

Spiritual Care in Palliative Care

What it is and Why it Matters

Megan C. Best
Editor

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Foreword

Spirituality is an essential element of whole person care. For centuries, healers from different cultures and religions were integrated into the holistic care of people. Scientific advances in the twentieth century shifted the emphasis of care to the physical aspect of care. However, leaders such as Dr. Paul Tournier in the 1950s and Dr. Cicely Saunders, the founder of Hospice and Palliative Care in London in the 1960s, resurfaced the importance of attending to the whole person. I was privileged to build on this work by establishing consensus models with a focus on addressing spiritual health and attending to spiritual distress. These models and the resurgence of research in spiritual care practice by clinicians and spiritual care specialists have helped to advance this important clinical area of care, particularly for patients with serious illness. It also impacted the inclusion of spiritual care in the World Health Assembly Resolution on Palliative Care.

This book, *Spiritual Care in Palliative Care: What It Is and Why It Matters*, is an excellent compilation of scholarly work from an international panel of authors offering guidance for adapting to cultural and religious diversity for a range of patient cohorts, as well as considering the differing roles in the multidisciplinary team. I strongly recommend this resource for all those interested in addressing the critical need for spiritual care in those with complex, serious, and life-limiting illness.

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Preface

I once heard the founder of the modern palliative care movement, Cicely Saunders, talk about how she would sit at the end of her patients' beds and record their stories. As she listened, she became aware of the multifaceted nature of their suffering, resulting from the many losses inherent within the end of life trajectory. Sources of distress were identified across all dimensions of the human experience—including not only the physical but also domains such as the psychological, emotional, social, financial, and of course, spiritual. This led to her conceptualisation of 'total pain', which is a key to understanding the need for spiritual care in palliative care. The World Health Organization has embraced this perspective in defining palliative care as healthcare that relieves 'serious health-related suffering, be it physical, psychological, social, or spiritual'. All dimensions of the person need attention if we are to provide the best possible care.

But spiritual care is not 'one size fits all'. As there are many sources of suffering, so are there a range of spiritual needs and ways to find spiritual strength. This book is an attempt to provide instruction on how to best support patients across a breadth of contexts, whatever your professional perspective. It combines the findings of empirical research with clinical wisdom from international leaders in the field to provide guidance for our quest to support our patients and their families through some of the most difficult experiences they will ever face. Patient case histories are provided throughout this book to assist in practical application of spiritual care principles. Patient details have been altered to ensure confidentiality.

We begin with a reminder of the spiritual nature of the end of life journey through hearing palliative care patients recount their experience of dreams and visions. We then explore the nature of spirituality in the context of healthcare and how our terminology developed, before considering spiritual needs for patients approaching the end of life, including challenges for their measurement.

Diversity exists within spiritual experience. Religion is one way of experiencing spirituality and at times will lead to distinctively religious needs which require familiarity with that religion's tenets if those needs are to be met. We therefore include a focus on religious care in the second section, addressing indigenous and major world faiths, and compare it to a non-religious approach.

One justification for spiritual care provision is the positive impact it can have. This is examined in the third section of this book. We examine some of the main areas where spirituality can impact patient outcomes, with a special focus on areas of particular interest in the palliative care setting, namely the interaction between spirituality and pain management, and mental health.

The fourth section focuses on the practice of spiritual care. We start by considering the nature of compassion as an essential component of care provision, before exploring a range of approaches to care. Barriers to care provision and ways to overcome them are also addressed.

Diagnosis of a life-limiting illness challenges the world view of the patient, and spiritual resources are required to cope with the threat to mortality. If existential questions remain unanswered, suffering can ensue. And so, in the fifth section of this book, we focus on the experience of spiritual suffering and existential distress—how it manifests, and ways it can be addressed.

Training in spiritual care is the strongest predictor of its provision, so in the sixth section we look at aspects of spiritual care training across the multidisciplinary team. We begin by considering some extant examples of interprofessional training and the need for practices to be both culturally safe for our patients and promoting well-being for ourselves. The distinctive nature of spiritual care for the doctor, nurse, chaplain, and social worker is described in detail.

Our spiritual journey across the lifespan and in different settings is not consistent, and so we then explore the variations in spiritual care that may at times be required. We traverse the spectrum of patients we may encounter in our work and illustrate how to care for the family members who accompany them.

We end by looking at policy issues, including the ethics that should guide our practice, and the difference that leadership at the institutional level can make in ensuring spiritual care provision for all who need it.

I am delighted that we have been able to include such a wide range of approaches to spiritual care and give some insight into the exciting areas of research that are advancing this field of knowledge. I hope it will spark new cross-disciplinary paths of inquiry. Our patients can only benefit from these initiatives.

I am greatly indebted to the authors who have generously contributed to this work and thank them for their involvement in this project. I can see that many of them have also sat with their patients and learned from their stories. I have learnt a lot from this book and hope that you will also.

Sydney, Australia
December 2023

Megan C. Best

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Part I
Introduction

Dreams and Visions at the End of Life



Christopher Kerr and Carine Mardorossian

Abstract Pre-death dreams and visions (end-of-life experiences) have been documented throughout history and across cultures. Yet, despite their universality and clinical significance, they have rarely been explained in a care-giving framework or presented as being clinically relevant. This chapter will explore this topic from the perspective of the dying rather than the observer. It is based on published, quantified data that draw on the dying experiences of over 1200 patients and their families. The objective is to explain, often in the patients' own words, why pre-death dreams and visions are extraordinary occurrences that bring comfort and exemplify human resilience. These are not regular dreams and distinct from states of confusion or delirium. They are momentous occurrences in patients' experience of dying, which they describe as 'more real than real' and that often marks a transition from distress to acceptance. These end-of-life experiences help patients restore meaning, make sense of the dying process and assist in reclaiming it as an experience in which the dying have say.

Keywords End-of-life experiences · Pre-death dreams and visions · Delirium
Hospice · Palliative care · Dying process · Spiritual care

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1 Introduction

I am a doctor, and all of my patients die.

