

The last hours and days of life: a biopsychosocial–spiritual model of care

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Abstract

Patients who are entering the last phase of their illness and for whom life expectancy is short, have health needs that require particular expertise and multidisciplinary care. A combination of a rapidly changing clinical situation and considerable psychosocial and spiritual demands pose challenges that can only be met with competence, commitment and human compassion. This article is concerned with the definition of suffering, recognition of the terminal phase and application of the biopsychosocial–spiritual model of care where family physicians play an important role in the community.

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Key words: biopsychosocial-spiritual care, dying, family medicine, good death, palliative care, suffering

Introduction

I think the best physician is the one who has the providence to tell the patients according to his knowledge the present situation, what has happened before and what is going to happen in the future. Hippocrates

Palliative care has encouraged medicine to be gentler in its acceptance of death, yet medical services in general continue to regard death as something to be resisted, postponed or avoided.¹

Both family medicine and palliative medicine provide continuing and comprehensive health care for the individual and family. They integrate the biologic, clinical and behavioral sciences, encompass all ages, sexes, each organ system and every disease entity. Consequently, both specialties are drawn toward a model that encompasses the course of illness and is unified by ‘quality of life’ goals.² Quality of life comprises structural, economical and social problems that lie beyond the immediate influence of clinical medicine.³ To attend to suffering rather than quality of life may seem to be a more realistic aim for palliative care.

Suffering stems from conditions or events that threaten the integrity of a person as a complex psychological and social entity. Suffering is universal and pervasive. As professionals we cannot prevent or stop suffering once it has begun but can reasonably expect to ease it.

Suffering is a unique individual experience; others can empathize but never completely share. Suffering is a complex state of being that involves our whole being, memory, insight and intelligence. Experiencing suffering may help individuals to move on in their lives ...they may emerge as slaves of circumstances or in some sense, masters of their souls.⁴

Family physicians have the understanding of the nature of suffering, the patients’ and their family members’ response to illness (particularly their ideas, feelings and expectations) and of the impact of illness on their lives. A holistic, comprehensive, patient-centred approach to the patient’s physical and psychosocial wellbeing, a focus on the family, continuity of care, and an emphasis on quality of life are four important principles that make the family physician uniquely suited to care for the terminally ill.⁵

Biopsychosocial–spiritual model of care

Palliative care developed as a reaction to the attitude that ‘there is nothing more we can do for you’ leaving the patient and family with a sense of abandonment, hopelessness and despair. This is never true – there is always something that can be done.⁶

The healing professions should serve the needs of patients as whole persons. Genuine holistic health care must address the totality of the patient’s relational existence – physical, psychological, social and spiritual.⁷

Making a diagnosis of dying (the last hours or days of life)

Making a diagnosis of dying is often a complex process, discussing with patient and family when recovery is uncertain, rather than giving them false hope. This shows a strength in the doctor–patient relationship and helps to build trust.

Observe the following signs as indicators of gradual, progressive and irreversible decline in the dying phase:

- profound weakness/gaunt appearance;
- poor concentration/drowsiness/disorientation;

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- diminished oral intake/difficulty taking oral medication;
- skin color changes/temperature change at extremities.

Ellershaw *et al.*⁸ have listed down some barriers to ‘making a diagnosis of dying’. Failure to recognize key symptoms and signs of dying, disagreement about the patient’s condition or uncertainty of diagnosis, poor communication skills, lack of knowledge of how to handle the situation and concerns about limited treatment plan and resuscitation, may pose barriers in making diagnosis of dying. Cultural, spiritual and medico-legal issues may contribute further difficulties.

Failure to make a diagnosis of dying may lead to a distressing and undignified death for the patient with uncontrolled symptoms. Patients and relatives may get conflicting messages from multi-professional teams that may result in a loss of trust, dissatisfaction and formal complaints about care. Cardiopulmonary resuscitation may be inappropriately initiated; cultural and spiritual needs of the patient and relatives may not be addressed appropriately.

Physical care

Professional experience combined with knowledge of the patient’s previous symptoms, concerns and wishes should be used as basic premises for a sensitive systematic assessment of the patient’s physical problems (**Table 1**).

Table 1 Physical assessment checklist¹⁸

Symptoms	Physical signs
Pain	Agitation/confusionseizures
Shortness of breath	Death rattles
Dry mouth	Stomatitis
Constipation	Faecal impaction/spurious diarrhoea
Difficulties in micturition	Distended bladder/urinary incontinence
Immobility	Pressure sores

As patients become weaker, they find increasing difficulty taking oral drugs. Drugs such as antihypertensives, corticosteroids, antidepressants and hypoglycemics are often no longer needed. Essential ones such as opioids, anxiolytics, antiemetics and anticonvulsants should be converted to a subcutaneous route with a syringe driver used for continuous infusion.

