

CODE OF ETHICS
for
HOSPICE PALLIATIVE CARE ASSOCIATION OF SOUTH AFRICA

EXECUTIVE SUMMARY

Hospice care consists of a holistic approach that takes care of the physical, psycho-social and spiritual aspects of the people with life threatening illness and their families through a multi-professional approach. Hospice personnel's primary commitment is to the patient.

Hospice care promotes the alleviation of suffering, and does not support euthanasia. The patient and family in consultation with the professional team will determine the provision, withholding or withdrawing of treatment as appropriate. There is always an appropriate care plan for every person.

All Hospice personnel should practice compassion and respect for the dignity, worth, and uniqueness of every individual, irrespective of race, religion, gender, sexual orientation, social or economic status, personal attributes, or the nature of the illness. Furthermore, they should also promote, advocate for, and strive to protect the safety and rights of the patient.

Hospice personnel should owe the same duties to self as to others, including the responsibility to preserve integrity and safety, to maintain competence, and to continue personal and professional growth.

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Definitions

- *Ethics* is used to refer to reasons and ways of understanding and examining moral life and how one ought to act.
- In general, the word *moral* overlaps with *ethical* but refers more to the norms (personal belief and cultural values) we employ to determine what is right and wrong human conduct.
- *Privacy* refers to a person's right to disclose information or of being private (secluded).
- *Confidentiality* means not disclosing any information shared in trust by another without the confider's permission.
- The Code of Ethics uses the terms *patient* and family member to refer to recipients of Hospice care.
- *Family* includes close family members, significant others and extended family.
- The term *practice* refers to the actions of Hospice personnel in whatever role they fulfil, whether as direct patient care provider, educator, researcher, administrator, policy developer, fundraiser or other. Thus, the values and obligations expressed in this Code of Ethics apply to hospice personnel in all roles and settings.
- *Members* refer HPCA member hospices.
- *Hospice personnel (or personnel)* refers to hospice staff and volunteers.
- A *proxy* refers to a surrogate decision maker who is authorised by the individual in question to reach decisions for doubtfully autonomous or nonautonomous patients who are no longer competent to make a decision.

PREFACE

The Hospice Palliative Care Association subscribes to the WHO definition of palliative care (see Appendix A).

Ethics is an integral part of the foundation of Hospice which has a distinguished history of concern for the welfare of people with life-threatening illness and for social integrity (wholeness or completeness). Hospice care consists of a holistic approach that takes care of the physical, psycho-social and spiritual aspects of the people with life threatening illness and their families through a multi-professional approach. Hospice care is promotes the alleviation of suffering, and does not support euthanasia.

The patient and family in consultation with the professional team will determine the provision, withholding or withdrawing of treatment as appropriate. There is always an appropriate care plan for every person.

Hospice recognises that dying is a natural process that should neither be hastened nor postponed. Through appropriate care, the promotion of a caring community and sensitivity to their needs, patients and families are enabled to attain a degree of mental and spiritual preparation for death that is satisfactory to them. Hospice furthermore recognises grief as a normal response to loss and therefore supports families of patients during their bereavement.

Hospice personnel act to change those aspects of social structures that detract from respect and dignity of the terminally ill. Member hospices and their personnel are expected to embrace and adhere to the ideals and moral norms of the Hospice family.

Commission

The HPCA Ethics Committee has been established to deal with the need for an appropriate body to address and discuss ethical care issues for/with patients, and to develop a comprehensive Code of Ethics. (see Appendix B) The aim of such a Code of Ethics is to make explicit the primary goals, values, and obligations of hospice personnel who are responsible for those in Hospice care.

The Code of Ethics establishes the ethical obligations and expectations of ethical behaviour of every individual who is involved in the work of Hospice. It is a dynamic document, and as the social context changes, changes to the Code of Ethics are also necessary.

The Code of Ethics describes the fundamental values and commitments of the member hospices and their personnel (staff and volunteers); addresses boundaries of duty and loyalty, and aspects of duties beyond individual patient encounters.

