



COUNCIL OF SOUTH AFRICA

GUIDELINES FOR GOOD PRACTICE IN THE HEALTH CARE PROFESSIONS

ETHICAL GUIDELINES ON PALLIATIVE CARE

EDITED BY THE HUMAN RIGHTS, ETHICS AND PROFESSIONAL PRACTICE

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THE INTENT OF PROFESSIONAL GUIDELINES

Practicing as a health care professional is based upon a relationship of mutual trust between patients and health care practitioners. The term "profession" means "a dedication, promise or commitment publicly made".¹ To be a good health care practitioner, requires a life-long commitment to sound professional and ethical practices and an overriding dedication to the interests of one's fellow human beings and society. In essence, the practice of health care professions is a moral enterprise. The HPCSA presents the following ethical guidelines to guide and direct the practice of health care practitioners. These guidelines form an integral part of the standards of professional conduct against which a complaint of professional misconduct will be evaluated.

[Note: The term "health practitioner" in these guidelines refers to persons registered as such with the HPCSA].

¹ Pellegrino, ED. Medical professionalism: Can it, should it survive? *J Am Board Fam Pract* 2000; 13(2):147-149 (quotation on p. 148).

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1 PREAMBLE

- 1.1 The World Health Organisation (WHO) defines palliative care as ‘an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’.
- 1.2 Palliative care:
- 1.2.1 provides relief from pain and other distressing symptoms;
 - 1.2.2 affirms life and regards dying as a normal process;
 - 1.2.3 intends neither to hasten or postpone death;
 - 1.2.4 integrates the psychological and spiritual aspects of patient care;
 - 1.2.5 offers a support system to help patients live as actively as possible until death;
 - 1.2.6 offers a support system to help the family cope during the patient’s illness and in their own bereavement;
 - 1.2.7 uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
 - 1.2.8 will enhance quality of life, and may also positively influence the course of illness;
 - 1.2.9 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.’
- 1.3 With the spread of HIV, South Africa shoulders a significant disease burden, and the Department of Health’s *National Policy Framework and Strategy on Palliative Care 2017–2022* acknowledges the importance of integrating palliative care as an essential component of health service delivery.

2 WHEN IS PALLIATIVE CARE PROVIDED

- 2.1 Palliative care is provided to those living with and dying from any advanced, progressive and incurable condition regardless of age or setting.
- 2.2 Palliative care is provided throughout the journey, from diagnosis to end of life.

- 2.3 As the patient's disease progresses, the need for palliative care will increase and the level of curative treatment will decrease.
- 2.4 The WHO recognises that palliative care is required for a wide range of diseases, including but not limited to:
- 2.4.1 Cardiovascular disease;
 - 2.4.2 Cancer;
 - 2.4.3 Chronic respiratory diseases;
 - 2.4.4 AIDS;
 - 2.4.5 Diabetes;
 - 2.4.6 Kidney failure;
 - 2.4.7 Chronic liver disease;
 - 2.4.8 Multiple sclerosis;
 - 2.4.9 Parkinson's;
 - 2.4.10 Rheumatoid arthritis;
 - 2.4.11 Neurological disease;
 - 2.4.12 Dementia;
 - 2.4.13 Congenital anomalies;
 - 2.4.14 Drug-resistant tuberculosis

3 WHY IS PALLIATIVE CARE PROVIDED

- 3.1 Palliative care is recognised by the United Nations as part of the human right to health.
- 3.2 The goal of palliative care is the achievement of the best possible quality of life for patients and their families, even if life expectancy is short.
- 3.3 Palliative care is an extension of the South African Constitutional rights of human dignity and access to healthcare.
- 3.4 The Constitution also guarantees the right to basic healthcare for children which includes the provision of paediatric palliative care, and not merely access to such care, as is the case with adults.
- 3.5 Evidence suggests that palliative care can reduce unnecessary hospitalisation and use of health care services, which lessens the costs of the health system.

4 WHO PROVIDES PALLIATIVE CARE?

- 4.1 Palliative care is provided by all health practitioners and other health care professionals working with people with life-threatening conditions.

- 4.2 Health practitioners providing palliative care should possess the requisite knowledge, skills and attitudes to meet the physical, psychological, practical, social and spiritual needs of their patients.
- 4.3 Health practitioners providing palliative care should keep their skills up to date.
- 4.4 As a result of the current inadequate provision of palliative care services in the country, the National Department of Health has developed a strategy to increase the scope of palliative care services in its *National Policy Framework and Strategy on Palliative Care 2017-2022*.
- 4.5 It is imperative that all healthcare professionals play an advocacy role on the importance of palliative care services in the public health sector and for palliative care to be included in the curriculum of health practitioners.

