

Tua o te Aria. Doorways into Dying: Meaningful Encounters at End of Life

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Abstract

As we age or become terminally ill, we are confronted by our mortality. Being confronted by our own or another's death can be a time of accelerated and profound growth and development. Using examples from research and personal experience working in a hospice, this article explores challenges facing our own dying as well as that of clients and family members. It discusses the relevance and benefits of psychotherapy at end of life. Throughout the dying process, disturbances can occur that may be dismissed or pathologized. This article goes further and suggests that the dying person's apparent confusion, complex language, agitation or unusual movements, dreams and visions are some of the ways they communicate their needs and let us know what is happening to them. These phenomena are doorways through which we can connect and assist the dying to find meaning in what is happening. The dying may also experience altered and extreme states of consciousness such as coma. It is believed that in these deep inner states they are continuing their development and making spiritual connections. Rather than leaving them alone to fend for themselves, innovative interventions such as joining the world of the patient and pacing their breath are suggested. The work described in this article is based on the methods and skills found in Process Oriented Psychology, and its application to palliative care.

Keywords: metaphor; visions; dreams; altered states of consciousness; metaskills; joining; coma

Introduction

In 2007 I was invited to join a hospice team as one of the counsellors was going on leave for three months. The three months relieving grew into 10 years! When I started work at hospice I was confronted by the reality of death, the days and moments leading up to a person's last breath, the intense loss and grief experienced by patients and their loved ones, the challenges faced by staff every day. I questioned how best to use my experience and training as a psychotherapist. What can I offer to patients who have days, weeks or months to live, who need to address long-standing issues and prepare for end of life? How am I to think about and understand what is happening in their diverse experiences of death?

Throughout my life I have had an insatiable curiosity about the mystical or spiritual dimensions of life, which at times of profound change seem close to awareness in the form of significant dreams, visions, physical disturbances, mystical and unexplained events or synchronicities, altered and extreme states of consciousness. I have endeavoured to approach life transitions, my own and others', with awareness, openness, curiosity, and some skills to navigate what is trying to happen.

I often ask myself why I am so interested in working with those facing end of life. One reason is that I am getting older and my own death is getting closer. I also have a desire to learn more about what happens as we die and understand the diverse approaches found within different cultures and belief systems. Many of us, particularly in Western society, are not prepared for what can happen and my hope is that this will change over time.

While working at hospice, I experienced the deaths of my father, mother, sister, half-sister and husband, as well as some dear friends. Death had infused itself into every corner of my life, inviting me to explore and learn. In this paper I will share with you some of the things I have learned and how I have grown as a person and a therapist through working in palliative care.

I am grateful to my ancestors and patients who have died and have taught me so much. I acknowledge the dedicated staff who work in palliative care and who model so well, compassionate care of the dying.

I am fortunate to have trained in the innovative phenomenological work of Arny and Amy Mindell. Their way of tracking and following experience happening in the moment, unfolding it to bring meaning to what is happening, has been invaluable to me, particularly when assisting patients who appear confused, or are in altered and extreme states of consciousness. At those times when we tend to leave the dying alone to fend for themselves, it is relieving to find a way to stay connected and support the person in their deep internal states. I enjoy teaching these skills to staff, family members and friends.

Working therapeutically with the dying and their families can be intense, disturbing, surprising, unpredictable, terrifying, joyous and mysterious. Being close to patients struggling with pain or disfiguring cancers, particularly around the more visible areas of face and neck, meant I was often confronted with feelings of helplessness, horror and almost unbearable feelings of loss and grief. All shades of pretence or awkwardness in our initial meeting were quickly stripped away as we faced our raw and fragile humanity. My capacity to hold and be changed by the depth and intensity of what was happening grew over the years.

As I worked I knew each session with a patient could be my last, that time and energy were limited. So I focused on what was happening in the moment, and learned not to have preconceived ideas about how things should be. I am grateful to all those people I was privileged to be alongside in their final days. Their courage, honesty, humility, their terror and their grace, have taught me so much about death and also about life.