There are interpretive statements that provide greater specificity for practice and are responsive to the contemporary context of Hospice care. The Code of Ethics provides a framework for ethical analysis and decision-making and establishes the ethical standard for the Hospice Palliative Care Association of South Africa (HPCA) and member hospices. It is only subject to revision or amendment by formal process of the Ethics Committee of the HPCA.

The Code of Ethics is a reflection of the proud ethical heritage of Hospice care, a guide for members now and in the future.

STATEMENT 1

Hospice personnel should practice compassion and respect for the inherent dignity, worth and uniqueness of every individual. There shall be no unfair discrimination directly or indirectly on the basis of race, religion, gender, sexual orientation, social or economic status, personal attributes, disability or the nature of the illness.

Interpretive statements

1.1. Respect for human dignity

A fundamental principle that underlies all care practices is respect for the worth, dignity and human rights of every individual. Hospice personnel should take into account the needs and values of all patients and family members in hospice care.

1.2. Relationships to patients and family members

The need for compassionate care is universal, transcending all individual differences. Hospice personnel establish relationships and deliver services with respect for human needs and values, and without prejudice. An individual's lifestyle, value system, religious beliefs and sexual orientation shall not influence the level of care they receive. Such consideration does not suggest that personnel necessarily agree with or condone certain individual choices, but that personnel respect the patient or family member as a person with individual choices.

1.3. The nature of health problems

Hospice personnel will respect the worth, dignity and rights of all human beings irrespective of the nature of the illness. The worth of the person is not adversely affected by disease, disability, functional status, or proximity to death. This respect extends to all who require the services of Hospice. The measures hospice personnel take to care for the patient enable the patient to live with as much physical, emotional, social and spiritual dignity as possible. Hospice care aims to maximize the values that the patient has treasured in life and extends supportive care to the family and significant others. Hospice care is directed toward meeting the comprehensive needs of patients and their families across the continuum of care.

Hospice members are leaders and advocates for the delivery of dignified and humane care during all stages of palliative care. Hospice personnel actively participate in assessing and assuring the responsible and appropriate use of interventions to relieve suffering and to

minimize unwarranted or unwanted treatment. Advance directives should be taken into account. Hospice personnel should provide interventions to relieve pain and other symptoms in the dying patient, even when those interventions entail risks of hastening death. However, under no circumstance may hospice personnel act with the sole intent of ending a patient's life even though such action may be motivated by compassion, respect for patient autonomy and quality of life considerations.

1.4. The right to self-determination

Respect for human dignity requires the recognition of patient rights, particularly the right to self-determination. Self-determination, also known as autonomy, is the philosophical basis for informed consent in health care. Patients have the moral and legal right to determine what will be done with their own person; to be given accurate, complete, and understandable information in a manner that facilitates an informed decision; to be assisted with weighing the benefits, burdens, and available options in their treatment, including the choice of no treatment; to accept, refuse, or terminate treatment without undue influence, duress, coercion, deceit, or penalty; and to be given necessary support throughout the decision-making and treatment process. Such support would include the opportunity to discuss and make decisions with family, significant others, knowledgeable hospice personnel and other health professionals.

Patients should be involved in planning their own health care to the extent they are able and choose to participate. Hospice personnel have an obligation to be knowledgeable about the moral and legal rights of all patients to self-determination and preserve, protect, and support those rights by assessing the patient's comprehension of both the information presented and the implications of decisions. In situations in which the patient lacks the capacity to make a decision, a designated proxy decision-maker should be consulted. The role of the proxy is to assist in the decision-making process based upon the patient's previously expressed wishes and known values.

In the absence of a designated proxy decision-maker, decisions should be made in the best interests of the patient, considering the patient's personal values to the extent that they are known and in accordance with societal norms and values. Hospice personnel support patient self-determination by participating in discussions with proxies, providing guidance and referral to other resources as necessary, and identifying and addressing problems in the decision-making process.

Support of autonomy in the broadest sense, also includes recognition that people of some cultures place less weight on individualism and choose to defer to family or community

values in decision-making. Respect, not just for the specific decision and the patient's method of decision-making, is consistent with the principle of autonomy.