5 WHERE IS PALLIATIVE PROVIDED

- 5.1 Palliative care can be provided in public, private facilities and patient's homes.
- 5.2 According to the National Department of Health National Policy Framework and Strategy on Palliative Care the different palliative care service delivery settings, are:
 - 5.2.1 Home-based palliative care;
 - 5.2.2 Mobile outreach services;
 - 5.2.3 Outpatient care;
 - 5.2.4 Inpatient palliative care facilities;
 - 5.2.5 Hospital based palliative care teams;
 - 5.2.6 Day care palliative services;
 - 5.2.7 Frail care and other care homes;
 - 5.2.8 Workplace programs; and
 - 5.2.9 Correctional services.

6 HOW PALLIATIVE CARE IS USED

- 6.1 Health practitioners must deliver care in a manner that upholds these principles, and the rights and values of the patient and their family, even in the midst of a dehumanising environment or in noisy facilities/areas”
- 6.2 Health practitioners providing palliative care should apply the bioethical principles of autonomy, beneficence, non-maleficence and justice that require respect for the worth, dignity and human rights of their patients when managing them.
- 6.3 Patients and their families faced with life-threatening illnesses, are likely to be vulnerable and anxious during this time, health practitioners providing palliative care will find the bioethical principles helpful in guiding decision-making.
- 6.4 Health practitioners must establish trust in the patient and their family through availability, listening, providing honest answers, and having a non-judgmental attitude.
- 6.5 In administering palliative care, health practitioners should also adhere to the HPCSA’s general ethical guidelines and the National Department of Health’s *National Policy Framework and Strategy on Palliative Care 2017–2022*.

7 PATIENT AUTONOMY AND PALLIATIVE CARE

7.1 MEANING OF PATIENT AUTONOMY

- 7.1.1 Patient autonomy recognises the ability of patients to make decisions for themselves regarding palliative care, and is in accordance with the constitutional rights to human dignity and bodily and psychological integrity.
- 7.1.2 Patient autonomy presumes that patients have the required information and capacity to make rational decisions about palliative care and that the circumstances allow them to give an informed consent.
- 7.1.3 When obtaining informed consent from patient’s health practitioners providing palliative care must comply with the National Health Act 61 of 2003 and the HPCSA’s guidelines on *Seeking Patients’ Informed Consent: The Ethical Considerations* (Booklet 9).

7.2 CAPACITY TO CONSENT TO PALLIATIVE CARE

- 7.2.1 Health practitioners providing palliative care should assume that every mentally competent adult patient and every sufficiently mature child patient over the age of 12 years have legal capacity to consent to, or oppose, medical interventions - unless it is shown that they clearly cannot understand the information given to them.
- 7.2.2 It is for the patient, and not the health practitioner providing palliative care, to determine what is in the patient's best interests.
- 7.2.3 Although health practitioners providing palliative care may recommend a course of treatment, they may not pressurize or manipulate the patient into accepting their advice.
- 7.2.4 Health practitioners providing palliative care must understand and respect that a patient's decision-making may be guided by values, customs and beliefs different from the practitioner's.
- 7.2.5 If a mentally and legally competent patient, who is fully informed of the benefits and risks of treatment, consents to or refuses a particular course of treatment, their decision must be respected, even if the health practitioner providing palliative care believes it will result in serious harm or even death.
- 7.2.6 Respecting patient autonomy, however, does not mean that patients are entitled to illegal, unethical or medically inappropriate treatment simply because they have requested it.
- 7.2.7 Health practitioners providing palliative care should only recommend and provide treatment options that are both scientifically grounded, and are, in their best medical judgement, reasonably expected to yield the intended benefits.
- 7.2.8 Should a patient request illegal, unethical or medically inappropriate treatment, the health practitioner providing palliative care should reassure them and their family of the sound treatment options available to the patient - subject to consent by the latter or his or her surrogate.

