

## **Caring When Cure Is No Longer Possible**

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## **Caring When Cure Is No Longer Possible**

### **Caring Through Life's End**

Care for persons who are dying is at once simple and complex. Comprehensive care for terminally ill patients is complex because dying is a multidimensional, multifactorial experience for the person whose life is ending. The evaluation and management of physical symptoms, such as neuropathic pain, intermittent bowel obstruction or pruritus, are likely to require anatomic, physiologic and pharmacologic considerations. Similarly, the psychological and medical evaluation and treatment of depression or of intermittent confusion in a patient with far-advanced disease may prove intricate and complex.

However, each of these clinical tasks is encompassed within a simple and straightforward orientation toward care for people who are dying and support for their families. As modeled by contemporary hospice/palliative care programs, care for people who are dying is organized around two major goals – alleviation of suffering and the enhancement of the person's and family's ongoing quality of life. The concept of personhood and a model of life-long human development can be applied to understand the nature of suffering, as well as quality of life of people living with progressive illness, disability and the approach of death. This chapter is intended to provide the reader with an understanding of this care.

## Personhood, Suffering and Quality of Life

There are two poles of human experience associated with the last phase of life – suffering at one extreme and a sense of well being at the other. Suffering is the term that best describes the human experience of pervasive distress associated with dying. Cassell defines suffering as the state of severe distress that is associated with a perceived threat to the integrity of the individual.<sup>1</sup> Personhood in this model is conceived as a dynamic multidimensional matrix of spheres that collectively comprise one's experienced identity or sense of self. The dimensions include one's body (physical self), mind, past, family of origin, present family, culture, ethnicity, spiritual beliefs, political beliefs, roles in family (Mom/Dad, sibling, child), roles at work and organizations, preferences, aversions, habits and so forth. (Figure 1)

A sense of meaning about who one is pervades a person's experience of self. A sense of meaning serves as a meshwork on and through which the process of personhood is woven.<sup>2,3</sup> Damage to this crucial dimension of self inevitably causes suffering, as if personhood were unraveling.

If suffering occurs when a person experiences himself or herself to be coming apart and if the loss of meaning represents an *unraveling* of personhood, suffering among the dying could be expected to be universal and irremediable. Debilitated by illness, ultimately perhaps confined to bed, a person's sense of self is clearly assaulted. Empirically however, we know that suffering is neither universal nor beyond our ability to affect through clinical interventions.

Interestingly, some people confronting the last phases of living report a new sense of wholeness and well-being despite progressive decline in function, the loss of roles and the loss of relationships.<sup>4,5,6,7</sup> Herein lies the essence of the phrase ‘*healing versus curing.*’ Seasoned clinicians working in palliative care recognize that people who have been hardened and made cynical by life frequently soften when illness forces them to accept kindness and caring from others. Anger that has kept one at odds with a family member or previous close friend commonly gives way to an attitude of openness to reconciliation. Those who have long felt isolated may once again, or for the first time, be able to feel loved. Such experiences are difficult to explain within the context of present day health care, focused as it is on disease, medical treatment and issues of service delivery and cost. Within hospitals and clinical settings, relief of suffering is the highest goal; however, it is too infrequently attained.<sup>8,9,10,11,12</sup> In these settings few dying persons experience an elevated quality of life and, when they do, these experiences go largely unrecognized.<sup>13,14</sup>

The phenomenology of positive experience in the phase of life called *dying* is of profound importance to developing a clinical approach to caring for people at the end of life. Instances of patients’ and families’ transitions from suffering to a sense of wellness and peacefulness are fundamental to understanding the human encounter with death. Patients and families have much to teach us about defining meaningful goals and emotional, spiritual and social interventions that may provide support during this phase of life and through the process of dying.<sup>15,16,17,18,19,20,21,22</sup>

In examining the range of human experience associated with dying, one principle becomes clear. Although symptom management is the first priority for palliative care, it

is not the ultimate goal. True person and family-centered care at the end of life strives not only to ensure comfort, but also to improve quality of life for people who are dying and for their families. This includes helping to preserve opportunities for them to grow through times of illness, caregiving, death and grief.<sup>23,24</sup>

## **Systems Issues**

### ***Integrating and Completing the Continuum of Cancer Care***

Nurses working in oncology routinely encounter patients whose illness progresses despite aggressive efforts to extend life. While there have been important advances in cancer care over the past several decades, and recent remarkable progress in treating a few specific neoplasms, approximately half of all patients diagnosed with cancer will eventually die as a consequence of their illness or related complications. Caring for people as they die is, therefore, an integral part of oncology nursing practice.