Death as Disturber and Teacher

Learn to die and thou shalt learn how to live - Sogyal Rinpoche

Being so intimately connected with death, personally and professionally, has changed me in many ways. Personally, I feel more connected to, appreciate and love life. As I engage with dying, death and life seem no longer separate but have become one, like the cycles of nature – one emerging out of and into the other. I feel grateful to be alive and to be who I am today. In my clinical work I am more detached from outcomes, and more trusting to venture into the unknown. I have a larger capacity to be present and be with what is there, both pleasant and disturbing. I am more skilful in connecting with people in out-of-ordinary states of consciousness. My trust in a process unfolding has grown and I am more patient to wait and curious to see what emerges. My capacity for compassion has deepened. I am more resourced to be with my own and other's suffering and take steps to relieve it wherever possible. I have learned the importance of being intimately connected to my patient, supporting them by entering their world while holding awareness of the overall process.

As we know, our own experiences and feelings about dying influence how we approach and work with others. Thinking about, exploring and preparing for my own

death, has been an essential part of integrating death into my life. I know a lot more about dying now and what it may involve. There is an increasing amount of literature about the dying process, near-death experiences, and the after-life. However, there is a large part of dying that is not known, that is full of mystery, that engenders fear.

In *Doorways into Dying: Innovative Teachings for End of Life* (2016), Rose and Ryan discussed death as a major disturber to our identity and way of life that, once faced, can accelerate our growth and bring a deep love and appreciation for life as well as a sense of wellbeing. However, death can also inhibit our development, keeping us from reaching our full potential. Death terror can be in the background of many of life's struggles, not only at the end. Irvin Yalom (2008) commented that psychotherapy tends to be more oriented to the past and how that impacts on the present. He said that Freud thought there was no point in looking to death as we can't learn from something we have not experienced. Yalom disagreed, saying that death terror does influence our development more than we might think. Using the example of the death of Ivan Ilych, Yalom revealed how facing death itself can bring about an awakening experience that transforms our approach to life. He showed how death terror, which can inhibit our development, once overcome brings freedom and fullness of life. This is evident for me personally as well as with those facing death. For many, the disease process and end of life experiences brought about radical changes in their attitude and behaviour. I heard patients saying how grateful they were for their illness as it had changed them in ways that they would not have thought possible.

I once worked with a 55-year-old woman, whom I will call Beth. She was terrified of dying. She believed that death was the end, that there was nothing after this life. I noticed how sad and depressed she was as her body showed signs of shutting down. She had told me how difficult it was for her to express her feelings to her family. Staff and family were concerned about her. Medication was used to little effect. Then one day she told me about a dream she had the night before.

I am walking down a road with my husband, my son and daughter. The road ahead is in darkness. As we walk together my two children step back and my husband and I keep going together. I notice that he has a lantern. He hands me the lantern and steps back and I go on alone.

At that point, Beth began to cry, overcome by feelings of grief. As I held her she became calmer and soon dropped into an exhausted sleep. I knew this dream had deep significance for her and what was ahead. I returned later that day to find that she had gone out for a coffee with her son. She was feeling much better and was talking about the things she still needed to do. I asked her about her response to the dream. She said it was when her husband gave her the lantern that she knew she would be all right. To her the lantern represented the love he had for her that was now supporting her to go forward. As she spoke about love I noticed her voice became softer and quieter, her face lit up and she smiled. I encouraged her to really feel what she was experiencing. She nodded, closed her eyes, going inside, and became silent for a few moments. I was touched by the feeling sense of love that emanated from her. Beth told me later that she had not really acknowledged how deep that love was until then. She said she was no longer afraid of dying. She went home and had several more weeks of special time with her family with a greater capacity to better hold their feelings in relation to her illness and death.

