

Existential suffering and the determinants of healing

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Our patients come to us complaining, not of disease, but of their subjective experience of illness.¹ Their quality of life is modified by all domains of personhood – physical, psychosocial and existential or spiritual.² Indeed, all of us, whether in sickness or health, find ourselves oscillating on a quality of life dialectic that extends from multidimensional suffering, described by Saunders as ‘total pain’,³ to the opposite extreme, a sense of wholeness, personal integrity and inner peace. ‘Healing’ may be conceived as a shift toward the latter pole of this continuum. The extremes of human deprivation⁴ and the crucible of terminal illness^{5,6} teach us that in even the direst circumstances, peace is possible. It is possible to die healed. What are the variables that influence healing? What is our role as care providers? What is the relevance of these issues to our personal sense of wellbeing?

Two teachers

Let me introduce you to two of my teachers about suffering.

Chip was 30 when I carried out his surgery for metastatic disease from his germinal testicular cancer. With postoperative chemotherapy and now negative serum tumour markers, we hoped that he was cured. Over the ensuing months, however, his disease progressed. Gracious, outgoing, a world-class athlete on our national ski team, Chip had always been a winner. He was engaged to be married, but now he was dying. All involved were devastated. Just days before the end, he married his fiancée and said goodbye to each of us. In our conversation, he commented, ‘You know Bal, this last year has been the best year of my life’. He confided that the source of this sense of quality time had been a journey inward that was characterised by peace and a sense of growth he had not previously known. Physical magnificence had given way to devastating weakness and cachexia, yet suffering had been transcended.

Mrs C, born in Eastern Europe and now a widow in her seventies, had been admitted to the palliative care unit for control of refractory pain related to her metastatic breast carcinoma. Everything suggested nociceptive pain that should have been easy to control, but our interventions failed. Alienated from her daughter, her only family member, Mrs C looked anguished. ‘When were you last well?’, I asked. ‘Do you mean physically?’ ‘No’, I responded, ‘I mean in yourself.’ Without hesitation she erupted, ‘Doctor, I have never been well a day in my life’. ‘Really? Well, if we are body, mind and spirit, where do you think the problem has been?’ With great feeling she answered, ‘I have been sick in mind and spirit every day of my life’. She then recounted her tale, a life filled with dead ends and broken dreams. Her anguish persisted until death, a byproduct, perhaps, of her well-established life script as much as the cancer that ended her suffering.

Two patients, one dying without suffering, at the age of 30, after a life spent in celebration and opening to others; the other dying with great suffering in her eighth decade, following a hard journey spent in closing to life and to others. What are the determinants of such a variation in suffering?

Determinants of suffering

Quality of life (QoL) and a sense of being healthy do not correlate with physical wellbeing. One may suffer terribly in the absence of physical symptoms; conversely, severe physical decline and pain may be present without anguish or suffering. In a qualitative study involving cancer patients aware of their diagnosis, Kagawa-Singer found that one-third of the participants considered themselves to be ‘fairly healthy’; and two-thirds ‘very healthy’, including 12 who died during the study. Their common coping objective was the maintenance of self-integrity.⁷ Similarly, Cassileth *et al* found that persons with malignant melanoma had levels of emotional wellbeing equal to those found in the general population.⁸ In another study, persons paralysed following trauma had similar life satisfaction to the general population.⁹

Eric Cassell has noted that suffering is personal and subjective. It may arise in any domain of personhood; it occurs with a threat to personal integrity and ends when the threat has passed, or integrity is otherwise restored.¹⁰ He states, ‘Our intactness as persons, our coherence and integrity, come not from intactness of the body but from the wholeness of the web of relationships with self and others’.¹¹

Our lives are shaped by ‘necessary losses’.¹² What other core issues create the existential ‘background noise’ that helps to define our view of, and response to life? Yalom suggests that there are four: *death* (our impending existential obliteration – always a day closer today than yesterday); *isolation* (the unbridgeable gap between self and others – ‘Only I can experience my birth, my life, my death’); *freedom* (the unnerving absence of external structure – the retirement syndrome of the workaholic); and *meaning* (the dilemma of meaning-seeking creatures living in a cosmos that is potentially without positive, ameliorating meaning).¹³

Frankl suggests that the fundamental human quest is not for prestige, fame or fortune. Nor is it the sexual drive. Instead, he asserts, it is the search for meaning. His experience in Nazi concentration camps taught him that we may find meaning in five domains: things created or accomplished; things left as a legacy; things believed in; things loved; and finally, the experience of suffering itself. These sources of personal meaning may lead to transcendence of suffering through identification with something greater and more enduring than the self.¹⁴

