End of Life Care

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Abstract
This chapter aims to tackle end of life issues for patients and their families. It will reflect on the process of disease to understand when “end of life” begins and what this stage entails. It will also address adjusting expectations and treatments, symptom management, and emotional and spiritual care at this stage of the disease. Care for end-of-life patients who are dying and their families will additionally be addressed, as well as the attention that healthcare professionals provide to patients and their families in consideration of different religious perspectives.

1 Introduction
Palliative care also involves caring for people who are nearing death and is referred to as end of life care. End of life care occurs in the last part of a patient’s life, but the timeframe can be difficult to predict. Typically, it happens in the last few months, depending on the underlying diagnosis and clinical course. End of life care is an important part of palliative care for people who are nearing death.

End of life care aims to help people live as well as possible and to die with dignity. It is not just about the practical and technical delivery of medical care, but rather also involves supporting and providing available information both to patients and the people who are important to them.

Healthcare professionals should ask about patients’ wishes and preferences and take them into account as they work with patients to plan their care.

2 Beneficiaries Of End Of Life Care
People in a variety of situations can benefit from end of life care. Some may have a life expectancy that does not go beyond the next few hours or days. Others receive end of life care over many months. This includes people whose death is imminent, as well as people who (NHS Choices 2015)

- Have an advanced, incurable illness such as cancer, dementia, or motor neuron disease
- Are generally frail and have co-existing conditions whose diagnosis gives them a life expectancy of less than 12 months
- Have existing conditions that make it possible for them to die from a sudden crisis in their condition
- Have a life-threatening, acute condition caused by a sudden, catastrophic event, such as an accident or a stroke
3 Changing The Goals Of Care

End of life care can be provided at home, in care homes, hospices or hospitals, depending on a patient’s needs and preferences. The important thing is to have the goals of care clear.

End of life care aims to help people live as well as possible and to die with dignity and to help patients, and the people most important to them, to maintain the best quality of life possible. Holistic assessments of the patient and global care are essential for providing high quality care that prioritizes achieving patients’ comfort and wellbeing, as well as that of the people closest to them, until the last days of life.

A number of healthcare professionals can be involved in care at the end of life in order to achieve the goals of care. For example, hospital doctors and nurses, general practitioners, community nurses, psychologists, hospice staff and counselors, as well as social care staff, chaplains (of all faiths or none), physiotherapists, occupational therapists, and complementary therapists, may all be involved. The healthcare professionals involved in a given care plan need to appropriately coordinate and to consider patients and families’ previous experiences, including their cultural and spiritual backgrounds.

4 Diagnosis of Impending Death

Predicting the prognosis of advanced diseases can be complex. Patients and their families often ask for specific timeframes, which are difficult to set. But when a patient is in his last days of life, several signs help to identify this situation and, in general, healthcare professionals are more precise when the prognosis is shorter rather than longer. Professionals should be alert and prepared to detect these signs and be able to inform the family, the patient and the rest of the team about the impending end. Palliative care professionals must incorporate this responsibility into their work, which is valuable for patients and other professionals (Pontin and Jordan 2013).

4.1 The Importance Of Knowing How To Diagnose Dying

A correct diagnosis allows patients to adjust their expectations and treatment objectives during their last days.

For the family, knowing in time allows them to call upon other family members that may be farther away, to finalize preparations and pending issues, to organize religious rites according to the patient’s beliefs and culture, and even to say goodbye.

For the medical team, identifying an impending terminal prognosis helps to focus all care on the patient’s comfort, eliminating elements that do not contribute thereto and that may interfere with or tarnish a person’s last moments. Healthcare professionals carefully review the patient’s surroundings, starting with medical orders and specific and individualized care plans. They change the focus of attention to the patient’s comfort in all senses, thus taking care of and accompanying him.

If an impending death is diagnosed in time, the patient can be transferred to the place where she prefers to die if it is suitable, whether that be at home or in hospice. If the situation is not properly identified, a patient may die in a place or under conditions that do not line up with their desires, or they may be on the receiving end of inappropriate or invasive measures during their last days. The task of adapting the care plan is easier for everyone if good prior communication – including a full understanding of the patient’s wishes before the crisis (advanced care planning) – was established beforehand.

4.2 How to Diagnose Impending Death

This requires taking into account certain signs that the patient presents (Hui et al. 2014), some measures that can help guide, as well as the team and companions’ perceptions. It is a clinical diagnosis that requires an overall view of the patient and his evolution.
4.2.1 The Signs

The most frequent signs include a marked functional deterioration and dysphagia, with patients gradually losing the ability to swallow liquids, or said task becoming very difficult, although they may still retain the ability to take small sips. Decreased levels of consciousness or, occasionally, terminal delirium may be accompanied by moaning that originates in the vocal cords, including grunting or groaning, which are a sign of neurological changes. Distal cyanosis and lividity in the knees or thighs are easily recognizable during physical examination. It may also be impossible to feel the radial pulse and coldness in the hands and feet is frequent. In addition, we find changes in breathing, including periods of apnea, sometimes a few seconds but sometimes lasting for about a minute, or Cheyne-Stokes respiration (growing and decreasing periodically, with intermediate periods of apnea), superficial respiration, noisy or rattling breathing with jaw movements or out of breath. One of the most obvious signs is oligoanuria, and sometimes edema. All this can be accompanied by tachycardia and a tendency towards hypotension (Hui et al. 2014).

4.2.2 Prognostic Scales

In patients with cancer, the use of prognostic scales can be useful, such as the Palliative Performance Scale (PPS), which measures several parameters, including evidence of disease, the ability of patients to walk and care for themselves, and their ingestion and awareness levels. The lower the PPS score, the shorter is the prognosis. A recent study concluded that a PPS of 20% or less associated with drooping of nasolabial fold is a reliable predictor of a 3-day life expectancy (Hui et al. 2015). Other scales, such as the Karnofsky index or the PPI (Palliative Prognostic Index), may also be helpful in determining prognosis.

4.2.3 A Global View and Communication

When a patient is thought to be in his last days, and the above points have been reviewed, it is time to share this information with the multidisciplinary team that cares for the patient, thus facilitating adequate coordination and comprehensive care. Doctors tend to overestimate patients’ prognosis, while nurses often realize the end is near first (Pontin and Jordan 2013). Sometimes, the patient himself may feel that the end is approaching. If there is a close and preestablished relationship with the patient, it is time to convey this impression and share it with the family.

4.3 How to Respond to Situation of Impending Death

The patient’s last hours and care objectives should be recorded in the clinical history.

4.3.1 Emotional, Social, and Spiritual Support

The end of life has a high emotional impact in patients, their relatives, and caregivers. If a medical professional only visits the patient occasionally, it may be more appropriate for their main doctor to talk to them about the situation. The medical professional in question should begin to review and clarify the patient’s wishes and their needs, which are physical, social, spiritual, and emotional, in an attempt to find out if the patient has the means and sufficient support to face the diagnosis.

The family should be informed about the signs as they present themselves, including those that will manifest in the future and their meaning and treatment. Exploring relatives’ fears and previous experiences may help to accompany them in the process. The doctor can delicately tell the family and patient about the availability of spiritual support in accordance with their beliefs.

