Approach and Nature of Palliative Care

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Abstract
Caring for people who are near the end of life has a relatively short timeframe as a specialist health care activity. In this chapter, the history of palliative care is briefly outlined along with a description of who might provide such care.

An introduction to aspects of learning in palliative care is followed by an emphasis on the importance of psychosocial-spiritual assessment and care; some of the universal needs of people who are dying is outlined. It is important to recognize the significance of understanding the social, emotional, psychological, cultural, sexual, and spiritual context of each clinical situation and to view these within our own and our institution’s and perhaps our society’s ethical framework. By doing so, we
can begin to understand how best to understand the nature of palliative care and how best we might approach this most significant aspect of care in people’s lives.

Caring for people who are dying is clearly not new but has been seen as a special form of care for centuries. In the first millennium, the Christian church was closely involved with this activity, and the original hospices were set up as resting places for travelers. Religious orders advanced the notion of care for people who were dying in the nineteenth century, and perhaps the first of its kind, St Joseph’s Hospice, was founded in London in 1905. It was however as a response to the perceived inadequacies of medical care that what has become known as the modern hospice movement was born (Clark 2002). The pioneering work of hospices such as St Christopher’s Hospice, which opened in Sydenham, London, in 1967, demonstrated that the principles of hospice care (good clinical practice, whatever the patient’s illness, wherever the patient is under care, whatever his/her social status, creed, culture or education, http://hospicecare.com/about-iahpc/publications/manuals-guidelines-books/getting-started/6-principles-of-palliative-care) could be applied in a variety of settings.

Dame Cicely Saunders introduced the concept of whole person care in that institution and developed the model of “total pain” which highlighted not only the physical aspects of a person’s pain but also psychological, social, and spiritual dimensions of their distress (Saunders and Sykes 1993). The term “palliative care” was coined in Canada in 1974 by Balfour Mount, a pioneering surgeon who had worked in London with Saunders and wanted to take the concept back to Canada where there could have been confusion among the French-speaking population about the term hospice. Using the term palliation to reflect the non-curative nature of care was not new – it had been used in the seventeenth century. This terminology was subsequently adopted in many countries, and a new medical specialty was proposed – that of palliative medicine. The discipline received recognition by the Royal College of Physicians, London, in 1987 as a specialty within medicine in the United Kingdom (UK). Since that time other countries have adopted that approach, and palliative medicine and palliative care are practiced around the world in over 100 countries. A universally agreed definition of palliative care was disseminated by the World Health Organization (WHO) in 1986, followed by a revision in 1990. A revised and updated definition of palliative care was accepted by the WHO in 2002 (Sepúlveda et al. 2002).

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of suffering and other problems, physical, psychosocial, and spiritual.

Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient’s illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- Will enhance quality of life and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

Definitions are helpful in gaining consensus about the limits of a specialty, but what does it mean in practice? Generally speaking, people with advancing disease need to be supported and cared for by clinicians with excellent skills.
1 Who Provides Palliative Care?

Palliative care is provided by two distinct categories of health and social care professionals:

- Generalist palliative care is provided by those working to provide day-to-day care to patients, families, and carers in their homes and in hospitals:
  - They should be able to assess the care needs of each patient and their families across the domains of physical, psychological, social, and spiritual needs.
  - Meet those needs within the limits of their knowledge, skills, and competence in palliative care, and know when to seek advice from or refer to specialist palliative care services.
- Specialist palliative care is provided by professionals with additional training in the discipline and who only work in palliative care (e.g., consultants in palliative medicine and clinical nurse specialists in palliative care).

2 Specialist Palliative Care Services

These services are provided by specialist interdisciplin ary teams and include:

- Assessment, advice, and care for patients and families in any or all care settings, including hospitals and care homes, also known as palliative care consultation
- Specialist inpatient facilities (in hospices or hospitals) for patients and families who benefit from the continuous support and care of those specialist teams
- Intensive coordinated home support for patients with complex needs who wish to stay at home (this may involve the specialist palliative care service working with the patient’s own doctor and community nurse to enable someone to stay in their own home).
  - Many teams also now provide extended specialist palliative nursing, medical, social, and emotional support and care in the patient’s home, often known as “hospice at home.”
- Outpatient clinic appointments and day-care facilities that offer a range of opportunities for assessment and review of patients’ needs and enable the provision of physical, psychological, and social interventions within a context of social interaction, support, and friendship. Many also offer creative and complementary therapies.
- Advice and support to all the people involved in a patient’s care.
- Bereavement support services which provide support for the people involved in a patient’s care before and following the patient’s death.
- Education and training (and for many, research) in palliative care.