Death as Transformation

I have come to view death as a transformative process. If we look carefully at events in our lives, we can spot how life prepares us for death. Throughout life we go through many transformations or “little deaths”. During these times we are challenged to shed parts of ourselves as new aspects come through, just as a snake sheds its skin. Some of us are aware of these “little deaths” and approach them as opportunities for growth and development. For others the process is more organic, meaning it unfolds naturally without much recognition of what was happening intra-psychically. When this happens facing death may send us into a place of resistance and denial (Rose & Ryan, 2016).

There are many different views about what happens when we die. Each individual goes through it in their unique way. How they make meaning of what is happening to them is influenced by their specific culture and beliefs. However, there are recognisable patterns or phases. These phases are not linear but appear at different times through the dying process. These are:

- Denial, anger, the sense of being in a dream or of the experience not being real.
- With the prospect of death, we may feel a push to fulfill our lives, to complete unfinished tasks that hold meaning for us. Questions may emerge such as, “Has my life had meaning?” “What is there I still need to do?”
- We encounter experiences of altered states of consciousness such as memory loss, fatigue, delirium, agitation, depression, ecstasy and joy.
- We are faced with the threat of extreme states of consciousness such as coma, paralyzing terror, overwhelming grief.
- We also discover ways to make spiritual connections and find meaning in what is happening (Rose & Ryan, 2016, p. 25).

Getting to know these experiences in my own life has been the best preparation for being with those who are dying. While on the one hand noticing where my own feelings, fears and hesitations reside and addressing them prepares me for being with others, learning some skills and interventions to assist with experiences as they occur is essential for effective therapeutic end of life care.

The Language of Dying

Each life is formed by its unique image, an image that is the essence of that life and calls it to a destiny - James Hillman

Personal experience, research and clinical work reveal how the dying communicate with us in ways that are surprising, often difficult to understand and indeed seem weird! Patients appear confused, in a dream-like state, absent-minded, revealing altered/irrational cognitive patterns, which could go on for some time and which seem inexplicable to the observer. The closer to death they become, the more this is the “usual” way of expressing or being. From a medical perspective these diverse states can be related to the dying brain, disease progression or effects of medication. However, they are much more.

The research (Fenwick & Fenwick, 2008; Callanan & Kelly, 1992) reveals how changes in communication and behaviour are a normal part of dying. Sacks (2012) related how he sat with a man in a delirium who was speaking rapidly and

incoherently. As Sacks listened the man became clearer. Sacks realised the man was telling his life story. When he had finished telling it, the man died.

The dying use metaphor to communicate needs, reveal their feelings and choreograph final moments (Callanan & Kelly, 1992). Metaphors used by the dying also reveal the gifts they give to those they are leaving behind which are often filled with wisdom and love. During the last week of my husband's life he would report seeing a boat coming into the harbour. We were in a bush setting so there was no actual harbour visible from his room. As time passed I was able to tell he was getting closer to death by where the boat was. The day before he died the boat was at the wharf. It was his way of preparing us, and himself, for his departure.

A patient who was near death told me she was frightened not of death, but that she felt like she was melting, that her solid form or sense of self was somehow dissolving. The process of melting was important for her, so I suggested that I stay with her and that we melt together. She smiled and nodded, giving me feedback that this was the direction for her. I held her hand, pacing her breath and imaged myself melting while encouraging her to follow herself as she became more fluid. I felt deeply moved by this simple yet profound way to experience death. In a short time she had fallen into a deep sleep from which she did not awaken.

Unfortunately, we all too often tend to dismiss what we don't understand and may be too quick to use medication to sedate and bring about a preferred more coherent and peaceful state. Approaching these experiences with openness and curiosity can lead to useful information for appropriate care. Rather than trying to bring the patient to a preferred and more manageable state, we can support them to believe in and trust their experiences. We can join them where they are in their reality, using the metaphor they are presenting to us. We support them to follow the lesser known experiences in the way they appear in their inner worlds, believing they will take the individual further along their path, bringing meaning and often completion of a growth process.