1.5. Equality

All patients and their families are in accordance with Clause 9 of the Bill of Rights as summarized in the Constitution of South Africa equal in receiving Hospice care. Hospice will not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth.

1.6. Relationships with colleagues and others

The principle of respect for persons extends to all individuals with whom hospice personnel interact. Hospice personnel strive to maintain compassionate and caring relationships with colleagues, students and others, with a commitment to the fair treatment of individuals, respect and compassion, to integrity-preserving compromise, and to resolving conflict.

This standard of conduct precludes any and all prejudicial actions, any form of harassment or threatening behaviour, or disregard for the effect of one's actions on others. Hospice personnel must value the distinctive contribution of individuals or groups, and collaborate to meet the shared goal of providing quality palliative care.

STATEMENT 2

Hospice personnel's primary commitment should be to the patient.

Interpretive statements

2.1. Primacy of the patient's interests

Hospice personnel's primary commitment is to the recipient of Hospice care. Where conflict of interest exists/arises between the patient and his or her family, commitment remains with the patient.

2.2. Conflict of interest for members

Hospice personnel are frequently put in situations of conflict arising from competing loyalties in the workplace, including situations of conflicting expectations from patients, families, physicians and colleagues. Hospice personnel must examine the conflicts arising between their own professional values, the values and interests of others who are also responsible for patient care and care decisions, as well as those of patients. Hospice personnel must strive to resolve such conflicts in ways that ensure patient safety, guard the patient's best interests and preserve the professional integrity of all personnel involved.

2.3. Collaboration

Collaboration is not just cooperation, but the concerted effort of individuals and groups to attain a shared goal. In Hospice this is very important since patients are approached by a team and not by separate individuals. By its very nature, collaboration requires mutual trust, recognition, and respect among the care team, shared decision-making about patient care, and open dialogue among all parties who have an interest in the patient. All hospice personnel should work to assure that the relevant parties are involved and have a voice in decision-making about patient care issues. Personnel should ensure that the questions that need to be addressed are asked and that the information needed for informed decision-making is available and provided. Hospice personnel should actively promote the collaborative multi-disciplinary planning required to ensure the availability and accessibility of quality care to all persons with life-threatening illness.

2.4. Professional boundaries

When acting within their roles as professionals, the hospice personnel recognize and maintain boundaries that establish appropriate limits to relationships. While the nature of care work has an inherently personal component, staff-patient relationships and staff-colleague relationships have, as their foundation, the purpose of alleviating suffering, and seeing to the emotional and spiritual needs of the patients. The intimate nature of care and the involvement of hospice personnel are important and sometimes highly stressful life events and the mutual dependence of colleagues working in close concert all have the potential for blurring the limits of professional relationships. Maintaining authenticity and expressing oneself as an individual, while remaining within the bounds established by the purpose of the relationship can be especially difficult in prolonged or long-term relationships. In all encounters, hospice personnel are responsible for retaining their professional boundaries. When those professional boundaries are jeopardized, personnel should seek assistance from peers or team leaders or take appropriate steps to remove themselves from the situation.

STATEMENT 3

Member hospices and hospice personnel should promote, advocate for, and strive to protect the safety and rights of the patient.

Interpretive statements

3.1. Privacy

Hospice personnel must safeguard and respect the patient's right to privacy. The need for Hospice care does not justify unwanted intrusion into the patient's life. Personnel advocate for an environment that provides for sufficient physical privacy, including privacy for discussions of a personal nature, and policies and practices that protect the confidentiality of information. The consideration for privacy applies to clinical, teaching and promotional activities.

3.2. Confidentiality

Associated with the right to privacy, Hospice personnel have a duty to maintain confidentiality of all patient information. The fundamental trust between patient and hospice staff (or volunteers) can be destroyed by unnecessary access to data or by the inappropriate disclosure of identifiable patient information. The rights, well-being, and safety of the individual patient should be the primary factors in arriving at any professional judgment concerning the disposition of confidential information received from or about the patient, whether oral, written or electronic. The standard of practice holds that relevant data be shared with those members of the care team who have a need to know. Only information pertinent to a patient's treatment and welfare is disclosed, and only to those directly involved with the patient's care. Duties of confidentiality, however, are not absolute and may need to be modified in order to protect the patient and other innocent parties. Undertakings of confidentiality must be signed by hospice personnel, students and donors or media personnel who have contact with hospice patients and/or their family members.