The specialist teams should include palliative medicine and palliative care nurse specialists together with a range of expertise provided by physiotherapists, occupational therapists, art and music therapists, dieticians, pharmacists, social workers, and those able to give spiritual and psychological support.

3 Who Should Receive Palliative Care?

Anyone with a life-limiting disease should be able to have access to palliative care services. Historically modern palliative care services were primarily involved with providing care for people with cancer and some neurological disorders such as motor neuron disease or other degenerative disorders of the nervous system.

The other major group of people who should receive palliative care are those with failure of one of the major organs of the body such as the lungs, heart, kidneys, liver, or brain. In these situations, people often have a prolonged period of time to adjust to the understanding that the body is failing. One problem though can be that medical science has become so adept at propping up failing bodies that the realization that death is approaching may
not be so apparent. This can produce problems for families and carers as death approaches.

It has been suggested that the clinical course of people who do not die suddenly tends to follow one of three trajectories (Dy and Lynn 2007). The first is the maintenance of relatively good function until a predicted decline a few weeks or short months before death. The second is the course of chronic organ failure which shows a slow decline with exacerbations that may end in sudden death. The third trajectory is one where there is poor functional status over a long time with a slow but relentless decline; frail elderly people with many comorbidities fit into this group. It is important therefore that services are developed for people who are dying in any of these ways. There are a number of models available – for example, the Gold Standards Framework in the UK which incorporates resources and end-of-life tools into primary care, hoping to enable people to have real choice about where they wish to die (Thomas 2003; King et al. 2007).

Of course, the majority of people who are dying would prefer to do so at home being cared for by their primary healthcare professionals. Primary care shares common values with specialist palliative care – holistic, patient centered, and delivered in the context of their families – but too often it becomes difficult for a number of reasons for people to be cared for in their own homes (Murray et al. 2004). Developing primary palliative care is essential if people are to exercise their right to die in the bed of their choice.

Twenty years ago, David Field, an expert in the sociology of death and dying, identified two important differences between patients with cancer and those with nonmalignant conditions (Field 1998). Perhaps not much has changed over those 20 years? First, differences in disease progression mean there is a continuing benefit from curative/restorative interventions and treatments for the latter category. Second, there was greater uncertainty about the fact and likely time of death with non-cancer patients. Field identifies the latter as appearing to be the key obstruction to extending specialist palliative care services to non-cancer patients. This is because they will not be seen as suitable candidates for palliative care until they have been defined as terminally ill. One of the reasons that this may occur is because of the difficulty many clinicians have in dealing with uncertainty in general. In medicine, and possibly in other disciplines as well, uncertainty stimulates and propels activity (Hall 2002) – doctors have a “propensity to resolve uncertainty and ambiguity by action rather than inaction” (Katz 1984). Increasing diagnostic uncertainty leads to a reluctance to withdraw from “active” interventions, leaving patients and families in a similar situation of ambiguity and doubt about the future (Christakis and Asch 1993). This relates to a tendency for the continuation of what might be deemed futile treatment in the face of relentlessly advancing disease. Taken out of context (i.e., without considering the person as a whole), almost any disease may be deemed “treatable” – such are the advances in medical science and technology. This confidence in the advancement of medical science is relayed not only to the medical and nursing professions but to the lay public as well, with a consequent sense of expectation that is unfortunately not wholly realized. This situation is compounded with the advancing age of people being treated. Many elderly patients have multiple clinical diagnoses involving multisystem pathology, and the diagnosis of dying is often made only by exclusion. Communication may be more difficult due to a combination of a higher incidence of confusion in elderly patients with nonmalignant disease than in younger people with cancer, and reduced social networks in the elderly may potentially lead to reduced care and support from family and friends. The incidence, duration, intensity, and type of symptoms follow a different pattern in cancer compared to other illnesses. People with nonmalignant disease also tend to be older. People aged 75 and over who do not die from cancer are more likely to have outlived their spouses, brothers and sisters, and even their children. They are predominantly women, and many live alone or in residential care and therefore present differing challenges for the provision of social support.

