

The Nature of Suffering and the Nature of Opportunity at the End of Life

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Clinics in Geriatric Medicine, Vol. 12, No. 2, pp. 237-252, May 1996.

Abstract

Encountering a patient who is suffering in the midst of terminal illness is an all-too-common occurrence for clinicians who care for the elderly. This chapter explores the personal experience of suffering in the context of life-limiting illness. The concept of personhood is utilized to illuminate the nature of suffering. Clinical observation documents that some persons experience a subjectively heightened sense of well-being as they die. The concept of personhood and the model of life-long human development is applied to the explication of this apparent paradox, enabling an understanding of the nature of opportunity at the end life.

Introduction

Encountering a patient who is suffering in the midst of terminal illness is an all-too-common occurrence for clinicians who care for the elderly. Yet despite familiarity with the general situation, the task of caring for a person who is suffering in their dying can seem overwhelming. The challenges presented and stresses for the physician will be different, but may seem equally daunting, whether the physician has had a long term relationship with the patient or has only recently become involved in the person's care.

Most physicians in current practice have had no formal education directed at the philosophy or phenomenology of human suffering, and very little training directed toward the management of the terminal phase of illness. Typically, empirical experience with human suffering accumulates during practice when the opportunities for being mentored, for formal study and for thoughtful reflection are scarce. Medical and nursing education remains focused on cure, life-prolongation and restoration of function. While these are among the primary goals of medicine, so too, is the relief of suffering.^{13,8,17,18}

Despite voiced acceptance of "whole person care", the Cartesian separation of mind and body continues to pervade clinical training. Suffering is understood mostly in terms of physical pain. Even within the domain of the physical, the theory and practice of controlling pain and various other sources of physical distress among the dying remains conspicuously absent from texts and from general medical and nursing curricula.^{9,16} As with any critical encounter in medicine, for the patient to optimally benefit and for clinicians to feel confident in the care they provide, it is essential that the approach to a patient who is suffering in their dying be preceded by thoughtful preparation.

Philosophy of Suffering

"For anyone who has developed...an interest in the most important, the most vital, the most practical of all life problems--those of philosophy and of religion, it is surely a great reward to be given the opportunity to apply what he believes in a way to help human beings in trouble....in medicine these problems are thrust upon us, urgent as a bleeding wound....Not a week passes in the practice of the ordinary physician but he is consulted about one or more of the deepest problems in metaphysics and religion--not as a speculative enigma, but as part of human agony."²

While a comprehensive review of the philosophy of suffering is well beyond the scope of this clinical inquiry, it is important to acknowledge that an articulated orientation to the place of suffering within the human condition is central to every religion and every ethnic culture. Characteristically, from within an individual's religious tradition and prevailing culture the philosophical stance toward suffering seems self-evident and is often unrecognized.

In modern, secular, western culture suffering is assumed to be wholly adverse and devoid of value. The predominant personal orientation toward suffering is one of avoidance or alleviation. When we suffer, we present ourselves as patients. Indeed the etymology of the word patient means sufferer.¹⁵

Traditional spiritual orientations toward suffering are instructive. The Buddhist world view holds that suffering is part and parcel of human experience. It is part of nature itself, the "stuff" of existence. For the Buddhist, suffering arises from a person's attachments to the world. These include material possessions, physical pleasures,

personal accomplishments and failures, relationships of love and of hate and, ultimately, attachment to one's very identity. Only through severing those attachments and achieving a desireless state can suffering be transcended. This for the Buddhist defines liberation and enlightenment. Even death may not end suffering, for existence continues through cycles of birth and death until enlightenment is achieved. Buddhism teaches that death is the central organizing feature of a person's life; it is to be prepared for diligently, through meditation and the progressive weakening of worldly desires.

In the traditional Christian world view, suffering also is seen as an inevitable component of human life. Hope for release from suffering exists not in this world, but in a heavenly hereafter. From a Christian perspective the purpose of human suffering has less to do with one's own enlightenment or purification, as with alleviation of the suffering of others. One's suffering can be "offered up" for the sake of others in distress whether they abide in this world or in purgatory; thus, personal suffering is transformed into a sacrificial act. The daily lay offering carries this intent, "Lord Jesus, I offer to you my prayers, works, joys and sufferings of this day for all the intentions of your sacred heart, in reparations for my sins and the sins of all the world."