In her book, *Intimate Dying* (1997), Marie de Hennezel, a psychologist, told a moving story about a 25-year-old drug addict who had advanced breast cancer. I want to share part of this touching story as it shows ways we can care for clients in their final hours. Marie related how her client lived, in her own words, "a wild life". Her head was shaved and tattooed with the slogan "March or die". She had lived through a loveless childhood, abandoned at birth by her prostitute mother and taken in by her grandmother. She grew up like a wild plant, thirsty for love and the meaning of things. She had done it all and was utterly without illusions. Her cancer came as hope of a kind: the hope that this dog's life would finally end. Marie says she feared that this young girl would suffer her death much like her life, in difficulty and torment, in revolt perhaps, or in great distress. Yet, as she related, things turned out quite differently.

"I found myself one morning at this girl's bedside. She was saying that she was going to die.She was laying on her back, her head raised a little by the pillow. She had oxygen tubes in her nose: it seemed clear her lungs were not functioning properly. There was a wet facecloth on her shaved head to bring down her fever. She was burning up, so I noticed when I took her hand.

She wanted to talk to me. But her voice was weak. I sat on a low stool so that I was at the height of her face and held my ear toward her lips. I could hear quite clearly that she was saying, "I am going to die". Then she

deliberately pulled out the plastic oxygen tube and threw away the cloth that was drying on her forehead. As I stared at her, spellbound, she moved her body into the position women adopt in childbirth, legs spread. Her breath got shorter and noisier, but she seemed to be calm and not in pain.

For several minutes, I wondered if I should reinsert the oxygen tube, but her gesture had been so deliberate and she seemed at ease, so I decided to do nothing, but stayed with her so that she wouldn't be alone. She said again, "I'm going to die". I began to stroke her forehead as she panted. She seemed to be pushing down on her legs, as if she were giving birth.

.....I was filled with an emotion I cannot describe, part tenderness, part awe. Her head slipped toward me a little. I lifted it gently and held it against me. At that moment her breath became blocked. I wanted to do something, reinsert the oxygen tube. But I thought better of it. She was dying, as she told me. Why should I disturb the simplicity and intimacy of this moment? She gasped in a mouthful of air and then stopped breathing again for several minutes. I murmured endearments to her that surfaced of themselves – from where, I have no idea. She could have been my daughter and they were mother's words, which all mothers are born with, and which come to them from all eternity.

A second later she got her breath back. I had an image of a fish gasping on the sand. I wished I could put her back in the water. There were tears in my eyes. It was the most intense moment I had ever experienced. She stopped breathing a third time, and the tension in her body suddenly gave way. I realised she had died." (p.178 -180)

Marie goes on to say how she would want to die with similar awareness and similar dignity.

As I read this story I was touched by Marie's ability to be impacted by the experience, as well as how she was able to hold her doubt about helping, choosing to stay with what was happening. She trusted and followed her intuition, bringing herself into the birthing metaphor as mother and midwife. She was fully present and engaged, supporting the process to complete itself. Marie showed courage and fluidity, as well as compassion for what was happening. These metaskills, or feeling attitudes, are what we need to develop to assist the dying. Other metaskills are patience, playfulness, and non-doing. They assist us to honour and respect all experience, pleasant or disturbing, and assist us to go further with what is happening.

Near-Death Visions and Dreams

As mentioned earlier, deathbed visions and dreams are two of the many doorways into a person's experience of dying. Deathbed visions, also called hallucinations, involve seeing people, or animals, who are not physically present or who have died. They are a normal part of the dying process and hold information for the person experiencing them.

I recall a patient who was staring into the corner of her room for several hours. She did not relate to anyone coming into the room. As I sat with her I encouraged her to take a good look at all the details of what she was seeing and perhaps hearing. She nodded, letting me know she was aware of my presence and was following what I was saying. I kept encouraging her to go further into her experience even though I did not

know what it was. After a short time, she started to cry. She re-focused, looking at me for the first time. She reported that she had seen her mother who had died some time ago and who was telling her not to be afraid as she was with her, supporting her. This patient died peacefully shortly after this experience. It is difficult to know whether this experience was actually her dead mother or an intra-psychic process of needing to mother herself. Either way it worked to allay her fears and helped her through the next phase.