The scope of palliative care therefore extends beyond people with a diagnosis of cancer to
include patients with other chronic life-threatening diseases.

Perhaps one of the greatest challenges for palliative care services is the provision of care for people with dementia – an area which until recently modern palliative care avoided (https://www.nhpco.org/hospice-statistics-research-pressroom/facts-hospice-and-palliative-care). The annual incidence of dementia in North Americans, for example, doubles nearly every 5 years from 7 in 1000 (65–69 years of age) to 118 in 1000 (86–89 years of age) (Hanrahan et al. 2001). The European Association for Palliative Care (EAPC) published a white paper which helpfully defines optimum palliative care for people with dementia and provides a set of 57 recommendations for practice, policy, and research (van der Steen et al. 2014). Further, the white paper provides a model of dementia progression and suggested prioritizing of care goals and a recommendation of further research into how to give shape to palliative care in dementia across dementia stages.

4 How Should Learning in Palliative Care Be Approached?

Clearly much of what is taught and what is learned is of a technical and knowledge-based nature. This is fundamental in any healthcare practice and particularly relevant in a specialty where so many patients have such a wide range of clinical problems. It would be seductive to imagine that the essence of palliative care lies within these technical and knowledge-based areas, but it is essential that those responsible for teaching and learning in this area maintain a focus on those aspects of the discipline that are less easily quantified and identified. In any domain of professional practice, it is important to identify the true nature of that practice. Professional practice involves not only professional content but also professional process, and it is in the untangling of these two elements that we can discern something of the difficulty facing those responsible for the training of palliative care clinicians for the future. Palliative care cannot be seen solely in terms of skills and knowledge – it must include those processes that can be identified as meta-cognitive and reflective as well (MacLeod 2000).

The care of seriously ill and dying people necessitates a philosophical and ethical basis. Palliative care must be based on a philosophy that acknowledges the inherent worth and dignity of each person. The ethic of care must include respect for autonomy, justice, non-maleficence, and beneficence. The context of death exerts a powerful influence over what is said, received, and interpreted, and professionals must relinquish control, share decision-making, and treat patients and families as partners.

Caring can be thought of in terms of behavior or as a motivation. As behavior, it is often thought to mean “looking after people and seeing to their needs.” As a motivation it can refer to being fond of someone, feeling sympathy or empathy for that person, being concerned for their well-being, or having a professional commitment to them. It could be argued that the best caring professionals show both of these aspects of care. If we care about anything or if we care for someone, it is because deep caring is part of the very nature of our being (van Hooft 1996).

Empathy is an essential component of the way that care is provided and can be an elusive concept in medicine. Empathy helps us to know who we are and what we feel. Empathy requires living and knowing – it requires the ability to put oneself imaginatively in the place of another. The aspect of empathy that is crucial for clinical practice is that of genuine attention to the individual’s concerns and the acceptance of those concerns. Empathy can be thought of as a mode of caring. Specifically, it involves caring for the fate of another human being – the concept of empathy is relevant to the care of people who are dying because more than anything they are people in need. Empathy is an understanding of how a disease or its treatment is likely to affect how patients actually live and hope to live their lives. It is an openness to, and respect for, the individuality of another human being.

Francis Peabody (1927) emphasized the importance of getting to know the patient as a major part of the art of medicine. By writing that the art of medicine and the science of medicine...
were not antagonistic but supplementary to one another, he was essentially saying that empathy is a prerequisite for the effective care of any patient. It was perhaps particularly poignant that Peabody was terminally ill when he wrote the article.