3.3. Protection of participants in research

Respect for the dignity, safety and wellbeing of participants should be of primary concern in hospice health related research. The research must be relevant to the health needs of hospice patients. The research findings must be translatable into mechanisms to improve their health status. The research proposal must demonstrate sound methodology and a high probability of providing answers to the research questions posed. Research should be conducted and directed only by suitably qualified persons.

Informed consent is vital to upholding the principle of respect for persons in research. Researchers must be particularly aware of the vulnerabilities of prospective hospice participants. Details of the research must be provided in a clear, simple and culturally appropriate manner. A participant is free to withdraw consent to further involvement in research without having to face any unfair negative consequences or disadvantage. Informed consent is valid only when it is obtained without coercion, undue influence, inappropriate incentives, deceit or misrepresentation. Where the participant lacks the capacity to exercise an informed choice to participate in research, proxy consent must be obtained from a legally authorised representative. Both the privacy and confidentiality of research participants must be respected.

Prior to implementation, all research should be approved by a qualified review board to ensure patient protection and the ethical integrity of the research. Hospice personnel have the duty to question and, if necessary, to report and to refuse to participate in research they deem morally objectionable.

3.4. Standards and review mechanisms

Hospice personnel have a responsibility to implement and maintain good standards of professional practice. They should also have the opportunity to be included in institutional ethics committees. Personnel should all have the opportunity to present difficult issues related to patient care and/or institutional constraints upon ethical practice for discussion and review. Hospice personnel should be active participants in the development of policies and review mechanisms designed to promote patient safety, reduce the likelihood of errors, and address both environmental system factors and human factors that present increased risk to patients.

When errors do occur, hospice personnel must follow institutional guidelines in reporting errors committed or observed to the appropriate supervisory personnel and to assure responsible disclosure of errors to patients. Under no circumstances should the members participate in, or condone through silence, either an attempt to hide an error or a punitive response that serves only to fix blame rather than correct the conditions that led to the error.

3.5. Acting on questionable practice

Hospice personnel's primary commitment is to the health, well-being, and safety of the patient. As an advocate for the patient, all personnel must be alert to and take appropriate action regarding any instances of incompetent, unethical, illegal, or impaired practice by any member of the hospice team that places the rights or best interests of the patient in jeopardy. To function effectively in this role, personnel must be knowledgeable about the Code of

Ethics. When the staff member or volunteer is aware of inappropriate or questionable practice, concern should be expressed to the person carrying out the questionable practice. Attention should be called to the possible detrimental affect upon the patient's well-being or best interests as well as the integrity of Hospice. If indicated, the problem should be reported to an appropriate higher authority. There are established processes for reporting and handling incompetent, unethical, illegal, or impaired practice within the Hospice setting and such reporting should go through official channels, thereby reducing the risk of reprisal against the reporting member. Accurate reporting and factual documentation, and not merely opinion, is essential to all responsible actions.

3.6. Addressing impaired practice

Hospice personnel must be vigilant to protect the patient, the public and Hospice from potential harm when a colleague's practice, in any setting, appears to be impaired. In a situation where a staff member or volunteer suspects another's practice may be impaired, the staff member's duty is to take action designed both to protect patients and to assure that the impaired individual receives assistance in regaining optimal function. Such action should usually begin with consulting supervisory personnel and may also include confronting the individual in a supportive manner and with the assistance of others, or helping the individual to access appropriate resources (see Appendix C).

Personnel in all roles should advocate for colleagues whose job performance may be impaired to ensure that they receive appropriate assistance, treatment and access to fair institutional processes. This includes supporting the return to practice of the individual who has sought assistance and is ready to resume professional duties. If impaired practice poses a threat or danger to self or others, regardless of whether the individual has sought help, the member must take action to report the individual to persons authorized to address the problem and to HPCA ethics committee and appropriate professional bodies.