What we know of dying we know as witnesses: scenes of grim physical decline and feelings of profound loss. Yet, as a Hospice doctor, I have been at the bedside of thousands of patients who, in the face of death, often speak of love, meaning, and grace. They reveal that there is often hope beyond cure as patients transition from a focus on cure to notions of personal meaning. As illness advances, ‘grace and grit’ collide and often bring new insight to the dying, insight that is often paradoxically life-affirming. These end-of-life experiences include pre-death dreams and visions that are manifestations of a time of integration and coming into oneself. So yes, all my patients die, but not before they find a path to affirming the love they felt, the relationships they cherished, and the life they led.

My own understanding of this process first came into focus after caring for a young man named Tom. Tom was only 40 when he arrived at hospice with end-stage HIV. Unlike most of my patients, he was not surrounded by loved ones. Not a soul came to visit. Ever. He was rather stoic, so I wondered if the absence of visitors was his choice rather than a symptom of his loneliness. Maybe that was his way of refusing to give death an audience.

I was puzzled but, wanting to respect his privacy, did not inquire. Despite a gaunt and haggard appearance, Tom’s emaciated body showed traces of once chiselled muscles. He had kept fit and was still quite young, which immediately gave me hope. In light of his age and physical conditioning, I thought that his body would be more likely to respond positively to life-prolonging treatment. Not long after he was admitted, I went to the nurses’ station and decreed that ‘I think we can buy Tom some time. IV antibiotics and fluids should do it’.

The charge nurse, Nancy, had been at hospice for much longer than I had. She knew her job, and everyone looked up to her. She was also not one to mince her words. Still, her response took me by surprise: ‘Too late. He’s dying’.

I said, ‘Oh really?’

She said, ‘Yep. He’s been dreaming about his dead mother’.

I chuckled awkwardly—equal parts disbelief and defensiveness.

‘I don’t remember that class from medical school’, I said.

Nancy did not miss a beat, ‘Son, you must have missed a lot of classes’.

I was a 30-year-old cardiology fellow, working weekends at Hospice to pay the bills while I was finishing my specialty training. Nancy was an exceptional veteran nurse who had little patience for young idealistic doctors. She did what she always did when someone was out of their depth, she rolled her eyes.

I went about my business, mentally running through all that modern medicine could bring to bear to give Tom another few weeks or even months. Knowing that Tom could not be ‘saved’, I was still determined to do everything possible to give him more time and make him less miserable. He was riddled with infections, so we administered antibiotics. Since he was also severely dehydrated, I asked for a saline drip. I did all I could do as a doctor to prolong his life, and within 48 hours, Tom was dead.

Nancy had been right in her estimation of where he was on the downwards slope. But how could she have known? Was it just pessimism—the numbing effect of having watched so many people die? Was she truly using a patient’s dream as predictor of life span? Nancy had worked in hospice a long time. She was tuned into aspects of dying I knew nothing about—the subjective dimensions of dying which were exactly what my training and expertise as a doctor had taught me to ignore.

Like many physicians, I’d never even considered that there’s more to death than an enemy to be fought. I knew about blind intervention—doing everything possible to keep people conscious and breathing—but had little regard for how any given individual might wish to die, or for the fact that, ultimately, death is inevitable. Since it had not been part of my medical education, I failed to see how the subjective experience of dying could be relevant to my role as a doctor.

It was ultimately the remarkable recurrence of pre-death dreams and visions among dying patients that made me realise how profound and widespread a phenomenon this was. These were powerful and stirring experiences that occurred in the last days or hours of life, moments of genuine insight or vivid re-centring that often brought them a sense of wholeness and tranquillity. These are not regular dreams. They are momentous occurrences in patients’ experience of dying, which they describe as ‘more real than real’ and that often mark their transition from distress to acceptance. They are unique to every individual and their needs, and give insight into the life that was led, lessen the fear of impending death, and establish connectivity between and across lives, both living and dead. They are centred on self-understanding, concrete relationships, personal histories, and singular events, not abstract preoccupations with the great beyond. They are made of images and tapestries that are rooted in each person’s unique life experiences. They are about a walk in the woods relived alongside a loving parent, car rides or fishing trips taken with close family members, or seemingly insignificant details like the colour of a loved one’s dress, the touch of a horse’s velvety muzzle, or the rustling sound of a cottonwood’s shimmering leaves in the backyard of one’s childhood home. Long-lost loved ones come back to reassure; past wounds are healed; loose ends are tied; lifelong conflicts are revisited; forgiveness is achieved. These are the intimate, ordinary but meaningful elements that populate my patients’ inner world before death, and amazingly, it is precisely in these seemingly unremarkable occurrences that the dying often find the most profound resolution to lifelong regrets and conflicts.

In restoring meaning, end-of-life dreams and visions help us by making sense of our final process and assist in reclaiming it as an experience in which we have a say. Dreams and visions at the end of life also benefit those left behind, the bereaved, who get relief from seeing their loved ones pass with a sense of calm closure. These subjective experiences are powerful reminders that beauty and love in human existence often manifest themselves when we least expect it. The patients who summon up comforting processes at life’s end are beset by symptoms of a failing body over which they have limited control. They are at their most frail and vulnerable, existing within suffering states of aching bones and air hunger. Catheters, IV’s, and pills may now be part of their everyday, sometimes literally functioning as extensions of their bodies under the daily medical management that is their new and irreversible lot.

They may experience various degrees of cognitive, psychological, and spiritual dissonance. Yet even as the inexorable march of time is taking its toll on their bodies and minds, many also have pre-death dreams and visions in the context of which they display remarkable awareness and mental sharpness. Herein lies the paradox of dying: patients are often emotionally and spiritually alive, even enlightened, despite their precipitous physical deterioration. Doing justice to their end-of-life experiences means accounting for this paradox, one in which death and dying are about physical decline and sadness, but also about spiritual awakening, beauty, and grace. It also means recognising the degree to which the self-soothing power of people's end-of-life experiences may be compromised by the medicalisation of the dying process.