Sir William Osler (1904) wrote “it is a safe rule... to have no teaching without a patient for text and the best teaching is taught by the patient himself”. This was written in 1904 in an attempt to encourage students to learn at the bedside rather than through books alone. This assertion encourages students to pay heed to the patients’ stories and the themes that flow from them. Empathic listening is a most powerful means of understanding a person and the things in their life that are of significance for them at that time. Until the start of the nineteenth century, the science of medicine was taught as an apprenticeship – not based on scientific principles but on clinical observation and narrative. Such stories were once the primary source of medical knowledge and the science of medicine developed through the collection of anecdotes. The case presentation is the narrative center of medicine as a discipline – the care of the patient begins with such a story, and the clinician translates those stories in a way that helps the patient understand their ill-health. Without the experience of such stories, the education of healthcare practitioners is incomplete. It is also possible though to encounter stories in other forms; literature, poetry, art, film, and music can all give indications of the human condition and can help us better understand the meaning of care.

Over the last 50 years, since the birth of the modern hospice movement, great progress has been made toward the alleviation of many symptoms that accompany the end of life – particularly in those who have malignant disease, so enabling the maintenance of the highest possible quality of life. Such progress has been made in clinical practice that in many minds the “mainstreaming” of palliative medicine into all healthcare is a given. Alongside this mainstreaming is a desire to see palliative care practiced with the same evidence-based approach that other specialties and subspecialties are adopting. This is clearly a laudable sentiment. However, there is a danger that in adopting such an approach much of what is unique about care at the end of life may be lost. If we are to focus on purely practicing from an evidence base, we will surely lose aspects of the art of clinical care as we become more and more seduced by the science of what we have been led to believe is predominantly a scientific discipline. For example, the doctor’s role as technician, guided by standard empiricism, does not exclude their adopting other roles as a consoler, healer, or even friend. The evidence that is built from the “gold standard” double-blind, randomized, controlled clinical trial has been a powerful instrument in furthering medical knowledge, but it is often not enough in recommending a form of management or treatment for a particular individual. Medicine is an art that is especially concerned with human beings as individual and unique creations, but it provides us with a context that shows us that our bodies are fragile and that ultimately they will fail us. The good that medicine in particular and healthcare in general is purported to achieve is not just the maintenance of organic functioning. It is also to maintain a spiritual, emotional, and social well-being that enables each individual to function to some degree within the society in which we live. If we focus too strongly on the achievement of biomedical good, there is a danger that the shortcomings of modern healthcare will be exposed. Evidence-based practice and the strong beliefs of standard empiricism offer a structure for analyzing clinical decision-making but are not sufficient to describe the more tacit processes of expert clinical judgment. It is not possible to find or provide evidence for all aspects of clinical competence. There is a generally widely held belief that medicine has become so powerful that it enables us to overcome not only the bodily ills that we may all experience but also some of life’s other misfortunes, not only physical pain but human suffering as well. Part of the difficulty with developments in the academic aspects of medical and nursing sciences is that they tend to have a narrow focus on what constitutes knowledge (and therefore the “evidence base”). It is the application of the knowledge base that becomes problematic in health sciences. It is not sufficient to address only the technical approaches to disease management; there must
also be a realistic context for social definition. Those who work with people at the end of life soon realize that we often face the limits of medicine and the temporal and physical limits of being human. When we acknowledge that all our efforts are for the “good of the patient,” we also are confronted with the limits of our clinical expertise and face the reality that ultimately what we offer people is not our role as doctor or nurse but as human being. The challenge for clinicians is to identify not only the evidence base for the practice of palliative care but also the features of sound clinical judgment and the character of those clinicians who make those judgments. It is in this aspect that we must identify the role of wisdom in palliative care. Professional practices are refined by science and corrected by wisdom (Cogan 1953). Wisdom is a form of understanding that combines the practicalities of knowledge with a reflective approach to the utilization of that knowledge over time. There are certain aspects of wisdom that can be readily identified. Practical wisdom is that habit of mind that enables one to choose well, not only with respect to a particular domain of human action but in the whole of one’s life. It is the “intellectual virtue that orders human practice in order to attain truth for the sake of action as opposed to truth for its own sake” (Pellegrino and Thomasma 1993).

So, understanding the nature of care, the importance of empathy, and the utilization of wisdom are all essential in our approach to the care of people who are dying. There are some specific dimensions of care that we need to address, and these are identified below.

