unique. Kelley argues that the spaces are part of the whole, 'what is not there is as significant as what is there in the formation of the whole' (2010, 5). A mosaic metaphor works because just as each mosaic is unique, and configured in a particular way, so too is grief, 'no two experiences of grief are the same' (2010, 5). And just as one steps back when viewing a mosaic to see how the fragments combine, to balance the

fragments with the patterns of the whole, an appreciation of wider patterns and theories of grief prevents seeing a grieving individual in limited or incomplete ways. Kelley supports her metaphor by scrutinizing the theoretical cornerstones of grief: attachment, meaning-making, coping styles and relationality. In each aspect of grief, the brokenness of individual experience scrutinizes general theory. And ultimately it is through brokenness that the light, or love, of God breaks through. This move justifies her choice of nebulae, which emerge from brokenness to represent grief (2010, 139-141). A nebula is a cloud of gases and dust particles that forms from the explosion of stars, and it is this creativity that emerges from implosion that resonates:

Our work is not to remove or smooth out all the broken pieces, but rather to help the pieces come together in a wholeness that brings hope because it is grounded in the love of God (2010, 140).

The turn to God to resolve and heal brokenness, matches with Cicely Saunders hope that even in dying all is well.⁸⁴ However, whereas Kelley reconfigures the brokenness of grief by turning to the love of God, Attig transcends suffering by carrying pain:

we learn to carry the pain as we reach past it to embrace cherished memories and legacies the world also holds. This is the hope that enables us to transcend our suffering and relearn the world in life-affirming ways (Attig 2011, ix).

He distinguishes the passivity of the grief reaction from the activity within the grieving response.⁸⁵ The latter focuses on being rather than knowing, and allows people to move through grief. In 'learning how to carry the pain' ... and learning how to love in separation' (2011, viii-ix) the 'soul and spirit are the principle driving forces' (2011, xxxiv). So far both voices portray grief as a journey to be travelled, as an experience to be worked through, with an endpoint in sight. However, this is not the experience of the people in my scenarios. Here they are

⁸⁴ Saunders is inspired by the mystic Julian of Norwich, who in a showing 'sees something in her hand as small as a hazelnut and said softly, 'What is this?' And God said, 'It is all that there is'. She wondered how it could last, and God said, 'It lasts because I made it and because I keep it and because I love it' (Clark, 2018, 295).

⁸⁵ 'Grief reaction' refers 'to the full range of our experiences of emotional, psychological, physical, behavioural, social, cognitive and spiritual impacts of bereavement' which people passively absorb or take in. In contrast 'the grieving response' refers to how people 'actively engage with the emotional, psychological, behavioural, social and spiritual impacts of grief (2011, xxvii).

static, and time stands still. This, rather than being a lack, is the locus of the sacred. The sacred breaks in in singular instances, that emerge from the darkness of intense sorrow, in ways that are beyond reason or understanding.

‘Grief literature’⁸⁶ is replete with references to moments of silence and moments when, against all expectations, and beyond any understanding, the spiritual breaks in. For example, in *A Grief Observed* (1961), C.S. Lewis famously wrestles with overwhelming grief, which felt like fear, over his wife’s death. Then out of nowhere he describes ‘the quality of last night’s experience’:

It was quite incredibly unemotional. Just the impression of her mind momentarily facing my own. Mind, not ‘soul’ as we tend to think of soul. Certainly the reverse of what is called ‘soulful’. Not at all like a rapturous re-union of lovers. ... Yet there was an extreme and cheerful intimacy. An intimacy that had not passed through the senses or the emotions at all. ... The intimacy was complete ... Can that intimacy be love itself (1961, 61-62).

Similarly, in *To Travel Hopefully* (2006), Christopher Rush describes living with the sudden death of his wife, and then works through inconsolable grief by following in the footsteps of R.L. Stevenson on a mountain trek in the Cevannes region of France. He woke one morning:

Outside the night was filled with the sound of crickets and the sky with stars. I stood for a few minutes. The terrible silences of Pascal’s universe didn’t frighten me here. I felt some peace. Up in my room I lay on my bed in the dark and fell asleep almost at once. Something woke me and made me sit up sharply. I peered at my watch. It was midnight, the exact time of my wife’s death one year ago. It just so happened that following in Stevenson’s footsteps had brought me here to this monastery of all places, this spiritual oasis, on the first anniversary. But what had wakened me? An alarm clock in the soul ... this for me was a turning point. ... the mountains were still beautiful. And though she was no longer in it, the world itself was still beautiful’ (2006, 193, 234).

⁸⁶ ‘Grief literature’, like ‘trauma literature’ mentioned above, ranges from first hand experiences—such as the collection of essays in Stephen Oliver’s *Inside Grief*, where ‘inhabiting grief is a matter of learning a landscape, recognizing an environment, in which you are going to live for a long time, probably a lifetime’ (2013, ix)—to novels—such as Ian McEwan’s *The Child in Time*, which explores the impact of grief on a couple who lose their daughter—to a vast range of theoretical literature, which is interdisciplinary (see Klass, Silverman, and Nickman, 1996; Kissane and Bloch, 2002, Kelley, 2010 and Attig, 2011).

For Cicely Saunders, it was spiritual awakenings that enabled her to overcome her grief, 'I've never been so close to God. So if I cry, it's not just for Antoni; it's for a peak of a spiritual experience' (Clark, 2018, 287).

And what strikes me about Julian Barnes's writing is the shift from a philosophical account of death and dying (2008) to a fully engaged experience of grief following his wife Pat's death (2013). Grief now 'becomes unimaginable' (2013, 69): 'we have lost the old metaphors, and must find new ones (2013, 96). Which he eventually does, without any reference to God:

It is all just the universe doing its stuff, and we are the stuff it is being done to ... we did not make the clouds come in the first place, and we have no power to disperse them. All that has happened is that from somewhere - or nowhere- an unexpected breeze has sprung up, and we are in movement again (2013, 118).

Each illustrates that the sacred is an epiphany, beyond any knowing. This section argues for a radical shift in understanding the focus of grief therapy, from knowing about grief, to coping strategies, such as learning to live with it. I am wondering whether the focus needs to shift further to focusing on sacred moments, and silences when the sacred unwittingly emerges.

With this section I have begun to trace the contours where 'deep silences' occur. Times and places when words fail, when cognitive impairment impacts understanding; where trauma shatters memory, or shame longs to be covered. Throughout these areas there is a lack, and an absence. This understanding of deep silence fits with a 'deficits', or 'spiritual needs' model of spiritual care. But I wonder if this is the whole story, whether an aspect of silence is missing, or being marginalised, and this is 'the sacred presence' of silence. Here, there is an alternative understanding: deep silences occur in places of depths and profundity when the spiritual breaks in. This concept of a 'presence' in the silences surrounding and within relationship, and in liminality or on the threshold, are explored in the following chapter where I accentuate the sacredness of silence. These fresh insights enrich my understanding of the orientation of spiritual artistry, and unsettle the current understanding of what it means to deliver specialist palliative care. They challenge current practice. A recovery of 'deep silences' enables spiritual care to engage with dimensions that are currently

hidden, silenced, or neglected. I now consider 'threshold silences', which create the conditions for 'sacred silences'.