Interestingly, the richest, most thoughtful and resonant discussions on the subject have come from the humanities: from writers, poets, and philosophers, rather than from the work of psychoanalysts, scientists, sociologists, or medical professionals. These latter disciplines aim to describe and prove hypotheses in a more or less objective fashion. By contrast, it is the role of the humanities to bear witness to the irreducible complexity of humanity's subjective experiences. There is no doubt a place for both of these perspectives in our approach to dying, but this difference is crucial when trying to redress the overmedicalisation of mortality in our contemporary lives. It explains why patients themselves, as well as their caretakers, are more drawn to the imaginative and creative arts to make sense of their end-of-life journey. The acceleration of the science of medicine has tended to obscure its art. Medicine, always less comfortable with the subjective, is more concerned with disproving the unseen rather than revering its meaning. Yet, it is through the humanities that we can touch human emotions that are inaccessible to science alone.

In the West, end-of-life dreams and visions have more recently been discussed as evidence of phenomena ranging from the neuronal workings of a dying brain to the consequences of oxygen deprivation, an approach that did not account for the view from the bed any more than previous ones. We have lost our way with dying, and with death. It has become easier to live longer, but harder to die well. Most Americans want to die at home in the care of loved ones, yet most die in institutions, often alone or in the care of strangers. The death people wish for often becomes the one they fear, a sanitised and undignified one. Amidst the current madness of medical excess, there is a need for spiritual renewal that medicine alone cannot address. By exploring the non-physical experience of dying, there is an opportunity to reframe and humanise dying from an irredeemably grim reality to an experience that can contain richness of meaning for patients and loved ones alike.

To this end, our research team conducted studies that used structured interviews aimed at defining a patient-centred perspective. We produced quantifiable data that drew on interviews of patients and their families, videotaped testimonies and written records of over 1200 discrete pre-death dreams and visions to explain, often in the patients' own words, how these extraordinary occurrences brought them comfort and exemplified human resilience at life's end.

We set out to make the collected data quantifiable rather than anecdotal. We made sure it came directly from the patients, not the observers. This was the gap

that needed to be filled. But to be able to do so, we first had to rule out the possibility that these experiences were just manifestations of confusional states such as delirium. Even a quick online scan of the literature on the topic will reveal how often end-of-life experiences get confused with altered mental states. Clinicians unfamiliar with end-of-life experiences routinely discount them as hallucinations caused by medications, fever, or confusional states like delirium. In doing so, they insinuate that these experiences hold little intrinsic value. Yet the distinction between the two is critical. Patients with delirium, by definition, exhibit disorganised thinking, loss of connectivity, and an inability to interpret their surroundings that often results in agitation, restlessness, and fear [1]. The experience of delirium is typically very distressing not only for the patients but also for the families and caregivers, while end-of-life experiences typically occur in patients who have clear consciousness, heightened acuity, and awareness of their surroundings. They are recalled with clarity and are memorable. They differ most from hallucinations or delirium by the nature of the responses they evoke, including inner peace, acceptance, subjective meaning, and a sense of one's impending death [2–5]. The distinction is crucial since end-of-life experiences, when mistaken for delirium, result in the patient being medicated, which robs the dying patient of the opportunity to have the comforting experience inherent in the dying process [4, 5]. An inappropriate medical intervention may further the isolation experienced by the dying and impair the person's ability to experience and communicate meaning at the end of life.

Neuroscientists and physicians too often interpret end-of-life processes as restricted to the last few minutes or hours in a patient's life, which is when delirious states are likely to happen. These are moments when the brain is compromised by diminished oxygen and alterations in neurochemistry. But these episodes of altered brain function, mostly restricted to the last hours to moments of life, are not representative of the sum total of each patient's end-of-life experiences. The point of reference is what counts. Dying is a process that cannot be judged solely on the last chapter of what is a protracted journey. Some patients live with a terminal illness for months or years before passing and begin experiencing pre-death dreams and visions when their minds are fully functional. They are able to do their taxes, drive, read, walk, and entertain company. A fair amount of the literature that confuses end-of-life experiences with hallucinations does so because it is referring to the hours or minutes before death when patients drift in and out of consciousness and may indeed have delirious moments. Just like we know better than to judge books by their cover, we may do well to remember not to judge end of life, or life itself for that matter, by its last lines or moments.

In the first of what would become a series of studies, we proceeded to gather over 400 interviews with 66 study patients, some of whom were enrolled for as long as three months [6]. Patients were interviewed near daily until their passing. This was significant as previous researchers had collected data either during random moments or very near death and failed to capture dying as a process that lasts from days to months. The first part of our study, the questionnaire, included unambiguous questions related to the presence or absence of end-of-life dreams and

visions: whether these experiences occurred during sleep or wakefulness, whether they were comforting or discomfiting and what imagery they included. We asked every participant the same questions about dream/vision content, frequency, and degree of realism. We used a numbered scale so answers could be quantified and compared.

The near universal response we received about end-of-life experiences was that they are categorically 'distinct' from 'normal dreams'. One of the most common statements we recorded was 'I don't normally remember my dreams, but these were different', 'they felt more real than real', and it was 'as though it actually happened'. Patients emphatically maintained that their dreams were not just lifelike, they were lived. When asked to rate the degree of realism of these episodes, most patients rated their end-of-life experiences as the maximum 10 out of 10. And that was the case whether they were asleep or awake, or both, during these events. What we would refer to as 'dreams' because they happened during sleep, patients themselves would call 'visions', as insistently as those who claimed to have seen dead people with their eyes open. In fact, in our survey of patients, 45% of pre-death experiences had occurred during sleep, while 16% took place in wakefulness and more than 39% in both states. Certainly, these statistics reflect the shifting levels of alertness that define the dying process, the bouts of realistic lucid dreaming when patients are aware that they are dreaming, as well as sleep punctuated by a degree of dream intensity that carries over into wakefulness. But in all these cases, our patients talked about their end-of-life experiences as the most awake, alert, and present they had ever felt. While this may make it more difficult for researchers to define wakefulness at end of life, the ambiguity is completely irrelevant to the dying patient, for whom the experience is as vivid, palpable, and impactful as if it had been experienced when awake, if not more so.