5 **Psychosocial Care**

Psychosocial care (a better term might be psychosocialspiritual care) has been defined as that which is “concerned with the psychological and emotional well-being of the patient and their family/carers, including issues of self-esteem, insight into an adaptation to the illness and its consequences, communication, social functioning and relationships” (National Council for Hospice and Specialist Palliative Care Services 1997).

Psychosocial care addresses the psychological experiences of loss and facing death for the patient and their impact on those close to them. It involves the spiritual beliefs, culture, and values of those concerned and the social factors, which influence the experience. Psychosocial care includes the practical aspects of care such as financial, housing, and aids to daily living and overlaps with spiritual care. Spiritual care is less easy to define and is often subjective, arbitrary, and personal. It is generally assumed to include an individual’s beliefs, values, sense of meaning and purpose, identity, and for some people religion. It may also encompass the emotional benefits of informal support from relatives, friends, religious groups, and more formal pastoral care. For many, existential questions about the human condition can be ignored during many phases of life but are brought into acuity at the end of life (Williams 2006).

Psychosocial care also includes the professional carers who are inevitably affected by their experiences and who thus require support.

Thus, psychosocial care encompasses psychological approaches, which are concerned with enabling patients and those close to them to express thoughts feelings and concerns relating to illness. It also incorporates interventions to improve the psychological and emotional well-being of the patient and their family/carers.

In the past there has been a greater emphasis on psychological needs than social needs – the National Council for Hospice and Specialist Palliative Care Services (NCHSPCS 1997) have emphasized the importance of social care to patients:

The social fabric of their lives is central to how they make sense of their illness experiences, the meanings they draw upon to understand these and the range of resources they can call upon to help them manage them.

In practice, the social aspects of palliative care are often limited to a focus upon the patient’s family, ignoring community influences.
6 Psychosocial Assessment

Patients and families face a range of issues which are not only related to illness and approaching death. Healthcare professionals need to assess individual strengths and coping styles, experience, and stress and attend to previous losses. The initial assessment of a patient is carried out by a member of the specialist palliative care team and will include a detailed assessment of the patient’s and family’s/carers’ needs. The time invested in this initial assessment is essential in creating a framework for the provision of future care, a partnership between patient and professionals. The initial assessment may indicate the need for more formal psychological, social, or spiritual assessment. This will for many include the need to maintain autonomy which includes respect for dignity and the opportunity to exercise choice.

In order to identify caregivers at risk of poor psychosocial functioning, self-reported anxiety and competence rating is suggested as an aid to care provision (Hudson et al. 2006). A small group of caregivers (35) was studied. Using a screening tool, these researchers identified the possibility of low-level psychosocial functioning as a potential determinant for family caregivers at risk of psychosocial distress.

There are however a multitude of assessment tools and techniques that will illuminate elements of psychosocial well-being and identify psychological and social needs of patients and caregivers.

The psychosocial aspects of care of the dying person whatever their diagnosis include the need for:

- Understanding – of symptoms and the nature of disease and of the process of dying
- Acceptance – regardless of mood, sociability, and appearance
- Self-esteem – involvement in decision-making
- Safety – a feeling of security
- Belonging – a wish to feel needed and not to feel a burden
- Love – expressions of affection and human contact (touch)
- Spirituality – an explanation of meaning and purpose, both religious and nonreligious
- Hope – for an improvement in any aspect of their life or of their living

In the provision of psychosocial care for people at the end of life, each of these needs must be identified and addressed.

7 Social Context

Social elements of care are often influenced by the disease that is ending a life. Dying from a nonmalignant disease, in many ways, creates a different social structure or standing than dying from cancer. The language that we use is quite different – for example, people who die from cancer are often referred to as “brave” in their “battle” with cancer. They often talk of “beating” the disease or “fighting” it. Nonmalignant disease does not seem to have that same social cachet. Death from end-organ failure is often silent and slow – in many ways relentless in its nature. Without heroic medical interventions to replace organs or use artificial means to support ailing bodies, many of these people would die earlier and perhaps more suddenly. In identifying social or psychological care for these people, it is important to recognize this significant difference in perception of disease that is possible to have originated both from the individual and from society.