Hospice personnel who advocate for others whose job performance creates a risk for harm should be protected from negative consequences.

3.7. Addressing family and patient complaints

Should it happen that either or both the patient and/or the family have concerns or complaints, these should also be dealt with in a professional manner. The patient and family will at all

times have direct access to the head of the team. However, if they feel that their needs are not met, they can address their concern(s) to the Hospice's management. If the management can still not satisfy the patient and or family's needs, the concern may be taken to the HPCA for consideration.

STATEMENT 4

Hospice personnel should be responsible and accountable for care in order to provide optimum patient care.

Interpretive statements

4.1. Acceptance of accountability and responsibility

Hospice personnel who bear primary responsibility for the care of the patient are individually accountable for their own practice and for those personnel under their supervision according to their scope of practice as defined by their professional body. Hospice personnel retain accountability and responsibility for the quality of practice and for conformity with standards of care. Hospice personnel must exercise judgment in accepting responsibilities and being accountable for the actions taken.

4.2. Accountability for judgment and action

Accountability means to be answerable to oneself and others for one's own actions. In order to be accountable, hospice personnel act under a code of ethical conduct that is grounded in the moral principles of fidelity and respect for the dignity, worth, and self-determination of patients, set out in this Code of Ethics.

4.3. Responsibility for judgment and action

Responsibility refers to the specific accountability or liability associated with the performance of duties of a particular role. Hospice personnel accept or reject specific role demands based upon their education, knowledge, competence, and extent of experience. Personnel must not engage in practices prohibited by law or delegate activities to others that are prohibited. Individual staff members or volunteers are responsible for maintaining their own competence. Supervisors are responsible for performance appraisal and ensuring workplace competency in keeping with the HPCA standards of patient care, management and good governance. When the needs of the patient are beyond the qualifications and competencies of the staff member, consultation and collaboration must be sought from qualified personnel, other health professionals, or other appropriate sources. Educational resources should be sought by members and provided by Hospice to maintain and advance the competence of personnel.

STATEMENT 5

Hospice personnel owe the same duties to self as to others, including the responsibility to preserve integrity and safety, to maintain competence, and to continue personal and professional growth.

Interpretive statements

5.1. Moral self-respect

Moral self-respect accords moral worth and dignity to all human beings irrespective of their personal attributes or life situation. Such respect extends to oneself as well; the same duties that we owe to others we owe to ourselves. Self-regarding duties include professional growth and maintenance of competence, preservation of wholeness of character, and personal integrity.

5.2. Professional growth and maintenance of competence

Though it has consequences for others, maintenance of competence and ongoing professional growth involves the control of one's own conduct in a way that is primarily self-regarding. Competence affects one's self-respect, self-esteem, professional status, and the meaningfulness of work. In all caring roles, evaluation of one's own performance, coupled with peer review, is a means by which the caring practice can be held to the highest standards. Continual professional growth, particularly in knowledge and skill, requires a commitment to lifelong learning. Such learning includes, but is not limited to, continuing education, networking with professional colleagues, self-study, professional reading, certification, and seeking advanced degrees. Hospice personnel are required to have knowledge relevant to the scope and standards of Hospice practice, changing issues, concerns, controversies, and ethics.

5.3. Wholeness of character

Hospice personnel have both personal and professional identities that are neither entirely separate, nor entirely merged, but are integrated.

Sound ethical decision-making requires the respectful and open exchange of views between and among all individuals with relevant interests. In a community of moral discourse, no one person's view should automatically take precedence over that of another. Thus hospice personnel are free to express moral perspectives, even when they differ from those of others, and even when they might not prevail.

This wholeness of character encompasses relationships with patients. When the patient requests a personal opinion from the member, the member is generally free to express an informed personal opinion as long as this preserves the autonomy of the patient and maintains appropriate professional and moral boundaries and is non-judgemental and non directive. Recognising the particular vulnerability of the patient and family members in the hospice setting, it is essential to be aware of the potential for undue influence attached to the staff member's professional role,. Assisting patients to clarify their own values in reaching informed decisions may be helpful in avoiding unintended persuasion. Where a staff member or volunteer's responsibilities include care for those whose personal attributes, condition, lifestyle or situation is stigmatized by the community and are personally unacceptable, hospice personnel must still render unbiased respectful and skilled care.