Chapter Six: Threshold and Sacred Silences

Introduction

The early chapters in this thesis argue for spiritual artistry to engage with depth and profundity that are integral to end of life care. I identified inner space as a locus of both meaning-making and healing connections. However, towards the end of life words often fail, and there is a profound encroachment of deep silence. The following chapters conveyed the complexity of deep silences, and their potential impact on the shape of spiritual care. I explored how trauma leads to loss of words, and invites a 'theology of remaining'. Shame leads to a fear of exposure, and invites a 'saving gaze'. The marginalisation of patients, due to cognitive impairment, invites 'a reframing' to restore a sense of belonging. A silence of betrayal may occur if trust is broken. And sacred silences unsettle traditional patterns in the grieving process. What is emerging here, and is a new emphasis in the delivery of spiritual care, is that the liminality of inner space and silence encountered there may be a privileged place of sacred encounter. This chapter explores this topic further, demonstrating that 'threshold silences' are a significant and 'dangerous' opening up to encounters with the sacrality of deep silence. This understanding is further developed in my final autoethnographic text. The section on 'sacred silences' re-imagines a sacredness in deep silences which exists in times of darkness and light. This chapter transforms inner space and deep silence from being a site for meaning-making, or healing connections, into being a locus of encounter with the sacred.

6.1 *Threshold Silences*



Figure 15: Pinks

The familiar sight of sea thrift, or ‘pinks’, brings colour to the shores of the West of Scotland, as in this photograph, looking over to the Small Isles in the Inner Hebrides. This liminal zone of quartz and granite rock to which the pinks cling to is exposed to the elements. Lying between the extremes of salt water and ‘machair’⁸⁷ the liminal shoreline is rich territory for rock-pools, plants and wildlife.

Between the place we leave and the destination we arrive at is a liminal (threshold) space where the old has been left behind and the new has not yet been achieved.

Zoë Bennett, et al (2018, 49).

This spiritual autoethnographic text explores threshold silences. These are the silences that occur in liminal spaces, of which there are many, in the hospice. The whole hospice is a liminal space, on the borderlands between life and death. This includes the waiting area at the front door, the bed-spaces, the smoking veranda, the chapel, the labyrinth, the hairdressing salon, the gym, the garden and so many more. The architecture, layout and incongruous activities of the hospice can create the ‘hospice effect’, which brings solace and comfort to many patients and

⁸⁷ The ‘Machair’, a Gaelic word meaning fertile low lying grassy plain. It is one of the rarest habitats in Europe and only occurs on exposed western coasts of Scotland and Ireland. The Machair is shared for grazing or divided into strips for agriculture, the traces of the plough are seen in grass covered furrows.

families, ‘without any intervention at all’. This strategy of designing threshold spaces, resonates closely with the mantra of David Reilly, to ‘create the conditions for spiritual care’.⁸⁸ Liminal spaces are located betwixt and between life and death, dark and light. What isn’t so often appreciated is the way threshold spaces and silences are both dangerous and sacred. While for some liminal space brings solace and comfort, for others it is fear and anxiety that comes in its wake. This text takes the reader on a journey, illustrating liminal spaces and what I call ‘threshold silences’ which are surprisingly neutral, yet hold the potential of despair, or the opening to a sense of the sacred.

Threshold silence 1. Rydal Water

Walking around Rydal Water, in the Lakes, it’s a rare autumn day. Stillness. Clear reflections dance lightly on the water, of golden leaves, of passing clouds; a pair of mallards, drift by. Barely a shimmer. I stop, stoop, then cast a stone. A splash, some ripples. And then another pebble, further to my left. For a fraction of time, there is a space between the two sets of ripples. A threshold moment. ‘What will happen next?’

Threshold silence 2. The chapel

Sitting around the trestle table in the refectory at Maynooth Seminary, Dublin. Clasp a black coffee, reflecting on the Summer School’s latest offerings. Mark Stobert whispers, ‘safe spaces for safe conversations’. This is what chaplaincy is all about, ‘holding silences and the holding silence’. That’s why, I have Janet Morley’s poem, ‘And you held me’,⁸⁹ etched onto the window of my chapel,

⁸⁸ ‘A conversation with Dr David Reilly’ describes his work at the Glasgow Homoeopathic Hospital. There he seeks fresh ways of approaching medicine and human caring, emphasizing the innate healing capacity in people, the factors that modify this, and their interaction with therapeutic process -especially in the therapeutic encounter. He won acclaim for achieving a new standard in healing environment created at Glasgow Homoeopathic Hospital. Accessed, 7th September 2018. <https://onlinelibrary.wiley.com/doi/pdf/10.1002/shi.236>

⁸⁹ And You Held Me

and you held me and there were no words
 and there was no time and you held me
 and there was only wanting and
 being held and being filled with wanting
 and I was nothing but letting go

including these words, 'and there were no words and there / needed to be no words / and there was no terror only stillness'.

The chapel, a liminal space? A thin space between earth and heaven. Absence or presence. The chaplain, holding silences and being held by the silence.

Threshold Silence 3: A bed-space.

I visited Helen today. I entered her room, on my tip-toes, leaving the door slightly ajar, to allow her to still hear the comings and goings. Staff tramping the corridor to their tea-break.

This morning she was burying herself under her covers. Fingertips only just visible. White linen sheets, pulled close, folded around her ears. Her mouse like hair flowing on her pillow. Eyes glazing over.

I could see she was numb. Recent days I knew had taken their toll. And I was hesitant to intrude.

and being held
and there were no words and there
needed to be no words
and there was no terror only stillness
and I was wanting nothing and
it was fullness and it was like aching for God
and it was touch and warmth and
darkness and no time and no words and we flowed
and I flowed and I was not empty
and I was given up to the dark and
in the darkness I was not lost
and the wanting was like fullness and I could
hardly hold it and I was held and
you were dark and warm and without time and
without words and you held me

Janet Morley

Prayer for the Day. 03/02/2015, BBC Radio 4. Accessed 4th August 2015.
<https://www.bbc.co.uk/programmes/b051qv1v>

‘Do you want me to go?’, I whispered.

A pause, a shake of the head.

I waited a minute.

‘Do you want me to stay?’.

A pause, a nod.

And so, for an hour, no words were spoken.