7.3 ADVANCED PALLIATIVE CARE PLANNING

- 7.3.1 Patient autonomy includes the need to protect patients with diminished autonomy.
- 7.3.2 Health practitioners providing palliative care should encourage competent patients to indicate their wishes regarding treatment options in an advance directive, such as a living will, and in such a document or a written nomination of a surrogate in terms of the National Health Act, to mandate a person to make decisions on their behalf if they become incapacitated.
- 7.3.3 An advance directive helps ensure consideration of the patient's values and preferences, even when they lack the capacity to express them.
- 7.3.4 Health practitioners providing palliative care should record any conversations with a competent patient regarding their goals for care in their medical records, and should review such goals regularly and as circumstances change.
- 7.3.5 The advance directive or other records of the patient's wishes should be kept inside the patient's file, with stickers indicating that the advance directive is available for ease of reference.
- 7.3.6 The *Patient's Rights Charter* introduced by the National Department of Health requires patients to advise their healthcare provider of their wishes regarding death, and to take care of any medical records in their possession – see *HPSCA National Patient's Rights Charter (Booklet 3)*.
- 7.3.7 An advance directive should include the following:
- 7.3.7.1 the patient's wishes and preferences with regard to future treatment;
 - 7.3.7.2 any beliefs or values that may influence the patient's decisions and preferences;
 - 7.3.7.3 the family members or surrogates that should be involved in decision-making;
 - 7.3.7.4 any interventions that should be considered and implemented in case of emergency, such as CPR;
 - 7.3.7.5 the patient's preferred place of care; and
 - 7.3.7.6 the patient's need for religious, spiritual, and other personal support.
- 7.3.8 As is the case with life-threatening illness, towards the end-of-life, it is not uncommon for a patient's mental capacity to be impaired.
- 7.3.9 When a patient becomes mentally incompetent, and an advance directive is available, health practitioners providing palliative care should give effect to the patient's wishes – provided that the directive is applicable to the present circumstances and represents the patient's current wishes.

- 7.3.10 If no advance directive is available, and no surrogate has been appointed, the health practitioner providing palliative care must, in consultation with the patient's family, determine the treatment option that is in the patient's best interest.
- 7.3.11 In determining an incapacitated patient's best interests during the decision-making process, the health practitioner providing palliative care must consider:
- 7.3.11.1 the medically appropriate treatment options available;
 - 7.3.11.2 any previous requests of the patient when he or she was mentally competent;
 - 7.3.11.3 what the practitioner knows about the background and preferences of the patient, in consultation with the patient's healthcare team;
 - 7.3.11.4 information regarding the patient's values, beliefs and preferences from third parties who may have other knowledge of the patient due to their relationship (e.g. a parent, sibling, child or spouse);
 - 7.3.11.5 where more than one treatment option is reasonably in the patient's best interests, the practitioner must, in consultation with the patient or the patient's surrogate, choose the option that least restricts the patient's future choices.
- 7.3.12 The health practitioner providing palliative care must take appropriate action in the case of illegal, unethical or inappropriate behaviour that jeopardises the best interests of the patient.

7.4 COMMUNICATION

- 7.4.1 Health practitioners providing palliative care must communicate effectively and timeously with the patient and their family, and the rest of the palliative care team.
- 7.4.2 Health practitioners providing palliative care must take into account the emotional toll that the circumstances regarding the use of palliative care may have on the patient and their family, and should communicate with them in an empathic and understandable manner.
- 7.4.3 If a patient's communication skills are compromised by their illness, health practitioners providing palliative care must communicate with the patient through verbal and non-verbal means.
- 7.4.4 Irrespective of the patient's level of consciousness, health practitioners providing palliative care should communicate any proposed interventions to the patient, based on the understanding that hearing is the last sense to die.

8 BENEFICENCE AND PALLIATIVE CARE

8.1 MEANING OF BENEFICENCE

- 8.1.1 The principle of beneficence requires the health practitioner providing palliative care to do good for their patients.
- 8.1.2 The health practitioner providing palliative care must weigh up the costs, risks and benefits of particular forms of palliative care and recommend those that are most beneficial to the patient, while leaving the final decision to the patient or their surrogate.
- 8.1.3 From the moment of diagnosis of a life-threatening condition, the health practitioner providing palliative care must monitor the patient and keep abreast of relevant medical advancements, and ensure that their knowledge and understanding of palliative care is up to date.
- 8.1.3 If the health practitioner providing palliative care is not able to manage severe or refractory symptoms, it is important for such practitioner to refer the patient to a health practitioner who is qualified to do so.