5.4. Preservation of integrity

Integrity is an aspect of wholeness of character and is primarily a self-concern of the individual staff member or volunteer. Threats to integrity may include a request to deceive a patient, to withhold information, or to falsify records, as well as verbal abuse from patients or co-workers. Threats to integrity also may include a request for the staff member or volunteer to act in a way that is inconsistent with the values or ethics of the profession, or more specifically a request that is in direct violation of the Code of Ethics. Hospice personnel have a duty to remain consistent in their professional values and to accept compromise only to the degree that it preserves integrity and does not jeopardize the dignity or well-being of the member or others.

Where hospice personnel are placed in situations of compromise that exceed acceptable moral limits or involve violations of the moral standards, whether in direct patient care or in any other forms of Hospice practice, they may express their conscientious objection to participation. Where a particular treatment, intervention, activity, or practice is morally objectionable to the staff member or volunteer, whether intrinsically so or because it is inappropriate for the specific patient, or where it may jeopardize both patients and caring practice, the member is justified in refusing to participate on moral grounds. Such grounds exclude personal preference, prejudice, convenience, or arbitrariness. The member who decides not to take part on the grounds of conscientious objection must communicate this decision in appropriate ways. Whenever possible, such a refusal should be made known in advance. The member is obliged to provide for the patient's safety, to avoid patient abandonment, and to withdraw only when assured that alternative sources of care are available to the patient.

STATEMENT 6

Hospice personnel should participate in establishing, maintaining, and improving care environments.

Interpretive statements

6.1. Influence of the environment on moral virtues and values

Virtues are habits of character that predispose persons to meet their moral obligations; that is, to do what is right. Excellences are habits of character that predispose a person to do a particular job or task well. Virtues such as wisdom, honesty, and courage are habits or attributes of the morally good person. Excellences such as compassion, patience, and skill are habits of character of the morally good hospice staff member or volunteer. For hospice personnel, virtues and excellences are those habits that affirm and promote the values of human dignity, well-being, respect, health, independence, and other values central to caring. Both virtues and excellences, as aspects of moral character, can be either nurtured by the environment in which hospice personnel practice or they can be diminished or thwarted.

Hospice personnel have a responsibility to create, maintain, and contribute to environments that support the growth of virtues and excellences and enable members to fulfil their ethical obligations.

6.2. Influence of the environment on ethical obligations

Hospice personnel, regardless of role, have a responsibility to create, maintain, and contribute to environments of practice that support members in fulfilling their ethical obligations.

6.3. Responsibility for the care environment

Hospice personnel are responsible for contributing to a moral environment that encourages respectful interactions with colleagues, support of peers, and identification of issues that need to be addressed. Administrators and managers have a particular responsibility to assure that hospice personnel are treated fairly and are involved in decisions related to their practice and working conditions. Acquiescing and accepting unsafe or inappropriate practices, even if the individual does not participate in the specific practice, is equivalent to condoning unsafe practice. Hospice personnel should not condone violation patient rights or compromise standards of practice or personal morality. As with concerns about patient care, personnel should address concerns about the care environment through appropriate channels.

STATEMENT 7

Hospice personnel should collaborate with other professionals and the public in promoting community, national, and international efforts to meet patient and family needs.

Interpretive statements

7.1. Needs and concerns

All hospice personnel should be committed to promoting the health, welfare, and safety of all people with life-threatening. The availability and accessibility of high quality palliative care require interdisciplinary planning and collaborative partnerships among professionals and others at the community, national and international levels.

7.2. Responsibilities to the public

Member hospices have a responsibility to be knowledgeable about the palliative care needs of the community whom they serve. Hospices, regional and national hospice associations should assist in efforts to educate the public, facilitate informed choice, identify and correct conditions and circumstances that contribute to adverse attitudes and actions towards life-threatening illness, death and the dying.