And in the distance, the rustle of papers, telephones ring tones, the scurry of feet and voices.

People all a hurry.

Here all in silence.

An hour later, I left Helen’s room. Swinging the door shut to allow her to sleep, I was greeted by a nurse, who’d seen it all and more: ‘Well that was a waste of an hour!’

And Helen slept on.

Threshold silence 4: Silk painting.

Early days into my time as a hospice chaplain, I was chatting away with our occupational therapist, Sheila, asking, ‘What do you do? What really matters?’

The way I tackle it, it’s just making space. Whether in relaxation, whether in art, whether I’m sorting a wheelchair. Making space to listen carefully, allow them to open up, share their sufferings, their hopes, to tease out the life they still have left, to find meaning, to help people manage in practical ways.

And again,

I bring myself into the spaces and the silences, it's about who I am and about how I connect, and because I have explored life myself it comes to the surface, the key is a good relationship, to create breathing spaces.

Together we watch her patient Rena, only forty years old, become immersed in silk painting, and slowly find the confidence to share her story.

I married young, became a teacher, then we had a daughter, Anna. She's still at home. Then breast cancer struck, and I thought to myself, 'I've been so busy all my life, I have lost who I am. I don't know who I am. I am somebody's wife, somebody's mother, a teacher ... but I don't know where I fit. And now I am so tired, exhausted'.

An hour later, having painted a silk scarf, her spirits seem to have lifted, as the brush moved across the silk, and she told her tale. The next week Rena, came back to the craft room and surprised us all saying,

I came here a broken woman and now I've found myself. And I have things I now want to do, and it's time to do it. I'm discharging myself from the hospice and going to Nepal with Anna.

Threshold silence 5: in a garden

I wrote this poem after sitting with a young mother who had only weeks to live, in her own home. Gazing out of her window into her garden, watching her two sons play, she then became entranced with a floating butterfly. The sight of such beauty and my awareness of its fragility seemed in some way to invite a reflection. I wrote of rapture and of ecstasy.

Cabbage White

Namaste, I greet the god within your delicate wings,

dancing on the breeze, entire, complete, consumed.

tumbling down, surprising, head over heels, incandescent

host, playful in the late summer sun

landing light

effortless among hazes of lavender blue and green.

verdant beauty, your delicate antennae

at once perfect yet fragile, still in space and time.

cabbage white you alone are

my grace note

at one with my inner eye surpassing

all of life and chasing away looming shadows of death.

unbearable nightfall

too soon

you and I are one united in the fading

gone

butterflying

out of mind

forever

white.

Ian Stirling.

6.2 Sacred Silences

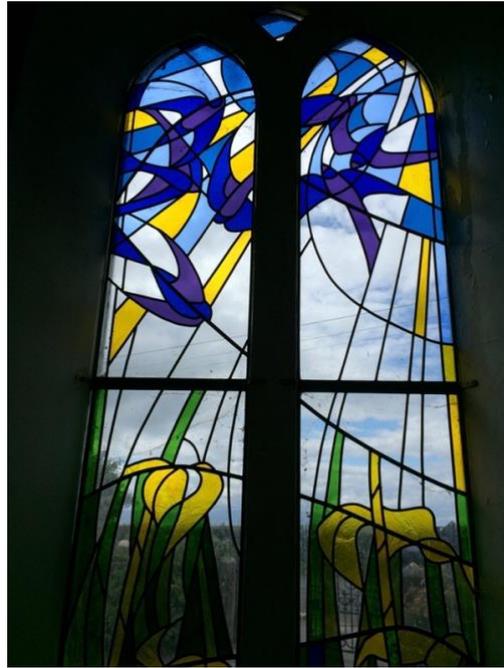


Figure 16: Stain glass window, Fisherton Church, Ayrshire

The stain-glass window: *'the birds of the air and the lilies of the field'* at Fisherton Church, Ayrshire, connects the interior sacred landscape with the rural landscape and seascape beyond its walls. There is no distinction between the sacred and secular. Just as there is no distinction between darklight.

In general, I don't believe so many things today as I did before; but my beliefs now are certainly held more deeply.

--Cicely Saunders, (2005, xii).

For the darkness and the light are both alike to you.

--Janet Morley (1992, 22-23).

My intent in this spiritual autoethnography is to wrestle with sacred silences across time. My relationship with Petya is unusual, in that it lasted over two years, from the first week of her admission into the hospice, through to her funeral. In hindsight, the sacred pervades through all Petya's experiences. What surprises me is how the sacred is present in both spiritual awakenings and depths of despair.

This text traces the sacred in healing connections with self, other and Other, and scrutinizes whether the sacred is evident in times of darkness and light.

Scene 1: the garden room

Snuggled into her bean bag, Petya looked up as I entered the garden room. Bright fabrics enveloped her matching her smile. A hostess welcoming me as her guest. But what I wasn't prepared for was the struggle to make a conversation with this clearly intelligent woman. She wanted to speak. But cancer was eating away at her throat, a huge swelling on her jaw, waiting to have her teeth removed, her tongue losing its power. How she retained her youthful glamour, only she knows. And amidst broken speech and long silences, there are only so many times I was comfortable saying, 'Sorry, can you say that again, I didn't catch you'. I just couldn't tune in. To her dialect, or her soft-spoken voice. Her irritation rose over the hour, we were not going anywhere fast or slow. She scribbled away on her laptop in Bulgarian, on her notepad in spiralling black ink and lambasted me for not being fluent in German, one of the several languages she spoke. Somehow, before I left, feeling at a loss, I risked asking, 'Would you like to email me?' I gave her my card.

Scene 2: my office

I was amazed by the way our email conversation developed. One day I sat at my computer screen and opened her mail. Speechless. Riveted. All ten of Harvey Chochinov's Dignity Therapy Questions, which I had sent her just this week, complete, including these fragments:

- *'My life story ... ha ha ha ! I can speak about that few months.*
- *When I feel most alive? When I was in love, even in most inopportune person:)*
- *What have you learned about life? ... without suffer there are no enlightenment. Terminal cancer gave me the opportunity to clear my karma and began a second life. And even if I dye it is not a big deal. It is simply like to change one dress with another one.*

Having spent all her time in the garden, Petya found the time, and the energy, and found the questions ‘very, very interesting’.

Scene 3: teeth

But I saw dark clouds on the horizons, ‘I will be operated on, teeth and neck at the one time’.

And in the emails following the operation I traced her angst,

I had some problems with myself after the operation. I was not very happy of my look 😊 without teeth and with big swellings from both sides of my face. And I’m a woman, and not only that, but I’m very vain 😊... so I was and I’m still not too happy.

Yet I was intrigued that in this moment, in her crisis, she found a way forward. At a time when she was lost for words, she turned to her art.

