The Relief of Existential Suffering

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Advanced and progressive illnesses bring existential suffering to patients as an inevitable consequence of the disease and its treatment. Physicians need a typology of existential distress to aid its recognition and improved management. The major forms of existential challenge include (1) death anxiety, (2) loss and change, (3) freedom with choice or loss of control, (4) dignity of the self, (5) fundamental aloneness, (6) altered quality of relationships, (7) our search for meaning, and (8) mystery about what seems unknowable. An adaptive response to each challenge promotes equanimity, peace, and fulfillment while sustaining engagement with life, creativity, and joy. Physicians can do much to nurture courage and maintain each person's sense of meaning, value, and purpose.

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An important goal of medicine is the relief of suffering, which is omnipresent in palliative care. Although huge strides are being made through pharmacology and science, existential suffering needs a biopsychosocial response found in the ancient art of healing.

THE MODERN CLINICAL CONTEXT OF EXISTENTIAL SUFFERING

Across the past century, social familiarity with death moved from a regular family experience in 1900 to something that could be postponed, managed, and rendered infrequent by 2000.[1] Mortality rates fell from 17 to 7 per 1000, with infectious causes diminishing from 33% to 4%, while cancer rose as a cause from 4% to 28%.[2] Death has become unwelcome and taboo. We recognize the following 3 common trajectories of dying: (1) slow decline from frailty and dementia, (2) sudden death with heart/lung organ failure, and (3) postponement with anticancer therapies until a terminal 2-month decline.[2] Advanced illness provides the opportunity for open awareness of the nearness of dying.[3] The success of disease management brings paradoxically the potential for existential distress and suffering to the fore, where patients wonder what their death will be like and when it will occur.

THE NATURE OF SUFFERING

Suffering in an existential framework develops from the threat to life or injury to the self, with resultant distress, grief at loss, emerging helplessness, and likelihood that this situation will endure.[4] Poignantly, pain can become overwhelming when its source is uncertain, its meaning dire, its treatment difficult, and control perceived as unlikely.[5] The modern founder of hospice, Cicely Saunders, described "total pain" from the combination of symptoms, impairments, disability, and handicaps, resulting in psychological, spiritual, and social disruption to equilibrium.[6] When the development of advanced neurological, respiratory, cardiac, or cancer illnesses chal-

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Table. Responses to the Common Existential Challenges

Common Symptom Cluster	Nature of Existential Challenge	Adaptive Adjustment	Maladaptive Response
Fear of process/state of being dead, uncertainty of future	Death anxiety	Courage, open awareness of dying	Panic, dread, angst, anxiety disorder
Waves of tears, sadness, and emotionality	Grief at loss and change	Mourning, continued focus on living	Complicated grief, chronic anger, depression
Obsessive need for control, fear of dependence	Freedom and autonomy	Responsibility, acceptance of caregivers, treatment adherence	Nonadherence to treatments, fear of being a burden
Shame, body image concerns, embarrassment	Dignity	Robust self-esteem, self-confidence, acceptance of frailty, feeling respected	Feeling stigmatized, agoraphobic, avoidant
Social withdrawal, loneliness	Fundamental aloneness	Secure with one's self, personal integrity, connectedness	Feeling insecure, isolated, alienated
Family conflict/dysfunction	Quality of relationships	Well-functioning family, mutual support	Feeling fractured, chaotic; having unsupportive family, poor supports
Pointlessness, hopelessness, futility, desire to die	Meaning of life	Fulfilled life, with accomplishments and legacy	Demoralization, clinical depression
Guilt, loss of faith, loss of connection with the transcendent	Mystery and the unknowable	Peacefulness, religious faith, contentment	Spiritual doubt, anguish, despair

lenges the usual assumptions that underpin our very existence, an existential gaze can lead to despair and demoralization about the value of continued life.[7] Relevant to the differential diagnosis of suffering are inadequate symptom control, undiagnosed depression, unaddressed existential angst, unrecognized family distress, communication breakdown, burnout, and demoralization.[8] Clinicians need a template to address such human suffering, including a typology of existential distress.