In its statement on Cancer Care During the Last Phase of Life<sup>25</sup>, the American Society of Clinical Oncology has stated:

“Cancer care optimizes quality of life throughout the course of an illness through meticulous attention to the myriad physical, spiritual, and psychosocial needs of the patient and family. ASCO believes that provision of optimal end-of-life care requires access to and availability of state-of-the-art palliative care rendered by skilled clinicians, buttressed when necessary, by palliative care experts.”

Currently, comprehensive palliative care is often instituted only after life-prolonging care is no longer available, effective treatment options have been exhausted, or have been rejected by the patient. (Figure 2a) However, the precepts of palliative care emphasize the importance of continuity of care, symptom management, skillful communication and psychosocial support throughout the course of illness.<sup>26,27</sup> (Figure 2b) The continuity of palliative care in the management of patients with progressive cancer is well represented by the simple diagram in the World Health Organization monograph on palliative care.<sup>28</sup>

Correctly understood, palliative care represents a “both-and” model of care, enabling a seamless transition from mostly curative and life-prolonging treatments to therapeutic interventions for improving comfort and enhancing quality of life. As a patient’s disease advances and there is proportionately less to offer in terms of life-prolongation, it is logical and natural for the goals of care to progress toward comfort and quality of remaining life. Thus, palliative and life-prolonging efforts complement one another and can properly proceed simultaneously.

The principle of proportionality, weighing the potential benefits of an available intervention against the risks, underlies the process of care planning and decision-making. The values and self-defined goals of the person, as well as the person’s currently experienced quality of life, form the fulcrum for this ongoing decision-making process. At times, even as the end of life approaches, some life-prolonging measures may be warranted if they have potential for advancing the person’s goals at a risk that is deemed acceptable. Such may be the case with yearly immunization against influenza, or oral antibiotic treatment for respiratory infection with fever in a debilitated, but stable patient.

This smooth progression of care requires excellent communication and coordination of a skilled interdisciplinary team. It also requires on-going involvement of the patient and family actively participating in the care planning and decision making as partners in care delivery. The nurse's role is central to this interdisciplinary, patient-family centered approach.<sup>29,30</sup> The inherently intimate nurse/patient therapeutic relationship provides a privileged opportunity for the nurse to work closely with the patient and family in coordinating care and treatment with other members of the caregiving team.

Caring for the elderly dying patient presents particular challenges. Comorbid medical conditions and disabilities increase susceptibility to complications and add to the symptom burden. Skillful care requires oncology nurses to be knowledgeable about the physiological changes in the aging process, concomitant illness, such as diabetes, renal disease and congestive heart failure, which may impact progressive illness and alter pharmacokinetics and response to treatment. Additionally, the social content frequently involves supporting and educating informal caregivers who may also be elderly.<sup>31</sup>

The accumulated life experience of older adults inevitably contributes to pre-conceptions, of which they may be unaware, but which can impact the quality of their lives during illness, caregiving and grief. Uncovering these expectations, hopes and fears during early evaluation enables clinicians to be alert for particular values and concerns of a patient and family. This is often best accomplished by listening to people's stories of others they have known during illness and dying. This developed level of familiarity with patients and their families enables clinicians to prevent specific problems



that people dread. It also allows clinicians to be reassuring and help people focus on realizing their own aspirations.

### ***Case Management and Care Planning***

The process of ongoing care planning involving the patient with his or her family underpins this seamless model of life-prolonging and palliative care. At each point from diagnosis through death, the patient or surrogate retains the right to make informed choices among a full range of indicated and available options for care. Introducing the goals of comfort and quality of life and the concept of palliative interventions early in treatment establishes a foundation that extends continuity of care through the end of a patient's life, and extends support to the family during bereavement. Advance care planning often includes completion of documents, such as a living will conveying an individual's preferences for care and a durable power of attorney for health care formally appointing a proxy to make decisions if the person becomes unable to decide for himself or herself. Increasingly, the term advance care planning encompasses the iterative process of discussion that identifies patient and family values, assesses their needs, and weighs the risks and benefits of each therapeutic option in making decisions for the short and mid-term future.