For many people with cancer, there are well-recognized social networks or programs that may provide both psychological and social support. Social supports for people with nonmalignant diseases should emerge from people in similar situations, family, and friends and from the wider community. With the exception of some of the neuromuscular degenerative diseases, many of the current support systems for people with nonmalignant disease are focused on raising awareness and funding for curative interventions rather than supporting people in the last stages of their disease. The professions, while openly supporting cancer networks and programs, have been slower to acknowledge the need for similar systems for people with incurable nonmalignant disease.
8 Emotional Context

Some feelings and emotions are almost universally experienced near the end of life.

- Fear of being left alone or having to leave loved ones, of breaking down or losing control – of the situation they are currently in, getting worse.
- A sense of helplessness in which physical and psychological crises show up human powerlessness. Alongside this is the knowledge of physical and emotional strength gradually deteriorating – loss of physical ability bringing with it attendant psychological and social helplessness.
- Feelings of sadness for what is not to be and for the loss to come.
- A sense of longing for all that has gone before and all that is not going to be, in the future.
- Feelings of guilt for being better off than others or regret for things that have been done or not done.
- A sense of shame for having been exposed as helpless, emotional, and of needing others or for not having reacted, as one would have wished.
- Anger at what has happened, at whatever caused it or allowed it to happen, that the treatment hasn’t worked, at the injustice and senselessness of it all and the shame and indignity and at the lack of proper understanding by others.

These feelings and emotions may also be influenced by memories of feelings or loss or of love for other people in their lives who have been injured or died, perhaps let down by doctors, by the system or society, or by the family.

9 Psychological Context

The fundamental clinical skill of medicine is acquiring the history of the illness from the patient, and providing the patient with the opportunity to identify their concerns is mandatory. Specific questions need to be asked to elucidate psychological distress; in particular, they should include questions concerning fatigue, hallucinations, and suicide risk (Macleod 2011).

Examples of psychological interventions include psychosocial support and psychotherapy, behavioral-cognitive therapies, and educational therapies.

Initially it is helpful to look for indicators of pathological levels of psychological disturbance such as clinical depression or other mood disturbance or personality disorder. These lend themselves well to specific psychological interventions. Variables suggesting that the patient or family is at serious risk of psychological disorder or distress may be identified (e.g., social isolation or a history of psychiatric hospitalizations). All members of the healthcare team may observe and subjectively report distress that they feel is psychological in nature (fear or anger) or psychologically mediated (pain or breathlessness) but may not meet the criteria of a discrete psychological disorder. The team should also look for the potential for preventative interventions that may forestall, minimize, or bolster resources for predictable areas or times of vulnerability and hardship (similar patterns of ill-health, pre-bereavement work, or anniversary calls to the bereaved).

Specific psychoeducational interventions that may enhance coping skills, psychological insights, and quality of life should be employed, regardless of the presence or absence of clinical levels of psychological distress. (For an extensive review of psychiatric syndromes and interventions, see Macleod (2011).)

People with neuromuscular degenerative disorders such as motor neuron disease, multiple sclerosis, muscular dystrophies, and less frequently seen disorders like Creutzfeldt-Jakob disease may have particular psychological needs associated with their care. Such disorders bring with them potentially challenging communication issues. For example, some patients may not be able to communicate verbally but retain effective cognitive functioning. It is important to help families to differentiate between behavioral disturbances associated with cognitive impairment from other communication difficulties. Cognitive
impairment, depressive symptoms, emotional incontinence, or lability all need expert assessment and careful explanation and management. All or any of these may significantly impact on coping ability, psychological adjustment, and communication both of the patient and family (Macleod 2001).

10 Cultural Context

In palliative care, the cornerstone of practice is the holistic approach to care that is exemplified by the management of “total” pain. As stated earlier, this classically includes physical, psychological, social, and spiritual pain. Cultural pain or distress can be expressed through any of these dimensions. Often closely allied to culture is spiritual and religious beliefs that have a bearing on how people approach and understand their disease. In many societies people define themselves by their religious, cultural, or tribal grouping, even when their faith or immersion in religion or culture is limited. There are wide variations between people of differing faiths, ethnic backgrounds and national origins, and their approach to the end of life. Although documented evidence is sparse, there is anecdotal evidence to suggest that there is a difference in approach to dealing with malignant and nonmalignant disease. In order to understand these differences, it is important to understand the culture from the perspective of the patient and family.