Suffering and divine grace have a connection in the Christian tradition. Many of the saints and Christian mystics (among them Theresa of Avilla and Hildegard of Bingen) recorded their experiences of ecstasy as being inextricably connected with experience of pain. Theresa of Avilla referred to being "wounded by the swords of angels."

C. S. Lewis, writing from a Christian perspective, comes to a conclusion with similarities to the Buddhist world view. For Lewis, the ultimate good for man is in consciously surrendering oneself to God, which entails a complete commitment to approach God in love, with total openness, vulnerability and trust. Without suffering in one's life, man would not, perhaps could not, turn toward God with utter faith, remaining instead, focused on one's own goals, desires and worries of the world. Suffering, thus, is given to man by God out of love, so that man might be made perfect through surrender.¹⁰

Suffering forms a strong, recurrent theme within the history, both ancient and modern, of Judaism. Judaism teaches that God chose the Jews for certain roles and responsibilities within a cosmic plan. While God loves and is responsive to pleas from his "chosen people", his actions conform to this timeless scheme for the world. Inevitably, some human suffering will occur and must be accepted for the sake of others or the community as a whole or in congruence with God's eternal plan. The parable of Moses on Mount Nebo illustrates another salient feature of the Judaic view of suffering.

After leading the Jewish people through forty years in the desert wilderness, Moses, the receiver of the Ten Commandments and the "servant of God", ascends the mountain and looks across the Jordan river to Canaan. The covenant God had made with Moses was for him to live to see the promised land, but he was neither to enter nor witness his people entering Israel. Now, having attained that goal, Moses bargains with the Angel of Death, imploring God to allow him to observe his people entering the promised land, if only as a bird flying high above or as a blade of grass on atop Mount Nebo. God declines, gently at first, later with fury. The covenant must be maintained. God demands that Moses' corpse be brought to him! The parable ends as the Angel of Death approaches the heavenly throne carrying the dead body of Moses and observes that God is weeping.

While adhering to the integrity of the eternal plan, God shares in the suffering of his people.

The Secular "Philosophy" of Hospice

While the practice of hospice or palliative care occurs within the secular health care system, an underlying philosophical orientation can be discerned. Dying is understood to be a part of living -- an important part. The nature of dying and of human suffering is understood to be fundamentally personal. This basic precept is consciously intended to support the cultural and spiritual orientation of the patient and family and, in so doing, it is designed to maximize individual autonomy.

The profoundly personal nature of dying and of suffering often seems unrecognized by the larger health care system. Contemporary medicine is focused on cure and organized around problems. The problem-based approach to medical care emerged in the early 1970's¹² and has proven effective in improving organization and communication within health care. This approach is, in fact, well-suited to the evaluation and treatment of physical distress among the terminally ill. It is axiomatic that the process of dying entails pathology and progressively severe pathophysiology. The dying person has physical needs and symptoms that require expert attention, but the process of dying cannot be reduced to a set of medical diagnoses. Viewed from the perspective of the life of the individual, even the myriad of medical problems are dwarfed by the enormity and depth of this final transition.

Personhood

If dying is, most fundamentally, a personal experience, it follows that to comprehend the nature of suffering among the dying it is essential to understand the person. While persons will always be known one by another, as unique individuals, there are important features of the human condition that are universal, or very nearly so, and which can be studied. Eric Cassell contributed a valuable model for understanding suffering in defining a "topology" of personhood.³ Personhood in this model exists as a dynamic matrix of dimensions or realms of the self.

Each person has a prominent physical dimension, a body, which is unique and yet, which has important features in common with the human bodies of other people. Additionally, each person possesses an inherent temperament and distinctive characteristics, preferences, aversions, habits and quirks that contribute to their uniqueness.

Persons exist in time, they have a past and perceive a future. And persons are inherently social beings. The period of infantile dependency of human beings is longest among mammals. It is not surprising that one's family is an integral part of who a person is, often at the core of one's sense of self. An individual's cultural background, imparted during infancy and early childhood, often strongly influences personhood, who the person experiences him or herself to be. Relationships with friends, coworkers and acquaintances similarly contribute to personhood proportionate to the closeness of the connection with the other.