4.3.2 Review Medical Records

Occasionally, patients with advanced diseases accumulate medications in the last year of life (McNeil et al. 2016).

(a) Necessary treatments should be determined, which include excluding possible treatments that do not contribute to the patient’s wellbeing or that could even diminish their level of comfort. This is often easy, for example, with primary prevention guidelines and
more difficult with secondary prevention guidelines in patients who have already had problems like ischemic heart disease or seizures. If the patient cannot eat, the risk of hypoglycemia secondary to insulin should be assessed. Treatments that are unanimously considered superfluous should be taken away first. In general, the minimum level of necessary medication should be maintained for symptomatic control to avoid side effects and interactions.

(b) Medical professionals should review how to deliver medication to the patient. If he or she has lost oral functioning, or is expected to lose it in the next few hours, the practitioner should make sure that alternative routes are identified. The intramuscular route is considered the last option, while the intravenous route is an option if already in place; otherwise, the first option is the subcutaneous route, which is also safe and accessible outside of the hospital context. The transmucosal or sublingual routes may be damaged by xerostomia. Adult patients and family members react poorly to rectal administration of medication in the presence of viable alternatives.

(c) Other medications should be maintained or prescribed to prevent undesirable situations, such as antiepileptic medicine or benzodiazepines in patients at risk for seizures. Certain prescriptions should be left to be administered according to the nurse’s assessment taking into account that some symptoms may appear when doctors are absent. Indications, dosage, and frequency of administration should be clearly specified.

(d) The benefits and possible disadvantages of artificial hydration in each case should be discussed. It is sometimes necessary to relieve symptoms related to dehydration, but it can worsen others such as rales, edema, and dyspnea. Artificial calorie intake does not improve energy, extend survival, or increase comfort in the last days when the patient cannot feed him or herself. These issues must be delicately addressed with the patient and family, allowing them to express their opinions and emotions.

4.3.3 Increased Focus on Specific and Individualized Care

(a) Attempts should always be made to include the patient’s preferences and the family’s participation. Active involvement helps both parties maintain a close relationship and a helpful disposition on the part of family member(s) or loved one(s). Instructing and educating the family in care is one of the essential missions of at-home care.

(b) Special care should be taken of the skin by attempting to maintain adequate hydration and preventing ulcers related to pressure. This includes postural changes when the patient can tolerate them. Healthcare professionals should also attempt to maintain the patient’s personal hygiene, adapting it to the maintenance of general comfort.

(c) Practitioners should ensure adequate care of the mouth, which is usually dry and can be painful, seeking to moisturize, moisten, and clean it carefully if the patient tolerates care and it brings him or her relief. For the lips, fatty preparations are better than glycerin, and sprays and swabs soaked or prepared in gel can be used for inside the mouth. Oral ingestion should be limited according to the patient’s level of consciousness and ability to swallow because of the risk of bronchoaspiration. If feasible, the patient can enjoy cold, thick foods.

(d) If the patient is unable to move to go to the bathroom or has lost all or part of his or her sphincter control, practitioners should seek the most appropriate and comfortable way to meet these needs, recognizing the need for privacy and the difficulty of adapting to the loss of autonomy. A bladder catheter can be considered in some cases.

(e) The patient’s surroundings should be taken care of, respecting natural light, but avoiding sound and excessive stimuli. Practitioners should facilitate the family’s presence. The monitoring of vital signs will become less frequent in an attempt to respect the patient’s
need for rest and so as not to alarm those present. Instead, monitoring signs of suffering should be intensified and the practitioner’s presence in this sense should be frequent, appropriate, and calming.

5 General Symptoms Near the End of Life

The end of life requires careful and expert management of symptoms, in addition to gentle and humane treatment at all times. Families should receive the message that this is a priority to which effort and resources will be devoted, which may comfort them and encourage them to transmit their concerns or perceptions of suffering (Blinderman and Billings 2015). Family members help healthcare professionals to detect changes in the patient’s facial expression and restlessness.

The following includes a description of the most frequent symptoms and their treatment. In the context of the end of life, practitioners should seek to implement the best possible symptom control in accessible and noninvasive ways, taking into account that the patient probably cannot swallow or experiences much difficulty doing so, and that a hospital is not the only place where care can occur (Kehl and Kowalkowski 2013; Bartz et al. 2014).

5.1 Pain

Pain is frequent at the end of life; 40% of hospitalized patients present moderate or severe pain in the last 3 days of life. If the patient complained of pain previously and is incapable of expressing it in his or her current state, practitioners should assume that pain medicine is still necessary and treatment should be adjusted accordingly.

Expressions associated with pain should be closely monitored; relatives and other healthcare professionals are to be asked if they detect signs of pain in the patient’s movements or gestures. Careful physical examination in search of pain that cannot be verbally expressed is unavoidable; therein, healthcare professionals should look at the patient’s facial gestures and his body position, trying to locate suspected pain points with palpation and any skin alterations or deformities that may cause pain.

Pain management should be effective and quick; thus, the administration of opioids is usually necessary. Oral slow release or transdermal administration is not appropriate in this situation because patients tend to eliminate waste less effectively and thus have more side effects from accumulation of metabolites. Rapid and short acting prescriptions should be used, preferably subcutaneously.

Recommended starting doses:

- Subcutaneous Morphine (consult the formulation available in each country and the recommended doses)
- Oxycodone, 2 mg, subcutaneous
- Hydromorphone, 0.4–0.8 mg, intravenous or subcutaneous

The dosage and frequency of administration should be periodically reviewed because the patient’s needs may change quickly. Prophylactic doses should be prescribed for procedures known to cause pain.

5.2 Dyspnea

Dyspnea can be accompanied by weakness or anxiety and is stressful for the patient’s loved ones. It is easy to recognize if the patient cannot express himself with words. It is not difficult to identify because the patient tries to open his airway as wide as possible by opening the mouth or using auxiliary muscles. Opioid management is similar to pain management, although the required doses are less and morphine is the best choice. The use or maintenance of oxygen therapy should be evaluated individually; if symptomatic hypoxemia presents itself, oxygen administration through the nasal cavity is preferable to a mask because it is tolerated better (Campbell et al. 2013). Other more general measures are effective in relieving the patient and they encourage
caregiver participation. Use of a hand or small battery operated fan near the nose and mouth, thus maintaining fresh air, as well as raising the head of the bed, leaving the patient space and trying to convey a sense of tranquility, help the patient to adopt a good breathing posture.

5.3 Delirium

Once reversible causes of delirium have been ruled out, this state is referred to as terminal delirium during the end of life. It is often associated with other symptoms and decreases in intensity when treating pain appropriately, for example. The treatment of choice for terminal delirium is haloperidol (0.5–1.5 mg subcutaneous or intravenous), and other atypical or second generation antipsychotics may be used (Boettger et al. 2015). If the patient does not respond to these medicines, it is useful to administer benzodiazepines subcutaneously or intravenously (lorazepam or midazolam). Appropriate prescriptions include the following:

- Haloperidol, 3–6 mg, subcutaneous or intravenously over 24 h
- Olanzapine, 5–10 mg, over 24 h

The patient’s surroundings must first be adapted to facilitate his or her bearings and need for rest, avoiding excessive stimuli. Professionals should explain what is happening and the treatment objectives to the family. The main objectives are to ensure calm, to prevent falls or other harm to the patient, and to alleviate the suffering it generates. Sedation is not the primary goal, although it is a frequent side effect of the most frequently used medicines.