I miss so much all of you in the Hospice. Miss my art hours, meditation ... nevertheless I paint, ... “Could we make one charity exhibition?” I will try to put my feelings into art.

Scene 4: the art exhibition



Figure 17: Butterfly, by Petya

This is one of Petya’s paintings, *Butterfly*. I see her love of colours, and her belief in reincarnation. The transient and vulnerable cycle of life is represented in a

butterfly's life cycle: caterpillar, cocoon and butterfly. She opened the exhibition with these words,

Welcome!

I am so happy to see you all today at the opening of my first exhibition. But I have to confess you something. All this paintings are not mine, they are yours too.

Today I'm here enjoying of the life and of the love I received every one minute.

Painting is my way to express myself, after I lost the possibility to speak normal. I was thinking to choose singing, but I decided not to torture you with this my talent! Anyway talents are different, but they are all carriers of the spiritual energy. The same like the sound and the smelt of rain who are so different in the spring, and all other seasons, but all the time raindrops are just piece of the Universe energy.

So with this paintings I'm trying to give you back a piece of whole positive energy I received last two years. Thank you all! Petya.

Scene 5: continuing struggles

Over the months, I continue opening Petya's emails, delighted she is so appreciative of our ongoing conversations, 'because for me is still difficult to speak alive with ppe, I wrote you, and if you find time I prefer to continue our mail correspondence. However, I was uneasy in reporting to the hospice team, 'all is well'. Despite the positives; despite completing the Dignity Therapy and despite putting on an art exhibition, I sense a darker thread,

Aggression in me is so great that I am able to kill someone with my own bare hands

And the ongoing angst of her lack of teeth, still lingering issue,

I'm still without teeth and this makes me a bit nervous cause I can't communicate with people normally. And I'm still not so strong mentally ... my pictures come

from the soul and when I'm not in a good mood they are ugly or I just haven't any wish for painting.

And her loss of esteem:

Thank you so much for a nice article about me and the exhibition, but the photo is really unbearable, I had never in my life moustaches and on this photo there is a tiny one.

Yet it would be a false witness, if I didn't say that even in the dark, Petya found glimmers of light, hope and humour:

by the way last few days I have a robin in my back garden. Another present from God! He definitely loves me so much, even without teeth! LOL. Thank you for your patience to listen to me. Stay with peace.

Scene 6: her last days at home

I struggle still with the downward spiral of Petya's last days, known only to a few. In the following quotes, Petya describes a journey into isolation.

- *Too many people around me, and I have to find me in whole this trouble*
- *I have to manage with my daughter, Sonia's feelings*
- *I'm very scared of all this medication ... I don't tell them but I take only sometimes, just so because with or without them I have not pain. They only bring me sleepiness, like people who takes drugs*
- *I stop to paint*
- *Definitely no, because for me the best now is to stay more of the time alone.*
- *Most of the people pitied me and this is the fastest way to kill me. So, I prefer to be alone*

- *Sonia couldn't sleep and stays in the bedroom all night staring at me*
- *For me it's absolutely exhausting*

Soon after this communication, Petya died at home alone, in very trying circumstances: overwhelming blood and darkness.

Scene 7: back at my desk, writing it out.

I return to my desk. I face the empty page. This darklight sacred is so hard to write, but I try. First, in memory of Sonia, her daughter who couldn't take her eyes off her mother through the night, a poem.

Midnight Hour

Your face is ingrained in my soul,

a precious diamond,

set in my heart.

Then finally for me a healing. Petya felt so much the shame of having no teeth, and would cover her face with a scarf; yet she embraced the metaphor of a new dress to interpret her dying, 'knowing that I cannot escape (death), I see no point in worrying about it. I tend to think of death as being like changing your clothes when they are old and worn out, rather than as an ending.'⁹⁰

⁹⁰ The Dalai Lama, in his foreword to *The Tibetan Book of Living and Dying* (Rinpoche, 2002), describes dying as putting on new clothes.

A new dress

Slipping on a new dress.

That's all

Catch a glance of me now,

I'll say "surprise".

Floating in a mirror, a spinning

Dervish, round and round.

Head back, eyes wide open to the heavens.

Yes that's me, and I'm free,

Just as I am, as I always will be.

Just see me

Poised, feminine sophistication

Sparkling intelligence.

Purple dress

Smooth as silk, soft

On my skin.

Clinging to my shapely hips,

Falling to the floor,

Colour accents catching my style, my hair

The colour of my nails, my heels.

Yes that's me, phenomenal.

Dying no need to fear,

Slipping my dress on now,

Waiting to slip away.

Ian Stirling.

6.3 *Threshold and sacred silences*

Spirituality refers to that which is deepest and most genuine in us, the ground of our being, and what we, and others, refer to as spiritual pain is the experience of alienation from this depth.

Michael Kearney and Harvey Mount (2000, 358).

Reading over 'Threshold Silences' surprises me by how counter-cultural holding silences safely is. The scenarios reaffirm the value of taking people into liminal spaces and silences, and the gift of being present with no agenda, with no answers, with unknowing and a commitment to remain. What challenges me is the courage to loiter in the silence, and not succumb to the temptation to either fill it, or move out of it. Threshold silences invite patience. What also surprises me is how risky this whole process is. It may be sacred or dangerous. It is no neutral venture, no 'waste of an hour', rather threshold silences are the locus of generativity and creativity. They are full of 'expectancy', that something may happen, but equally full of 'unknowing' about what may happen. Uncertainty, about whether there is absence or presence, joy or despair, fills the silence. Liminal spaces and threshold silences often signify the end of something old and the beginning of something new. A bridge across which something moves, 'boundary-dwellers'- are not necessarily 'marginal' but rather on a threshold, signifying the end of something old, the beginning of something new' (Ward and Wild, 1995, 2). However, not everyone moves across a threshold, some remain betwixt and between. I often describe myself, as living in the empty silences of Easter Saturday. Conscious of the sorrow of Good Friday and not yet enjoying 'little Easters'. Threshold silences may become the critical space to see well.

Reading over 'Sacred Silences', I see all the places where I encounter Petya, the garden room, the computer, the art room, and her home, as liminal spaces which embrace both danger and sacredness. There is a blurring of dark and light. A sacredness when things are going well, such as within dignity therapy and during her art exhibition. And equally a sacredness during her recurring challenges, the loss of her teeth, the longing to be alone and even her traumatic dying. This text reflects a constant cycle of light and dark, hope and despair, coherence and chaos. Sacredness is hard to represent.

The final section of this chapter explores what I believe is happening in threshold silences and sacred silences, and the interface between them. I limit myself to weaving together three threads

- Liminal spaces are sacred and dangerous.
- Liminal spaces in dying invites spiritual awakenings.
- Liminal spaces invite a new understanding of sacredness.