We also asked patients to score the degree of comfort or discomfort of their end-of-life experiences, and those dreams or visions that involved deceased relatives and friends were shown to provide the highest comfort rating. This may be a startling reversal of our cultural association of death with grief, sadness, and struggle, but the numbers speak for themselves: patients rated the comfort level of seeing the dead as 4.08 out of 5 (with 5 being the highest comfort) as opposed to an average of 2.86 out of 5 when seeing the living. And the end-of-life experiences that they most frequently reported as soothing included the presence of dead friends and relatives (72%) followed, in order, by living friends and relatives, dead pets or other animals, past meaningful experiences, and only last, religious figures. Taken together, the data suggest that the dying process includes a built-in mechanism which soothes our fears as our inner world becomes ever more populated by those we have loved and lost. Remarkably, the greatest comfort comes from our most basic and foundational needs and relationships, and from moments that capture the beautiful simplicity of everyday life.

When 91-year-old Anne was admitted to our inpatient facility with congestive heart failure, she was having such vivid visions of her long-deceased sister, that, upon waking one day, she looked around and asked 'where is Emily?' Emily had passed away 16 years ago, but to Anne, her presence and appearances were as real

as her doctor's. Anne was subsequently admitted to our inpatient unit in acute respiratory distress, where she woke up, stared up at the ceiling, and acted like she was seeing things that were not there. At one point, she sat up straight in bed and stretched her arms out to the ceiling as if to embrace someone. She asked her family, 'Am I going to die now?' When her condition improved, she awoke, looked around and asked again for her dead sister, explaining that Emily had been there all along, sitting beside her on the bed. Anne also reported having frequent dreams of a more youthful Emily, going about 'doing the usual things' around the house. She could describe her sister's appearance in detail: the strong, jutting chin, the dark blond hair pulled in a high, loose bun, the sagging pea green cotton jersey dress whose sleeves were rolled carelessly at the elbows. Sometimes, Emily put her hand over her mouth and laughed, before moving on to the next task at hand. Few words were uttered but the dreams were heart-warming and invigorating, with Anne often envisioning herself as a much younger self going for walks with her sister. She had been one of five siblings, but she was closest to Emily, who 'had raised' her: 'I am not going alone—Emily will be with me', she insisted.

Despite my inability to share in her perception, I was nonetheless grateful that Anne was not alone, that she was comforted by Emily. The next day, Anne continued to have dreams of her sister, and two days later, after she had stabilised clinically and resumed sleeping, she was discharged home. Like most patients, the stalling of her physical decline towards death coincided with a cessation of her pre-death experiences, and like Ryan, she regretted not having visions anymore. Anne died peacefully at home about a month later, and although I was not at her bedside when she made the transition, I doubt that she went alone.

Another striking feature of end-of-life experiences is their ability to reconstruct or edit memories. Significant moments, often derived from childhood, are condensed, modified, and restructured, so patients' most pressing needs can be addressed and redressed. Tim, a 73-year-old lifelong labourer with end stage colon cancer, had end-of-life experiences that both evoked and restructured his childhood memories so he could relive them free from the pain of poverty with which he had grown up. He first began seeing his parents, grandparents, and old friends, who kept 'telling me I will be okay'. Then, four days before passing on, his dreams placed him back in the formative years of his early teens. He had grown up amidst the tragedies of the Great Depression, in a blue-collar neighbourhood of South Buffalo in the United States of America (USA) where he had helplessly watched lives get broken and displaced. His own father had fought to support his family with low-paying and sporadic work. Like many who lived through those hard times, the single most important fear that overshadowed their happiness was about the family's collective struggle to make ends meet and find hope and purpose among the despair.

Tim's end-of-life dreams helped ease the burden of insecurity that this pivotal period in his life had occasioned. He reimagined himself as a young boy walking through and out of his house, a metaphor for his childhood journey. First, he passed the kitchen where, from the corner of his eye, he could see his mother kneeling in prayer. The meaning was clear: Tim had described his mother's devotion to God as his family's source of strength. He then saw himself walking out of the house, only

to be overtaken by his best friend who lived next door. The boy was holding a baseball bat and a ball and summoning him to come and play. Significantly, this friend would remain his lifelong best friend and 1 day even become his brother-in-law. Finally, he sees his father pushing a wheelbarrow, a sign of employment and a sense of worth restored. Tim's old psychic wounds were healed; his world was now safe, sustaining, and complete.

As Tim recounted his dream, I was no longer looking at a frail dying man but at the sparkling eyes of a child who had rediscovered the early love that had nurtured and warmed his life. What had first looked like the separate acts of a three-act play, his mom in prayer, his friend playing ball, and his dad walking off to work, provided instead visions of the most important forces at play in his early life, variants on the same theme of love. These were rich and connective enactments of the layered relationships that had mattered to him most growing up and that made him who he was. Far from containing a singular content or meaning, they offered a multi-faceted and meaningful version of an imagined but essential reality in response to his most deep-seated fears and needs. Tim himself interpreted his dream as an archetypal resolution that brought him back to a sense of wholeness and peace. He felt a profound sense of connection that, as for many other patients, ironically bypassed words and language. In end-of-life experiences, little may be said but much is understood.

In Tim's dreams, meaningful past events were condensed, reordered, and repackaged to put him back in touch with the most sustaining and uplifting aspects of his past life. For others, this reality makeover entailed a much more radical editing process that excluded as much as it selected and abbreviated.

One of the most touching realisations we had early on in our study was that it was not the fear of death that end-of-life experiences confront. We uncovered instead a remarkably expansive ability to address the injuries people acquire from having lived, those they don't speak of, the ones that haunt and send them to therapy and the traumas that could not be cured. We had designed the study thinking that the therapeutic value of end-of-life experiences resided in easing the dying process. We had no idea that their potency extended to injuries whose genesis could be traced back to childhood. End-of-life experiences are not just about life's final transition; they address life in its entirety. Sometimes, they do so by cutting out the injurious past or by offering an alternate ending. The means is as varied as the goal is consistent, namely the resolution of what was once a crippling affliction into healing and redress.