5.4 Anxiety

In a patient’s last days, it is difficult to distinguish anxiety or anguish from agitation. If healthcare professionals know the patient and have ruled out delirium, anxiety can be treated with benzodiazepines on demand or in perfusion. Doses are lower than those used for other situations and are usually sufficient with 10 mg of midazolam or 1.5 mg of lorazepam over 24 h. These doses, however, may be higher if the patient was previously treated with benzodiazepines for a prolonged period.

5.5 Nausea

As with every stage of illness, healthcare professionals should always think about possible causes to recommend the most successful treatment. At the end of life, there is an additional possibility that respiratory secretions or constipation may rarely cause nausea, although patients do not usually vomit at this stage. At times, in conjunction with postural changes, for example, patients can involuntarily expel secretions or food remains. It is likely that the cause of nausea is not specifically treatable, such that careful symptomatic management should be undertaken. Medication is chosen based on the suspected etiology and sometimes it is necessary to combine two medications to achieve adequate control.

- Metoclopramide is the first choice, between 30 and 60 mg over 24 h subcutaneously or intravenously.
- Haloperidol, if a central cause is suspected, 1.5–2 mg of haloperidol subcutaneously over 24 h.
- Dexamethasone, 4–8 mg subcutaneously or intravenously every 24 h, as adjuvant or in cases with clear cerebral edema or bowel obstruction; if bowel obstruction is clear and established, add Octreotide 300-600mcg over 24 h subcutaneously or intravenously.

5.6 Seizures

For patients with a history of seizures who were already being treated with antiepileptic medicine, an attempt will be made to continue administering the same medication, although the delivery method may change in accordance with the
patient’s state. There is evidence that supports administering some medicine subcutaneously, like phenobarbital or levetiracetam (Remi et al. 2014). For crises or patients who present seizures for the first time in their last days or hours of life, benzodiazepines are the most appropriate treatment.

5.7 Fever

Some patients have a fever at the end of life. If no obvious infection is present, it is typically associated with oncologic disease or brain damage. If a patient is unable to swallow, intravenous administration of paracetamol is effective, especially if the patient or family wishes to avoid rectal administration. If the only possible means of administration is subcutaneous, ketorolac may be used. Physical interventions help improve levels of comfort.

5.8 Rales or Death Rattle

Noisy breathing (bubbling or rales) is due to the accumulation of bronchial secretions and saliva, usually in the bronchi, trachea, and oropharynx. It may be unpleasant for the family and companions, but it is important to let the family know the person is not “drowning.” Practitioners should take into account the impact that these noises have on caregivers and try to treat them when possible.

Some general measures work very well, such as postural changes, raising the head of the bed 30 degrees or the gentle aspiration of secretions if the patient is unconscious.

Depending on the availability and commercialization of some pharmaceuticals, different guidelines are used in different countries. They can cause sedation, worsen dry mouth, and even favor urinary retention. The use of pharmaceuticals that require oral administration is not feasible because patients have usually lost the ability to swallow when they have rales (Kintzel et al. 2009).

There is not enough evidence to show that any intervention is superior to placebo in the treatment of noisy breathing, and there are insufficient data (Wee and Hillier 2008).

The tested pharmacological alternatives include the following:

- **Hyoscine butylbromide (buscopan)**, 60–90 mg every 24 h or more, subcutaneously or intravenously
  - It does not cross the blood-brain barrier and is less sedative.

- **Hyoscine hydrobromide (scopolamine)**
  - It can be used subcutaneously, transdermally or intravenously and the usual subcutaneous dose is 1.5 mg/24 h.
  - It may cause sedation and confusion or worsen delirium.

- **Glycopyrronium bromide.**
  - The subcutaneous dose is 0.6–1 mg / 24 h; an oral dose can be used sublingually reducing the dose to 0.4–0.6 mg every 24 h.
  - It does not produce sedation or confusion.
  - A recent study advocates for the use of **atropine** (in ophthalmic form) administered sublingually (Protus et al. 2013).

  There is not enough evidence about the cardiac effects it can produce (Protus et al. 2013).

6 Holistic Care

As explained in the section above, patients experience physical changes, as well as emotional and spiritual ones, as they approach the end of life. All of these changes are part of the natural way in which the patient prepares himself for this final stage of life. The emotional and spiritual process is individual since each person is unique and needs to do things his or her own way. However, some general considerations of common emotional and spiritual processes are explained in what follows.
6.1 Emotional Care

The following includes an overview of some of the most common emotional reactions at the end of life, aiming to help understand them and to offer some suggestions on how to deal with these reactions. Hope, anger, maintaining control and dignity, and meaning-making will be discussed as part of the process of coping with and adapting to the end of life.

6.1.1 Hope

The concept of hope has been linked with treatments and cure. At initial stages of disease, patients may manifest hope for a cure, but, as the disease worsens and the end of life approaches, patients may feel that all hope is gone. This state of hopelessness can be associated with intensifying depression and a desire to die (Rodin et al. 2009). In a study involving advanced cancer patients, 48% reported at least some sense of hopelessness (Wilson et al. 2004).

Hope is present throughout the illness trajectory and changes accordingly. Palliative care certainly includes hope, though with a slightly different perspective (Nekolaichuk 2005); it identifies other things to hope for that are more achievable and involves hope for the individual. The therapeutic value of hope when it comes to life-threatening illnesses is documented. Hope has been positively linked to effective coping. Living with meaning and hope is one of the six essential elements for psychosocial and spiritual well-being (Lin and Bauer-Wu 2003). Several papers highlight the need to intentionally incorporate hope within end of life care (Sullivan 2003). This can be done by jointly identifying other things to hope for – e.g., good symptom control, staying at home, being with family – and developing realistic plans to achieve them. In addition, some interventions focused on hope for terminally ill patients (e.g., viewing a video on hope and choosing one of three hope activities to work on over a week) could be used given that there is some evidence that hope offers a statistically significant improvement of quality of life for the intervention group versus the control group (Duggleby et al. 2007).

6.1.2 Anger

Anger may arise from fear or feelings of impotence and is a reflection of one’s response to the loss of control. During illness, the patient is forced to deal with a series of losses such as the loss of his or her role in life, of functional capacities, of independence and even the awareness of dying. Approaching death leads to another loss that can be expressed with inadequate demands or complaints. Anger can temporarily give a dying person the sense of being in control and block out the emotion of fear. Expressing this anger can be a process towards accepting reality and should be understood as the inability to deal with the situation at hand.

Family members may also become angry because of perceived inadequacies in care and struggles to accept that their loved one is dying. This feeling is difficult for health professionals and requires a team response. Anger, no matter its cause, can obstruct effective interaction between the patient and the caregiver. If dealt adequately, the patient usually moves on; a painful experience full of fear can become an opportunity for forgiveness and meaning-making.