A TYPOLOGY OF EXISTENTIAL DISTRESS

Expanding on the work of Yalom,[9] the major forms of existential challenge include (1) death anxiety, (2) loss and change, (3) freedom with choice, (4) dignity of the self, (5) fundamental aloneness, (6) altered quality of relationships, (7) meaning, and (8) mystery (**Table**).

Death Anxiety

In 1966, Simone de Beauvoir wrote that "There is no such thing as a natural death. . .for every man his death is an accident, and, even if he knows it and consents to it, it remains an unjustifiable violation."[10(p106)] Patients defend against the possibility of death with an omnipotent sense of specialness, religious belief in heaven or rebirth, the heroism found in workaholics, or active denial. Ultimately, people adapt to awareness of dying with courageous acceptance, but when patients struggle to achieve this, common symptoms include fear of the process of dying, panic at physical change, protest at uncertainty, or spiritual despair about what lies ahead. A pending sense of stress, agitation, dread, sleep disturbance, nightmares, avoidance of medical care, and desire to escape can prevail.

Strategies to help ease death anxiety include the use of psychotropic medication, relaxation-meditation therapies, and supportive psychotherapy with encouragement to focus on continued living, thus staying present in the moment. Clinicians can ask patients if they would like to learn more about the dying process because knowledge helps to promote mastery. Then, having gained permission, the physician could describe the likely mode of organ failure causing death, placing emphasis on optimal symptom control to assuage suffering. The physician effectively invites the adoption of courage as the psychological stance that helps patients to prepare for death. Tillich[11] saw this as the vital courage of living, with self-affirmation and acceptance of a goodness about life that is sufficient. This "courage to be" is taken on for a fuller positivity about life. Nietzsche spoke of "anchorite and eagle courage"[12(p327)] to take on the abyss of nonbeing. Aristotle argued that life needs the right degree of balance between cowardice and temerity. Person-centered care will lead the clinician to respect the right of any patient who chooses not to want to know.

Loss and Change: Human Grief

Many forms of loss afflict the body, whether amputation of limb or breast; disfigurement via stoma, alopecia, or multiple scars; disability through altered cognitive function, continence, mobility, and independence; or abjection via wounds, oozing fluids, and malodorous smells. Abjection is a defense using expulsion, disavowal, and rejection of what is disgusting, smelly, or unclean, whether vomit, feces, or bodily sores.[13] Humanity has long used civilizing processes to counter the threat of the abject by adorning bodies and using order, created by boundaries, as a function of containment of the clean from the unclean. Nursing makes use of systems, regimens, and processes to contain the chaos of the abject, always striving to sterilize, dress, and use protective barriers.[14]

The physician listens to and acknowledges the emotions of grief, normalizing the response and patiently allowing time for adjustment and integration of acceptance of the new self, albeit with the impairment of changed function. Encouraging the sharing of the grief, the family is sought to help support the distressed, bringing comfort and love to the fore.[15] Eventually hope about the future is promoted, seeking new meaning and purpose as the pursuit of continued life replaces grief at loss and change. Living is sustained until death intervenes.

Freedom: Our Personal Autonomy

Our desire for autonomy, personal choice, and sense of control is captured within the existential state of true freedom. Accompanying this desire is the fear of loss of control, dependency, and becoming a burden to others, with fear of loss of dignity as the illness dominates life. Patients adapt to these challenges by acceptance of frailty from illness and loss of independence. Patients struggle to adapt when preoccupied by a need for control, becoming overly obsessive, sometimes indecisive, or poorly adherent to recommended treatments as they fight to stay in command. Frustrated, angry, or stubborn interpersonal disputes emerge as obsessional personality traits insist on one direction of care or anxious traits lead to a phobic avoidance of another.

Gentle, supportive reality testing aids the person coping with avoidance, whereas reframing expectations induces movement toward acceptance for the independent individual wanting to stay in control. Distortions of reality, such as all-or-nothing or black-or-white thinking, magnification of the horror, and insistence through use of directives framed in sentences using verbs including *should*, *ought to*, or *must,* can be steadily corrected toward a more balanced perspective. Many adjunctive approaches, such as relaxation therapies and use of music, art, and physical therapy, can assist adaptation.