Significance of the spiritual domain

For cancer patients, the existential or spiritual domain is an important determinant of QoL throughout the disease trajectory. In the palliative phase of the disease it is more important than physical symptoms, physical wellbeing, psychological wellbeing and support – the other factors monitored by the McGill Quality of Life instrument (MQoL).^{15,16} Furthermore, it is responsive to competent palliative care, showing an improvement within one week of end-of-life admission to palliative care units.¹⁷ In persons who are HIV positive, the existential domain is only important when the CD4 T-cell count drops below 100 (that is, with AIDS), but then, it is the most important contributor to QoL.¹⁸

An increasing body of research suggests that quality of life and a broad range of health-related outcomes correlate with religious adherence. Koenig and colleagues have recently published a comprehensive, systematic analysis of 1,200 studies and 400 research reviews examining the relationship between religion and health¹⁹ and a further volume examining the involvement of psychoneuro-immunology in this relationship.²⁰ The latter documents current understanding of the hard-wired connection between the immune and neuroendocrine systems, as well as other aspects of the central nervous system. Chronic exposure to stressors impedes immune functioning. There are, it would seem, several mechanisms at play in the favourable impact of religious adherence on health. They include: modification of behaviours that influence health risk (cigarette smoking, diet, sexual practices, alcohol intake, drug abuse, enhanced social support); altered healthcare utilisation (likelihood of earlier diagnosis, greater treatment compliance, closer monitoring); biological mechanisms (impact of changes in stress, perceived support and psychological functioning on neuroendocrine, immune and cardiovascular systems).

The basis for a mind-body connection is now clearly understood; the implications, becoming clearer. A study by Bower *et al* showing an association between meaning and mortality is thought-provoking.²¹ Forty HIV-seropositive men who had recently experienced an AIDS-related bereavement completed interviews to assess their use of cognitive processing and their discovery of meaning in bereavement. They also provided blood samples during a two- to three-year follow-up. As predicted, men who engaged in cognitive processing were more likely to find enhanced meaning. Furthermore, men who found meaning showed less rapid decline in CD4 T-cell levels and lower rates of AIDS-related mortality (all $p < 0.05$), independent of health status at baseline, healthy behaviours and other potential confounds. These results suggest that the discovery of meaning may be linked to positive immunological and health outcomes.

There is a problem with the vocabulary of spirituality in our pluralistic society.²² We would distinguish between 'spirituality' and 'religion',²³ and agree with Palmer who said, 'We need to shake off the narrow notion that "spiritual" questions are always about angels or ethers, or must include the word God. Spiritual questions are the kind that (our patients) and we ask every day of our lives as we yearn to connect with the largeness of life: "Does my life have meaning and purpose?" "How does one maintain

hope?" "What about death?"'²⁴ To be human is necessarily to be spiritual, whether the person is religious or not.

Spirituality is relational in its expression. It is expressed in one's relationships at three levels – to the self (in the individuation of Jung);²⁵ to others (at a *quantum level* we are one with the cosmos in a state of undivided wholeness;²⁶ at a *psychic level* we share with others the collective unconscious;²⁵ at the *transpersonal level* a potential for 'I-thou' relating);²⁷ and to ultimate meaning however conceived (often experienced as a paradox of transcendence and immanence) – God, the More (that which is nameless, yet the ground of existence), and the cosmos.

Spiritual/existential distress must be a primary concern for palliative care physicians and all others on the caregiving team. Not only is it a significant determinant of subjective wellbeing (QoL) and one's place on the total pain/integrity dialectic, it is also a reason for cancer patients ending their lives.^{28–30} Moreover, patients who are depressed or are experiencing existential meaninglessness may have a lower pain threshold,^{31,32} thus feel more pain and require interventions beyond simply adjusting the opioid dose.

A model of the psyche

A metaphoric schema of the psyche that considers two components – the *surface mind* and the *deep mind* – may clarify the dynamics involved in healing.^{33,34} According to this model, the *surface mind* is characterised by conscious, literal, rational, linear patterns of thought. It is the home of the *ego*, the organising aspect of psyche that one recognises as self. The ego needs to feel in control; it fears the unknown and when faced by a threat reacts defensively with grasping, closing, striving, competing, wishing and denying.