Persons possess beliefs (ranging from political to metaphysical), moral values, and a sense of meaning. Persons also do things and identify with what they have done or wish to do. The active aspect of self extends from the outermost layers to the deepest concentric core of the person: from "activities of daily living" and mundane chores, to routine work-related projects, civic affairs and the normal relationships of community life to work toward the most meaningful of one's aspirations and relations of the most intimate nature. Considered collectively, activities form the medium through which nearly all the dimensions of self are given shape and texture. They are the medium through which the rich, unique composition of personhood can emerge.

Some dimensions of personhood are more or less open for observation and may even be asserted to others. Most notably, a person's professional activities, community projects or political beliefs contribute to one's public self. Other realms of personhood are inherently or intentionally interior. Quite probably every person has dreams, aspirations, memories, beliefs, and fears that are kept to oneself out of concern that they would seem silly, trivial or even frankly objectionable to others. It is not rare that intimate, long term relationships which occupy a central place in a person's present or past are kept secret. They may exist outside of the bounds of marriage or because they challenge acceptable norms of sexual preference or boundaries of race, culture or class. Persons may also carry within them thoughts that seem too particular to one's self to have interest or relevance to others. Here may reside memories from one's past that involve friends who no one in one's current life knows, memories which continue to have value and meaning for the person.

Each person has a realm of the unconscious, most evident in our dream states. Intuition resides within the unconscious or pre-conscious dimensions of the person as do memories of taste, touch or smell which are experienced as emotions and impressions rather than as cognitive recollections. Considered together these aspects of the self comprise a person's private, inner life.

Whether an individual has strong religious convictions, is agnostic or an atheist, each person has a transcendent dimension. This is experienced as a felt connection to something which will endure beyond the life of the individual. Many people have a sense of connection to their family which will live on for generations to come. Others may express a sense of meaning in being part of nature's ongoing process of life, the cycling of elements through the biosphere. Soldiers in battle commonly express a connection to the country that will endure, partly through their own sacrifices. And, of course, many people do experience a vital sense of a supreme being.

The Nature of Suffering

This model of personhood can illuminate the suffering that clinicians observe among the dying. Cassell conceptualizes suffering as occurring when a threat to the integrity of the person is perceived and asserts that the experience of suffering persists until the threat has passed or until integrity of the person can be reestablished in some manner.³

If this is true, it might seem that suffering among the dying would be universal and irremediable. For the dying patient, personhood often appears to be coming apart. Debilitated by illness, ultimately perhaps, confined to bed, a person's sense of self is clearly assaulted.

As death approaches certain dimensions of personhood are particularly vulnerable. Vocation becomes assigned to the past as illness progresses. No longer is one the valued coworker or supervisor, handyman, clerk, teacher or physician. Activities in community affairs, such as team sports, one's congregation, service groups or

local government or a myriad of other interests which had previously given purpose to the person's daily life are, similarly, now relegated to the realm of the past. More poignantly, the dying person no longer experiences himself or herself as the breadwinner of the family or the keeper of the household; no longer feels able to fulfill the responsibilities of husband or wife, parent or child.

The dimension of the future is under direct attack for the dying person. Whereas previously the future was filled with hopes and plans, it now seems empty and bleak. Expressions of suffering commonly are set in the near future: "If my breathing (pain or weakness) gets any worse, I'll not be able to take it."

In *Man's Search for Meaning*, a book which recounts the author's internment in Nazi concentration camps, psychiatrist Victor Frankl emphasizes that the dimension of meaning is central to the human experience of suffering.⁵ Pain and privation are insufficient to explain suffering, Frankl asserts. Human suffering requires the felt loss of meaning and purpose in life. Pain and privation can be endured if it is for a purpose.

The experience of childbirth provides a common, yet powerful, example of the dichotomy between physical pain and suffering. Indeed, only very rarely is the pain of labor and parturition expressed in terms of suffering; despite physical distress for most women childbirth is experienced as enhancing the meaning and purpose of their lives. For the dying person, however, suffering may seem inescapable. All that has given meaning and purpose to an individual's life would appear to be dissolving.