Dignity: Preservation of the True Self

Maintenance of a robust sense of self-worth despite infirmity or frailty points to an adaptive response to any existential challenge that threatens human dignity. Symptoms that point to a less adaptive outcome include shame, perception of stigma, and distress at an altered body image. Dignity can be challenged by lymphedema, the need for a prosthesis, rehabilitative therapies, or the presence of a stoma or a keloid scar.

The clinician listens to the patient's life story, with its strengths and vulnerabilities, accomplishments and failures, and sources of legacy and fulfillment. Affirmations of the patients can be supportive, honoring who they are, celebrating successes, and valuing their contribution to the community. Life requires a balance between being individually unique and yet altruistic to others. Models of "dignity therapy"[16] and family therapy[15] define each patient's legacy to his or her relatives, helping to celebrate the patient's life and express gratitude while saying goodbye.

Aloneness: Each Unique Journey in Life

Born alone, we die alone. Personal experience of illness rekindles awareness of our unique personhood and with this our fundamental aloneness. Our human nature is essentially relational in its needs, and patients counter aloneness through connectedness with their family, friends, and community. Despite such social supports, people can feel very alone. Symptoms are expressed through comments about loneliness, isolation, having few supports, even alienation through conflict, misunderstanding, cultural or ethnic difference, or community neglect. Aloneness brings a special type of human pain, sometimes accompanied by sense of personal failure, stigma, difference, and nonacceptance by others due to varied beliefs, attitudes, convictions, and values. Patients counter existential aloneness through confidence in their personal integrity, their "true self" in psychoanalytic terms,[17] such that they appreciate what they bring to our shared humanity, are enthusiastic in relationships, and help others as they meet their personal needs. Validation of self comes ultimately from within and includes acceptance of missed opportunities and regret at mistakes, failures, and a life that is less than perfect.

The clinician can seek to understand the patients individually, appreciate something special about them, find ways to affirm what is valued in their life, and acknowledge the personal choices they have made. What does the physician like about the other? What can he or she respect? How can genuine regard be conveyed? Loneliness can be assisted by fostering a network of support provided by community volunteers, patient-to-patient contacts, referral to groups, social resources, and care by the whole psychosocial treatment team. At the heart of this clinically is commitment to care, accompaniment, presence, reliability, and consistency of service.

Quality of Relationships: Family, Friends, and Community

Children thrive through forming deep bonds with parents and family members; we are social creatures in need of relationship. These attachments nurture our security, which in turn empowers our exploration of the world. As adults, patients continue to gain from the deep connections that are found in partnerships, marriage, family, friends, and involvement with local community. The success of relationships helps define roles within society, whether as spouse, parent, grandparent, coworker, or neighbor. Symptoms are expressed through distress at the lack of support, marital tension or conflict, separations and fractured relationships in families, and alienation and isolation from those who were previously close and supportive.

Group therapy is a major source of support for many patients, who feel better understood by those sharing a similar journey. Family therapy is another treatment modality to harness caregiving and support from within what is often the most accessible network of support. Membership in a family brings historical connection, a sense of kinship and duty, and a loyalty that can be called on at times of crisis. Meeting with the family opens communication about topics that might be avoided lest distress be incited, optimism threatened, or hope destroyed. However, such protectiveness is often at the cost of teamwork and cohesive mutual support. All inpatient admissions in palliative care settings are helped by a routine family meeting that reviews the goals of care and needs of the patient and the patient's family.

Meaning

People are fulfilled by building a personal sense of purpose and mean-

ing in their lives, whether through their roles, occupation, contribution to family and community, creativity, or appreciation of nature's beauty. Patients create a legacy for others through what has been most meaningful in their lives. Common symptoms develop when people fear that their life is pointless, lacks continued meaning, or appears futile without a worthwhile role or potential continued contribution.[7] Viktor Frankel saw the cultivation of meaning as a means to transcend suffering.[18] Life without meaning can invoke deep anguish and despair. Clinicians can do much to support each patient's search for meaning despite their illness.