There are several steps to be taken into account when approaching anger (Philip et al. 2007). The first one involves preparing oneself for the fact that the patient is angry and seeking out an adequate atmosphere that transmits openness and allows for time to discuss. Professionals ought to clearly demonstrate being fully present with eye contact, body language, and verbal response and avoid responding with advice, critique, or reassurance. They should also offer therapeutic validation by identifying the underlying emotions and responding in a way that demonstrates an understanding of them. And they can demonstrate empathy with phrases such as, “I am sorry to hear that.” It is important to listen and to engage with the patient in respectful communication, avoiding taking anger personally by remembering that anger can be a coping strategy that contains a different worldview.

In conversation, the angry person can be invited to redirect his or her emotions, encouraging reflection with questions like, “How do you manage to cope?” “What keeps you going even
though you have endured so much?” “What do you think you need right now?” “How can I be most helpful to you?”

Anger can be an expression of the patient or the family’s suffering. If anger persists, the care team needs to support each other when dealing with them (Philip et al. 2007).

6.1.3 Maintaining Control and Dignity

The experience of living and dying with a terminal illness shocks and shakes aspects that are otherwise taken for granted. The patient may feel more vulnerable and question his identity, future, worth and even change his perception of dignity. In this situation, the patient is looking to gain some control over his life and death; some patients even express a desire to die in order to demonstrate some measure of control (Monforte-Royo et al. 2012).

One’s perception of dignity can also be affected. The dignity of the person has become increasingly relevant in recent years in the healthcare field. A critical review of dignity models in healthcare concludes that all models consider dignity an intrinsic feature of human beings, but at the same time contemplate a subjective dimension that depends on personal experience. This subjective dimension of dignity is influenced by the person’s own view of himself, the repercussion that the disease has on this view, the context, and even healthcare professionals’ behavior (Errasti-Ibarrondo et al. 2014). These aspects acquire special relevance during terminal illness because the patient may feel more vulnerable. The review points out that Chochinov’s Dignity Model is one of the most empirically based models applied to clinical practice (Chochinov 2002) (see the ▶ Dignity chapter for further study). It is important to highlight the concept of care tenor, which refers to the attitudes and behaviors of people who interact with the patient, which is especially applicable to healthcare professionals.

Research points out that relationships and the way in which healthcare professionals care for a terminally ill person make a difference in that patient’s experience. Patients convey that authentic relationships with their nurses make them feel valued and dignified and alleviate inner loneliness (Errasti 2015). The way patients perceive of their care echoes dignity-conserving care, which promotes “being there” for the patient and interacting not only according to respective roles, but also as unique persons.

In this framework, clinical interventions have been developed to preserve and promote the patient’s perception of dignity, which can be useful at the end of life. To this end, the Patient Dignity Question (Chochinov et al. 2015) stands out. It is a brief intervention to promote the patient’s perception of self-value and recognition. The Patient Dignity Question proposes developing a conversation with the following questions:

What should I know about you as a person to help me take care of you?

What are the things that concern you most?

Who else is affected by what’s happening with your health?

Who should be here to support you?

This kind of short intervention allows healthcare providers to get to know their patients and incorporate their values and perspectives into the care plan. A review suggests that this novel intervention is useful in approaching and getting to know a patient as a person (Arantzamendi et al. 2016). The TIME questionnaire (Pan et al. 2016) has also been developed and includes a set of questions based on identifying primary themes that emerge from the PDQs qualitative responses in order to elicit personhood and enhance dignity.

6.1.4 The Search for Meaning

The diagnosis of advanced disease and the possibility of dying often involve reprioritizing values and points of views. The patient often “opens his eyes” and sees what is really important in life. This situation leads to rethinking priorities and focusing more on what is really important as the reality of life’s finiteness becomes more patent. The patient desires to achieve reprioritized goals and create a bearable or meaningful existence in the face of death.

Forgiveness may be one of these goals and may entail forgiving people who have hurt the patient, as well as asking for forgiveness from the people that the patient wronged. This is a
way to diminish negative emotions and to generate well-being and calm (Mickley and Cowles 2001). This process helps re-establish relationships, close pending issues, and achieve a sense of transcendence.

Another goal entails meaning-making, even if this process is sometimes unconscious. Patients draw on their underlying beliefs, personal identities, moral principles, and religious beliefs to make sense of their situation. And, in so doing, they search for meaning. The meaning left in their lives often corresponds to caring for others, resolving pending matters, and doing what they can to improve the lives of those they leave behind.

Valued relationships become even more important and relationships that were previously taken for granted, often with partners, children, and grandchildren, become more cherished (Sand et al. 2009). This sometimes entails saying goodbye and transmitting gratitude and love to loved ones. In this process, in cases where there are small children, the patient may aim to help them understand the situation and to transmit messages they consider vital. This can be seen as a luxury, since, as one patient said, “Saying farewell to my children has been hard, but it is a luxury. Yes, yes, I said goodbye to the relatives that matter most to me and my best friends... It was a truly beautiful and fantastic experience that meant a lot to me because I could say goodbye to my wife, my children, my mother, my brothers, my friends ... to all the people that matter to me! I told them that probably not even Onassis or Rockefeller or anyone else had the opportunity I had. And that, to me, is a luxury” (Garcia 2017).

Some people find meaning themselves, while others may benefit from specific interventions such as meaning-centered therapy (Breitbart et al. 2010; Breitbart 2002), dignity therapy (Chochinov et al. 2005; Aoun et al. 2015; Chochinov et al. 2011) (Martinez et al. 2017), or life reviews (Ando et al. 2010) that enhance a sense of meaning, peace, and purpose in their lives as they approach the end of life. Spirituality can be another source of meaning for people at the end of life and indeed constitutes an integral part of human life, which will be explored in what follows.

6.2 Spiritual Care

An acknowledgment of spirituality is necessary at the end of life, as well as throughout the advance of illness (Balboni et al. 2007), and influences decision-making when it comes to care (Silvestri et al. 2003).

From its origins, palliative care has included spiritual care as an essential part of caring for patients (Saunders 2001; Saunders 2003) (see the chapter on Spiritual Care). It is one of the eight domains of quality palliative care and, as the consensus report developed by 40 health-related Canadian national leaders states, it is crucial (Puchalski et al. 2009).

The term spirituality has different connotations in relation to different backgrounds (e.g., Roman Catholic, Protestant, Eastern religions, or those with no faith at all). Herein, a broad definition is employed. Spirituality is understood as “the dynamic dimension of human life that relates to the way person[s] (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred” (Leget et al. 2014).

Spirituality is a movement of personal searching in three directions: towards the innermost self in search of meaning, towards one’s surroundings in search of connection, and towards the beyond in search of transcendence (Gomis et al. 2017). In this movement, many people who are confronted with a life-threatening illness begin to ask themselves “big questions,” such as “What did I do wrong?” “Why do I have to suffer?” “Why should I go on living?” “Am I not just a burden to others?” This line of questioning can be called spiritual or existential questions.