8.2 WITHHOLDING OR WITHDRAWAL OF TREATMENT

- 8.2.1 The health practitioner providing palliative care is required to balance the intended benefits of palliative care against the risks and burdens of treatment.
- 8.2.2 In some instances, the quality of life which follows palliative treatment may raise questions as to whether such treatment is in the best interests of the patient.
- 8.2.3 Treatment can legally and ethically be withheld or withdrawn if the patient refuses further treatment, further treatment is futile, or if it is no longer in the patient's best interests (e.g. when treatment merely prolongs the dying process).

- 8.2.4 The decision to withhold or withdraw treatment must not be taken lightly, and must be considered by the health practitioner providing palliative care in consultation with the patient and their family.
- 8.2.5 When the possibility of withholding or withdrawal of treatment arises, the health practitioner providing palliative care should discuss with the patient and their family, arrangements for basic care and other appropriate treatments.
- 8.2.6 At end-of-life, discussions about withholding or withdrawal of treatment should include plans to manage the final stages of the lives of patients, before they are incapacitated, and include personal matters such as wills, as well as any other concerns that patients believe are important to ensure that they die with dignity.
- 8.2.7 When dealing with end-of-life decisions health practitioners providing palliative care must approach the withholding or withdrawal of treatment in a manner consistent with the HPSCA's *Guidelines for the Withholding and Withdrawal of Treatment* (Booklet 7).

9 NON-MALEFICENCE AND PALLIATIVE CARE

- 9.1 Non-maleficence requires health practitioners providing palliative care not to harm their patients and complements beneficence and the balancing of risks and benefits.
- 9.2 Euthanasia and doctor-assisted suicide are often perceived as inconsistent with the principle of non-maleficence.
- 9.3 Euthanasia and doctor-assisted suicide are presently prohibited under South African law, and the courts frequently do not distinguish between the two when it comes to culpability.
- 9.4 Euthanasia is the employment of any medical intervention primarily aimed at ending a patient's life (e.g. giving a patient lethal drug or injection).
- 9.5 Doctor-assisted suicide occurs when the health practitioner provides the means necessary to enable the patient to end their own life (e.g. handing a patient a lethal drug or prescribing a lethal drug for a patient).
- 9.5 At present, South African courts have acknowledged that both euthanasia and doctor-assisted suicide are fundamentally incompatible with a practitioner's role as a healer, and a practitioner guilty of either is regarded as having acted unethically and unlawfully.

- 9.6 Due to the stress of extreme pain and the prospect of facing a life-threatening illness, a patient may request a health practitioner providing palliative care to end their life.
- 9.7 The role of the health practitioner providing palliative care in this instance is to discuss the concerns and fears that have led to the patient's request, and to provide alternate approaches to address these issues.
- 9.8 When medical treatment relieves suffering - but has the effect of accelerating the dying process - the health practitioner providing palliative care must consider whether the palliative benefits justify the shortened life expectancy before pursuing that course of treatment.
- 9.9 Palliative care treatment where life is shortened as a side effect, is not regarded as unlawful or unethical – provided the patient or their surrogate has given informed consent.

10 JUSTICE OR FAIRNESS AND PALLIATIVE CARE

- 10.1 The World Health Organisation (WHO) states that 'palliative care needs to be provided in accordance with the principles of universal health coverage'.
- 10.2 This means that everyone, 'irrespective of income, disease type or age, should have access to a nationally determined set of basic health services, including palliative care' and is consistent with the South African Constitution.
- 10.3 The WHO also states that 'financial and social protection systems need to take into account the human right to palliative care for poor and marginalized population groups'.
- 10.4 Palliative care should be available to all patients from birth until death, and should be accessible at all levels of the health care service and this is what the National Department of Health's *National Policy Framework and Strategy on Palliative Care 2017–2022* aspires to do.
- 10.5 Health practitioners providing palliative care must treat patients equally and without discrimination.
- 10.6 According to the National Department of Health's *National Policy Framework and Strategy on Palliative Care 2017–2022* health practitioners providing palliative care must give special consideration to the following groups of people in their provision of palliative care services:

- 10.6.1 Persons with disabilities;
 - 10.6.2 Children (including neonates and adolescents);
 - 10.6.3 Older persons including those living in residential care settings and frail care facilities;
 - 10.6.4 Asylum seekers and refugees;
 - 10.6.5 Inmates of correctional services; and
 - 10.6.6 Persons in long term care facilities such as TB and psychiatric hospitals or residential care facilities.
- 10.6 Palliative care practitioners should use the country's limited health care resources responsibly, fairly and effectively to ensure all patients receive appropriate palliative care.

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