Even at the time of diagnosis, professional caregivers err if they assume that every patient confronting a serious, life-threatening illness will choose aggressive life-prolonging care. It is particularly important in caring for the elderly patient to establish a context for medical decision-making that is rooted in the person's values, life goals and

general preferences. Some patients carefully consider all options and decide to forgo curative or remissive therapies despite a fair chance of disease-modifying efficacy. Inevitably there will be instances when clinicians disagree with the choices a patient or family makes. It can be intensely frustrating and emotionally painful for a nurse or doctor who feels that surgery, chemotherapy or radiation therapy is indicated to support a patient who refuses a treatment.

Ultimately, clinicians can best serve patients and their families by providing the most current information available in words they can comprehend, and by offering clear recommendations throughout the course of illness and treatment. Within the ongoing process of care planning, it is the persons served who appropriately determine the proportion of life-prolonging to palliative treatments within the continuum of care at any point in time. In the end, it is the patient or appropriate surrogate whose lives are most affected and whose choices among available options must prevail.

## **Clinical Issues**

### ***Principles and Practices***

The essence of expert end-of-life care lies not merely in the technical competence of its components, but in the intention, vision, and synergism that permeates the whole. Within the current health care delivery system, excellence in care is best modeled by leading hospice programs.<sup>32</sup> A number of organizations have published definitions and

precepts for hospice and palliative care.<sup>33,34,35</sup> The defining features of palliative care can be concisely conveyed by describing five basic principles of care.

### **Principle One: Symptom Management is the First Priority**

This principle was introduced in the discussion of suffering and the notions of healing and curing. Pain and other types of physical distress commonly occur during the course of far-advanced illness. Fear of pain is among the most frequently expressed source of dread among patients and families who are facing a life-limiting illness. Symptoms of advanced illness have the power to destroy the quality of peoples' lives. Indeed, without effective control of severe pain and other sources of physical distress, the quality of life for the dying person predictably will be unacceptable. Witnessing a loved one live and die in physical agony impacts the lives of family members forever. For all these reasons, symptom management is the first priority for the palliative care team.

Regrettably, multiple studies have documented an astounding prevalence of unmet physical distress among people who are dying. Regulatory, financial and cultural barriers to appropriate prescribing and inadequate education relevant to symptom management contribute to problematic patterns in medical and nursing practice.<sup>36,37,38,39,40,41,42</sup>

Whatever resources are needed and the highest level of expertise available must be employed in service of controlling persistent symptoms. Symptom alleviating treatments can include analgesics and co-analgesics, chemotherapy, hormonal therapy, radiation therapy, neurosurgical, orthopedic and oncologic surgical procedures, and behavioral therapy techniques. The commitment to alleviating suffering must be strong

and the clinical approach must be organized, comprehensive and ongoing. Palliative care teams, especially the physicians and nurses involved, must remain dedicated to do whatever is necessary to control physical discomfort.

A focused assessment of the patient's symptoms begins, quite simply, with a history and physical examination. Laboratory and radiologic evaluations are appropriate when they are needed in discerning the underlying pathophysiology of the person's discomfort. This information is processed by the clinician and the interdisciplinary team in developing a palliative plan of care. Implementation of the resulting care plan must be accompanied by ongoing evaluation of the person's subjective quality of life.

It is important to emphasize that there are no biologic or pharmacologic limits on the ability to control physical suffering in the context of far advanced illness, nor any legal or ethical reason for persons to be afforded less than whatever is required to achieve relative comfort as they die. Simply stated, no one need ever die in physical agony. In practice, even severe physical distress usually yields to fairly routine interventions. Adequate control of symptoms is not always easy and in unfortunate cases can prove to be very difficult. There are times when physical comfort can only be achieved at the cost of alertness. Infrequently, sedation is required to relieve otherwise intractable physical suffering.<sup>43,44</sup> But relative comfort is *always* possible.<sup>45,46</sup>

### **Principle Two: The Patient with His/Her Family is the Unit of Care**

An important commonality in the human encounter with death is that peoples' lives remain interconnected – emotionally and physically – through the end of life and

into grief. Palliative care recognizes the patient *with his or her family* as the unit of care. Families in this context are not defined solely by shared genetic endowment, marriage or adoption, but rather by the phrase “for whom it matters,” encompassing the network of a person’s relatives and close friends. Families have always and will always participate in this final transition from life and will always grieve for someone they love and have lost. The impending death of a loved one is as profound an experience in the lives of family members as is the coming birth of a new member. Each person in the patient’s family, as well as the family as a whole, is inevitably, inescapably affected. As a corollary of this principle, extending support to a patient’s family through the initial period of bereavement is an integral component of hospice and palliative care.<sup>47</sup>