Whether or not a person has expressed spirituality at other moments, the end of life experience will often lead to further exploration of this realm. Many people seek answers from within their life view or religion.
6.2.1 The Natural Course of A Spiritual Process

On life’s path, everyone goes through a kind of spiritual process by which the uncertainty of existence is replaced by a kind of purpose or meaning. In this natural process, a number of themes can be distinguished (Leget et al. 2014).

- **Awareness of finiteness:** The moment that disease poses a threat to existence, the patient becomes aware of his or her finiteness. Some people struggle with it, while others panic. This awareness may also cause the patient profound loneliness as they struggle to deal with and talk about it.

- **Loss of grip on life:** Being aware of one’s finiteness causes the patient to feel as if he has lost his grip on life. The constructs of meaning he regularly relied upon no longer suffice for many aspects associated with a threat to existence.

- **Loss of meaning:** When death approaches, a sense of the future is lost. The patient often perceives his experience as unreasonable and meaningless.

- **Bereavement process:** The bereavement process begins when an awareness of all the things one must let go of, such as loved ones and plans, sets in.

- **Experience of connectedness:** This term is used to distinguish it from ways in which the patient previously searched for and found meaning. This experience may be new for the patient and therefore difficult to verbalize.

- **Integration of meaning and the experience of connectedness:** This happens when the search for meaning and the experience of connectedness are again integrated. When finiteness has been integrated into a system of meaning, the patient focuses more on the here and now and usually undergoes a shift in priorities.

6.2.2 Healthcare Professionals and Spiritual Care

During this natural process, the patient is searching and sometimes struggling to find his or her way. Healthcare professionals should be open to considering the spiritual dimension. What should healthcare professionals do specifically?

It is indispensable for healthcare providers to be open, which facilitates an appropriate atmosphere and attitude. Next, healthcare professionals should seek to offer some spiritual accompaniment, understood as the practice of recognizing, welcoming, and giving space to the patient’s inner dialogue, such that he himself can give voice to his questions and life to his answers (Gomis et al. 2017). This spiritual accompaniment is part of palliative care’s dynamic of interdisciplinary teamwork. It requires detection, exploration, and intervention.

- **Detection** is the responsibility and task of all team members; it consists of using various indicators or “warning signs” to detect the emotional expressions, values, and ethical conflicts, etc., that accompany spiritual experience. One must be attentive to expressions of hopelessness, to phrases like “I do not feel prepared to face the end” or “I think it’s time to throw in the towel,” and to objects that support a spiritual practice (e.g., certain books the patient is reading or religious icons in the room).

- **Exploration:** Some suggest that the relevance of spirituality for patients should be systematically evaluated. Instruments have been developed to this end, such as FICA (Borneman et al. 2010) or SPIRIT (Taylor 2006).

From a different perspective, the beginning of spiritual exploration requires establishing a relationship of trust and a therapeutic link to identify suffering and its perceived causes or threats and to try to resolve or neutralize problems that can feasibly be dealt with (Gomis et al. 2017). In this preliminary part, exploration of the experience of suffering as a problem is fundamental, as well as being aware that people define existential suffering differently (Boston et al. 2011). Subsequently, variables in the experience of suffering are seen as a mystery, as an existential condition. In this approach,
three levels are involved in spiritual exploration (Gomis et al. 2017).

The **general level** explores worries, as well as the degree of difficulty in facing them, resources where help can be found, and the patient’s expectations about the extent to which healthcare professionals can help. Questions that may be useful are: Is there something that, in this situation, worries you? In your current situation, what is most helpful to you? Is there something more that you think we could do and that could help you? The **intermediate level** explores the resources and/or concepts that help patients through the process of dying, as well as the existence of certain questions (which express unresolved needs) and the degree to which they influence the patient’s process. Some useful questions include other patients in situations similar to yours tell us that, in order to better support illness and everything associated with it, it is very useful to have a certain meaning in life, a way of understanding illness, relationships, your personal story, and so on. Do you have something like that? The **specific level** explores more explicitly the spiritual and/or religious realm, its potential benefits, one’s desire to deepen therein, and the need to search for another interlocutor. Some questions that may be useful for this exploration include: Do you have any spiritual or religious beliefs? If so, how are they helping you in your situation? These questions may be useful for exploring spirituality in a natural and nonthreatening way, but should not be used as a questionnaire, thus respecting the patient’s personal dynamics. In fact, depending on the patient, third-level questions may appear in the conversation associated with the first level.

- **Intervention:** The mere fact of exploration has a therapeutic element and supposes – in some way – a potential first-level intervention because the patient perceives that someone cares about his person in its entirety. In addition, exploration already has a therapeutic edge because it facilitates a clarification of the internal world (Gomis et al. 2017).

Specific guidelines have been published addressing the issue of spiritual support or accompaniment (Lo et al. 2002) (Rodin et al. 2009), and interventions have also been developed (Boston et al. 2011), such as a life review, meaning-centered therapy, or dignity therapy, which were mentioned earlier as therapies that promote meaning.

In the process of accompanying a person at the end of life, there may be conversations about death and about how he or she envisions and wants to prepare for it. The patient may appreciate having someone to talk to about this and patients often choose healthcare professionals to have this conversation with. In this type of situation, the practitioner must take a deep breath and stop to really listen to the patient, taking into account that, although death is a universal fact, not everyone faces it in the same way since one’s history and culture strongly influence this realm. Listening attentively and responding to concerns, as well as taking about the patient’s wishes at the end, are key elements of this conversation (National Institute for Health and Care Excellence 2017).

Reaffirming that the patient will be cared for until the end and that the medical professionals involved will accompany him and help him through the process of death is vital for the patient to feel comforted and recognized as a person. In some situations, various interventions meant to adequately relieve end of life suffering fail and palliative sedation may be considered (see the chapter on ▶ Palliative Sedation).

### 7 Caring for the Family

As mentioned previously, the end of life affects patients, as well as their families. The concept of family is in constant evolution. It has cultural, legal, and sociological definitions – and different cultures define family in a variety of ways. Traditional definitions of family include what is referred to as the nuclear family – including a
father, mother, and one or more children – or the extended family that includes grandparents, aunts, uncles, and cousins. Here, family caregiver is broadly defined and refers to any relative, partner, friend, or neighbor who has a significant personal relationship with and provides a broad range of assistance to a person with a chronic or disabling condition (Blum and Sherman 2010).

Palliative care includes caring for the family through the disease process, including at the end of life. The patient’s family is like an important ally whose power must be recognized. Family members know the patient better than anyone and can help healthcare professionals do their jobs. However, the end of life is an emotionally demanding time for the family and they also require the attention of healthcare professionals, taking into account the family’s beliefs about health and illness, the culture they belong to, as well as the family’s dynamics.

7.1 Preparing the Family for Impeding Death

A loved one’s last days have an important emotional impact on the family. Healthcare professionals should consider who they are, as well as their family culture and history (especially religious/spiritual leanings) when caring for the patient and family. Healthcare professionals should consider the following:

* Provide the patient’s family with **accurate information** about the prognosis, explaining any uncertainty and how it will be managed and, in so doing, avoiding false optimism (National Institute for Health and Care Excellence 2017). The disease progresses and the patient experiences functional decline. The family perceives that the situation is worsening and that their loved one is becoming weaker, but sometimes is not aware that death is so near. Healthcare professionals can help the family adapt and understand that their loved one is close to death.