Inappropriate interventions, including X-rays, blood tests, measurement of vital signs and continuous electrocardiography monitoring, should be discontinued. Artificial fluids in the dying phase is of limited benefit⁹ and cardiopulmonary resuscitation is a futile and inappropriate medical treatment.¹⁰ Forced food or fluids can be very distressing to a dying patient, because it increases hard-to-control secretions, or induce nausea, vomiting, diarrhea or edema.

Good nursing care and good symptom control should be carried out. Attention to mouth and eye care is essential. Family members can be encouraged to give sips of water or moisten the patient’s mouth with a sponge. Catheterization may be needed in the presence of urinary incontinence or retention but invasive procedures for bowel care are rarely needed.

Ethical issues of a limited treatment plan, terminal sedation, double effect for uncontrolled pain, dyspnoea

and other physical symptoms, may need to be addressed and discussed with the patient and family members.

Distressing acute terminal events such as massive hemorrhage from tumors around major blood vessels and acute airway obstruction from mediastinal and tracheal tumors can be anticipated. Patient, carers and professionals can plan ahead to minimize distress. Since these events cause death within minutes, staying with the patient is the most important aspect of care. Drugs are used to reduce fear, pain and level of awareness of the patient.

Models of community care should be developed to ensure 24-hour service to support patients dying at home and to prevent inappropriate admission to the hospital.

Psychological care

Patients’ insights into their conditions and issues relating to dying and death should be explored appropriately and sensitively. Truth may hurt but deceit hurts even more.¹¹ Patients need to plan and make decisions about the place of their death, put their affairs in order, say goodbye or forgive old adversaries and be protected from embarking on futile therapies.

Intimate encounters with the patient implies the ability to accept the psychological and physical intimacy of exchanges, as in the recognition of one’s own fears, failures and vulnerability. Paradoxically, showing someone we are helpless, deeply moved or vulnerable helps the patient to accept their human condition and the difficulty of their fate. It is the best way of making them feel that they are not alone in their suffering¹² The willingness to be intimate allows us to share the one thing we all value, genuine human warmth.

Social care

The family’s insight into the patient’s condition should be assessed. They should be told of the clinical expectation that the patient is dying and will die. Relatives and friends will have the opportunity to ask questions, stay with patient, say their goodbyes, contact relevant people and prepare themselves for the death.

Non-abandonment is one of a physician’s central ethical obligations to the patient. There is a world of difference between facing an uncertain future alone and facing it with a committed, caring, knowledgeable physician who jointly seeks solutions to problems with patients throughout their illnesses and will not shy away from difficult decisions when the path is unclear.¹³

Spiritual care

Healing the whole person means restoration of right relationships intrapersonally (relationships between the various parts of the body and biochemical processes between the mind and the body) and extra-personally (relationships between the patient and the environment/patient and transcendancy). Symptomatic treatment restores the relationship between the body and the mind while facilitation of reconciliation with family and friends is healing the relationship between the human person at the end of life and the environment.⁷

No matter what the patient’s spiritual history is, dying raises for the patient questions about the value and meaning of his or her life, suffering and death. For the dying individual to experience love, to be understood as valuable and to accept the role of teacher by providing valuable lessons to those who survive are all experiences of healing.⁷

At the end of life when standard medical approaches have lost their curative, alleviating and life-sustaining efficacy, the only healing possible may be spiritual. Clinicians have the obligation to ensure that a spiritual assessment is performed for each patient and to recognize

the value of appropriate referral.

A good death

Most people in developed countries today die in the hospital, even though they say they would prefer to die at home. Death has been medicalized, professionalized and sanitized, thus, it is now alien to most people's daily life.¹⁵

What is a good death or rather, dying well? By definition, death is beyond life and the ability of the living to know, while dying is part of living. The latter preserves the subjective nature of the personal experience. Culture, religion and secularism influence ideas about good death.¹⁵ The shift from seeing death as a time of physical misery and emotional distress to understanding it as a part of full and healthy living, contributes to a healthy re-incorporation of the value of dying within the mystery of life.¹⁶

Some of the principles of good death as identified by the authors of the final report on 'The Future of Health and Care of the older people' include awareness of approaching death and knowledge of what to expect in the dying process, good symptom control, availability of spiritual and emotional support, ability to make decisions with regard to care and place of death, to have time to settle unfinished business and to say goodbye to loved ones; at the same time not to have life prolonged pointlessly.¹⁷

Conclusion

Ensuring a good death for all is a major challenge not only for healthcare professionals but also for society. Family practice through palliative care services delivers direct patient care and should also have an advisory and educational role to influence the quality of care in the community.

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