The *deep mind*, however, is characterised by intuitive, imaginal, unconscious, metaphoric thought. It is the repository of memories, the collective and personal unconscious, the unresolved psychic baggage of childhood, and that aspect of the psyche that may be experienced as an 'internal other' and was referred to as the *Self* by Carl Jung.³⁵ The Self is conceived as that archetypal aspect of the psyche that holds the personal potential for wholeness. It is viewed by some as being immortal and continuous with the More. It is involved in healing; noted in all wisdom traditions, and rendered conscious (in collaboration with the ego) in the process of individuation.

For PW Martin, it is the *Deep Center*.³⁶ Martin notes that all wisdom traditions identify this inherent potential of the psyche. He notes that in Christian parlance, it is the 'Kingdom within' (gospels); the 'living Christ' (St Paul); 'the unknown gate remembered'; 'the timeless moment'; 'the point of intersection of the timeless with time'; 'the still point' (TS Eliot); the 'birth of God within' (Richard Law); 'the spirit in the soul' (Meister Eckhart); 'the inward light', 'the seed', 'that of God in every man' (Quakers). In other traditions, it is 'Atman' (Hindu); 'the Secret' (Islam); 'the diamond center' (Chinese wisdom traditions); 'the Kundalini serpent' (Tantric yoga); 'the inner source of strength' (Marcus Aurelius);³⁶ the open center (Confucian); the pedestal of awareness (Buddhist); 'the mysterious pass', 'the primal opening' (Taoist). The Deep Center may be conceived as exercising its healing potential through opening, accepting, slowing, centering, trusting, hoping and letting go.

The dynamics of healing

Kearney has differentiated between care that is *Hippocratic* (the caregiver acts as an external agent, doing to, prescribing for, or acting on, and represents an external locus of control), and care that is *Asklepian* (the caregiver accompanies and 'prepares a space for' healing to occur, a process dependant on an internal locus of control in the sufferer).³⁴ Wisdom traditions, clinical experience and qualitative research³⁷ suggest that healing depends on an adaptational response shift involving enriched meaning born through healing connections. The caregiver-healer performs an Asklepian function in supporting a secure environment and sense of safety (the patient's paradoxical comment, 'I never would have thought that it would be safe to die here'). Healing occurs in the present tense, in the now.^{38,39} It is fostered by a loosening of the ego's need to control ('learning to fall').⁴⁰ It is as if the Deep Center says to the ego, 'You take one step towards me and I'll take five towards you'.

The healer negates the intrinsic power differential between caregiver and sufferer; recognises his or her own personal needs and, with humility, is open to an empathic interaction in the tradition of the wounded healer.³⁴ The healing relationship is an archetypal connection characterised by mutual openness involving a parallel process in which each brings out in the other 'exactly what is most in need of attention and what we are often most unwilling or unable to acknowledge or honour within ourselves'.⁴¹

The healer engages in active listening (plain language, figurative speech, non-verbal communication) and asks, 'Who is she?' (the sufferer); 'Who am I?' 'What is the meaning of her illness - for her, for her family, for me?' The healer recalls that, 'Care in how it is given can reach the most hidden places';⁴² that healing interventions are those that support the discovery of meaning and connectedness, whether or not that is consciously intended.

Healing is encouraged by *acceptance* - not a passive giving up, but an active integration of reality. ('So that is the way my cookie crumbled. Now what can I do with it?') It is fostered by *hope*. Hope is not the same as wishing. Hope is a perspective on reality, a point of view (the glass half full, rather than half empty). It reflects a degree of inner peace. Hope is a child of the human spirit. It arises from an experience of personal meaning. *Wishing*, however, arises from a sense of need, dissatisfaction and unrest. It reflects a sense of incompleteness. Hope is the product of adversity transcended, wishing of adversity denied. Hope is linked to acceptance, the transcendent alternative to denial and the conscious attitude that accompanies integration. Once we accept our givens, we are free to assume an attitude to them; to exercise our options; and to take responsibility for ourselves. While it is true that we may be unwitting healers through our natural compassion, in general, we are more likely to be effective as healers if we are consciously on the spiritual path and seeking self-knowledge, thus making our own inner life needs a priority. We cannot be all things to all people - use a team.

We stand on the brink of the third epoch of healthcare, the epoch of Whole Person Medicine. The interdependence of body, mind and spirit calls us to look beyond the biology of disease to the broader landscape that underlies human suffering. While continuing to probe the genome and strive for longer life for those under our care, the path Saunders

has set leads us to re-examine ancient questions that pertain to healing, wholeness and the true meaning of *health*. The dying have much to teach us in this regard if we have eyes to see and ears to hear. Our clinical laboratory at their bedside is well placed to shed new light on the connections between psychoneuro-immunology, meaning, neurotheology and the healing potential that is the human birthright. The challenge and the opportunity are ours.

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