REFLECTIONS ON DEATH AND DYING

The transition from life unto death: end-of-life dreams, visions and the lived experience of unconsciousness.

Michael Barbato

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Joseph Turner's masterpiece, *Fishermen at Sea* (1796), contrasts the hazardous turbulent shallow waters of the Solent and the calmer waters of the English Channel beyond. The painting evokes the challenge, danger and fear in navigating troubled waters and the calm that awaits those who have done so. Throughout this uncertain and sometimes dangerous journey there is light, which represents the wholeness that awaits those who partake of such a journey. I frequently use this image to symbolise the inner journey undertaken by those who are dying and those who grieve.

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Glossary

AWARENESS is the first-person subjective experience and is primarily assessed with command-following at the patient bedside.

> INNER OR INTERNAL AWARENESS refers to mental imagery, inner speech and mind-wandering that is independent of environmental stimulus and external awareness.
>
> OUTER OR EXTERNAL AWARENESS is the awareness of what is happening to and around you.
>
> COVERT AWARENESS: awareness that is clinically undetectable.
>
> META-AWARENESS is the explicit knowledge of the current contents of consciousness that is unrelated to perception. A good example is daydreaming – when one engages internal thoughts and emotions, but remains unaware of the demands of the external environment.

BIS: Bispectral Index Score (see Appendix 1 for details).

BRAIN is an organ inside the skull comprising billions of nerve cells (neurones), supporting glial cells and countless connections or synapses between neurones.

CONSCIOUSNESS is a fundamental property, ontologically autonomous of any known physical properties. It is your awareness of yourself, your unique thoughts, memories, feelings, sensations, and the world around you.

> CONNECTED CONSCIOUSNESS is the subjective experience where the content of consciousness is induced and modulated by incoming sensory information.
>
> DISCONNECTED CONSCIOUSNESS is a subjective experience in which the content of consciousness is internally generated (e.g. dreaming).
>
> PHENOMENAL CONSCIOUSNESS is conscious experience.
>
> COVERT CONSCIOUSNESS are subjective experiences that are not accompanied by external signs and are, therefore, unrealised by those at the bedside.

DACD: Donation after cardiac death.

DBV: Deathbed vision.

DHYANAS: A Sanskrit term that refers to stages of meditation. In the Theravada Buddhist tradition, there are four stages that are distinguished by a shift of attention from the outward sensory world:

1. Detachment from the external world and a consciousness of joy and ease.
2. Concentration, with suppression of reasoning and investigation.
3. The passing away of joy, with the sense of ease remaining.
4. The passing away of ease also, bringing about a state of pure self-possession and equanimity.

DMN: Default mode network. A poorly studied network in the brain that is activated when the brain is at rest, leading to greater inner awareness.

ECN: External or executive control network, which is associated with external awareness.

ELDV: End-of-life dream or vision.

ELE: End-of-life experience.

EMG: Electromyogram or electromyographic changes in muscle tone.

fMRI: Functional magnetic resonance imaging.

IANDS: The International Association for Near-Death Studies.

ICU: Intensive care unit.

LIS: Locked-in syndrome.

MIND: The sum total of all your conscious thoughts, feelings, desires, memories, imaginations. The mind is not an organ, yet 'it' resides within the brain.

MIND WANDERING: Engaging in cognition unrelated to the current demands of the external environment.

NDE: Near-death experience.

NTDE: Near-to-death experience.

PET: Positron emission tomography.

PHENOMENOLOGY: The description and classification of phenomena or experiences associated with consciousness.

PVS: Persistent vegetative state (see UWS).

RASS: The Richmond Agitation-Sedation scale (an objective measure of wakefulness).

RESPONSIVENESS: Corresponds to behavioural interactions with the outside world (excluding reflex behaviour).

SIT: Stimulus-independent thought.

UWS: Unresponsive wakefulness syndrome. Now used in place of PVS – persistent vegetative state.

WAKEFULNESS: Behaviourally defined as eye opening – an action that is mediated by the brainstem.

Introduction

We search after truth. We see but in part.

Thomas Hollis (1659–1731)

I never cease to be amazed by the many and varied experiences that have been described or observed around the time of death. Once ignored by medical science or considered unworthy of its attention, near-to-death experiences, end-of-life dreams and visions, paradoxical lucidity, terminal lucidity, out-of-body experiences and deathbed visions are now acknowledged as normal and frequent accompaniments of dying. While there is considerable debate as to how and why these phenomena arise, there is no doubt about their validity. They are real rather than imagined and are often 'life changing' for the person who is dying.

As the aforementioned experiences suggest, these phenomena are more likely to occur in the very late stage of a person's life. This may seem bizarre, but evidence suggests it is the very proximity of death that lifts the filmiest of screens – described by William James more than 100 years ago – and opens a person to experiences of consciousness that are unique to dying.[1] It is these exceptional and potentially transformative experiences of consciousness that I wish to explore in this review.