Clinical Response to Suffering among the Dying

A purely philosophical approach to suffering, unbalanced by an experienced, therapeutic perspective, could engender a nihilistic attitude on the part of care providers. If some degree of suffering is inevitable, perhaps attempts to effectively respond are destined to be futile. This conclusion is insufficient for the clinician who must respond to people in distress. Compassion, from its roots in the old French, "to suffer with" compels the clinician to action.¹⁸

Subtle manifestations of therapeutic nihilism exist in current clinical practice, being revealed by the language we choose. The tendency to label difficult symptoms, such as neuropathic pain or nausea, "intractable" or to refer to a person's suffering as "uncontrollable" can prove self-fulfilling. Difficult symptoms elude control until the right intervention is found. Deeply personal suffering persists until the person finds his or her own way through.

Loved ones and caring professionals can help, at a minimum by easing the sense of "aloneness" the dying person may feel. The occasional phone call or physician's home visit acknowledges the person of the patient and communicates caring. Even when suffering derives from the deepest realms of the personal -- psychosocial, existential or spiritual -- experience teaches that clinicians can be helpful, but only if they remain involved.

A fundamental commitment of a hospice or palliative care team is to never abandon a patient. This commitment derives from the knowledge that, at times, simply being present can make a critical therapeutic difference. Frequently patients with agitated delirium or advanced dementia are observed to calm in the company of another person who by intention projects a calming influence by means of humming a lullaby, gently caressing the person or through a variety of complementary techniques. The physical presence of the physician can contribute enormous comfort by occasionally being at the bedside, checking a pulse, touching the brow or holding the person's hand.

Intellectual models for understanding of suffering represent valuable resources for the clinician who encounters a patient dying in distress, yet the unique suffering of patient can only be known by knowing the person. The optimum way to know the experience of another person is to ask. In asking patients to help us understand the nature of their experience, the responses will, at times, prove unpredictable.

It is common for the dying patient's subjective experience to change over time. Indeed, the effective treatment of physical distress may allow other sources of suffering to arise.

"[A] young medical student working in our [palliative care] unit some years ago... pointed out that if a newly admitted patient was asked to list ten things he hoped we would relieve to make his life more bearable, no less than eight were physical the others emotional. If asked the same question 4 or 5 days later, he would list only five physical and the rest would be psychological and social. If after a further 5 days the same questions were asked, he would scarcely mention any physical problems but always would he now include spiritual ones. clearly not all the physical problems had been removed but the edge had been taken off that side of his suffering, and now he felt free to ventilate other needs and at last to open his heart to us."⁴

As with any other critical clinical parameter, routine reassessment of suffering is essential. Both the level of intensity and the quality of the professional care provided can powerfully influence the person's experience and quality of life during the dying process.

Symptom management remains the first priority for the prescribing physician and the palliative care team. Without effective control of severe pain and other sources of physical distress, quality of life for the dying person will be unacceptable. The patients that hospice and palliative care programs serve are among the very sickest in the health care system. When the level of care is adequate to meet the needs of the patients and families served, hospice and palliative medicine becomes a form of intensive care.

A patient who is experiencing severe pain or dyspnea or agitated confusion must be considered a medical emergency. No less emergent is the suffering of a person whose physical symptoms are controlled and whose agony derives from the sense of impending disintegration or the loss of meaning and purpose in life. The appropriate response to situations of high clinical acuity will commonly require multiple members of the clinical team and consultations with appropriate specialists. In the effort to control symptoms and suffering there is no medical evaluation or intervention that is inherently disallowed on the bases of cost or complexity. Interventions likely to yield short term comfort, but which carry potentially serious long term side effects, may be indicated. Each must be judged in the context of achievable goals and the preferences and priorities of the patient and family.

Fortunately, suffering among the dying is not universal; in palliative care settings, unremitting suffering is becoming quite rare. Most people do achieve relative comfort and an acceptable resolution of interpersonal and internal conflicts during the months, weeks, days, or even hours before death.

Opportunity at the End of Life

Any examination of the human experience of dying would be incomplete without exploring the nature of opportunity at the end of life. Ironically, and in contrast to sudden or traumatic deaths, the process of dying from a relentlessly progressive illness embodies a number of discernible opportunities which range from the fairly mundane to the frankly extraordinary. A survey of the personal experience of dying must confront the clinical observation that some people emerge from the depths of suffering -- and the virtual disintegration of the person they once were -- to report a sense of wellness as they are dying. While seasoned geriatricians and hospice providers confirm the existence of such seemingly paradoxical transformations, the frequency of these experiences is not known. Here again, systematic clinical studies are lacking and we must learn what we can from empirical observation and anecdote.