* Provide family members an opportunity to talk about their fears and anxieties and to ask questions.

* Provide **information about how to contact healthcare professionals** – especially if the patient is at home – including contact details for relevant after-hours and emergency services.

* Explore the family’s fears and previous experiences, since they sometimes make demands that do not line up with the patient’s situation based on previous negative experiences.

* Explore whether the patient has prepared a written statement or has verbally stated **preferences about their care during the last days of life** (including any anticipated prescriptive decisions, advance decision to refuse treatment in certain cases, or details about any legal power of attorney for health and welfare).

* Explain that you will continue to care for the patient, prioritizing her comfort and wellbeing. This is an emotionally intense situation for the family, making it advisable to explain that healthcare professionals are on their side and will continue to care for both the patient and the family. In this phase, family members pay close attention to the interactions between healthcare professionals and the patient; it is thus essential to continue providing respectful and quality care that conveys that the patient is truly valued.

7.2 Caring for a Dying Person’s Family

Healthcare professionals are supposed to witness and support the family’s growing awareness of their loved one’s deterioration and medical issues, including what these revelations mean for the family’s future. Healthcare professionals have two important roles: to support family-patient interactions and taking care of family members.

The dying process is a roller coaster of emotions for the family too. **Sometimes family members do not know how to interact with a dying person.** Staff should suggest that family members remain themselves as the dying person continues...
to need intimate, natural, and honest relationships. The family should understand that they do not have to hide their tears, as crying is a way of showing love.

Healthcare professionals should promote discussions with the family about the role they want to play in the patient’s care, remembering that it is very important to treat this topic delicately. Some family members may want to be involved in simple activities such as mouth care, while others may not feel comfortable being involved in direct patient care.

Healthcare professionals can encourage the family to think about and discuss how they want to spend the final weeks and days, taking advantage of the time that remains with their loved one. They can decide to spend time together talking, simply being, or recalling old memories. It is important to promote meaningful interaction for the current situation and for future memories.

Healthcare professionals can also explain to relatives the importance of being thoughtful and that the patient feels their love and care. It is important to show kindness, as well as convey care and acceptance, thus building trust and enhancing self-esteem. It is helpful for family members to hold the patient’s hand, listen to his stories, or just be with him, which will mark the family’s future memories. It is not the time to try to change a loved one, but rather a time for full acceptance, support, and comfort.

It is also important to explain to the family the importance of talking about death when both parties are ready. While it is difficult to talk about, discussing death can ultimately alleviate fears and foster stronger emotional bonds between the patient and the family. It can help the family reflect on the importance of understanding their loved one’s final wishes, so that they can carry them out as fully as possible. Some suggestions for this conversation include the following (Family Care 2016):

- Always use language about death that everyone is comfortable using. Try not to avoid using the word, but feel free to use metaphors or softer words (e.g., “pass away”) as long as the fact that death has occurred is clearly explained.
- Do not rush the conversation. Make time for your loved one and realize that you might have to do so on a flexible schedule – predicting when someone will feel comfortable discussing death is often difficult.
- Do not discredit any of the emotions that you, or your loved one, feel. Be sure to acknowledge that these emotions may influence both parties’ words and behavior. This will help your loved one to better understand.
- If a loved one brings the topic up and it scares you, do not shut the individual down by saying something like, “don’t say that.” Instead, even if you are not ready to talk about it, let your loved one discuss his/her feelings. Keep the conversation going by saying things like “really?” or by rephrasing what he or she has already said.
- Finally, talk about your loved one’s current condition and his/her hopes or fears for the future.

Saying goodbye is an important part of the patient-family interaction at the end of life. Staff can facilitate it by highlighting its importance and suggesting it as a final gift of love since it contributes to closure and makes the final release possible. It may be helpful to suggest that family members sit close to the patient, take his hand, and say everything they need to say. It may be as simple as saying things like I love you or thank you; or it may involve recounting meaningful shared moments or saying sorry for whatever contributed to any difficulties in the relationship. Tears are a normal, natural part of saying goodbye and should be understood as an expression of love. Healthcare professionals should, in turn, promote an environment that facilitates saying goodbye. This includes adequate symptom control, giving the patient and family privacy by allowing them to be alone and ensuring a pleasant environment.

Healthcare professionals need to address caregivers’ needs in a sensitive way, supporting
them emotionally. Some suggestions include the following (Centeno et al. 2009):

1. Recognizing the family’s suffering and taking an interest in how they are, may be enough for them to open up, improve their attitude toward professionals and share their concerns. It is important to use room visits to assess the family’s needs, asking what help they need and how they perceive the patient’s state.

2. Be willing and accessible so that the family can express their emotions. Reiterate your offer to help with any of their current needs.

3. Explore with the family the role they wish to have in caring for their loved one. This serves as a manifestation of affection and helps them to feel useful.

4. Explain that you cannot know exactly when the end is near, but do explain the patient’s possible course to the family. In particular, it is important to explain, as mentioned previously, possible cognitive changes, the progressive decrease of consciousness, and respiratory difficulties. The impending death of a loved one is always a difficult emotional time, but knowing what to expect can help the family prepare.

5. In the case of families with children, it is important to help children situate themselves and prepare for their loss. The sooner children know what is happening, the better. It is important to reassure children that they did not cause this loss. When adults do not explain things to children, they are faced with drawing their own conclusions, which tend to be much worse than the facts. Ultimately, children are flexible and resilient and can deal with reality.

6. Allow the family to participate in decision-making, ensuring that the family agrees to and understands any changes to the care plan and that said changes are recorded in the clinical record.

7. Offer spiritual support to the family according to their beliefs. Spiritual care as a component of palliative care is also important for those close to the patient since their loved one’s impending death can evoke spiritual questions for them as well.

8. Help the family prepare for the death of their loved one, as they may be prepared for the dying process but not for the actual moment of death. It may be helpful to encourage the family to think about and discuss what they want to do at death (i.e., funeral home, prepare the body). They may have talked with their loved one about it or they may know what he or she would like.

9. At the right time, the professionals in charge of the patient’s care should discuss with the family the paperwork that needs to be done when the patient dies. Planning a funeral is a complicated process, which is made even more difficult by the emotional stress that accompanies the death of a loved one. Thinking ahead of time about these arrangements decreases the burden on those left behind.

10. Healthcare professionals should support family members who arrive after the patient has lost consciousness or has died, and thus have missed the opportunity for meaningful interaction. They may benefit from information about the patient’s state, such as skin temperature and color change, or the jaw being relaxed and the mouth slightly open. Professionals should support them in having private time with the patient should they wish. This might not be an intuitive step for families, and encouragement from staff may be needed.

11. When the patient dies, the family should be supported and, without rushing anything, should be given a few moments of privacy if they wish. After this, the care needed in this situation can be performed, which will be explained later.