Although each family is unique, there are common needs and opportunities that families tend to share. Each family wants to know that their loved one received the “best care possible,” although they often only have a general sense of what this means. It almost always includes knowing that the person received, or had the chance to receive, the most current and effective treatments to cure illness and prolong life. It also extends to care that ensures that their loved one is as comfortable as possible. Whether it is stated, or simply assumed, the “best care possible” also extends to meeting the person’s basic needs for hygiene, grooming, privacy and dignity. Families need to know that their loved one’s values and preferences for care were followed to the extent possible. It is not the details of an advance directive as much as the spirit of the person’s and families’ values that are important. Family members expect and need to know that the care extended will respect their loved one’s inherent dignity. This is an important component of “the best care

possible.” A family that feels their loved one is treated in an undignified manner will be dissatisfied and at high risk for coming into conflict with clinicians.

Families who know that time with a loved one is limited value having an opportunity to say and do the things “that matter most.” Expressing love for the person who is dying is a normal component of healthy family grieving which begins prior to death. In their time together and in their caring, loved ones value the opportunity to honor and celebrate the person dying. Lastly, many families feel a need to grieve together, honoring and celebrating the person who has died, and comforting one another in their shared loss. (Table 1)

### **Principle Three: Palliative Care is an Interdisciplinary Team Approach and Process of Care**

Care for people who are dying is optimally practiced as a team process and as a coordinated whole. Each member of the interdisciplinary clinical team represents a valuable resource during the procedure of devising and implementing a patient/family centered plan of care. Members of the team contribute through specific roles. The nurse case manager is the pivotal person coordinating care and serving as a conduit of information between members of the team and with the patient and family. The nurse regularly assesses physical and functional status, administers treatments, identifies new or impending problems and drafts a plan of care. The patient’s physician or the palliative care physician has responsibility for performing a medical evaluation, prescribing medications and symptom-alleviating treatments, and ensuring that an ethically sound process of decision making and informed consent has preceded significant treatment

decisions. The social worker undertakes the financial and psychosocial evaluation and accesses sources of support for the patient and family. The chaplain explores spiritual or existential questions the patient might have, provides pastoral support, and helps the patient connect with his or her own local faith community and resources. Yet a reductionist approach to explaining a clinical palliative care team misses the essence of the model. In practice, the whole is more than the sum of its parts. Synergy is consciously recruited in the work of the team.<sup>48,49</sup>

Interdisciplinary care planning is the central dynamic – a genuinely creative process that invites input from all members of the clinical team. Thus the social worker or bath aide can lend their eyes and ears in gauging the impact that pain is having on the patient’s activities and functional status. The nurse or physician may respond to a fearful patient’s question about the future in a way that leads to a therapeutically valuable discussion of meaning and spiritual connection. In addition to providing respite to a patient’s spouse, a volunteer may help the patient label pictures for an album or record spoken stories aiding the person in developing a sense of completion, or assist in spiritual care by transporting and sitting with the patient for an hour in a cathedral or at the ocean or a riverside.

#### **Principle Four: Dying is a Part of Living**

The most fundamental feature of palliative care is a recognition of dying as a part of living – an important part.<sup>50,51</sup> Dying is characteristically hard, unwanted and often tragic. Nevertheless, dying is a natural and normal human experience. While the symptoms and physical needs of dying persons require expert medical attention, dying is

more than a set of medical problems to be solved. The fundamental nature of dying is as a *personal experience*. Viewed from the perspective of the life of the individual, even the multitude of medical problems is often dwarfed by the enormity of this final transition.

The philosophical stance of approaching dying as fundamentally personal and experiential distinguishes palliative care from even the most comprehensive problem-based medical care of people who are dying. The goal of improving quality of life and personal experience is a guiding principle in the design of each patient's palliative plan of care and is reflected in the subsequent interventions by members of the clinical team. Whether patients are at home, in a nursing home or in an acute care hospital, medical testing and treatment should be as unobtrusive as possible, arranged whenever possible to accommodate the patient's and family's schedule and the sanctity of their time. The patient's and family's priorities dictate the priorities for the plan of care. Family visits, attendance at important family celebrations, such as weddings, graduations and reunions, and participation in religious and cultural rituals often become important objectives for patients and, therefore, important objectives within a plan of care. Medical services may creatively utilize sophisticated home-based services and novel routes of medication administration in support of these goals. Psychosocial and spiritual support can focus on personal preparation and achieving comfort and a sense of completion and closure.