"From time to time, a terrible event happens to someone, and yet the survivor finds herself or himself better off. Through injury, a person is rendered paraplegic, or even quadriplegic; cancer strikes, requiring debilitating chemotherapy and raising the specter of a shortened life. The person suffering the calamity transcends the suffering and the loss finds new meaning in life. Living becomes a richer, more satisfying experience and, in extreme instances, people feel that they never really appreciated life until their tragedy."⁷

Actor Anthony Perkins arranged for the following statement to be released posthumously:

" I chose not to go public because, to misquote Casablanca, I'm not much at being noble but it doesn't take much to see that the problems of an old actor don't amount to a hill of beans in this crazy world. There are many who believe that this disease is God's vengeance, but I believe it was sent to teach people how to love and understand and have compassion for each other. I have learned more about love, selflessness and human understanding from the people I have met in this great adventure in the world of AIDS than I ever did in the cutthroat, competitive world in which I spent my life."¹

A few years ago, on the completion of a workshop presentation I had given on end of life care, a woman stopped to speak with me and offered me a copy of the last letter her son had written to her. She asked that I use it if it seemed meaningful to others.

"Dear Mom, This last part of my life could have been very unpleasant, but it wasn't. In fact, in many ways, it has been the best part of my life. I've had the opportunity to get to know my family again, a chance very few people have or take advantage of. I've enjoyed a life full of adventure

and travel, and I enjoyed every instant of it. But I probably never would have slowed up enough to really appreciate all of you if it hadn't been for my illness. That's the silver lining in this very dark cloud... When you get down to it, I'd have to live several hundred years to fulfill all the dreams I've had. I have done pretty well with the time allotted me, so I have no regrets... "

And the letter closes,

"If anyone ever asks you if I went to heaven, tell them this: I just came from there." ⁶

Illustrative Case

Mrs. G., a 60 year old woman with metastatic lung carcinoma had been a wife and mother throughout her adult life. She grew increasingly despondent as her illness progressed and her functional status declined. Her physical pain could be controlled with narcotics and anti-inflammatory medications, but she had lost the ability to do any of the things that had brought her life meaning. Instead she was becoming dependent upon others, the very people she still felt a need to nurture and protect. She was painfully aware of the burden that her care represented to her family. She felt worthless and hopeless. Her suffering manifested as agitation, at times with confusion and paranoid delusions. Medications would calm her outbursts, but her suffering persisted. Additionally, her family suffered to see her in such distress and wished that her life would end quickly and with comfort.

Intervention involved listening attentively to the patient's story of her life and focused on exploring the patient's feelings of unworthiness and her fears of what she had left undone. She was able to speak openly about her impending demise and voiced concern about her children who continued to struggle in their adult lives. Her feelings of inadequacy were gently challenged by reflecting on the content of her life story and on how much she had accomplished and done for others in her life. It was suggested that the work she had remaining to do was about completing her full and meaningful life. In counseling, each of her close relationships were reviewed with attention to "what would be left undone" if she were to die before important things were said. The patient was able to meet with each of her children. These poignant visits included mutual expressions of forgiveness, of appreciation and of love. In a real sense the patient was completing her relationships and saying goodbye.

Furthermore, in counseling, Mrs. G. was asked to consider that an important task for this stage of life for any person might include the acceptance of care from others. Specifically, it was suggested that her willingness to receive care was the single most important thing she now could do for her family. During a subsequent meeting with Mrs. G. and her children in which this notion was shared, her children's response was tearful, but enthusiastic agreement. One of them said, "We need to care for you Mom. Please let us do this for you as you have raised us and done so much for us in our lives." Collectively, they expressed a need to provide care as a means of completing their relationship and grieving the loss of their beloved mother.