6.3.1 *Sacred and dangerous*

Hannah Ward and Jennifer Wild, in *Guarding the Chaos*, offer a useful starting point in understanding the nature and impact of living on the threshold, which they say is a boundary, a liminal zone, betwixt and between the old and the new. 'Liminality' is a locus, an ambiguous, sacred, social state in which a person or group of persons is separated for a time from the normal structure of society' (1995, 22). And liminal experiences are a process. For example, initiation rites at puberty, the 'bardo' state in the Tibetan Buddhist tradition, located as it is between death and re-birth, offering the greatest potential for enlightenment, and wilderness experiences in the desert, which in the Christian tradition, is often a testing of God's presence and absence, are dynamic and enjoy 'a particularly sacred quality' (1995, 2). The pattern of liminality is of movement, and journeying. However, this can be sacred or dangerous. Living on the edge, in liminality, is a crisis moment which can go either or two ways, towards danger or towards opportunity, as captured in the Chinese symbol for crisis (1995, 19). The sense of movement is further developed by reference to Paul Ricoeur's three-stage model of change, orientation, disorientation and reorientation.⁹¹ And to the tension between clinging to the past, and discovering a revitalised identity in the future (1995, 16). The process of liminal experiences they say, is to 'guard the chaos' by guarding the creative potential and guarding, or containing the

⁹¹ Walter Brueggemann (1984) employs this same framework of orientation, disorientation and new orientation in his theological commentary on the message of the psalms.

accompanying threat of disintegration (1995, 5). Their framework resonates with the natural human drive away from danger towards recovery or renewal. For example, Frances Young finds her way out of the 'pain of godforsakenness' by developing a notion of a God who is 'both passionate and passionless at the same time' ...God 'is the ocean of love that can absorb all the suffering of the world and purge it without being polluted or changed by it' (Pembroke, 2017, 54-55). New movements from the threshold, may be towards something familiar, such as Cicely Saunders's conviction, borne from her reading of Julian of Norwich, that 'all is well' (Clark, 2018, 294), a new identity, such as Jacob being given a new name after wrestling with God at the Ford of Jabbok (Genesis 32, 22-32), or radical new insights into faith, such as Walton's insight of the 'gifts that accompany our griefs' (2015, 19). What I suspect in their argument, is that even though there is mention of the silence of Easter Saturday, 'the in-between day' (1995, 55), and even though they mention the 'emotional chasm' experienced by C.S. Lewis after the death of his mother, only 'traversed', fifty years later, when he came to terms with his wife Joy's death (1995, 65), their stress on either extremes of reorientation (recovery) or disorder / chaos (danger) undervalues what it means to stay in the threshold.

6.3.2 *Spiritual awakenings*

In contrast, Monica Renz (2016) stresses not so much movement across a threshold, but spiritual awakenings.⁹² People in the 'liminal sphere', on the boundary of life and death, have deep longings, deep desires, and difficult fears to overcome. They fear abandonment, live with beauty and darkness, have a slumbering experience of God, struggle through nothingness, sense God's remoteness only then to discover a closeness with the 'numinous Thou'. Their former world is collapsing and a new world emerging (see 2016, 35-48). What matters says Renz is that conditions for hope are created, which opens a door to grace.

⁹² Mark Cobb reckons that the notion of transcendence lies at the core of spirituality:

Transcendence, at its heart, is about going beyond the self, the body, the physical and the mortal. It is becoming one with a greater whole or reality, such as the depth of one's being, the universe, or with the Other. This may be like an 'oceanic' mother/baby experience of unbounded union or else connection with ultimate reality. In the latter, 'the abdication of the ego allows one to be at one with the universe' (2001, 22-25).

Finding hope is a process, which can lead us through darkness, indeed through and beyond an often dreadful impasse, a nadir of suffering, to a new quality of existence (2016, 14).

This is a spiritual experience. Spirituality is an ‘experience of the inconceivable’, at the limits of the known world (2016, 23). Moments of transcendence such as, on seeing cherry blossom being at one with the universe (Potter, 1994) illustrate the feelings of awe and terror, light and dark that encompass the spiritual dimension of life—the *mysterium tremendum et fascinans* (the fearful and fascinating mystery, described by Rudolph Otto (2016, 23-34, 44)).⁹³ Renz laments how the prevalent ‘needs-based’ approach to spiritual care, which focuses on well-being, has caused a ‘spiritual amnesia’, in which the ‘spiritual’ experiential moments that matter, that comfort and console the dying, are forgotten (2016, 144). Sacred encounters come by grace. Grace, she says, is a free gift of God, which breaks in, to open a new and hopeful horizon even in the nadir of suffering. The hope that grace confers, of being connected to something beyond, creates feelings of serenity and peace. The strategy of spiritual care therefore rests on spiritual therapies, such as music therapy, which sustain the power of hope, of keeping oneself open and of expecting grace. It is in this relationship, ultimately with the Other, that hopelessness is relieved. By countering the momentum of ‘spiritual-needs’ and by arguing for a relational ‘spirituality-based’ approach Renz is reinterpreting spiritual care, creating a new world.⁹⁴ She reinforces the vision of Michael Kearney, who stresses that from the outset spiritual care attends to ‘care for soul’ (1996, 16). That dimension of personhood which does not die. That dimension which exists in a deeper stream. This deep silence, the connection with God, the sense of union with the universe, the rapture, is what Monica Renz calls ‘spirituality based’ spiritual care as expressed in her poem, *Experience at Night*.

⁹³ Renz describes ix threshold experiences: Loss of voice; Intensity; Angels; Desert; Unity; and Being and relationship. Aware of the otherness of the sacred (2016, 82-143).

⁹⁴ David Lyall describes how Donald Capps in *Pastoral Care and Hermeneutics* (1984) borrows from Paul Ricoeur to construct a new frame for pastoral care. Ricoeur had previously connected meaningful human action with written texts. Both leave their mark; both may have unintended consequences; both create new worlds and both are open to reinterpretation (2001, 50-55).

I admit. I am hurt, I stray, exposed

to the mocking and the walls of silence.

The freedom is mine, arising on the narrow

toe board of being loved,

to get to the heart of my suffering

and to offer it to the night itself,

to the non-existent.

In the morning,

I am 'found',

not knowing by whom,

by YOU.

--Monica Renz (2016, 5).

For Renz, deep silences encompass both the human and the divine horizons. Psychological depths and threshold moments. And her insights, of grace notes bringing hopefulness in liminal zones, resonate with both Rambo's (2010, 2017) 'theology of remaining' and Walton's (2017) 'strange season of the empty tomb'. Though Walton offers a radically alternative understanding of the source of grace, light or vitality,

A ray. It does not come from the sun. It comes from the damaged and the derelict re-forming into piercing power (2017, 2).