In contrast to clinical depression, conceptualized as a loss of happiness or interest in life, the anhedonic mood state, demoralization, has been described as the loss of meaning, purpose, and hope that sustains the will to live or the loss of any potential for future joy.[7] When accompanied by feeling trapped, helpless, unable to change the predicament, or alienated from others, a desire to die readily develops. Heidegger saw the problem of "everydayness" as another challenge to authentic living.[19] Caregivers of patients dying of AIDS were noted to sustain contentment and happiness through the meaning they derived from caring for a dying partner.[20] Folkman and Greer[20] recognized the value of this meaning-based coping to sustain resilience and positive affect. A new emphasis on meaning-centered therapy[21] has confirmed the benefit in asking patients what matters most about their life. What goals, roles, values, and pursuits sustain the continuity of meaning in their lives? Demoralization can be assuaged by the clinician echoing the coherent story of a person's accomplishments, reframing the value of the patient's life and the patient's continuing opportunity to sustain a meaningful life with family, thus creating goals that sustain purpose, value relationships, express gratitude, and focus on living until death intervenes.

Mystery

The prospect of nonbeing in a universe without limits and without a humanly comprehensible sense of its purpose and reason creates a deep anxiety in people.[11] The "unknowable" generates mystery about life and its purpose. Tillich[11] argued cogently that life requires the courage to balance self-fulfillment with contribution to the collective processes of society and even (philosophically) the universe. This balance leads to a sense of belonging, participating, being creative, and adapting to the challenge of the unknowable through a spiritual peace gained by connectedness with a higher power and transcendence of the finiteness of life. Faith is not about believing in the unbelievable, but rather, according to Tillich, "a state of being grasped by the power of being that transcends everything that is."[11(p173)] The common clinical symptoms that hint at this existential issue include expressions of spiritual doubt, anguish at a perceived futility of life, a sense of chaos and bewilderment, or guilt about past wrongs, missed opportunities, or unfinished business.

An adaptive response to the unknowable and mystery is through expressions of awe, wonderment, and reverence about life. Plato saw reverence as an ancient virtue. Reverence develops from a deep understanding of human limitations and leads first to a capacity for respect and tolerance of others, a genuine civility in the world. Second, reverence guides acceptance of a "human goodness that is sufficient" and an awareness of something greater than the self. Humility grows from this as a counterpoint to ambition and narcissism. Third, out of our sense of awe and wonderment at the beauty of nature and the universe grows a capacity for ritual that marks our respect for the sacred and its sources. Religions have developed as organized structures that nurture this expression of ritual. Spiritual pain can develop symptomatically through the loss of capacity for reverence, loss of faith, religious doubt, feeling overwhelmed by fear of the unknown, loss of "the courage to be," loss of meaning in the purpose of life, or nonacceptance of the true self. Puchalski[22] argues for the routine addition of a spiritual history to medical and psychiatric assessments, whereas Cassem[23] asks about beliefs in God, use of prayer, relationship with a community of believers, values, and philosophy of life. If a clinician is uncomfortable with such a spiritual assessment, inquiry about the relationship with a rabbi, minister, or chaplain endorses the importance of attending to these needs.

CONCLUSIONS

A typology of existential distress strengthens the clinician's ability to understand a patient's angst, offer explanations that contain and support the patient, and guide therapeutic interventions that ameliorate the patient's suffering. Affirming the emergence of courage and optimizing any search for meaning become vital clinical goals to achieve this end. Moreover, patients can be greatly reassured by the fact that this existential framework for distress does not involve psychiatric disorder per se but rather arises from universal challenges that are givens in our human existence.

The skills referred to herein are based on the physician as healer, listener, and doctor to the person rather than the symptom or disease. How can physicians learn this ancient art of medicine? Although formal communication skills training can help[24] and lifelong learning is crucial to maintain competence, physicians need to interact authentically and with genuine compassion. The resultant relationships among the patient, family, and physician can be empowering, creative, deeply caring, and beneficial. Not every physician finds this easy to do; indeed, it can be immensely challenging, sometimes perplexing, and greatly demanding of time and commitment. However, the healing goals of medicine require that physicians strive to acquire these skills so vital to the amelioration of suffering.