In addition to patient and family counseling, ongoing adjustments were made in Mrs. G.'s medications and meticulous attention to medical aspects of care continued by the hospice interdisciplinary team. Over a period of two weeks, Mrs. G.'s suffering improved. Her paranoia dramatically diminished, occasional night time confusion responded to calm reassurance and she was able to accept care from her family with grace and even a sense of humor. She died in her home, surrounded by family in comfort and peace.

As is evident from the examples chosen, even at the end of life the range of human experience remains vast, extending from intense suffering at one extreme, to a sense of comfort and genuine peace to, at the other extreme, a sense of profound wellness.

Often the term "good death" is used to describe the goal of terminal care. It has the disadvantage of connoting something that is static and formulaic. Furthermore, it perpetuates the confusion between death -- about which we arguably know nothing -- and dying, the personal process of living with progressive decline and impending demise. The phrase "dying well" seems better suited to describe the positive end-of-life experience that people desire. In conceptualizing "dying well" and the related notion of "wellness in dying" it is not necessary -- and would be misleading -- to glorify the experience. Dying, even for those who attain a sense of wellness, is rarely easy and may, instead, be arduous and unpleasant.

Hospice practice experience provides strong empirical validation for the historical and literary observations that suffering among the sick and the dying -- suffering which to the healthy reader or observer may seem inevitable and unendurable -- can, at times, give way to a heightened sense of well-being and quality of life. This aspect of the human experience of dying has, as yet, not been incorporated within the medical model. It is both wonderfully provocative as well as intellectually unsettling to confront the implications of this observation. How can this apparent paradox be explained?

A Developmental Model

In approaching this paradox it is necessary to restate the most fundamental tenet of the hospice or palliative approach to care: Dying is a part of living. The period of time referred to as dying can, therefore, be considered as a stage in the life of the individual person and the family. Modern psychological theorists, among them Erik Erickson, Jean Piaget and Abraham Maslow, whose work collectively forms the basis of modern behavioral medicine, all asserted that human development is a life-long process.

There is a tendency within contemporary culture and reflected in medical practice to assume that on receipt of a terminal diagnosis meaningful life has ended. Within this perspective the person is constrained to wait for death, being reduced to hope only for some measure of comfort and to avoid being a burden to others. This attitude is incongruous with the basic philosophy of modern palliative care for it inappropriately devalues and separates this last stage of living from the continuum of a person's life.

It is useful to conceptualize dying as a stage of the human life-cycle, comparable to infancy, childhood, adolescent, adulthood and advanced age. While individuality, of course, extends through the very end of life, characteristic challenges, or developmental landmarks, can be discerned and representative task work toward achievement of these goals can be identified. [Table 1] The specific landmarks and task work delineated will vary from one author or clinician to another. The specifics are far less important than the conceptual framework of life-long human development.

It is important that a developmental approach to dying not be misconstrued as introducing a set of requirements against which to judge the personhood of an individual. These broad landmarks are intended to serve as diagnostic tools enabling clinicians to anticipate issues with which patients may struggle and from which suffering may arise. This framework provides a means of recognizing opportunity that may otherwise remain overshadowed by the person's distress. The word opportunity is carefully chosen to describe in general terms the status of dying patients who have an acceptable level of physical comfort. The dictionary defines opportunity as "a combination of circumstances favorable for the purpose".¹⁹

The task work offered in Table 1 represent various means through which persons in their dying may develop a sense of completion, satisfaction and even a sense of mastery within areas of life that are of subjective importance to the person. The examples listed are intended illustrate the conceptual framework and are not meant to be exhaustive. The task work involved in the process of dying is the person's own to do -- or not do -- as they so choose. As clinicians, we can explain opportunities, offer suggestions and, if there is interest expressed, we can facilitate the person in his or her own work. In this manner people can be gently assisted in achieving a sense of readiness as they approach death.

The Cassell's multidimensional construct of personhood and the model of life-long human development provide a means for understanding the human experience of dying. Together they suggest a language for its expression. The key to solving the apparent riddle of how suffering can give way to a heightened sense of well-being lies in the realization that during each phase of life the personhood of the individual changes. In fact, throughout a person's life the sense of who one is changes most dramatically in the process of responding to the challenges and crises that virtually define the developmental stages of infancy, childhood, adolescence, mid-life and late-life.