In caring from people of a different culture to our own, it is imperative that we understand the expectations of that culture in order that we act appropriately. For example, the notion of individual autonomy is essentially a western one – many peoples live together and make decisions together in extended families. Many people in China, Japan, and the Pacific Islands as well as many Māori in New Zealand, for example, consider the family as the fundamental unit of society and will expect the family to make medical decisions. Without the accurate and honest provision of information in the right form, at the right time, and in the right place, there can be little hope of an understanding being reached about the situation the patient and family is facing and the goals of care that are being formulated. Without asking, we cannot know what individuals need to make a difference to the end of their life. That asking must include an acknowledgment of difference – difference in culture, in religious beliefs, in understanding of the nature of disease, in expectations in a particular situation, and in perceptions for hope at the end of life.

11 Sexual Context

Sexuality is an element of being that is often easily sidelined or overlooked when caring for people at the end of life, particularly if those people are elderly. It is too often assumed that because people approaching death are weak and tired that their sexual identity or needs are minimized, this fails to recognize the many ways in which human beings can express their sexuality. Staff often view people’s sexual interests as “behavioral problems” rather than natural occurrences or expressions of needs for loving contact (Steinke 1997; McPherson et al. 2001). Many people approaching the end of life with a nonmalignant disease have had a relentless decrease in their physical being for some time. Much of their time may have been spent in repeated hospital admissions and the physical isolation that encourages. Many treatments, as well as the diseases themselves, can affect sexual function, and of course sexual activity will most often not be at the forefront of people’s minds as they approach death. Acknowledging that all people are sexual beings is a starting point in helping people address their sexual needs and wishes – it is in no way different to acknowledging that they are physical or emotional beings as well. This is one aspect of their functional health that can contribute to their sense of self-worth or self-esteem. Changes in physical appearance, size, skin color, and texture as well as increasing fatigue often decrease an individual’s sense of self-worth or attractiveness. Identifying psychological elements of their functional health may help to reverse this decrease. Providing information and advice on ways of expressing sexuality
other than through sexual intercourse may help to restore an individual’s sense of worth in this aspect of themselves.

12 Spiritual Needs

Understanding spiritual needs is essential in the care of people who are dying as these needs are intertwined with an individual’s meaning of life, hope, transcendence, and beliefs as they arise from social relationships. Near the end of life, for example, pain can present that defies the efforts of clinicians to manage it. Increasingly clinicians, researchers, and educators have acknowledged the importance of spirituality in the end of life. The presence of spiritual pain, especially in people who are dying, can be recognized in terminal agitation or restlessness in the absence of other obvious factors. This can manifest as a pre-death event that indicates physical, psychological, and/or spiritual discomfort or distress.

A particularly helpful definition of spirituality that has been articulated by Puchalski et al. (2009) was arrived at by consensus in a conference of invited expert practitioners. This definition states: “Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.”

Meaning as related to life purpose is aptly described as “having a sense that one’s life has meaning, or involves the conviction that one is fulfilling a unique role and purpose in a life that is a gift” according to Frankl (cited in Chochinov and Cann 2005, pS107). Palliative care aims to recognize and facilitate resolution of spiritual, social, emotional, and physical issues to enable dying well. Clinicians need to be able help people to identify any sources of spiritual unrest and to contemplate their contextual meaning and importance so assisting in the alleviation of spiritual suffering at the end of life.

13 Ethical Context

In all of our care for people near the end of life, one of our goals is to help people to do what they want in the way that they want. In many ways that is what has become known as autonomy. People’s choices at the end of life are often different to those they may make earlier in their life. Patients’ authority to choose what interventions they have and even to refuse interventions is seen as one way of protecting dignity and autonomy. Being in charge is better than having control taken away (Carter et al. 2004). That idea of being in charge though will be different for people from different ethnic groups. Professional carers need to ensure that they understand the nature of communication and decision-making that is the norm for each person and family they encounter. Assessment of family dynamics from a different culture may help ensure that their ethical constructs are not overridden.