The story of John, a decorated war veteran, was a case in point. John was admitted to our facility due to persistent insomnia. When I walked into his room, I was struck by this broad-shouldered man who wore the distraught and exhausted face of someone who had seen too much. John had participated in the battle that General Eisenhower had named the 'Great Crusade' of World War II, the Battle of Normandy, and when I asked him about his condition, he summed it up with three words: 'A war problem'. He then let his family members elaborate.

John's family explained that although he had never so much as mentioned his war experiences until the last few weeks, he was now unable to close his eyes

without reliving the unimaginable carnage of D-Day. He had recurring nightmares from which he woke up drenched in sweat. It took his end-of-life experiences for John to come to terms with the haunting memories of his war experiences. He went on to share with me details of the past he had kept only to himself. Maybe he had wanted to spare his loved ones the knowledge of the agony and nightmares that had defined his troubled sleep after the war or perhaps he could not find words to describe his horror.

John was only 20 when he enrolled as a gunner on the SS James L. Ackerson which entered Normandy beside the USS Texas. He was and would always remain a proud Texan who took his duty as a soldier to heart and believed in the ideals of his country. On June 7, 1944, he was part of the Infantry Division that was sent ashore to Omaha, the bloodiest of the D-Day beaches. Their assignment was to retrieve the soldiers who had been isolated from the rest of the forces ashore. The mission was successful, and the landing craft came back with the wounded Rangers they had been sent to rescue. Still, John would never be able to wipe away the vision of the bloodied beach strewn with the mutilated bodies and floating limbs he saw upon landing. This was the experience in the war that was going to haunt him for the rest of his life.

As he lay dying in the Hospice, John was assailed by nightmares about the fallen American soldiers he could not save: 'There is nothing but death, dead soldiers all around me'. I had witnessed people in a state of fear before, but John was not just frightened. He was terrified. His terror was palpable. I had never been able to adjust to the idea of a young man facing the horrors of war, the possibility of death at life's beginning, but watching John return to that site of terror a second time as an old man defied words. He described his nightmares as so intensely real that they felt lived. He could not overcome his pain, and his dreams reflected it.

This is why the complete transformation he underwent a few days later was all the more remarkable. I came to see him, and he was visibly comfortable, even at peace; he could sleep, he said smiling. He credited two of his more recent dreams for this welcome development. In a first joyful dream, he had relived the day he had finally gotten his discharge papers from the military. His second dream sounded more like a nightmare, but to him it was anything but. He dreamt he was approached by a soldier who had been killed on Omaha Beach and had come back to tell him: 'Soon, they are going to come and get you'. John instinctively knew that 'they' referred to his fellow soldiers, and that the dream was about reuniting with his comrades, not judgement. He finally had closure. He could close his eyes and rest.

John's end-of-life experience did not deny his reality, or his war, but it did recast these in such a way as to grant him his hard-earned peace. The soul within that courageous 20-year-old boy had fought the war's ghosts for 67 years was finally released from his enormous obligation and from its injustice.

John's story exemplifies the process through which even the most difficult dreams can provide substantial psychological or spiritual benefits to the dying patient. For him, the tortured memory of the deadliest of the D-Day assaults morphed into the site of the very military camaraderie he thought he had betrayed. He needed to be released from the obligation he had been unable to fulfil and from

the overwhelming shame he could not escape. Most importantly, he needed to forgive himself for his inability to save his brothers in arms. Thankfully, his end-of-life experiences allowed him to do just that.

In another study, we identified distinct thematic categories in the wide variety of end-of-life experiences we were surveying [7]. For instance, a large group of patients described dead friends and relatives in their dreams as ‘waiting for them’ while standing ‘just there’, in a quiet presence that felt like the tightest embrace. This watchful silence involved no judgement, just pure love and guidance. Bridget had no doubt about the supportive nature of her vision when her two dead aunts appeared to her, simply standing and watching silently over her in her sleep. She needed no explanation to decipher the meaning of their presence or to take in the ubiquity of their love.

After demonstrating the soothing role of end-of-life experiences, we soon discovered that the dying patient is often graced with more than a feeling of comfort. One of our more recent studies confirmed the role that pre-death dreams and visions play in post-traumatic growth as well, the growth an individual experiences after encountering stressful life events such as dying [8]. In other words, there is meaningful adaption, substantive, spiritual yet cognitively meaningful, a mechanism through which the patient can emerge from the dying process with a positive psychological change. After comparing dreamers to non-dreamers, we found that patients who reported end-of-life experiences had higher scores in positive growth in multiple areas, whether it was in terms of personal strength or spiritual development. Interestingly, although research shows a lack of religion in dream content, spiritual growth is by far the largest change we see in our dreamers.

In light of the inseparable nature of the spiritual to the physical aspects of dying, it is somewhat paradoxical that patients rarely report religious content in their end-of-life experiences. Although our studies have documented several accounts of patients dreaming of religious themes, this trend is disproportionate when compared to the totality of our data. Other investigators have similarly shown a near absence of religious references in the dreams and visions of the dying. Still, while this paradox is certainly remarkable, it is also hardly the point. Family is our first church, and the tenets of faith are love and forgiveness, the very themes of pre-death dreams and visions.

This is an insight that is exemplified in the writings of Kerry Egan, a hospice chaplain in Massachusetts, USA. In her short but powerful piece ‘My Faith: What people talk about before they die’, Egan explains that she is routinely called to the bedside of dying patients who want to talk, not about God or any big spiritual questions, but about their families and ‘the love they felt, and the love they gave [or] did not receive, or the love they did not know how to offer, the love they withheld, or maybe never felt for the ones they should have loved unconditionally.... people talk to the chaplain about their families because that is *how* we talk about God. That is *how* we talk about the meaning of our lives.... We live our lives in our families: the families we are born into, the families we create, the families we make through the people we choose as friends’ [9]. In a world where people’s success is often measured by the number of relationships they sacrifice along the way, the dreams of the

dying help us visualise a world where human relationships define our purpose and our true accomplishment.