All hospice personnel should also recognize that care is provided to culturally diverse populations in this country and in all parts of the world. In providing care, the personnel should avoid imposing their own cultural and religious values upon others. Hospice personnel should affirm human dignity and show respect for the values and practices associated with different cultures and faiths and use approaches to care that reflect awareness and sensitivity.

STATEMENT 8

All Hospice personnel should be responsible for articulating values, for maintaining the integrity of the organisation and its practice, and for shaping social policy.

Interpretive statements

8.1. Assertion of values

All hospice personnel should communicate and affirm the values of the organisation. Hospices must encourage discourse that supports critical self-reflection and evaluation within their organisations. Member hospices, regional and national associations must communicate to the public the values that Hospice considers central to social change that will improve public attitudes toward terminal illness, death and dying.

8.2. Executing collective responsibility

Hospice must continue to develop ways to clarify its accountability to society. The contract between the member hospices and the society served is made explicit through such mechanisms as:

- (a) Code of Ethics
- (b) Hospice Palliative Care Standards and Accreditation of member hospices
- (c) Quality Improvement Programmes
- (d) Palliative Care Education and Research

8.3. Intra-professional integrity

Hospice is responsible for expressing the values and ethics of the organisation and for encouraging its members to function accordingly. Thus, one of its fundamental responsibilities is to promote awareness of and adherence to the Code of Ethics and to critique the activities and ends of the organisation itself. Values and ethics influence the power structures of the organisation in guiding, correcting, and directing its activities. Through critical self-reflection and self-evaluation, Hospice must foster change within itself, moving towards its stated ideals.

APPENDIX A

WHO Definition of Palliative Care

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

Palliative Care:

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

WHO Definition of Palliative Care for Children

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO;1998a):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres, and even in children's homes.

WHO August 2002

APPENDIX B

Hospice Palliative Care Association Ethics Committee

AIM: the HPCA ethics committee aims to promote the highest standards of ethical palliative care and ethical decision making in patient and family care, hospice management and palliative care education and research within member hospices and to contribute to the ethical framework of policy makers with regard to end-of-life care in South Africa.

Term of office: 3 years renewable

Objectives:

- To develop a body of knowledge and expertise in the ethics of palliative care to advise and guide hospice members.
- To enhance ethics committee members' knowledge of ethical principles and practice in the areas of patient care, hospice management, palliative care education and research, related policies and regulatory issues.
- To promote knowledge of ethical decision making in palliative care.
- To review research proposals to ensure that they follow the ethical principles required in health care research.
- To develop statements regarding ethical policies in palliative care which would impact on policy-making where appropriate.
- To promote the integration of ethical principles and decision making in palliative care training and education.

APPENDIX C

Procedure to address concerns regarding ethical practice and/or professional conduct:

Any Hospice personnel may raise concerns and initiate discussion of ethical practices and/or professional conduct.

Faced with such a concern, the individual or group should:-

- Document the incident immediately, e.g. complete incident form
- Approach the senior team member on duty, if immediate advice and assistance is required, or;
- Request in writing a discussion on the ethical issue by the Hospice Ethics Committee, within a period of thirty (30) days;

The concern will then be addressed in the following manner:-

- Ethical dilemmas will be thoroughly investigated in clinical/medical, moral and legal terms;
- The advice of all relevant sources, including reference to HPCA Code of Ethics, will be sought and considered in arriving at a decision;
- Any decision made regarding an ethical dilemma will be documented for future reference;
- If at all possible, the individual or group who instigated the inquiry will be involved in discussions of the ethical dilemmas. This will enable him/her/them to raise and discuss their personal points of view;
- Open and honest communication is essential to addressing ethical dilemmas effectively;
- Relevant resource material (which will aid in the ethical decision making process) will be obtained and made available;
- Hospice personnel will be offered emotional support when confronted by an ethical dilemma and decision making, which has a negative effect upon him/her/them;
- A report on the incident and actions taken will be submitted to HPCA Ethics Committee.

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