6.2.3 Sacredness

This appreciation of spiritual awakenings leads me further to consider the insights emerging from Heather Walton's quest for sacredness which I believe offers an interpretive frame to understand sacred silences. This section emphasises three key turns in her thinking, 'sacred and eloquent silences' (2002, 2), 'gifts accompanying griefs' (2015, 19) and poetics, which inform 'the strange season of the empty tomb' (2017, 1). This turn towards poetics to represent sacredness, resonates strongly with Rowan Williams's Gifford Lectures, *The Edge of Words* (2014). Williams' final Gifford lecture, 'Saying the unsayable: where silence happens' (2014, 156-185), is a fascinating exploration of where silence happens and culminates in his conviction that

the most comprehensive and thickly textured account of what is recognizably human is deeply implicated in concerns about 'the sacred' -about what is not yet said, what is not sayable, what precedes our understanding and both confirms and challenges specific acts of understanding (2014, 184).

What this means is that time-bound, embodied, and creative language which emerges at the edge, or at the limits, of understanding, fractures what is here and now, and orientates people to what lies beyond the threshold. The unknown. The sacred. In this move, Williams connects the depths of humanity with sacred depths.

In her landmark paper 'Speaking in Signs' (2002), Walton argues that 'storytelling lies at the heart of the healing encounter' yet there are times of intense suffering and trauma when 'words fail'. What she means by this is that in the face of intense suffering, not everyone can either connect to 'God's story' or if lives are shattered people may lose a narrative agency and therefore be unable to create life story.⁹⁵

⁹⁵ Canonical narrative theology enjoys its origins in Karl Barth, who emphasises the centrality of the Jesus story. It continues to be grounded in theologians such as Hans Frei, George Lindbeck, and Stanley Hauerwas. Critically in canonical narrative theology there is no suffering, tragedy or trauma that cannot be borne by the sacred narrative, even the death of a child. The challenge to this theology is whether God's sacred drama 'domesticates the rage' of trauma and suffering (Hauerwas, 1990, 38). The latter, constructivist narrative theology, Walton contends, emerged in the philosophy of Paul Ricoeur. Human beings shape and sculpt their lives from birth to death, drawing outlines and creating patterns of coherence which resist the threat of chaos and non-sense. Arthur Frank (1995) is the father of narrative in healthcare. His text, *The Wounded Storyteller*, in which 'the wounded storyteller is a moral witness reenchanting a disenchanted world' describes how narrative brings hope. *Illness Narratives* describes three distinct paths in illness, 'quest, chaos, reconciliation'. Frank has inspired many to employ narrative within

Words fail, says Walton, in situations ‘where the experience of suffering exceeds the conventional means employed to give it voice (2002, 4)⁹⁶. Walton’s innovation is by having the courage not to collude with those who use coherent narrative to cover up wounds, or use theodicy ‘to bridge gaps and fissures’ in human experience (2002, 4). Instead, when words fail to redeem or heal the chaotic/embody symptoms of trauma then this opens the vista of either the poetic, image, symbol and metaphor, or else the preservation of ‘a sacred and eloquent silence’ (2002, 2). Walton preempts the company of theologians now wrestling with silences (see Jasper, 2004; Maitland, 2008a; MacCulloch, 2014; and Williams, 2014). They disclose many kinds of silences, for some silence is absence, for others silence is presence⁹⁷, and for Williams’s silence is framed by what has gone before, and what comes after. So, it seems, silences speak according to circumstance⁹⁸.

In *Not Eden* (2015) Walton connects the sacred and the everyday. Sacredness is present in vital moments, and in the radical counter-story, of ‘gifts’ accompanying ‘griefs’⁹⁹ (2015, 19). Walton evokes this ‘ambiguous and enchanted environment’ (2015, 20), in her own story of infertility, using the metaphors of gardens, growth,

healthcare and led to the evolution of medical humanities. These people hold in common the conviction that by witnessing, listening and ‘hearing others into speech’ pastoral carers assist individuals to re-pattern and re-negotiate their broken and fragmented lives. Joining dots and putting the pieces back together, but in a new way (2002, 3).

⁹⁶ Walton supports her argument with the critical insights of Paul Antze and Michael Lambek, who defy accepted wisdom that storytelling leads to healing: ‘there is nothing liberating in narrative per se ... merely to transfer a story from embodied symptoms into words is not necessarily to exorcize it’ (1996, xix). And Laurence Kirmeyer, who illustrates how trauma is located on the edge of consciousness and conveyed in fragments: there is no narrative of trauma, no memory - only speaking in signs’ (1996, 175).

⁹⁷ For example, Williams introduces the mystical or apophatic tradition in spirituality, represented by voices such as Meister Eckhart who paradoxically called God ‘*omninominable*—knowable in every way—as well as *innominable* - not nameable at all’ (2014, 175).

⁹⁸ For example, the silence of John Cage’s famous 4’ 33” performance invites unheard sounds to emerge; or the atrocity of the Holocaust forces a silence due to the impossibility of poetry after the horror. And there is the silence of those who have been silenced by power or violence, a silence waiting to be broken. The corrosive silences of survival, evidenced in oppressed communities and the intentional silences of those who let go of self to become one with God.

⁹⁹ Walton succinctly describes a history of spiritual life writing as moving from ‘establishing coherence’ to ‘allowing for chaos’ (see 2015, 7-17). The issue now is whether contemporary writers are overwhelmed by the situation and lean towards ‘a loss of faith in all traditional structures and loss of hope in radical social change’ (2015, 18) or whether they can embrace ‘a new sense of wonder’ (2015, 19) in which the freedoms, fragilities and brokenness of our world do not lead to dark despair, but an appreciation of ‘dwelling in a place of light and shadows’ (2015, 20).

fecundity and blight. Spiritual awakenings emerge from light and shadows, from starry heavens and bare wood.

I was at the centre of the whole turning universe. I could hear the song of the Spirit sounding out across the starry heavens and all along the darkling plain (2015, 61).

And her final chapter, 'Flowering Rod', Walton speaks of 'blossoms coming straight out from the bare wood' (2015, 137), which resonates with earlier convictions, 'I could be broken and still put out new shoots from within myself (2015, 118). This interpretive stream, of gifts accompanying griefs informs the darklight moments in 'sacred silences'. There is a sacredness in both light and shadows. For example, a sacredness in the light: the delight of a gardener seeing 'dirt under my fingers' - a re-engagement in life; or describing the hospice as 'a little piece of heaven', because I now belong; or the joy of feeling the 'fresh air and a kiss of sunshine'; or of forgiveness 'before I meet my maker'; or renewed zest for life having been entranced by a ballet, 'The Bolshoi', for the first time. And alternative examples, of a sacredness in the shadows: a man longing to die in 'a mist of morphine and merlot', a man shamed by the cancerous growth on his face; a lady with Motor Neurone Disease lamenting, 'you've stolen all I have left', after health and safety protocols denied her access to a wheelchair; in the tears of a mother, 'I long for my daughter'; and in the torment of a man who took a life, 'I am beyond the pale'. Walton allows me to be more honest and transparent with what is happening before my eyes. And to resist sheltering 'behind normative buffers' (2018, 227) and to see that every moment is a door to the sacred.