Not all visions/hallucinations are pleasant. Some are disturbing, such as spiders and bugs crawling around the walls. These are often related to the effects of medication, and reducing the medication relieves them. I find the more disturbing images can always be talked about at a later date when the person is more at rest.

Dreams are also significant doorways into the dying experience. Taking time to listen to dreams is also a way we can join the dying and support what is trying to happen. Dreams often reveal a pattern or metaphor for the person's dying that we can use to support them. Many near-death dreams have a pre-cognitive nature and may anticipate the death of the person. In their book, *Dreaming Beyond Death: A Guide to Pre-Death Dreams and Visions* (2005), Bulkeley and Bulkley related the following:

Suzanne, an elderly lady, who was struggling with the final stages of her disease, had the following dream. She sees a candle lit on the windowsill of the hospital room and finds that it suddenly goes out. Fear and anxiety ensue as the darkness envelops her. Suddenly the candle lights on the other side of the window, and she awakens. That same day Suzanne died completely at peace (p.63).

Although we may be tempted to interpret dreams at end of life I find that for many, no interpretation is needed as they speak for themselves. Such dreams have a numinous quality that stays fresh and impacts on the dreamer for days. These significant dreams can change the person's attitude to dying, provide meaning and engender hope of something new emerging. They often reveal a pathway for the dying to follow (as in the dream of a lantern above). I can recall several dreams of those near death where the dreamer was in full health and enjoying life.

In her research Marie-Louise von Franz (1998), Jungian Analyst, studied the near-death dreams of 2,500 patients. She reported that dreams of people facing death indicated the unconscious preparing the conscious mind not for an end, but for a profound transformation and a kind of continuation of the life process. She observed the unconscious archetypal symbolism found in dreams, pre-death or close to death, resembled the symbolism of the individuation process experienced during the person's life time. It looked like the process of psychic development and the attainment of higher states of consciousness do not cease with the death of the body but continue after death, in the spiritual world, beyond our rational minds. She thought that this symbolism lead to the completion of the inner psychic world or the Self. Von Franz found that almost all symbols appearing in near-death dreams are archetypal and are mirrored in various religious beliefs about life after death. Rather than analyse these dreams she felt "compelled to leave them in space as a symbolic statement about another reality" (p. 157).

In more recent New Zealand research, Iordache (2012) studied the dreams of palliative care patients. His study revealed how dreams of those facing death also revealed current concerns, which provided information for their care and support. These concerns included unresolved conflicts with significant others and issues

related to their death. Developing our ability to work with and value dreams and visions of those at end of life is a gift to the dying as well as to those caring for them.

Coma Communication

One of the difficulties we encounter as professionals and family members during the dying process is the loss of communication as the patient becomes less responsive and shifts into a non-verbal state of consciousness. I often hear comments such as “They have gone now”, “We should leave them be”.

However, we know through experience and research (Amy Mindell, 1999; Arnold Mindell, 2008; Morin & Reiss, 2010), that not only is the person still present, they are also continuing to work on themselves, finishing off business, planning for what is ahead and making spiritual connections. Working closely with those moving in and out of comatose states, reveals how some can get stuck and need assistance. So rather than leave them alone we hold a belief that what is happening has meaning for the person and is a potential source of strength. These inner states are for many, a time of growth and development which, once completed, enable the person to die peacefully.