My interest in altered states of consciousness was triggered well before I entered the field of palliative care. At the age of seven I got out of my depth in a lagoon and almost drowned. Seventy-plus years later I still vividly recall my desperate yet futile attempts to stay afloat, the gasping for air and the absolute terror that had gripped me. At the height of my panic, I abruptly left my body and found myself hovering above the water. I had no sense of my body nor did I feel any attachment to it. I was unmoved by the struggle it was engaged in and the efforts being made to rescue me. I had been consumed by an unbelievable peace and sense of oneness with everything and everybody. Being outside of time as well as my body, I have no sense of how long this disembodied experience lasted. It was ultimately broken by the voice of my extremely emotional Sicilian mother chastising me for the alarm I had caused. I, on the other hand, could not understand her distress for I had, as Stafford Betty describes, experienced the momentary merging of two worlds that at all other times remain tightly compartmentalised and mutually inaccessible.[2] The feeling of ecstasy stayed with me for some time, and while the experience gradually receded into memory, it has had a deep and lasting effect, one I find hard to comprehend let alone put into words. Although there is no obvious connection between the out-of-body experience and me becoming a doctor, there has been a remarkable synchrony about my life that ultimately led me into palliative care.

I am well aware of the pain and suffering that can accompany dying, but my childhood experience has led me to believe there could be a kinder side to dying that may be more common than many of us realise. Any lingering doubts I had about the existence of this kinder side to dying were quickly put to rest after witnessing my first deathbed vision. I had read about these experiences, but to have one unfold before my very eyes was an unforgettable and moving experience that left me in no doubt that something exceptional and mysterious happens in the mind of those on the edge of eternity.

Hazel was in her late 70s and had been admitted to our palliative care unit for end-of-life care. She was gaunt from the ravages of cancer and on the occasion of my last visit she had been unconscious for more than 48 hours. Her hands were cold, her breathing shallow and her pulse barely palpable. Knowing death

was imminent, I stayed at the bedside, hoping her family, who had been notified, would arrive before she died. As soon as I sat down beside her, Hazel opened her eyes and literally sprung to life. Unassisted, she sat bolt upright and gazed straight ahead. Her arms were outstretched as if reaching for someone or something she alone could see. She did not acknowledge her family when they arrived and remained engrossed in what I could only assume to be a vision that had captured her attention as well as her imagination. She remained mute, motionless and mesmerised for several minutes before lying back on the bed. Her breathing ceased the moment her head hit the pillow.

Consciousness is the greatest of all unsolved mysteries and continues to challenge philosophers, neuroscientists and theologians alike. This alone may have you wondering why someone with nothing more than a medical degree would take on the seemingly impossible task of writing about the alterations in consciousness that occur around the time of death. I have asked myself the same question and always arrive at the same answer – it is too important an issue to ignore, yet very few involved in the care of the dying have taken up the challenge.

Those who are dying tell us in their own unique way what it is like to die. Up until recently we have not heard their message, or worse still, we heard it but did not understand the significance of what was being said. I feel I am on a journey similar to that described by the theoretical physicist Lee Smolin who, in his latest book, *Einstein's Unfinished Revolution,* says…[3]

> A book project is a kind of mental therapy, which forces you to examine your confused thoughts and intuitions and develop them to their logical conclusion … to bet that the truth requires something as yet undiscovered, we must spend our time searching for that unknown completion. We can't just sail down one shoreline and up another. We head west: out of sight of land, following our own compass, or the best facsimile thereof that we can cobble together from the clues we take seriously.

Because of my out-of-body experience and the many near-to-death experiences I have witnessed, I am searching for that unknown completion. I am heading west and as I do, I hope to get a glimpse of what dying brings other than death. It is a tentative step towards a better understanding of a person's journey towards death. One that is guided by 50 years of caring for people who are dying – the first 20 years as a general physician in a country town and the last 30 as a palliative care doctor.

What follows are reflections and insights into the many experiences I have witnessed at the bedside. I share these with you, but in so doing I have used fictitious names to ensure patient anonymity. I take detours into the field of neuroscience and not infrequently engage in speculation. In so doing, I am cobbling together the clues that have been presented to me, but with no expectation of finding answers to the mystery of death. My particular interest is in the so-called 'unconsciousness' that precedes death and why this altered state of consciousness predisposes to a variety of near-to-death experiences, of which Hazel's is just one example. It is this shoreline that I wish to explore in greater detail, hoping the clues left by those at the edge of death will help us to better understand what it may be like to die.

This review is written mainly for the palliative and aged care network, but will also benefit those who work with dying people, as well as the wider community. I hope it stimulates interest, ongoing discussion and further research, not so much to satisfy an inquisitive mind, but to better understand a person's experience of dying. In the words of Doctor Joanne Lynn, Past President of Americans for Better Care of the Dying, 'Concerning death and dying, we need to understand what is happening in order to improve

care.’ At present, we know very little about the experience of unconsciousness, or what I prefer to call unresponsiveness, yet decisions concerning the care of these patients are made using methods that are at best unreliable, and at worst misleading. I hope this review is one small step in bridging the yawning gap between what is known and what we need to know to ensure that people who are dying, especially those who do not have a voice, receive holistic, evidence-based care up to and including the time of their death.