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REFERENCES

1. Callahan D. Frustrated mastery: the cultural context of death in America. *West J Med.* 1995;163 (3):226-230.
2. Lunney JR, Lynn J, Hogan C. Profiles of older Medicare decedents. *J Am Geriatr Soc.* 2002;50(6): 1108-1112.
3. Seale C. *Constructing Death: The Sociology of Dying and Bereavement.* Cambridge, England: Cambridge University Press; 1998.
4. Chapman CR, Gavrin J. Suffering and its relationship to pain. *J Palliat Care.* 1993;9(2):5-13.
5. Cassell E. *The Nature of Suffering and the Goals of Medicine.* 2nd ed. Oxford, England: Oxford University Press; 2004.
6. Clark D, ed. *Cicely Saunders: Selected Writings 1958-2004.* Oxford, England: Oxford University Press; 2006.
7. Kissane DW, Clarke DM, Street AF. Demoralization syndrome: a relevant psychiatric diagnosis for palliative care. *J Palliat Care.* 2001;17(1):12-21.
8. Cherny NI, Coyle N, Foley KM. The treatment of suffering when patients request elective death. *J Palliat Care.* 1994;10(2):71-79.
9. Yalom ID. *Existential Psychotherapy.* New York, NY: Basic Books; 1980.
10. de Beauvoir S. *A Very Easy Death.* O'Brian P, trans. New York, NY: GP Putnam Sons; 1966.
11. Tillich P. *The Courage to Be.* New Haven, CT: Yale University Press; 1952.
12. Nietzsche FW. *Thus Spake Zarathustra: A Book for All and None.* Common trans. 2008:327. http: //www .forgottenbooks.org/info/Thus_Spake_Zarathustra _1000137967 .php. Accessed July 1, 2012.
13. Kristeva J. *Powers of Horror: An Essay on Abjection.* New York, NY: Columbia University Press; 1982.
14. Rudge T, Holmes D, eds. *Abjectly Boundless: Boundaries, Bodies and Health Work.* Burlington, VT: Ashgate Publishing; 2010.
15. Kissane DW, Bloch S. *Family Focused Grief Therapy.* New York, NY: Open University Press, McGraw-Hill; 2008.
16. Chochinov HM, Krisjanson LJ, Hack TF, Hassard T, McClement S, Harlos M. Dignity in the terminally ill: revisited. *J Palliat Med.* 2006;9(3):666-672.
17. Winnicott DW. *The Maturational Process and the Facilitating Environment.* New York, NY: International UP Inc; 1965.
18. Frankel VE. *Man's Search for Meaning.* New York, NY: Washington Square Press; 1959.
19. Heidegger M. *Being and Time.* Stambaugh J, trans. Albany: State University of New York; 1996.
20. Folkman S, Greer S. Promoting psychological well-being in the face of serious illness: when theory, research and practice inform each other. *Psycho-oncology.* 2000;9(1):11-19.
21. Breitbart W, Applebaum A. Meaning-centered group psychotherapy. In: Watson M, Kissane D, eds. *Handbook of Psychotherapy in Cancer Care.* West Sussex, England: Wiley-Blackwell; 2011:137-148.
22. Puchalski CM. Spiritual issues in palliative care. In: Chochinov HM, Breitbart W, eds. *Handbook of Psychiatry in Palliative Medicine.* 2nd ed. New York, NY: Oxford University Press; 2009:341-351.
23. Cassem EH. An overview of care and management of the patient at the end of life. In: Chochinov HM, Breitbart W, eds. *Handbook of Psychiatry in Palliative Medicine.* 2nd ed. New York, NY: Oxford University Press; 2009:23-38.
24. Kissane DW, Bultz BD, Butow PN, Finlay IG. *Handbook of Communication in Oncology and Palliative Care.* Oxford, England: Oxford University Press; 2010.