During each major life transition there may be suffering. At times people may be broken and never fully recover an integrated sense of self, but most find a way to grow through these turning points, achieving a measure mastery as they look ahead. One need not undergo a "peak experience" or achieve ultimate "self-actualization" to experience growth in the last stage of their life. People who can be said to have grown in their dying are those who express satisfaction in the direction of personal change that occurred in response to progressive stresses of disabling illness and for whom an enhanced subjective sense of self emerges during the process.

Dying is surely the most profound of life's challenges. We speak of growing up and growing old; perhaps, we can refer to those who emerge from suffering into a subjective sense of wellness in their dying as "growing on."

Abrupt disability can result in the patient feeling as if critical dimensions of self had been amputated. When the clinical course provides sufficient time and when aid is available through support of caregivers, social roles and responsibilities can be completed and dimensions of self to be consciously released from the person. Business can be completed, legal and fiscal responsibility transferred, the value of others can be acknowledged and appreciation mutually expressed. Even intimate relationships gradually can be brought to a sense of completion. Families can be helped to effectively resolve problems of communication such as the "conspiracy of silence" in which neither patient nor family will openly acknowledge the terminal nature of the illness in order to protect one another from the pain of separation. In actuality, the shared pretense only adds isolation to the grief each person is feeling. One example of a

"clinical tool" for assisting in the completion of relationships is the "saying of the five things". Years ago a nurse colleague taught me that in order for people to feel complete in any close, personal relationship they need to have conveyed and acknowledged five things: "Forgive me." "I forgive you." "Thank you." "I love you." and "Good-bye."

In contrast to a sudden, "easy" death, progressive illness, offers a precious opportunity to reconcile previously strained relationships -- perhaps between previous spouses, or between a parent and estranged child. The history of a relationship (and family) is transformed when the story of two persons ends well. Completion does not require an ending of interaction or a severing of relationship. Rather, it conveys a sense that there is nothing left unsaid or undone. When a dying person and loved one come to feel complete between themselves, subsequent time together is as often marked by joy and the exchange of loving affection as it is by sadness.

Inwardly, as well, the process of dying in a progressive, rather than sudden fashion, provides an opportunity to acknowledge achievements and savor a sense of accomplishment and satisfaction. It is a rare individual who achieves all that he or she had hoped for in life, and this waning phase of life also offers the opportunity to come to terms with life's frustrations and disappointments and to accept one's own imperfections. A clinician who enjoys a good rapport with a patient can point out that the person is "only human" and that humans, by their very nature, tend to be imperfect. In this and similar fashion a patient who is suffering from low self-esteem can develop -- perhaps for the first time in life -- a feeling of self-worth.

Life Review

While a person's past is protected from the ravages of illness, through life review a broader perspective can be achieved. Previous mistakes and misdeeds can be understood as part of a larger whole, self forgiveness can be extended. Here, as with the history of strained relationships, a life story that ends well casts a positive light on all that has preceded. In this manner a person may come to feel "enlarged", even as he or she is so physically diminished.

Geriatricians Lewis and Butler have emphasized this point: "The therapeutic possibilities of the life review are complex. There is the opportunity to reexamine the whole of one's life and to make sense of it, both on its own terms and in comparison with the lives of others. Identity may be reexamined and restructured. There is the chance to resolve old problems, to make amends and restore harmony with friends and relatives." ¹¹

The process of storytelling as a particular form of life review often has valuable salutary effects and should be encouraged. Stories from the person's past can be elicited by an interviewer with even modest experience (such as a trained volunteer) and can be aided by leafing through a family photo album. Patients who have interest in having their stories recorded in their own voice can be assured that others, especially their children, grandchildren and, quite possibly, those yet unborn will regard the recordings as heirlooms to be treasured. In this manner persons who can no longer contribute in accustomed ways to their families, and who may feel a burden to others, can regain a sense of tangible meaning in the effort to preserve and transmit their stories.