The final turn by which Walton deepens my understanding of threshold and sacred silences is the turn to poetics, which is liminal language, the language of edge-walkers, and the language of end of life care¹⁰⁰. I turn now to three of Walton's essays to develop my understanding of poetics and its interface with the sacred, deep silences and the delivery of spiritual care.

In 'Approaching Poetics' (2014b), Walton argues that poetics enhances theology by pointing to 'something beyond' (2014b, 134); by embodying a 'rebellious,

¹⁰⁰ Over recent years Walton has been a pioneer in establishing the value of theological reflective writing (2014a) and poetics in Practical Theology (see Walton 2014b, 2014c, 2014d, 2014e, 2017, 2018).

anarchic and chaotic force' (2014b, 135), and by being 'the human genius to create meaningful lives out of the ephemeral and material' (2014b, 136). Poetics unifies meaning-making, relationships, and artistic endeavour. Translating these insights means that a poetics of spiritual artistry, is also embodied, relational, and grounded in art/culture.

In 'Poetics and Practical Theology' (2014c), Walton describes the different 'temperaments' of poetics and theology, which are comparable to the different temperaments of spiritual artistry and specialist palliative care (Walton, 2014c, 137). In contrast to a practical leaning, poetics and spiritual artistry create a 'something else ... beyond the limits of the matter-of-fact, everyday world' (2014c, 137), the 'capacity of metaphoric utterance to embody the exotic, the beautiful, the tragic, the unknown and the unnameable' (2014c, 137). Poetics and spiritual artistry engage with the 'particular, embodied and contingent' (2014c, 137); and can linger, or remain in the silences. They also challenge 'imposed frameworks' (2014c, 139). Just as literature confronts 'the tragic aspects of existence' (2014c 144) and metaphors enjoy 'an imaginative capacity to create something new out of the meeting of different terms' (2014c, 144), so too can spiritual artistry extend the vision of palliative care to embrace the ambiguity, profundity and chaos of dying. For example, Rebecca Chopp's (2001) poetics of testimony expresses unique experiences beyond the capacity, or 'usual registers', of rational discourse¹⁰¹. Poetics says the unsayable, and brings the unbearable, such as trauma, abuse, ecstasy or pain, into speech. It bears witness and testimony

¹⁰¹ Chopp's 'poetics of testimony' envisions theology and culture in new ways. Inspired by the stories of Elie Wiesel, whose experience of the holocaust impelled him to bear witness: 'I knew that I must bear witness'; the Soviet poet Anna Akhmatova, whose poem *Requiem* expresses her experience of waiting outside a prison in which her son was held, and Shoshona Felman's definition of testimony as 'a discursive practice, as opposed to a pure theory', Chopp charts the way for a poetics of testimony. Using the imagery of a legal court, she portrays the way reason and logic, represented by such thinkers as Lock and Lessing, Hume and Kant, interrogate the power of testimony. Quoting Lessing: 'in this trial by reason, testimonies become powerless, emptied of spirit, not convincing for proof'. In contrast the 'jarring witnesses' and testimonies of captured in poetics, turns the tables in the court. In that the judge and the courtroom are now on trial. Poetics is a discourse that 'reshapes, fashions in new ways, enlarges and calls into question the ordering of discourse within ... the "social imaginary"'. What is emerging is an understanding of a poetics of testimony which 'is for the mending of life, the healing of life, the ability of life to live and survive and thus conquer this extremity'. Significantly, this genre includes poetry, theology, novels, and other forms of literature that express unique events or experiences outside the representation of modern rational discourse, and thereby is an approach that supports spiritual artistry (2001, 56).

to the marginalised, thereby challenging the social imaginary¹⁰² and refigures, refashions and reshapes the world (Chopp, 2001, 61).

Finally, in 'Seeking Wisdom in Practical Theology: Phronesis, Poetics and Everyday Life' (2014e), Walton introduces a radical new way of seeing. Drawing on Henri Lefebvre, one of France's leading intellectuals in the early 1900s, Walton describes the way the Surrealist gaze influenced his thinking with the result that rather than rising above 'inchaote, chaotic, unformed mess of living' (2014e, 178) by abstraction, he saw a 'veritable profundity' (2014e, 178) in everyday life and 'an ecstatic energy at the heart of things' (2014e, 178). For Lefebvre, it is the intensity of the moment, or 'the irruption of the tragic in everyday life' that turns it upside down (2014e, 179). This resonates with my sense of the sacred located in the sometimes chaotic and messy worlds of the dying. Michel de Certeau moves beyond Lefebvre's vision. By drawing on the philosophy of Lacan - human beings 'have to relinquish an originary state of union with the maternal ... (and) exist now as human beings through the trauma of our loss ... we are outcasts and seekers. We are pilgrims who will never arrive at the sacred' (2014e, 181) - the sacred, the spiritual is ever restless and journeying. And poetics 'reinscribes' life with a sacredness (2014e, 183). The world no more is coherent, but by chaotic and dynamic, understood by 'a hermeneutics of wonder' (2014e, 184) or a mystical gaze. Walton is describing here an 'incarnational theology' (2014e, 185),

as a radical kenosis that does not so much raise up as gaze down, touching the very depth of matter as it splits, fissures and proliferates and finds in stone, the street, the dance, the dress the very flesh of God. This view is less interested in incorporation and harmony than in sharing the passion, the wounding and the glory of this living. This everyday life. This living God (2014e, 185).

It is the ability to wonder that allows chaplains to see the sacred in the chaos and complexity of a dirty dying, an anxious dying, a lonely dying and an abandoned dying, none of which sit comfortably in the current lexicon of spiritual care.

¹⁰² Walton adopts Charles Taylor's definition of the 'social imaginary' as the way 'people imagine their social surroundings ... carried in images, stories and legends ... the social imaginary is that common understanding that makes possible common practices and a widely shared sense of legitimacy' (2014c, 146).

Walton's stance invites spiritual artistry to embrace a mystical wondering within every threshold and sacred silence,

For transcendence lurks in the loveliness of everyday life and our immanent desires compel us to reach out and touch the heavens (2018, 228).

This final chapter has introduced threshold silences and sacred silences, and explored the interface between them. I have woven together three threads: the sacred and dangerous, spiritual awakenings, and sacredness, which illuminate my understanding of deep silences. This imaginative weave discerns a poetics flowing through and re-invigorating spiritual artistry, to enable people to dive into the depths of dying, grief, deep silences and be surprised by a shifting sense of sacredness.