Arnold Mindell (2008) provided a wonderful example of interacting with an 80-year-old patient, close to death, who had been in and out of comatose states for weeks. He was disturbing other patients and hospital staff with his groaning and yelling. Mindell described his interaction with the man as follows:

When I saw him, the man was lying in his hospital bed moaning and shouting out something that no one could understand. I groaned with him, “ohhh, oohh, wow, yeah.” I introduced myself, put my hand on his wrist and paced his breath. After about 20 minutes, his muffled shouts became distinguishable words. John, who had not said a word to anyone in days, or uttered a complete sentence in six months, now said “yeah...wow...no...yeah...oh”(p.14)

After elaborating on and extending the sounds and words that John was making, Arny began to distinguish more words. John was talking about a big ship coming for him, and yelled that he was not getting on that ship. “No man – not me!! I’m not getting on that ship. That ship’s ...going on... vacation. I gotta get up at eight in the morning and go to work!”(p.15)

Arny invites the man to take a good look and say who is driving the ship. John replies that it is angels who are driving. Arny asks John to check out how much it costs to get on the ship and John replies with amazement that it costs nothing! “It’s a free trip,” says Arny. “Have you ever had a vacation?” When John responds in the negative, Arny says, “Listen, man, you never had a vacation. You’re a working man. You should consider a little trip. If you don’t like it, you can come back. If you like it, then you can just keep going”. John replies, “yeah... yeah. Vacation, to the Bahamas, Ba...ha...mas.... hmmm.... no work.”(p.16)

With that John quietened down, closed his eyes and went to sleep. When Arny returned to check on him a half hour later, the nurse reported that John had just died. The old man had decided to go on vacation.

We can see that John was stuck because he had a strong work ethic that did not allow him to “go on vacation”. Arny was aware that John was seeing something by following his eye movements. By joining his sounds and imagery, Arny supported John to go further and unfold what was trying to happen – death as a vacation.

The goal in working with someone in coma is to assist them to bring awareness to what is happening on the inside and to complete their process. We hear in the story above how Arny made contact with John through placing his hand on John’s wrist and pacing his breath, joining him as he breathed. Pacing the breath has been found to be an effective way to let the patient know you are there and support them with what is happening. This is a simple yet profound way to connect and assist those in less responsive states. I have found it easy to teach family members and friends so that they can stay connected to their loved one.

If we are to connect with and support someone in deep internal states, then we need to be aware of and work with minimal signals. Training in picking up feedback through signals such as raising an eyebrow, changes in breath, skin colour changes, swallowing, coughing, twitching, slight movements of fingers and toes, are some of the ways that create a feedback loop for our interventions. As we pace the patient’s breath we can comment on what we notice, just as Arny did as he followed John’s sounds and eye movements. Knowing our own comfort with and limits around touching patients is an important part of this work. Where do we feel comfortable? Where are we sensitive, or feel hesitant or stopped?

It is helpful to know something of the patient’s story, as in their final hours they can be reliving parts of that. I remember a man who was unconscious, and who appeared at first glance to be agitated. He was throwing his body around the bed, one arm stretching out in a circular movement. When my colleague saw these movements, she had an image of someone fly-fishing. His family confirmed that he was an avid fisherman. She was able to comment on this activity and use it for the man to continue to choreograph his final hours (Rose & Ryan, 2016).

In Summary

In this paper I have discussed how facing our own death, “staring at our own sun”, (Yolum, 2008), knowing our altered states of consciousness and how far we can go, growing our capacity to hold and process disturbance, not only resources us for our own death but are key to being effective in our work with the dying. I have presented some doorways into dying that are available to us. Changes in communication and behaviour are viewed as a natural part of the dying process and are ways the dying communicate with us and prepare for what comes next. These changes include the use of metaphors, body movements, agitation, visions, and dreams. Rather than dismiss them, we believe they hold potential meaning for the person. I have highlighted the usefulness of visions and dreams, as potential sources of strength and direction.

We are now aware that those close to death and in coma are still present and can communicate using minimal signals. We can learn skills to continue to support and assist them. For more information about coma communication see www.comacare.com; Youtube: Arnold Mindell and coma work; www.aamindell.net.

As we grow, may our engagement with death and dying propel us into fullness of life!

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