Meaning and the Transcendent

The transcendent dimension commonly assumes greater subjective importance as one nears the end of life, perhaps because the person's perspective becomes unobstructed by the priorities and demands of an active life. The related dimension of meaning which is so pervasive and central to the nature of suffering is also pivotal to the resolution of suffering and the subjective experience of personal growth. Each religious and philosophical tradition provides a method for infusing the suffering of a person with meaning. The person may come to experience suffering as a sacrifice for sake of others or as a means by which they are connected to the transcendent realm. Hospice experience confirms that suffering often becomes endurable -- or miraculously dissolves -- when it becomes meaningful for the person. The personal meaning of suffering may seem to others to be abstract but for the person dying meaning is a tangible entity, deriving substance and shape from the individual's life history. The profound, therapeutic power of meaning for human beings is at the crux of Victor Frankl's logotherapy. This school of psychotherapy which he founded focuses on helping the person find a sense of meaning in his or her life experience, including the most adverse of experiences.

The personhood of the dying individual can be conceptualized as gradually becoming less dense as some spheres of self fall away and others are consciously released. Those dimensions of self which only require the person to "be" -- such as one's past, one's sense of meaning and the transcendent realm -- gradually assume prominence. The person's experience of self identity often becomes fluid at the end of life. The person's sense of self tends to become less complex, however, personhood may remain subjectively intact.

TABLE 1 - DEVELOPMENTAL LANDMARKS AND TASKS FOR THE END OF LIFE

- Sense of completion with worldly affairs
 - Transfer of fiscal, legal and formal social responsibilities
- Sense of completion in relationships with community
 - Closure of multiple social relationships (employment, commerce, organizational, congregational). Components include: expressions of regret, expressions of forgiveness, acceptance of gratitude and appreciation
 - Leave taking; the saying of goodbye
- Sense of meaning about ones' individual life
 - Life review
 - The telling of "one's stories"
 - Transmission of knowledge and wisdom
- Experienced love of self
 - Self-acknowledgement
 - Self forgiveness
- Experienced love of others
 - Acceptance of worthiness
- Sense of completion in relationships with family and friends
 - Reconciliation, fullness of communication and closure in each of one's important relationships. Component tasks include: expressions of regret, expressions of forgiveness and acceptance, expressions of gratitude and appreciation, acceptance of gratitude and appreciation, expressions of affection
 - Leave taking; the saying of goodbye
- Acceptance of the finality of life - of one's existence as an individual
 - Acknowledgement of the totality of personal loss represented by one's dying and experience of personal pain of existential loss
 - Expression of the depth of personal tragedy that dying represents
 - Decathexis (emotional withdrawal) from worldly affairs and cathexis (emotional connection) with an enduring construct
 - Acceptance of dependency
- Sense of a new self (personhood) beyond personal loss
- Sense of meaning about life in general
 - Achieving a sense of awe
 - Recognition of a transcendent realm
 - Developing/achieving a sense of comfort with chaos
- Surrender to the transcendent, to the unknown - "letting go"

Conclusion

Dying well, therefore, can be understood in terms of the subjective experience of personal growth, embodying a sense of renewed (at times enhanced) meaning and a sense of completion, at times even fulfillment in life. Personal growth is rarely easy at any stage of life, and a growthful dying may actually be difficult. It probably must entail a measure of suffering. The touchstone of dying well -- the sense of growing in the midst of dying -- is for the experience to be important, valuable and meaningful for the person and their family.

Care for persons who are dying is at once complex and simple. The details of managing atypical pain, intermittent bowel obstruction, fistulas or pruritis all may be intricate, yet the general orientation toward care for the dying patient remains straightforward. Comprehensive care for people who are dying rarely requires more than careful management of symptoms and attention to the basic psychosocial needs of the individual -- as a person -- and their family. Beyond symptom management, hospice and palliative care intervention can be directed at helping the person to attain a sense of completion within the social and interpersonal dimensions, to develop or deepen a sense of worthiness and to find their own unique sense of meaning of life.

Most fundamentally, clinicians can serve the dying person by being present. We may not have answers for the existential questions of life and death any more than the person dying. We may not be able to assuage all feelings of regret or fears of the unknown. But it is not our solutions that matter. The role of the clinical team is to stand by the patient, steadfastly providing meticulous physical care and psychosocial support, while people strive to discover their own answers.

The poet Rilke wrote:

"...have patience with everything unresolved in your heart and try to love the questions themselves... Don't search for the answers, which could not be given to you now... And the point is, to live everything. Live the questions now. Perhaps then, someday far in the future, you will gradually, without even noticing it, live your way into the answer." ¹⁴

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