### **Principle Five: Palliative Care Represents Intensive Care**

It is axiomatic that dying patients are among the very sickest in the health care system. While palliative care is often spoken of in terms of "supportive care," many



patients seen by hospice and palliative care programs have multi-system failure and require many hours a week of skilled care and many more hours of supportive care. They may be taking 10 or more medications on any given day. Clearly in meeting the needs of the patients and families, palliative care often represents *intensive care*.

It is a mistake to assume that hospice and palliative care must avoid sophisticated or expensive diagnostic workups and treatments. Issues of the cost or the “aggressive” nature of a proposed intervention do not obviate consideration of therapies of curative intention and must not limit consideration of treatments to relieve a patient’s distress or improve quality of life in advanced illness. The intensive nature of some palliative interventions – such as neurolytic blocks for unrelenting neuropathic pain or sedation for management of severe terminal agitation – is properly limited only by patient-imposed restrictions.

## ***Intervention Strategies***

An important monograph from the Standards and Accreditation Committee of the National Hospice and Palliative Care Organization outlines a “treat, prevent, promote” intervention strategy.<sup>52</sup> It represents a systematic approach to comprehensive care planning throughout the terminal phase of illness. The Pathway assessment and intervention schema focuses on opportunities for clinical action. Consistent with the principles presented in this chapter, the Pathway assumes that the most pressing priority for patients and families is treatment of immediate sources of suffering – physical, emotional, social or spiritual. The team then focuses on preventing symptoms and complications for which the patient is known to be at risk, and on early signs or

foreseeable family conflicts or inter-personal discord. The interdisciplinary team plan of care also attends to promoting opportunities for a patient and family to grow, individually and together, through this final stage of life.<sup>53,54,55</sup>

When patients and families are supported at these levels, it is more likely that they will perceive that life retains value and offers treasured moments even as they face physical decline.<sup>56</sup>

### **Developmental Landmarks and Taskwork**

In approaching the apparent paradox of *'healing versus curing,'* it is worth emphasizing a fundamental tenet: Dying is a part of living. The period of time referred to as *dying* is a stage in the life of the individual and the family. Modern psychological theorists, among them Erik Erickson, Jean Piaget and Abraham Maslow, have recognized that human development is a life-long process. Clinical experience in palliative care reveals that the end of life can be a time of remarkable opportunity and a time of profound richness and depth for the patients and families<sup>57,58,59,60,61,62,63,64</sup> The magnitude of the personal growth nurses witness is often surprising to both the patient and family. Furthermore, experienced nurses recognize that these developmental opportunities not only can be preserved, they can also be nurtured. People can be helped to identify the things that matter most to them now during this concluding phase of their life. Are there important things that they feel a need to say to another? Are there things that would be left undone if they were to die suddenly? Palliative care is practiced one patient and one family at a time. Through the skillful, effective management of symptoms, opportunity is preserved and through skillful, sensitive counseling, growth can be facilitated.

The specific characteristics of personal experience with advanced illness, dying and grieving vary widely from person to person. The particular work that a person has need for, or interest in, doing as they confront life's end will vary. However, a person's individuality is not diminished by recognition of elemental commonalities within the human condition as life ends. Issues of life completion and life closure are available to each individual. One need not await serious, life-limiting illness for these issues to have relevance, but knowledge that time is limited lends urgency to these matters. The developmental landmarks and examples of end-of-life task work outlined here represent predictable personal challenges as well as important opportunities of persons as they die. Importantly, within a developmental model one need not sanitize nor glorify the experience of life's end to think of a person as having died well or, similarly, as having achieved a degree of wellness in their dying. Personal development is rarely easy. The touchstone of "dying well" is that the experience is of value and meaningful for the person and their family.<sup>65,66</sup> (Table 2)

Empiric support for this developmental model is provided by a study conducted by Steinhauser and colleagues involving focus groups comprised of patients with advanced illness and their families. Qualitative content analysis of transcripts revealed that people assign importance to domains of preparation for death, a sense of completion, and feeling that they are or have contributed to others.<sup>67</sup> In a detailed ethnographic, participant-observer study of nine terminally ill individuals and their primary caregivers, Staton, Shy and Byock demonstrated the relevance of this construct and of these developmental landmarks in the lives of people who are aware that they have only a few months to live.<sup>68</sup>