The ethics of the provision of palliative care are really no different to those required for any form of healthcare; however, in providing care for the most vulnerable, there are particular issues to address. Palliative care must be based on a philosophy that acknowledges the inherent worth and dignity of each person and in order to understand that worth and dignity every facet of their being should be explored – not just the physical. This philosophy must be based on an ethical framework – this is most commonly represented by the “four principles” postulated by Tom Beauchamp and James Childress in their textbook Principles of biomedical ethics – autonomy, beneficence, non-maleficence, and justice (Gillon 1994). These principles encourage a sharing of decision-making between carer and cared for but also create the right environment for promoting patient well-being. In addition to this framework, virtue-based ethics may give some indicators for the way in which we could practice our professions. Virtues are often thought to be “old-fashioned,” but they are particularly relevant to end-of-life care.

Integrity and trust are perhaps the cornerstones of the caring relationship. Development of these can be gained by attending to the psychosocial
and spiritual as well as the physical wants and needs of individuals and families. Trust is essential in any human relationship but in one where one party is so vulnerable then perhaps it is even more important. In all of our dealings with patients and their families, we must be truthful and honest. People who are dying have lost so many elements of their being that it is essential that they can maintain trust in their professional attendants.

Compassion, a further virtue required in all our dealings with patients and their families, could be described as suffering together with another or participation in suffering. Suffering is clearly not only related to the physical elements of our being, and in order to understand suffering in its broadest sense, we must address social, psychological, and spiritual elements as well.

Phronesis is a virtue rarely mentioned in modern practice, but it is essentially prudent. Nowadays this can be regarded as timidity, undue self-interest, or unwillingness to take risks, but it might also be considered to be discretion or common sense. In history, phronesis was thought to be practical wisdom – the link between the intellectual and moral life. Phronesis urges us to look for the right way of acting.

In modern healthcare practice, working from an effective evidence base, where randomized controlled trials are sought for as many interventions as possible to guide us, it is often forgotten that practical wisdom, phronesis, can guide us where there is no concrete evidence to do so.

The virtue of justice or fairness requires that people are not put down or labelled in any way. Such labels can determine how people are cared for in the future, and they may often have arisen from isolated encounters. So often, labels can imply intolerance – this in turn can lead to an expectation that there is a particular “right” way to live or a right way to die.

Integrity defines the nature of the individual, and it also integrates all the virtues.

A person with integrity is someone who can judge the relative importance in each situation of principles, rules, guidelines, and other virtues in reaching a decision. It implies honesty and righteousness. The integrity of a person is shown in the right ordering of the parts in relation to the whole, the balance, and the harmony between the various dimensions of human existence necessary for the healthy functioning of the whole organism (Pellegrino and Thomasma 1993). It is a balanced relationship between the physical, psychosocial, and intellectual elements of their lives. This could be a definition of what palliative care should be about.

The doctor/patient relationship relies on integrity and trust. Neither party must impose their values on the other. Overriding another person’s values is an assault on their humanity and their person.

Using these principles and virtues enables carers to address some of the challenging moral or ethical issues near the end of life. Aspects such as people asking for or insisting on futile treatments, balancing ordinary and extraordinary treatment, the doctrine of double effect, and the relationship between killing and letting die have attracted much discussion and comment over the last four decades, and the debate has been considerably better informed by research, investigation, and dialogue between those in the palliative care community and their colleagues in the field of medical bioethics.

The developments in the provision and understanding of palliative care have enabled a more informed discussion of these topics, but resolution for many in our broader society is still a long way off. However, by attending to people as whole people within the context of their family whoever that may be, we stand a much better chance of meeting their needs – not just their physical needs but their psychological, their social, and their spiritual needs as well.

One aim of palliative care then is to care for people in a way that facilitates dying well. This notion is dependent on many variables that encompass the holistic dimensions of our existence. Dying well is likely to be different for everyone, and seeking a universal definition of what it means may be futile. Dying is, to a greater or lesser extent, a social event (Kellehear 2008), and denying the psychological, social, and spiritual aspects of the dying person leads to a less than optimal dying experience. Understanding the
many dimensions of the approaches to and the nature of care then is a prerequisite to starting to get that way of caring right for each person and their family that we encounter as they approach the end of life.

References


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