To Egan, not mentioning God directly does not create conflict with her own religious faith or role as chaplain because it is in the love felt by family members for each other that she recognises God and the teachings of her religion: 'If God is love, and we believe that to be true, then we learn about God when we learn about love. The first, and usually the last classroom of love is the family'. At the bedside, I have witnessed again and again a quiet process of peaceful surrender and well-being, a version of grace and beauty that can indeed only be described as spiritual. But if end-of-life dreams are spiritual, they are not so in content so much as in experience. They are spiritual in the manner in which they alter perception and the sense of well-being they provide. They are spiritual because of the deeply personal process of renewal they trigger in the most secret corners of the self. They are spiritual insofar as they free us from fear and pain and connect us to each other. At the hour of our death, spiritual transformation is no longer external to the self. It happens in the innermost recesses of our being. As we progress towards acceptance, illness and death place us on a spiritual path that ultimately affirms who we are and how to love and forgive. In chaplain Egan's words, 'We don't have to use words of theology to talk about God; people who are close to death almost never do. We should learn from those who are dying that the best way to teach our children about God is by loving each other wholly and forgiving each other fully—just as each of us longs to be loved and forgiven by our mothers and fathers, sons and daughters'.

End-of-life experiences are also rarely of a deep philosophical nature. They don't involve punch lines, big existential questions, exuberant pronouncements, epiphanies, or reckonings. They often simply consist of dreams or visions about family, everyday events, or even pets. It is through these reconstituted relationships that the dying often put themselves back together and recover a sense of self. It is exactly this act of connecting, reconnecting, and connectedness that patient after patient testifies to experiencing when they describe the effects of their dreams and visions at life's end. Our patients' pre-death dreams and visions help the dying reunite with a more authentic sense of self, with the people they have loved and lost, those who have secured them, who have brought them forgiveness and peace. Their needs are addressed, whether it is to be guided, reassured, forgiven, or simply loved.

All of us get injured or injure for having lived, yet end-of-life experiences appear to make us whole again, through forgiveness, love, and the return of those we lost. Old wounds heal as time and distance fade and the span of one's life narrows to what matters. There appears to be some of final justice as end-of-life experiences exclude those who have caused us harm and embrace those who have nurtured and loved best. It's fitting, perhaps, that the circle that gets completed is one of restoration, and we return to the best parts of having lived. End-of-life experiences deserve to be recognised as evidence of the life-affirming and inspiring resilience of the human spirit that drives them. They are proof of humanity's built-in, natural, and profoundly spiritual capacity for self-sustenance and self-healing, grace and hope.

From a clinical perspective, I believe presence is more important than intervention. Presence brings acceptance, creates space for reflection and allows times for

expression and therefore dignity. In fact, I have rarely encountered a patient who requested interpretation of their end-of-life experiences. The journey is over; we are behind the curtain. Perhaps, it is even worth asking whether the analysis of dreams serves the needs of the clinician as opposed to the patient. End-of-life experiences provide answers to questions that no longer need answering. They represent a culmination point rather than a doorway. These experiences are not about thinking so much as about remembering, feeling, sensing, breathing, and smiling.

Despite their significance, end-of-life experiences are rarely validated or placed within any clinical context, particularly within a pure medical model. A humanising approach to care at the end of life must recognise that dying is a unique vantage point that brings distinct perceptions and perspectives, such as end-of-life experiences. The isolation and loneliness of dying are made worse when the patient's inner experiences are ignored, denied, or refuted. In fact, patients' end-of-life experiences may be 'medicalised' and mistaken for delirium. Such patients may even receive medication to treat delirium and thereby sterilise the patient from their own meaningful inner end-of-life processes.

The role of any palliative or spiritual care provider is to address the totality of suffering which includes existential or spiritual distress as well as create space or permission for the patient to acknowledge end-of-life experiences. There is even some data which suggest that patients are reluctant to share end-of-life experiences for fear of being ridiculed. It is often helpful to introduce the topic of end-of-life experiences with patients by stating that it is common for dying patients to report vivid dreams that feel real to the point of feeling virtual. Moreover, the dying process is typically defined by progressive sleep that alters normal sleep architecture such that realities blur between dreams and wakefulness. Once defined and explained, patients will often freely acknowledge their end-of-life experiences. Again, the emphasis is on validation and providing space for acceptance as well as reflection.

When caring for the dying patient, we are caring for them in the context of their lives, which includes those they love. Sadly, we often see families and friends unsettled by a patient's end-of-life experiences and references to unshared realities. We hear uninformed families attribute end-of-life experiences to the effects of medication, a brain metastasis or even fear of death. For example, I once saw a patient's daughter sitting in the corner of the room, hands on lap and staring out the window—avoiding looking at the direction of her mother in the bed. The patient was speaking in her native Polish language and making frequent references to her inner experiences. We explained to the daughter that end-of-life experiences are common and overwhelmingly comforting for the patient. The next day, the daughter was sitting beside her mother's bed, taking notes and documenting aspects of her mother's childhood that were previously unknown—vivid descriptions of her childhood friends and experiences that had drifted over time and distance. This is an example of one of the critical roles of the team, which is to help interpret the patient experience and thereby narrow the space between the person in the bed and those at the bed side. We have looked at the impact of end-of-life experiences on the bereaved and published several papers [10, 11]. Simply put, what is good for the patient is

good for those left behind. Families commonly witness their dying loved one's experiences of pre-death dreams, and they are reported as overwhelmingly positive. The effect on grief was quantifiable using validated measures—family members felt that witnessing these experiences helped with their overall grief, accepting their loss, working through the pain of grief and continuing the bond with their loved one.

Dying is so much more than a physical event. Where medicine fails, dying becomes what it has always been, a human event—the closing of a life. And dying with dignity, just as living with dignity, is so much more a spiritual event than a biomedical process. There is nothing new in this observation. The German poet Rainer Maria Rilke best captured the importance of each individual's spiritual expression of meaning in life's final moments when he stated 'I don't want the doctor's death. I want my own freedom'.