Conclusion



Figure 18: Ghlas

Gaelic is a poetic language, rippled through like metamorphic rock with metaphoric glides. A concept, or rather, a feeling like ghlas, simply doesn't map directly onto Newton's spectrum of seven colours. Instead, the Gaelic reflects the shifting hues of a living and dynamic world. One definition of Ghlas, for example, might be: the colour of the moods of light from ever-changing skies, reflected on the surfaces of water.

--Alastair McIntosh, *A Poacher's Pilgrimage* (2016, location 745).

Deep silences and sacredness are like light dancing across water. Evasive, shifting endlessly, and enjoying many moods, hues and colours.

Today's early morning walk took in a kelp strewn shore, and then, after a climb into ancient woodlands, a clamber over fallen trees. A sorrow, after yesterday's storm. I stood still for a while and gazed up. Wondering. "What now will fill the canopy?" Still skies and storms, at the beginning, and recurring at the end of my doctoral journey.

The motivation for this thesis was a suspicion that something was lacking in the delivery of spiritual care. A huge investment of time and energy, at all levels, into scientific, evidence-based models, to justify and warrant the place of spiritual care in palliative care was bringing some rewards. But I still felt a disconnect. A loss of original vision. My sense of lack and loss revolved around a strategic shift from 'hospice to specialist palliative care', reflected in the systemic changes

happening around me; new processes and procedures, and subtle changes almost unnoticed; even memorial books, which held the handwritten names of every patient, hidden away from sight. The question in my unease was which way to turn, to find, or to rekindle, the trick of living?

It is the slow and difficult

Trick of living, and finding it where you are.

--Mary Oliver, *Going to Walden*, (1992, 239).

It gradually dawned on me that a new vision would emerge by reclaiming spiritual artistry, and I decided to dive deeper into the depths of where I already was. So, I turned to spiritual artistry, as a way, to encounter the chaos, ambivalence and profundities of those confronting death. Through this journey I came to understand that spiritual artistry comes alive in inner space and deep silences, on the edge of words and at the limits of language. Also, Allan Kellehear's argument for a more nuanced creative arts research to represent 'the voice of those who suffer' and the dying, sustained my quest (2009, 394). And I embraced a new way of seeing: spiritual autoethnography. The intimacy, and attention to detail, that this innovative methodology allows creates a new critical stance to explore inner space and deep silences. Some learnings in this study are that silences emerge from trauma, shame, cognitive impairment, betrayal, and grief and are best understood as an absence or lack. However, not all silences are negative. Many are positive.¹⁰³ I began using the term deep silence, as a poetic and heuristic construct, to convey what happens in liminality, when time stands still, spiritual awakenings and people sense the sacred. What I discovered is a litany of lasts and a litany of losses. Sacredness has taken on new forms. The sacred is evident not only in epiphanic moments of transcendence, such as in the litany of lasts:

¹⁰³ Sara Maitland describes 'moments in human experience where there is no speech, no noise, but clearly no sense of loss or deficiency' (2008a, 277). For example, a mother with her infant at the end of night feed; an awed response to a landscape; seriously good sex, where there is no shame of nakedness; listening to music, rainfall and ocean waves; the silence of the cosmos and the silence of death. These silences are outwith language and narrative, and convey a blurring of the boundary between Self and Other (see 2008a, 277-279).

a last day in the garden and the delight of having ‘dirt under my fingernails’; a last trip to see the ‘setting sun’; a last drink of ‘ice cool water from a spring’; a last moment to feel the breeze on my face and the sun in my eyes’; a last sacred text, such as Psalm 139 being whispered in my ears.

But the sacred is now evident in the tragedy of loss and brokenness, such as in the litany of losses:

I long to die in ‘a mist of morphine and merlot’; ‘you’ve stolen all I have left’; ‘I am beyond the pale’; ‘I feel betrayed’; ‘God will not judge me because of my vulnerability’.

A key feature in this study is the way I employ the terms ‘inner space’ and ‘deep silence’. They are heuristic constructs—useful for exploring things but not having a reality ‘as such’ beyond their modelling use. However, I intentionally develop them to help me see and respond to things that are important, such as attending to sacredness. Something that currently is rarely addressed in palliative care, but lies at the heart of dying and grieving. A heuristic approach, despite its limitations, still has value. I embrace this approach and offer its fragility to the reader, on the strength of Walton’s critical observation in her theo-poetics of practice,

But after all this what exactly have I put before you? Simply a framework that may enable us to begin to imagine a theo-poetics of practice. It might appear to have content and structure but what is it really? The modernist artist and religious poet David Jones described poetry seeking the divine as still ‘a made thing with a shape’. This is what this is: a made thing with a shape. To talk about theo-poetics is to talk about a made thing, a heuristic frame, a gesture reaching out awkwardly to fashion and form an understanding of what unites God’s making and our own creative practice. In that way it is not any different from the rest of theology actually— although tactically we might claim it to be so. But even as a made thing with a shape it has its own fragile life and purpose and so I place it in your hands (Walton, 2017, 26).

I return now to my morning walk. To still skies and storms. The question, ‘What now will fill the sacred canopies?’ My discovery, and delight, in this thesis, is that the trick of living question, of reimagining spiritual care, and of discovering that

encountering the sacred happens through learning to ‘love the country of the here below’ (Simone Weil, quoted in Walton, 2015, 42), and ‘to adore the sacred within its blemished beauty’ (Walton, 2015, 20).

I have moved away from a vision of spiritual care dominated by the alternative approaches of evidence based assessment and meaning-making and narrative. I have looked back to the original vision of hospice pioneers, who value healing connections; and I have found a new vision, of spiritual awakenings and reclaiming inner space and deep silence as the locus of the sacred. I hope that sacredness will now fill new ‘sacred canopies’ in palliative care. I hope that spiritual artistry, founded on poetics, will enable people: to inhabit inner space and deep silences, to say the unsayable, and to delight in the gifts that accompany griefs. I trust that this new understanding of the role of the hospice chaplain, and of the delivery of spiritual care, will benefit those confronting their mortality and their grief.

In this thesis, I have carved some runes, and now I am content to return again to the pastoral spaces of deep silence.

Epilogue



Figure 19: Horseshoe Fungi

Zeki, a young man, learning to live in the pine woods of The Braes of Glenlivet, took me into the woods to reveal some secrets of survival. The plants to eat, and how to strike a fire with flint. In ancient days, he said, the elders of a community were entrusted to carry fire, from camp to camp, by wrapping the glowing embers of the horseshoe fungi, in reeds. Who carries the fire of sacred silences?

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