## **Saying the Five Things**

The impending loss of relationships is emotionally painful for almost every person who is aware that death is near. Predictably, achieving a sense of completion in significant relationships is an important opportunity for ill persons and those who love them. The simple exercise of saying “The Five Things” – “Forgive me. I forgive you. Thank you. I love you. Goodbye.” – has helped many people develop a sense of having left nothing important unsaid. Relationships that become “complete” in this manner need not end. In acknowledging the inevitable loss that approaches, continued time together with friends and relatives often reflects a poignant, loving, solemn and yet celebratory quality.

Sometimes relatively simple interventions can have profound clinical effect. The practice of eliciting stories can stimulate a process of life review that contributes to a patient’s sense of meaning of their life. The clinician, family member or trained volunteer who assists in the process can focus on highlights and major transitions in the person’s life. Life review is not insight therapy and need not dwell on a person’s history of loss and grief. Indeed, Kast recommends assisting patients in constructing “biographies of joy” as a way of balancing the grief that people facing the end of life often feel.<sup>69</sup> Stories also can be a gift that the ill person gives to others. People living with debilitating effects of illness may struggle with feelings of unworthiness and a sense of being a burden to others. The recording of family stories involving the marriage of matriarch and patriarch, seminal events, and the history of the family during war or natural disasters is a tangible way that people can contribute to their children, grandchildren and the generations to come.

## **The Professional Caregiver**

### ***The Therapeutic Stance of the Clinician***

Training and experience are always valuable and while clinical competence is essential, also fundamental to providing superior care at the end of life is a *therapeutic stance* of the clinician from which team involvement and direct clinical interaction occur. Critical attributes of this caring orientation and attitude include the following:

#### **Reliability**

Patients who are dying are in an inherently chaotic period of time and process. Health care providers must make preparations for predictable problems, but also develop contingency plans for the unpredictable problems that will arise. Doing so requires a systems approach. There must be enough resources and skillful, experienced personnel in the health care system to handle any emergency or contingency. Achieving this end requires broad and on-going education not only to staff and colleagues working on hospital floors or specialty units, nor only to hospice and palliative care staff, but also to the staff of area nursing homes, and the community's emergency medical services providers. Education and system planning should reflect the interdisciplinary and collaborative nature of the care that is desired.

## **Honesty**

Truth telling is a fundamental principle of clinical bio-ethics – and it is certainly applicable to palliative and end-of-life care. Patients have a clear right to be offered information about their condition and the treatment options available. Withholding bad news in an attempt to shield an ill person from the truth is virtually always a mistake and frequently arises from a misguided desire to protect the holders of the information, whether they are family members or professionals. Secrets tend to isolate people at the very time when closeness is most needed.<sup>70</sup>

In some cultures it is taboo or otherwise unacceptable to talk openly about dying with the ill person. Often the patient can be asked if he or she would like to discuss and make medical decisions. If not, the patient can indicate with whom clinicians can discuss care and who can make these decisions on his or her behalf.

## **Non-attachment**

Non-attachment is a component of the therapeutic stance that refers, firstly, to outcomes. While clinicians' commitment to alleviating suffering and enhancing the quality of life cannot be stressed too strongly, despite the very best of palliative care, sometimes, bad things happen. The world in which patients live, and therefore die, is imperfect. By contributing to reliability in their local health system and by ensuring that competent, caring attention is consistently provided, nurses model social responsibility one person to another. Professionals who choose to care for people who are dying do not deserve and must not accept guilt – including self-imposed guilt – when a patient or family's suffering persists despite concerted, good faith efforts to prevent and treat

distress.

Non-attachment also refers to maintaining a non-judgmental attitude toward our patients regarding their emotions and reactions. Even the most sensitive care during this trying time of life may provoke displaced anger toward professional caregivers.

Alternately, expressions of love and devotion toward caregivers may be out of proportion to services rendered. The challenge for professionals is to absorb these emotions – somewhat like a sponge – while not reacting in overly personal ways to either.