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Health-Related Spirituality: Empirical, Historical, and Conceptual Clarifications



Simon Peng-Keller

Abstract To clarify the term of ‘health-related spirituality’, this chapter takes three approaches: historical research on the genealogy of this term, empirical research on current forms of spirituality, and conceptual analysis. An improved understanding of the many pasts of ‘spirituality’, of its distinct current usages, and of its multidimensionality, contributes to a better perception and understanding of the fluid, emergent and sometimes contradictory phenomena related to this term. It is argued that in the diversity of contemporary popular and academic usages of the term ‘spirituality’, distinguishable strands of a long conceptual history converge. This term’s success is that it transcends a duality constitutive of (Euro-American) modernity: the distinction between religious and secular. However, the integration of spiritual aspects responds not only to a societal change but also to a functional differentiation and reintegration in healthcare. Using the example of the World Health Organisation (WHO) discussion on the ‘spiritual dimension’ of health, it is pointed out that health-related spirituality is inevitably imbued with values and connected with healthcare politics and law.

Keywords Health-related spirituality · Spiritual beliefs · Spiritual practices · Spiritual experiences · Spiritual attitudes · Spiritual distress · Spiritual needs · Spiritual resources · World Health Organisation · Spiritual care · Palliative care

More than a decade ago, Swedish psychologist Pär Salander criticised the tendency to broaden the concept of spirituality. His thesis was: ‘Outside of the religious context, “spirituality” lacks a theoretical foundation and a systematic meaning’ [1]. If the vertical-religious dimension is removed from the term, as is often the case in

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health-related discourses, it arguably loses its specificity and is therefore not suitable for describing a professional activity. To the extent that spiritual care is guided by such a vague understanding of spirituality, it adapts like a chameleon to the tasks of psychological counselling and psychosocial support. Salander's criticism points to the need for conceptual clarification. To this end, this article, drawing on previous studies [2–4], chooses three approaches to this topic: the empirical research on current spiritualities is deepened by a genealogy of this term and leads to a conceptual analysis. The aim is to show that in the diversity of contemporary popular and academic discourses on spirituality, distinguishable strands of a long conceptual history converge.

I proceed in four steps: First, I overview the empirical knowledge about contemporary usages of the term 'spirituality', before I turn to their complex genealogy in the second part. With regard to the topic of this book, the third section summarises a remarkable discussion on the 'spiritual dimension' of health taking place within the World Health Assembly at the beginning of the 1980s. Against this background, in the final section I outline some perspectives for a conceptual clarification of 'health-related spirituality'.

1 Plural and Hybrid Spiritualities

The usage of the term 'spirituality' has expanded greatly over the course of the twentieth century, and with it the range of ways in which one can understand oneself as 'spiritual'. To describe oneself or others as spiritual is often to relativise the modern contrast between religious and secular beliefs. Those who use the term 'spiritual' as a self-designation today are not necessarily saying anything about their relationship to religious institutions and traditions. The concept of spirituality owes its current popularity not least to the increasing restriction of the concept of religion to its institutional forms. As will be shown in the next section, what is currently described as religious and spiritual diversity, spiritual hybridisation, 'fluid religion' [5], or multiple belonging, is anything but new. What is new, however, is the wider establishment of these trends, which can be seen in the increasing popularity of describing oneself as 'spiritual, but not religious' [6]. This development bespeaks a form of globalisation marked by the worldwide circulation of spiritual and religious ideas and practices [7]. While modernity appears to be characterised by the need to decide between a religious and a secular orientation, there is now, within the space of (post-)secular society, a burgeoning spectrum of options which often do not belong exclusively to one tradition but draw on many. These, in turn, extend into the sphere of traditional religiosity, such that the boundaries between religious and secular spheres are blurred. According to John Cottingham, the term 'spirituality' is perfectly suited for our collective situation:

The concept of spirituality is an interesting one, in so far as it does not seem to provoke, straight off, the kind of immediately polarised reaction one finds in the case of religion. This may be partly to do with the vagueness of the term [...] Yet at the richer end of the spectrum,

we find the term used in connection with activities and attitudes which command widespread appeal, irrespective of metaphysical commitment or doctrinal allegiance. [...] In general, the label 'spiritual' seems to be used to refer to activities which aim to fill the creative and meditative space left over when science and technology have satisfied our material needs. So construed, both supporters and opponents of religion might agree that the loss of the spiritual dimension would leave our human existence radically impoverished. [...] Spirituality has long been understood to be a concept that is concerned in the first instance with activities rather than theories, with ways of living rather than doctrines subscribed to, with praxis rather than belief. [8]

Despite all the individualisation and hybridisation, spiritual pluralisation is not haphazard. Rather, a limited number of basic types of contemporary spirituality are emerging. Nancy Ammerman distinguishes three of these [9]. She assigns to the first type all those forms that are defined by an explicit reference to God. The second group consists of those forms that deny any reference to God but affirm a belief in something 'higher'. The third type is characterised by a belief in 'horizontal transcendence', where this may be construed in humanistic or cosmologic terms.

Ammerman's typology can be further differentiated. On the basis of extensive empirical data, Heinz Streib, Ralph W. Hood and colleagues [10] distinguish the basic forms of contemporary spirituality with regard to their ideas of transcendence (*theistic vs. non-theistic*), their relationship to institutional forms of religion (*close to religion vs. distant from religion*) and their primary form of self-transcendence (*mystical vs. humanistic*). If one applies these distinctions to the statement above, it represents a spirituality that is non-theistic and distant from religion, and which exhibits a clearly mystical character. If the three types described by Ammerman are transposed into Streib and Hood's coordinate system, the following dimensions emerge (see Fig. 1):

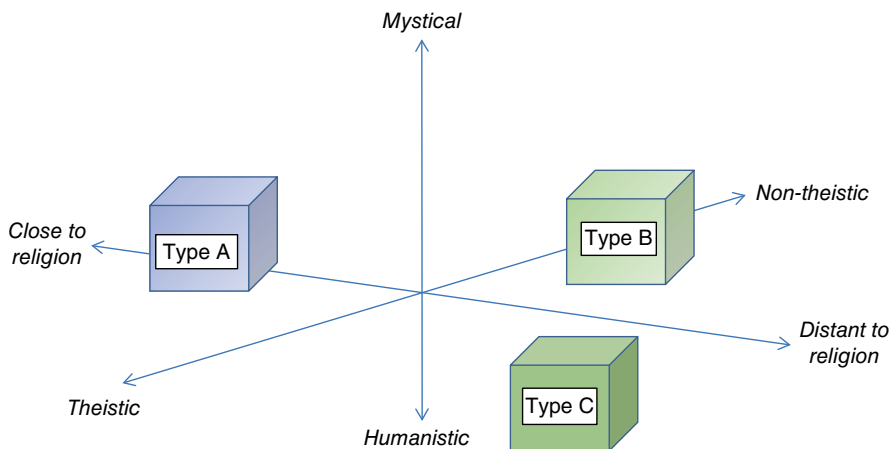


Fig. 1 Types of contemporary spirituality. According to H. Streib and R. W. Hood, these appear in forms that are more or less religious, theistic or non-theistic, and more mystical or more humanistic [2]