12. Help the family with the bereavement process. This can include a phone call to see how the relatives are doing or a condolences letter. There are also a variety of interventions specific to bereavement care, as shown by a systematic review (Forte et al. 2004).
8 Impact of End of Life Care on Healthcare Professionals

Working with patients who have incurable diseases and those in the process of dying exposes professionals to the physical, psychological, and spiritual suffering of patients and their relatives (Hanks 2009). This exposure means that working in palliative care can be challenging, rewarding, and stressful (Bruera et al. 2015). Professionals face a difficult reality that contains different kinds of suffering, a mix of feelings, and questions without answers. This reality may also force professionals to deal with their own mortality, fears, vulnerability, and the meaning they draw from life.

8.1 Definition and Overview of Distressing Experiences

There are a number of distressing experiences that palliative care professionals have to deal with. The most frequently researched are stress, burnout, and compassion fatigue.

8.1.1 Stress
Stress is defined as the body’s physical, mental, or emotional response to change (Selye 1980). The European Agency for Safety and Health at Work has defined work-related stress “in terms of the ‘interactions’ between employees and (exposure to hazards in) their work environment. Within this model stress can be said to be experienced when the demands from the work environment exceed the employee’s ability to cope with them.”

Some studies have found that staff working in palliative care have less stress than other professionals working with patients (Bruera et al. 2015; Berman et al. 2007), but this does not mean that stress does not occur.

8.1.2 Burnout
Burnout is defined as “the progressive loss of idealism, energy and purpose experienced by people in the helping professions as a result of the conditions of their work” (Edelwich and Brodsky 1980). In addition, “The root cause of burnout lies in people’s need to believe that their life is meaningful, and that the things they do- and consequently they themselves- are important and significant” (Pines 1993). It is a response to work-related interpersonal and emotional stressors and has three key dimensions: (1) overwhelming emotional exhaustion (EE), which is the basic individual stress dimension of burnout, (2) feelings of cynicism and detachment from the job, i.e., depersonalization (DP), which is the interpersonal context dimension of burnout, and (3) a sense of ineffectiveness and lack of personal accomplishment (PA), which is the self-evaluation dimension of burnout (Pines 1993). Yet, recent research shows that staff working in palliative care may in fact experience lower levels of burnout than professionals from other disciplines (van Staa et al. 2000; Hospice Friendly Hospitals Programme 2013).

8.1.3 Compassion Fatigue
This fatigue refers to an acute onset of physical and emotional responses in relation to work that culminate in a decrease in compassionate feelings towards others (Sinclair et al. 2017). It is considered a significant stress response in healthcare providers. The signs and symptoms of compassion fatigue can be classified as physical, behavioral, psychological, and spiritual and are thought to have a global impact on healthcare providers’ wellbeing (Sinclair et al. 2017).

Six occupational areas are associated with the factors that add to distressing experiences, including: (1) workload and intensity of work, (2) lack of autonomy, (3) social climate at work, (4) emotional demands on staff associated with multiple bereavements and grief, as well as exposure to patients and families’ distress, and personal discomfort with suffering and death, (5) conflicting values and meanings that arise between the employee and health institution, and (6) working conditions (Bruera et al. 2015).
8.2 Facing Difficulties: Resilience

Resilience is an individual’s ability to adjust to adversity, maintain equilibrium, retain some sense of control over one’s environment, and continue to move on in a positive manner (Jackson et al. 2007). About resilience nature, Jackson (Jackson et al. 2007) believes that individuals can develop and strengthen personal resilience by developing strategies that reduce their own vulnerability and the personal impact of adversity in the workplace.

8.2.1 Strategies Against Professional Distress

A recent literature review (Hospice Friendly Hospitals Programme 2013) presented five elements that are effective in promoting resilience and avoiding distressing situations: (1) self-care strategies, (2) the creation of support groups, (3) the cultivation of supportive inter-professional relationships, (4) education and skill-building, and (5) meaning-making through ritual or commemoration.

1. **The four dimensions of self-care**

   Caregivers cannot meet their patients’ needs if their own needs are not met (Huggard and Nichols 2011) (Cohen et al. 2001). Self-care is associated with lower levels of stress and burden (Merluzzi et al. 2011) and emphasizes the obligation to take time for self-care (Cohen et al. 2001). This dimension includes maintaining one’s health and wellbeing and exploring the feelings derived from being surrounded by difficult situations.

2. **Inter-professional or specialty-based support groups**

   Inter-professional support groups are based on the idea that supporting the needs of professionals working with incurable disease may improve job satisfaction and prevent compassion fatigue (Hospice Friendly Hospitals Programme 2013) (Huggard 2012) (Wenzel et al. 2011). Several types of support groups are recommended depending on the characteristics of the person in need of support (Huggard and Nichols 2011) (Le Blanc et al. 2007) (van Staa et al. 2000).

3. **Building supportive teams**

   Teamwork is the central idea of palliative care. This strategy is found in the idea of becoming a supportive team instead of just practicing teamwork. Some studies show improvements as a result of becoming a supportive team (Le Blanc et al. 2007) (Wenzel et al. 2011).

4. **Education and skill-building**

   There is a need for continuing education focused on developing strategies that enhance professionals’ coping skills (Wenzel et al. 2011) so that they can effectively assist in daily patient care. One study argues that end of life care providers “need to be taught a rational concern, which allows the expression of feelings without impairing the ability to make decisions, rather than a detached concern” (Le Blanc et al. 2007).

5. **Meaning-making.**

   Spending “therapeutic time” with patients can be beneficial for both the patient and the caregiver (Cohen et al. 2001). This can help the professional to consolidate his or her experiences into meaning structures; the individual ability to make or find meaning can transform intensely stressful situations into positive experiences and can serve as a “profound motivational force” that improves quality of life (Desbiens and Fillion 2007).

9 After a Patient’s Death

Procedures after death may vary locally so practitioners should be aware of local regulations, considering that they may differ depending on if death occurred at home or in the hospital.

9.1 Tasks to Be Completed After a Patient’s Death

In today’s hospital environment, it is clear that some relatives do not know what to do after their family member dies, so it is necessary for healthcare professionals to guide the family in the tasks to be completed, including:
(a) Tell the health professional to certify the death.
(b) Contact a funeral service.
(c) Specify the conditions, time, and place of burial/cremation.
(d) Write a notice for dissemination, indicating if a religious funeral will take place and the place of burial/cremation.
(e) Talk to the people close to the deceased and invite them to attend the funeral(s) and burial/cremation.
(f) The deceased’s religious creed and his last wishes in this regard must be respected. The funeral chapel and the family and friend gathering will accommodate the deceased’s traditions.
(g) After a few days, it is recommended that relatives respond to the condolences they received.

Although the patient has passed away, healthcare professionals still have other things to deal with, including caring for the family, caring for other patients who were close to the deceased, as well as caring for the medical team and for the deceased patient (corpse) (Centeno et al. 2009).

9.2 Caring for Family Members

The death of a loved one affects relatives emotionally, which is why the medical team must employ special tact. Family members can react very differently immediately following a loved one’s death, and professionals need to know how to understand and respect all of these reactions. Professional must be available and must act naturally, displaying certain closeness. Words may be superfluous at this time and the family is often just grateful for the company (Centeno et al. 2009).