### **Authenticity**

In contemporary, colloquial shorthand, authenticity is referred to as *being real*. It refers to openness and emotional availability on the part of a clinician. This aspect of the therapeutic stance initially may seem antithetical to the quality of non-attachment. It is not. Instead, the willingness and ability to act with caring intention, while acknowledging the tension between the temptation to emotionally detach and flee on the one hand and the seductive draw of emotional involvement on the other, imbues a professional's practice with authenticity. The commitment and readiness to act out of genuine caring despite an acknowledged lack of complete clinical or philosophical clarity also contributes to the authentic quality of the clinician-patient relationship.

At its best, authenticity refers to a willingness to engage the patient in a personal, non-objectified manner. It is a willingness to extend friendship while maintaining professional standards of human interaction. This invites true compassion – which from its roots means not simply sympathy or kindness but a willingness to *suffer with* the other. To see the dying patient as a person to be met in friendship, shoulder to shoulder

on a journey neither would choose, invites this meaning of compassion.

Additionally, authenticity implies willingness and the courage to say difficult things to patients when necessary – this may include an ability to set limits on inappropriate behaviors or demands. It may also extend to the clinician sharing with the patient his or her own feelings of frustration, disappointment and sadness.

Authenticity is not merely an attribute that is valuable to the recipients of care. Within this personal investment lie the rewards for care providers. Clinicians who make home visits to hospice patients and their families have been known to remark on an ambience that often surrounds anticipated home deaths that is wonderful. It is notable how frequently the word “sacred” is used to describe these poignant scenes – even though the experience is stressful and always exhausting for the family. When friends and relatives gather to support one another in anticipation of their loved one’s death, there is often a sense of solemnity; but sometimes, there is also a sense of celebration, accompanied by tears as well as interspersed moments of laughter. Participation in such experiences is an earned privilege of the caring professions. The clinician’s commitment to service of others – investment in training and willingness to be present at difficult times – carries with it the opportunity to share in these most meaningful and intimate experiences in the lives of the person and family they serve.

## **Imagination**

Imagination is an essential element of the therapeutic relationship. One person cannot really know the intimate experience of another. Indeed, the assertion, “I know what you’re going through,” can sound callous. However, if the clinician has taken the



time and invested the emotional energy to actually do so, the statement, “I can only imagine how difficult this must be for you,” can communicate genuine empathy. This process involves what may be termed the *receptive imagination*. From within this stance the clinician listens to the patient’s story as if he or she were the speaker and looks at the world *as if* through the patient’s eyes.

The clinician can also draw upon the creative capacity of his or her *generative imagination* in helping a patient or family envision a satisfactory sense of completion and closure.<sup>71</sup> When working with a person who acknowledges that their life is limited, and after being confident of a therapeutic alliance, a clinician may invite a patient to look at the events of his or her illness as the middle portion of a poignant biographical novel. The person’s imagination can be enlisted to address several questions: “What would be left undone if the hero/heroine of the story died suddenly, today?” More provocative still, given what is known of the main character’s history, values and current terminally ill condition, “What would success look like, even now?” or “How might the story end in a way that was meaningful and valuable in the hero’s or heroine’s own terms?”

This use of generative imagination also gives rise to hope. Within the medical model, when there is no longer any realistic expectation of cure, hope is often spoken of as an expectation of comfort. This is tantamount to saying that all people who are living with a terminal illness can hope for is to avoid suffering. If human potential does exist at the end of life, our concept of hope can and must expand. The dictionary definition of hope specifies, “a desire for some good, accompanied with at least a slight expectation of obtaining it, or a belief that it is obtainable.”<sup>72</sup> By sharing with the patient the knowledge that growth, at times, does occur in the context of terminal illness – that it is possible, and

that the person can be supported in this process – the person is invited to have hope. He or she is presented with a goal that is both valuable and achievable.

## Conclusion

Dying is more than a set of medical problems to be solved. Dying is fundamentally a profound personal experience for the person and family. Nurses in oncology have essential roles to play in ensuring comfort and enhancing the quality of life for the dying person and the family. Pain and other sources of physical distress associated with far-advanced disease can be controlled. Even suffering that arises from deeply personal and spiritual or existential sources is clinically approachable. The first step is to acknowledge the person's suffering by listening in a skillful manner.

Simply by doing what nurses do best – caring for the persons who are our patients – and by providing care without embarrassment about the inevitability of death, by caring within a team of committed providers, by keeping one's own commitment and that of the team strong, by preparation and education, and by acknowledging the lifelong human capacity for human development that exists within each dying person and his or her family, nurses can contribute to a healthy re-incorporation of the value of dying within the ongoing mystery of life

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