As helpful as such typologies may be for providing an initial orientation in the sometimes confusing field of religious and spiritual convictions and practices, they should nevertheless be treated with caution. Typological approaches tend to underplay ambivalences and ossify exploratory movements into fixed positions. Neither the developmental dynamics nor the inner tensions of actual spiritual experience are adequately represented in such cartographies.

Trajectories of spiritual exploration and transformation can be found today in both religious and secular variants. They are often sparked by an encounter with serious illness or death and move the individual beyond previously unquestioned ideas and practices. The Czech theologian Tomáš Halík, who has studied these experiences with particular care, notes that ‘seekers among believers (those for whom faith is not a legacy, but a way) and among non-believers, who reject the religious notions put forward to them by those around them nevertheless have a yearning for something to satisfy their thirst for meaning’ [11]. The function of this appeal to the vocabulary of the spiritual is often precisely to ‘describe experiences and denote positions and aspirations that are “more than” or “move beyond” either secularity or religion’ [12]. In this sense, ‘spiritual’ points towards a sphere that both presupposes and transcends the religious/secular dichotomy typical for Modernity.

There are some paradoxical aspects of contemporary ‘spiritualities of life’ [13]. For example, the simultaneous emphasis on intense relationship to the sensual world and a trans-sensory inner orientation: ‘Rather than being flatly individualistic or purely ‘internal’ in nature, spirituality appears today to designate an ensemble of (often disparate) technologies—linguistic, ritual, praxiological, associative, etc.—through which inner and outer worlds are connected’ [10].

This diversification of the religious-spiritual field is most noticeable at the micro level of everyday spiritual care. As Wendy Cadge and Emily Sigalow have observed, healthcare chaplains navigate the pluralised life-worlds of their patients with the aid of two different communication strategies: on the one hand, by using religiously neutral language; and on the other hand, by moving back and forth between different forms of language, a kind of ‘code-switching’ [14]. These communicative strategies reflect a specific challenge that spiritual care faces in pluralistic contexts: the task of dealing with indeterminacies and ambiguities in a relationship.

2 Genealogies of ‘Spirituality’

This first section responds to the critique that current discussions of spirituality, especially in the realm of healthcare, lack a sense of its historical and cultural background [15]. Mikhail Bakhtin’s formula ‘every meaning will have its homecoming festival’ [16] is certainly true for ‘spirituality’ and its metaphorical background. The older meanings survive while new amalgamations arise in highly complex interactions. What is often decried as the ‘fuzziness’ of the term might be better described as the co-presence of diverging usages. As already indicated, the career of this

‘travelling term’ [17] in the twentieth century is closely linked to that of ‘religion’. A closer look at the complex history of this term helps to better understand how it came about.

Firstly, note that what follows is not just a history of ‘spirituality’ as a concept, but also a history of its fluid metaphorical matrix. The semantic richness to the Latin word *spiritus* is due to its metaphorical quality and its oscillation between anthropological, cosmological, and theological meanings typical to classical Roman literature as well as biblical writings. The biblical Old Testament term *ruah*, which was consistently translated into Latin as *spiritus*, was used for the human spirit as well as for the spirit of God. In St Paul’s letters in the New Testament of the Bible, *pneumatikos* is to be understood exclusively in the theological sense of ‘inspired by the Holy Spirit’, while the noun *pneuma* is also used in an anthropological sense (e.g. in 1 Thessalonians 5:23 where ‘spirit’, ‘soul’, and ‘body’ constitute the totality of human being). Regarding the complex reception of this broad metaphorical fund, the history of spirituality can be considered as numerous parallel attempts to conceptualise metaphorical language in theological, philosophical, legal, or scientific discourses.

The tension between metaphorical density and conceptual disambiguation is a constant in this history to this day. With the emergence of the abstract noun *spiritualitas* in the fifth century, the threshold between metaphorical and conceptual language was crossed at an identifiable historical point. This abstract noun partly preserves the pneumatological meaning of the biblical term *pneumatikos* (‘*spirit[u]alis*’). Nonetheless, it already foreshadows the more ontological denotations which became dominant no later than in the twelfth century. In the context of the emerging scholasticism, *spiritualitas* was increasingly used in contrast to the term *corporalitas* and served as an umbrella term for all things and practices that did not belong to the realm of worldly affairs but to an ontologically higher sphere of things with immaterial value. Even more important for the later development is the circumstance that the contrast between the spiritual (eternal) and the secular (temporal) realm, between the spiritual care of the priesthood and the bodily care of the physicians, was politically shaped by the Gregorian Reform (eleventh–twelfth century) and is consequently reflected in canon law. The jurisdiction of the Church, in distinction to the worldly law, is bound to the spiritual realm. Whoever and whatever belonged to it was to be called *spiritual*. With this legal denotation, the Latin term was later translated into the vernacular.

With the *longue durée* of the canon law, the legal distinction between spiritual and secular influenced terminological usage until the twentieth century. To quote only one remarkable example: Article 37 of the Geneva Convention for the Amelioration of the Condition of the Wounded and Sick in Armed Forces in the Field, ratified in 1949, reads as follows: ‘The religious, medical and hospital personnel assigned to the medical or spiritual care [...] shall, if they fall into the hands of the enemy, be respected and protected’ [18]. Although the Geneva Convention abstains from any ontological commitment, in discriminating between spiritual and medical care it harks back to a distinction formed by medieval theology and politics.