9.3 Caring for the Team

The death of a patient affects caregivers and, when it happens on a daily basis, caregivers’ moods can be affected. It is therefore important to develop protective mechanisms for both individuals and for palliative care teams. In this context, it helps to share lived experiences, to review how the patient was cared for, and to recognize the work completed (Centeno et al. 2009).

9.4 Postmortem Care

Once the patient has died, death should be confirmed through available techniques by checking unmistakable signs, usually by means of an electrocardiographic record at the time that the doctor responsible for certifying the death of the patient deems necessary.

Professionals must take into account that sedated patients may have prolonged apnea pauses before dying, so they must rule out any confusion with a situation of apparent death.

After the health professional has verified the patient’s death and confirmed it with the family, they should be allowed to remain as long as they need with the deceased, so that they can express their emotions.

Once the family has stayed with the patient as long as they need, they will be invited to move to another unit while health professionals proceed with the postmortem care of the deceased. This care consists in hygiene, withdrawal of clinical devices, and arrangements so that the deceased is in adequate conditions to be seen by relatives who wish to say goodbye. The corpse must be wrapped in a clean sheet or shroud. The deceased’s privacy and right to professional secrecy should still be protected.

9.5 Farewell Rituals

A wake involves caring for and accompanying the deceased, and traditionally happened at night. Previously, the wake took place in the deceased’s home since people usually died at home. Today, most deaths occur at a hospital, so the deceased is usually transferred to the hospital’s mortuary or to the morgue (Centeno et al. 2009).

The deceased’s religion and customs determine the relevant funeral rites. Today, different cultures and religions coexist and the rites involved in each case should be respected.
10 Religion and the End of Life

Care for dying patients has always existed in one form or another, but the modern hospice and palliative care movement is intimately associated in its origins with religious orders that cared for those suffering from life-threatening illnesses and nearing the end of their lives. In fact, by the middle of the nineteenth century, a number of institutions and hospitals started establishing centers uniquely devoted to care for dying patients (Clark 2016).

Nowadays, even in the most commonly used definitions of palliative care, the spiritual component is included as a key element. The World Health Organization defines palliative care as “an approach that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual” (WHO 2017). After all, palliative care supports the person as a whole, which necessarily includes the spiritual dimension.

The importance of religion in palliative care is thus evident, and when reviewing current literature, there is a reasonably large body of research on this topic. Most existing studies have evaluated different religions and their impact on perceptions of palliative care (Steinberg 2011); they commonly note that most palliative care patients have spiritual needs that palliative care providers do not properly address (Richardson 2014). Similarly, in another study, under the assumption that “attending spiritual needs ensures that a dying patient has the chance to find meaning in the midst of suffering,” a list of beliefs and traditions from Judaism, Islam, and Christians are presented, along with the way in which they portray dying and mortality (Puchalski et al. 2004). The idea of spirituality being a fundamental element of human experience is deeply established, along with how – viewed in this sense – “spirituality can be a key factor in how people cope with illness, and achieve a sense of coherence” (Puchalski et al. 2004).

Religion is also important during end of life care because it influences ethical (and therefore medical) decisions, which suggests that physicians and nurses should understand religion and spirituality in order to understand people’s choices and “to respect their conscience and worldview” (Broeckaert 2011).

The importance and existence of diverse religions suggests the need to better understand them and how they consider issues related to dying since views associated with different religions can be essential knowledge when treating patients. Different religions hold diverse premises that most certainly influence the way a patient should be cared for. There are a few manuals/guides that present information on each religion, focusing on doctrinal elements and beliefs in relation to the concept of illness and death, as well as morality, behavior and commitments, practices and rites, prayers, organization, etc., which are all related to and closely conditioned by the specific religion (Unescocat et al. 2013).

Table 1 presents the most relevant considerations on illness, rituals, and death associated with the world’s major religions (Unescocat et al. 2013), but a deeper reading is recommended when caring for patients of each religion or a patient of another minority religion.

The implications for medical practice are subsequently based on the fact that spirituality is an essential dimension of integral attention and that death and dying is interpreted depending on specific religious or personal convictions when facing the end of life. Thus, in the end, we aim not only to be respectful of everyone’s beliefs, but also to know or at least have material on hand that provides information about the different religions and their associated convictions.

11 Summary

This chapter has explained the context of end of life care and its goals in caring for the patient and family. Palliative care prioritizes comfort, wellbeing, and dignity until the end.

The text additionally highlights the importance of diagnosing impending death such that
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<th>Table 1</th>
<th>Considerations by religion (Unescocat et al. 2013)</th>
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<tbody>
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<td></td>
<td>Illness</td>
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<tr>
<td><strong>Catholicism</strong></td>
<td>Pain, disease, and death are all part of life. Everyone should care about the sick, seeking to heal them and alleviate their suffering.</td>
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<tr>
<td><strong>Islam</strong></td>
<td>Illness is considered a test of faith but not a punishment. The sick are encouraged to find healing and doctors to thoroughly seek a remedy. But ultimately God allows for healing; doctors and remedies are only means. When death nears, place the patient on his side, with his head facing the Qibla. If that is not possible, then place him lying on his back with his feet towards the Qibla. When suffering becomes intense, people in the room recite the Surah Ya-Sin and recite the profession of faith.</td>
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<tr>
<td><strong>Buddhism</strong></td>
<td>Illness is inherent in the nature of living beings. It is the result of negative actions in the past and, at the same time, an opportunity to be free of them. The patient should be in an atmosphere that supports peace of mind. Sometimes, Buddhists give up painkillers to preserve a certain lucidity of conscience before death, which allows them to meditate.</td>
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<td><strong>Hinduism</strong></td>
<td>Some consider Western medicine to numb the mind and pollute the body. Thus, they may resist treatment. When death is imminent, the patient is placed with his head facing eastward and the family may request that a lamp be lit near his head, asking those around him to focus on his mantra. The body is left in the foyer or on the floor of the hospital facing south.</td>
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<tr>
<td><strong>Chinese traditions</strong></td>
<td>The rupture of the harmony in human relationships (Confucianism) or of human beings with nature (Taoism) manifests itself in disease since, in Chinese medicine, health is a state of physical and spiritual harmony with nature. Before death, the dying must see each of his relatives. Death is announced in community. The body is bathed in fresh water to make the trip to the next world comfortable. Relatives light an oil lamp at the feet of the body to illuminate their loved one’s way to heaven and immortality.</td>
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healthcare providers are able to offer personalized quality care for the patient and the family as the end nears. Recognizing that a patient is nearing death helps professionals adapt physical care and symptom control, in addition to helping them accompany the emotional and spiritual process that facing death involves, whether as the patient or a family member.

Caring for patients and their families at the end of life is challenging, and it is important that healthcare professionals incorporate activities that promote self-care and resilience to avoid falling into burnout or compassion fatigue.

For reflection
The way in which the end of life unfolds leaves an indelible mark on those who accompany the dying, thus healthcare professionals have a fundamental role in ensuring that companions’ memories are full of peace and, as much as possible, the absence of suffering.

References


